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Dementia and values-based practice – a case of facts, evidence, rights or values?

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Abstract

Dementia is a progressive, terminal health condition affecting millions of people globally, for which there is no cure, and available treatments are of limited efficacy. Values-based practice (VBP) is a theoretical and practical framework that aims to support practitioners and people using health and social care services in situations where particular disagreements arise. These disagreements involve situations where the evidence base for care or treatment interventions is limited, disputed or non-existent, and there are conflicting values held by people regarding the best course of action to take. To date, dementia has not featured significantly in VBP literature or activities. Using evidence from twenty of my published works, I show in this thesis the relevance of values relating to dementia and dementia care to VBP. In particular, the publications highlight the relevance of values expressed through the lived experience of dementia. They also highlight the interaction of dementia care practice with values underpinning or expressed in different legal frameworks, especially involving mental capacity, social care and the social model of disability. The thesis presents an important and original narrative based on my published works that challenges VBP but also offers new ways in which it could develop in the future.

Contents

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Glossary of abbreviations used in the thesis

DEEP – Dementia Engagement and Empowerment Project

DFC – Dementia friendly community

DHSC – Department of Health and Social Care (formerly the Department of Health – DH)

DoLS – Deprivation of Liberty Safeguards (part of the Mental Capacity Act 2005)

EBM – Evidence-based medicine

EBP – Evidence-based practice

ECHR – European Convention on Human Rights

FREDA – Fairness, Respect, Equality, Dignity, Autonomy (principles for HRBA – see below)

HRA – Human Rights Act 1998

HRBA – Human rights-based approach

JRF – Joseph Rowntree Foundation

MCA – Mental Capacity Act 2005

MHA – Mental Health Act 1983

MHF – Mental Health Foundation

NICE – National Institute for Health and Care Excellence

PANEL – Participation, Accountability, Non-discrimination, Empowerment, Legality (a tool for HRBA – see above)

PI – Principal Investigator

PPI – Public and Patient Involvement (in research)

SCIE – Social Care Institute for Excellence

SMD – Social model of disability

UDHR – Universal Declaration of Human Rights

UNCRPD – United Nations Convention on the Rights of Persons with Disabilities

UWL – University of West London

VBP – Values-based practice

Note on terminology

The thesis uses the term ‘service user’ and ‘patient’ interchangeably to denote a person receiving care and / or treatment (‘service user’ is a preferred term for people with mental health problems). ‘Person / people with dementia’, ‘people living with dementia’ or ‘people with lived experience of dementia’ are terms used to denote people with a diagnosis, or suspected diagnosis, of dementia. ‘Family carers’ denotes family members and friends providing unpaid care and support to a relative or friend. ‘Practitioners’ is used to denote both qualified professionals (e.g. doctors, social workers, etc.) and other paid staff who provide care and treatment.

Introduction

This thesis describes and analyses twenty publications I have authored or co-authored that involved values in dementia, especially those expressed by people with dementia, and the interaction of personal and professional values with values expressed in law. Through a critical analysis and evaluation of how my publications present the interaction of values with dementia, the thesis identifies both challenges and opportunities for the theory and practice of values-based practice (VBP). VBP is an internationally recognised framework for health and social care practice, designed to work in partnership with evidence-based practice (EBP).

VBP was devised to support service users, family carers and practitioners in situations where evidence supporting care and treatment interventions is limited, contested, or non-existent. VBP literature points out that in these situations, decisions about care and treatment are made based on values instead, but differences in values means that disputes or conflicts may arise. To date, the theory and practice of VBP has rarely been applied to dementia. However, I provide evidence in the thesis, based upon my publications, that there are important and unique aspects to dementia which are relevant to the future development of VBP. The publications include six research studies, described in papers in peer-reviewed journals, reports, books, and book chapters. The narrative I identify from these publications make an original and important contribution to the theory and practice of VBP and its relevance to dementia care.

The thesis has three main chapters.

Chapter One: The chapter provides background and context for VBP and particular aspects of dementia relevant to the publications included in the thesis. These also relate to the key themes which make up the main narrative of the thesis. The areas of particular interest in dementia and dementia care include values expressed by people with dementia, values expressed in legal frameworks and how these interact with personal and professional values, and social care and other non-pharmacological interventions in dementia. (Appendix A provides more details of the legal frameworks discussed in Chapter One and the rest of the thesis).

Chapter Two: The chapter offers a critical analysis and evaluation of the twenty publications included in the thesis. It synthesises evidence from the publications that supports the key themes and narrative of the thesis, and indicates how these relate to the background context. In addition, the chapter summarises the originality of the publications and research studies they were based on.

The publications are divided into four sections in the chapter. The first section considers eight of my publications which explored different aspects of the values of people with dementia. The second section discusses a further nine publications involving the interaction of values in dementia with values expressed in legal frameworks, with a focus on social care and other non-pharmacological interventions. Evidence from the publications in these two sections supports several themes that pose several unique challenges to VBP which, to date, VBP literature has not considered. However, my publications in the first two sections do not explicitly refer to VBP or VBP literature. The third section concerns two books I co-authored where VBP was explicitly applied to the use of law that had significant implications for dementia, and where VBP was applied to health and social care practice specifically concerning dementia. These two books drew on and synthesised evidence from the publications in the two previous sections and identified challenges posed by dementia and legal frameworks to VBP. In the final section, I present a taxonomy for ‘dementia friendly communities’, based on evidence from a research study in my last publication included in the thesis. I contend that this taxonomy both reflects the challenges identified in the chapter, and the areas of investigation involving dementia that would help VBP develop in the future.

Chapter Three: In this chapter, I critically reflect on my professional development as a research practitioner. The chapter provides autobiographical context for the time before, during, and after the period covered by the publications included in this thesis (2011-2020). This includes reflecting on and critiquing aspects of the methodology used in the research studies covered by thirteen of the publications. I also discuss the significance of the seven publications not based on primary research. The chapter gives examples of the contribution made by the studies and publications to the subject area since they were completed. Finally, the chapter describes my development as a research practitioner in the time since the last publication was completed, including further publications of mine. Appendix B discusses these issues in more detail regarding each publication, listed chronologically, including the contribution I made where I was a co-author.

A PhD by Publication requires a critical re-evaluation of one’s publications, and some retrospective identification of the evidence they contain that supports the key themes and narrative of the thesis. My research career was largely in an independent, not-for-profit research organisation rather than a university, although several publications in the thesis involved research studies carried out in partnership with universities. The range of my publications included in the thesis reflects this, with some that were peer-reviewed, and some that were published as research reports, for example. There are also a larger number of published works in the thesis than is required for a

PhD by Publication. This is to ensure that there is a coherent thread, linking the peer-reviewed papers with the overall narrative, supported by research evidence, findings and discussion from my other relevant publications.

Chapter 1

Background context

1.1. Introduction

This chapter gives an overview of the two key themes in the published works featured in this thesis; values-based practice (VBP) and dementia. The chapter also provides a brief background to several important sub-themes contained in my publications in relation to dementia and VBP. These include social care and some other non-pharmacological interventions related to dementia; the lived experience of dementia; and the interaction of dementia with various legal frameworks in the UK concerning mental capacity, disability and human rights. All of these are large and complicated areas encompassing theory, practice, policy, research, and other epistemes. Consequently, each has extensive bodies of literature associated with it. Therefore, this chapter focuses on areas of interconnectivity in the literature (including grey literature), where it exists, primarily between VBP and dementia, but also with the sub-themes described. This provides the context for the published works that form the basis of the thesis, and the originality of the narrative and contribution to knowledge that the published works demonstrate.

A PhD by Publication does not require a systematic literature review and several of the published works contained in the thesis include these types of review. In order to strike a balance between brevity and rigour, this chapter is based on a narrative (non-systematic) literature review with a focus on key, recent literature in the areas described above (Sukhera, 2022).

1.2. Values-based practice

Values-based practice (VBP) is an internationally recognised model that was developed to assist health and social care practitioners in providing treatment, care and support (Fulford *et al.*, 2012). VBP is particularly focused on situations where 'evidence-based practice' (EBP) is problematic because the evidence base for possible interventions is limited, inconsistent, or non-existent. In these situations decisions about care and treatment will be driven by other factors including professional and organisational values (implicit or explicit), but also the values of service users and family carers. Trying to make decisions in these situations may result in disagreements and conflicts if there is not a consensus on whose values are 'right'. VBP proposes a framework for understanding values in a different way to help overcome these difficulties. The aim of VBP is not to replace EBP but to work in partnership with it to ensure care and treatment decisions draw on both evidence and values.

1.2.1. Evidence-based practice

Evidence-based practice (EBP) in health and social care is an empirically based approach that draws on western traditions of science and research to ensure that the best possible evidence is used when making health and social care decisions in providing support and treatment (Cochrane, 1972). It is closely linked to the concept of 'evidence-based medicine' (EBM). EBM as a term was introduced in the 1990s by Gordon Guyatt of McMaster University and others (Guyatt *et al.*, 1992). It quickly became established as the principal paradigm for the delivery of care and treatment in areas of the world where Western medicine was dominant, including the UK.

> “Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine means integrating

> individual clinical expertise with the best available external clinical evidence from systematic research” (Sackett *et al.*, 1996 p.71).

EBP developed as a way of applying EBM using policies and guidance produced by organisations set up to evaluate scientific research and evidence for treating different illnesses and health conditions. The most notable of these in the UK has been the Cochrane Collaboration, established in 1993, and the National Institute for Health and Care Excellence (NICE), established in 1999. Cochrane is an international network which gathers and summarises the best evidence from research to help clinicians and practitioners make informed decisions about health care. NICE produces “evidence-based guidance and advice for health, public health and social care practitioners”, taking into account value for money. It largely determines the types of treatment and care that are available through the National Health Service in England, including where they are jointly delivered or require input from social care (NICE, 2022). Another organisation, the Social Care Institute for Excellence (SCIE), promotes EBP in social care with the aim of improving “the lives of people of all ages by co-producing, sharing, and supporting the use of the best available knowledge and evidence about what works in practice” (SCIE, 2022). EBP is also a central component in the training, education and ongoing professional development and standards of clinicians and practitioners (e.g. Royal College of Psychiatrists, 2017; Nursing and Midwifery Council, 2015; Social Work England, 2023).

Yet the existence of health conditions such as some neurological conditions and forms of cancer where cure, treatment or care are still limited, contested or non-existent indicates that there are limits to relying entirely on an evidence-based approach. And even where there is a strong evidence base other factors may influence patients and service users when they make decisions about care and treatment they are offered. These could include personal and religious beliefs, side effects, requirements for receiving the care or treatment, and having different interpretations or views about their illness, health condition, or mortality from those held by professionals. EBP acknowledges that clinical expertise and patient values should be integrated as part of the approach (Sackett *et al*., 2000).

One such example illustrating the limitations of relying too much on evidence is the field of psychiatry. Severe and enduring conditions such as schizophrenia lack universally effective treatments and cures, and for many years some people diagnosed with the condition have refused to accept the diagnosis or have presented alternative explanations for their “symptoms” and resisted treatment (Lacey *et al.*, 1993; Rogers and Pilgrim, 2014). People may also refuse treatment because of their dislike of its side effects, even where evidence suggests a good prognosis if that particular treatment is followed (*ibid*). Legal enforcement involving compulsory detention in hospital and treatments for mental health disorders is commonly used around the world for people who resist treatment. Both narratives and practice challenging this approach have developed proposing radically different explanations and interventions from those offered by conventional psychiatry (Reaume, 2021). Some of these difficulties have arisen in the past partly because EBP in psychiatry was too closely aligned to a narrow, biomedical model that focused only on pathology and a disease view of mental disorders. In recognition of the problems generated by the biomedical model, it has gradually been replaced by a ‘biopsychosocial’ model in psychiatry which aims to take into account psychological and social factors, as well as medical aspects, in understanding and responding to mental disorders (Engel, 1977). Yet despite there being a fairly extensive evidence base for the biopsychosocial model (Novack *et al*., 2007) it has not resulted in the disappearance of the difficulties described (Benning, 2015). As one indication of resistance or non-acceptance of biopsychosocial interventions, by 2018 rates of involuntary detentions under the Mental Health Act in England had trebled since the 1980s (Keown, *et al.*, 2018) and between 2016 and 2024 increased by 16% (NHS Digital, 2024b).

1.2.2. The development of values-based practice

VBP emerged in the late 1990s in the UK, firstly in psychiatry, to try and address the difficulties posed where EBP was of limited use (Fulford *et al*, 2012). VBP drew on a methodology in philosophy developed in Oxford in the 1950s known as 'ordinary language philosophy' which examined concepts such as 'values' by exploring how they were used in ordinary, everyday situations (Austin, 1956-57; Hare, 1952). Fulford *et al* made the observation that in clinical situations, decisions were based on both values and evidence; values informed the goals to be achieved, and evidence identified the means of achieving them (Fulford *et al.*, 2012). Where there was explicit or implicit agreement about the relevant values (usually based on evidence) on which to make a clinical judgement, decision-making was unproblematic. However, where a consensus on values did not exist, often due to limited, disputed or non-existent evidence to inform clinical decisions, then decision-making was likely to be more problematic and involve disputes about which were the 'right' values on which to base the decision. These included professional values held by practitioners, but these can differ between professions such as doctors, nurses, social workers or psychologists. Decision-making could also be informed by the values of the organisations that practitioners worked for, sometimes societal and personal values, but crucially, also the values of service users and family carers. Fulford *et al* made the point that where all the different values were aligned about the best course of action in terms of care and treatment in any given situation, there would be a consensus and no difficulties would arise (*ibid*). However, for the reasons already described, such as in psychiatry, this often was not the case, leading to disagreement and conflict, including inter-disciplinary disputes. Furthermore, while professionals might overtly express their commitment to EBP's inclusion of patient values and a biopsychosocial model, which could be seen as a broad and inclusive approach to values, it was often more narrow, implicit values that actually informed their decision making, adding further to potential conflict. These differences in values, both implicit and explicit, held by practitioners from different disciplines as well as service users and carers, is illustrated in a 2003 study by Colombo *et al*, that is key to VBP (Colombo *et al.*, 2003).

VBP acknowledged that medicine, including psychiatry, had recognised that values were important in clinical practice through the use of medical ethics. Patient autonomy, beneficence, non-maleficence, and justice are four key values (or principles) that for some time have sat at the heart of medical ethics (Beauchamp and Childress, 2008). But VBP argued that medical ethics was based on a too narrow conception of values; it took little account of values held by or influencing other professional disciplines, service users, or family carers, or a deeper understanding of what values really are. By proposing certain values as the 'right' ones, medical ethics also implied that there could be 'wrong' ones. All of this increased the likelihood of conflict and disagreements where values were the drivers in decision-making. This was particularly the case in psychiatry where conflicts arose involving values that went beyond medical ethics, such as patient autonomy being overridden by considerations of public safety.

Using empirical approaches involving practitioners, service users and family carers, as well as documentary analysis, VBP puts forward a strong case for a much broader understanding of values. VBP stresses the importance of recognising that values are located in many different places: with individuals, organisations, policies and guidance, and communities; that values are diverse and may be defined differently, depending on who you are; and that divergences in values are very common. Apart from values that actively encourage or endorse the oppression of other people, such as racist values, VBP takes an almost totally inclusive view of values; there are no ‘right’ or ‘wrong’ values, and claims to the contrary will only lead to disagreement and conflict. VBP simply sees values as ‘action guiding words’ so makes no claims about what key values in medicine or psychiatry should be. Instead, the main point of VBP is to support balanced decision-making of shared values, based upon VBP’s main premise of mutual respect for differences of values.

VBP emphasises that good outcomes in decision-making involving values can only be achieved if there is a good process. To this end, it proposes ten key elements of ‘good process’ for health and social care practitioners to support balanced decision-making in practice. These include developing practice skills in awareness, reasoning, knowledge and communication around values, and linking with EBP wherever possible, so decisions draw on relevant science and evidence. The pointers emphasise the importance of a multi-disciplinary approach involving different professions and roles, partnership in decision-making involving service users and carers, and embracing the values diversity these bring. If consensus about values cannot be achieved then ‘dissensus’ is acceptable, meaning that it is recognised there are differences in values but they all remain relevant, not that some are ‘right’ and others are ‘wrong’. One key element is an emphasis on person-centred practice; that the first source of information on values in any given situation should be the perspective of the service user and wherever possible these should drive decisions.

However, other relevant values such as those of practitioners and family carers should also be included and may be crucial in certain decision-making situations.

1.2.3. The impact of values-based practice

While VBP cannot claim to have had the scale of influence that EBP has achieved, it nevertheless has established itself in several different areas of medicine and health care, both in the UK and internationally. VBP has its own institution, in the form of a 'Collaborating Centre' at St Catherine's College, Oxford University, which has been operating for over ten years. The aim of the centre is "to support the development of values-based practice through shared learning".[1] This includes initiatives in education and training, providing resources, information and guidance, seminars and webinars, and developing collaborations and networks to promote VBP, including VBP's role as an essential partner to EBP.

VBP's education and training programme has a strong focus on psychiatry but the Collaborating Centre is also a key partner in a programme on Values-Based Surgical Care for practitioners. VBP has networks involving academics, practitioners and people with lived experience that focus on addictive behaviours, childbirth, digital health, paramedic practice, as well as a range of mental health conditions. Over 50 organisational partners are listed on the Centre's website including universities based in the UK and in Austria, Bulgaria, Hong Kong, Italy and South Africa. Almost 200 individual project partners are also listed including professionals and academics from over 20 different countries including Australia, Brazil (which has its own VBP network), France, Germany, Iran, Japan, Singapore, South Africa, USA, and the UK. There have been five books published by Cambridge University Press in a series

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[1] https://valuesbasedpractice.org/

about VBP, and over 250 other books, chapters, articles and reports about VBP listed on the Centre's online library.

VBP has also been influential on policy and practice, particularly in shaping the application of mental health legislation in England and Wales. This includes VBP's involvement in developing the guiding principles of the Mental Health Act 2007 (MHA) which are contained in its Code of Practice, and practitioner training materials for the Act (Department of Health, 2015a; Fulford, Dewey and King, 2015). VBP describes collaborations with several service-focused organisations, particularly those in the UK responsible for inspection and regulation, including NICE. NICE guidelines make it clear that the values of patients should be taken into account as well as the content of specific guidance, and values are much in evidence in specific NICE guidelines, such as their guidance on shared decision-making (NICE, 2021).

1.2.4. Debates in values-based practice

VBP is not without its controversies (Fulford, 2013; Loughlin, 2014). These include debates about its philosophical basis of VBP, and its prohibition on certain values, which apart from racism are rather ill-defined other than being ones which oppress the values of others (Brecher, 2014). VBP has also been challenged on what some have described as VBP's "master value" of 'mutual respect' (Hutchinson and Read, 2014), suggesting there are in reality some 'right' and 'wrong' values (Kingma and Banner, 2014). Little on the other hand argues that there are 'foundational' human values of 'survival, security and flourishing' that underpin all social interactions which VBP fails to properly acknowledge (Little, 2014).

Criticisms have also been made about VBP's relativist, 'anything goes', stance towards virtually all values (Cassidy, 2013) although proponents of VBP cite values pluralism as better reflecting VBP's position (Fulford *et al.*, 2015). VBP's insistence on adhering to a prescribed process to resolve disagreements has led to criticisms of it being 'neo-liberal' or 'radical liberal'. For example, Thornton argues that VBP does not take into account its own 'normative status' because its focus on following the 'right' process to resolve disagreements fails to address the values that underpin this process (Thornton, 2014). Thornton goes on to argue for a more 'modest particularist' approach to VBP to avoid this problem. The laissez-faire criticism also links with concerns that for VBP to be effective, it has to engage more proactively with the very real power dynamics, hierarchies and conflicts involving values in everyday health and social care that relate to issues of policy and resources, and socio-economic factors (Fulford, 2014).

Recent debates about VBP have also arisen in relation to the concept of 'person-centred care', which has become a key concept in health and social care practice, but also a key element of VBP's 'good process' (Mitchell and Loughlin, 2023). However, as Mitchell and Loughlin point out, despite the ubiquitous nature of the term 'person-centred' and a general consensus that it is a 'good thing', definitions of it vary considerably because it lacks a theoretical and philosophical underpinning (and is value-laden) making it "at best contentious and at worst unclear" (p.2, *ibid*). They also criticise other aspects of VBP, such as its confident division between 'facts' and 'values'; the former may emerge from scientific projects and research which are value-driven. Moreover, and echoing the criticism of VBP as needing to engage more proactively with everyday practice, Loughlin suggests that the expression of values in ordinary language in day to day practice is not just diverse, it is actively contested (Loughlin, 2020). In this respect, VBP's 'good process' for balanced decision making may still be necessary, but insufficient on its own to ensure outcomes that significantly reduce or remove conflicts over values.

From a philosophical point of view, VBP can be criticised for the lack of clarity as to where it sits in relation to arguments about values relativism, pluralism, principle-ism or particularism. While these debates are important, many aspects of VBP remain useful and relevant to everyday health and social care practice, such as its observations about the role that implicit values play in decision-making, and the elements that make up its ‘good process’. My published works in this thesis raise issues about these more practical aspects of VBP and are not of a philosophical nature, although indirectly they have implications for the philosophical side of VBP. The published works are also important because they lead to important new questions for VBP that hitherto have attracted little or no attention in VBP literature.

1.3. Dementia

Dementia is an umbrella term for a range of symptoms affecting memory, cognition, communication, decision-making, behaviour, and other functions (Pepper, *et al.*, 2024). Dementia is caused by a number of diseases, Alzheimer’s being the most common (*ibid.*). Dementia is a progressive, terminal condition for which there is currently no cure, and treatments are still limited in their efficacy (*ibid.*). It can be the cause of enormous distress for the individual, their families and friends, especially when appropriate care and support is not provided or unavailable. Although ageing is the most significant risk factor for developing dementia, it is not inevitable that people develop the condition as they grow old, and there are a number of other, modifiable risk factors, such as diet and physical activity (World Health Organisation, 2021; Livingston, *et al.*, 2024). Before the COVID-19 pandemic, dementia was the most common cause of death in the UK and it was the most common pre-morbid condition among people who died of COVID-19 in the UK (Office of National Statistics, 2022).

The most recent detailed estimate of the number of people aged 65 and over with dementia in the UK stood at 885,000 and this was estimated to rise to 1.6 million by 2040 (Wittenberg *et al.*, 2019). Previous research had indicated an additional 40,000 people under the age of 65 live with dementia in the UK (Prince *et al*., 2014). Two thirds of people with dementia live in their own homes (Prince *et al*., 2014).

As dementia progresses activities of daily living such as attending to personal hygiene and preparing meals become increasingly difficult, and a person with dementia may become prone to risk such as falls, self-neglect, exploitation or abuse (Pepper, *et al*., 2024). Sixty per cent of people receiving home care support to help with activities of daily living activities (social care) have dementia (UK Homecare Association, 2015). People with more severe dementia usually require 24-hour residential care and it has been estimated that 69% of people living in care homes have dementia (Prince *et al*., 2014). The total cost of dementia to the UK economy is £34.7 billion annually, which includes the contribution of unpaid family carers (£13.9 billion), and social care costs of £15.7 billion (Wittenberg *et al*., 2019). There are no current figures for the numbers of family carers supporting people with dementia, but in 2014 this was estimated at 700,000 people (Lewis *et al*., 2014).

1.3.1. *The lived experience of dementia*

VBP emphasis on the centrality of service user values requires evidence and awareness of what those values are. A particular focus of this thesis is the availability of evidence concerning the values of people with dementia drawn from the collective, active participation of people with lived experience in research studies, and how this could enhance VBP.

Literature about the lived experience of people with dementia goes back to the 1990s when data started being collected from them as participants in research studies (Wilkinson, 2002). However, until very recently there has been no ‘service user movement’ involving people with dementia, akin to activism involving people with other health conditions such as physical disabilities, mental health problems and learning disabilities which date back to the 1970s (Campbell and Oliver, 2013). Consequently there has been a lack of evidence about possible shared values held by people with dementia. Evidence of more active participation by people with dementia, as individuals and collectively, began to appear in the mid-2000’s, using their lived experience to improve understanding of the condition, and becoming involved in activities such as awareness-raising, research, training and education, service and policy development. A rapid literature review undertaken in 2012, contained in one of the publications that will be discussed in this thesis, identified 36 papers (peer-reviewed and good quality ‘grey’ literature) that provided evidence and examples of the active participation of people with dementia in service development, research and evaluation, campaigning and training and education (Williamson, 2012).

A number of more recent literature reviews about different aspects of the active involvement of people with dementia have also identified relevant studies, but the vast majority of these were published after 2012 or identified in the literature review referred to above (Rivett, 2017; Bethell *et al*., 2018; Daly *et al.*, 2018; Suijkerbuijk *et al.*, 2019; Rai *et al*., 2020; Weetch *et al*., 2021; Groothuijse *et al*., 2024). Similarly, first person narratives of the experience of living with dementia are potentially an important source of values but it is only more recently that publication of these has occurred (for example, Rohra, 2016; Swaffer, 2016; Oliver, 2019; Mitchell, 2022).

The same can be said for more general dementia texts that include the lived experience of people with dementia (for example, Whitman, 2015; Oliver *et al*., 2024).

Although as one would expect, VBP literature draws on many published studies about the values of service users and patients, direct contributions to VBP literature by people with lived experience has been much more limited. While their voice is becoming more prominent as authors in VBP literature (Sadler *et al*., 2015), including at least one key VBP text (Stoyanov *et al.*, 2021), this has not included people with dementia. There is some acknowledgment of the significance of the emerging voice of people with dementia in literature connected with VBP, especially in relation to Kitwood's work on personhood and person-centred care, and biographical narratives ('life story' work) in dementia care (Morgan *et al.*, 2015). However, as literature on the lived experience of people with dementia increases, their continued absence from VBP literature is potentially depriving VBP of opportunities to reflect on what dementia could mean for it.

1.3.2. *Dementia, social care, and other non-pharmacological interventions*

Because of the absence of a cure or condition-reversing treatments for dementia and the longevity of the condition, generally measured in years, the care and support needs of people with dementia are usually met by social care organisations. Systems for providing social care vary from country to country but in the UK, responsibility lies with local authorities where it is financially means-tested unlike health care, so approximately 35% of all people receiving social care (including people with dementia) pay for this themselves (Henwood *et al.*, 2024). Social care interventions are primarily supportive and palliative, aimed not at cure but values-based concepts such as quality of life, which involve many variables. As a result, they are harder to measure and the evidence base for them is much more limited than it is for health care treatments (Dickson *et al.*, 2017). Even where there is evidence of the effectiveness of social care interventions, challenges to the implementation of EBP have also been identified (Scurlock-Evans and Upton, 2015). Furthermore, social care, and social work, are also associated with having a strong, explicit value base. These have included religious beliefs and concepts of 'deserving' and 'undeserving' poor that emerged in the 19th century, through to a focus on anti-discriminatory practice, personalisation, inclusion and the 'social model of disability' (discussed below) since the 1970s (Glasby, 2017; Jones, 2020; Henrickson, 2022). An important example relevant to this thesis of how the personalised approach to meeting individuals' needs has developed in social care is provided by the example of 'direct payments'. This involves users of social care being given funds by a local authority to pay for and manage their social care themselves, based on an assessment of their needs (Glasby and Littlechild, 2009).

Dementia is one of the major conditions associated with social care. In 2022/23 around two thirds of people receiving long term social support arranged by local authorities (mainly care homes and home care) were over the age of 65 years (542,545 people) and between 60-70% of these were likely to be affected by dementia (NHS Digital 2024a; UK Homecare Association, 2015; Prince *et al.*, 2014).

Apart from social care interventions a range of other non-pharmacological approaches have been developed, aimed at addressing some of the more common symptoms of dementia such as distressed behaviour and cognitive decline. A recent review of reviews identified music, sensory stimulation, simulated presence, validation therapy, exercise, light therapy, cognitive stimulation and reminiscence as all showing some evidence of effectiveness in alleviating some symptoms of dementia (Meyer and O'Keefe, 2020). NICE guidance on dementia states that cognitive stimulation, cognitive rehabilitation, cognitive training, group reminiscence therapy and interpersonal therapy are all non-pharmacological interventions that services should consider offering to people with dementia (NICE, 2018). Because of the range of possible interventions, values are likely to be a factor in informing decisions about which one to provide and therefore potentially of interest to VBP.

Another important area in dementia policy and practice of particular relevance to this thesis has been an international movement to develop 'dementia friendly communities' (Alzheimer's Disease International 2016a). Dementia friendly communities (DFCs) are geographical localities where public services, shops and other customer-facing businesses, charities, sports, leisure, arts, cultural and faith organisations, employers, and public transport are encouraged to be as supportive and accessible as possible for people with dementia. This is done through various collective activities including awareness raising campaigns, staff training, changes to what and how they provide to the pubic including physical environments and design, to accommodate the impairments associated with dementia (Alzheimer's Disease International 2016b). There are DFC projects and campaigns in over 40 countries, including at least 20 in Europe (Alzheimer Europe, 2021). In some countries, including England, DFCs have been part of national dementia policies and strategies (Department of Health, 2012).

Recent literature reviews on DFC studies identify key values and principles that underpin DFCs, such as the active involvement of people with dementia, challenging stigma and discrimination associated with dementia, the importance of partnerships and collaborations between organisations, and a focus on inclusion, including environmental design (Hung, L. *et al.,* 2021; Shannon, *et al.,* 2019). DFCs are complex phenomena operating at many different levels, individually and collectively, and therefore difficult to evaluate: the lack of evidence about their effectiveness has been commented on (Novak, *et* al., 2020; Buckner, S, *et al*., 2022). There is no other health condition that has attracted anything remotely similar to DFCs and the wide range of values to be found in both their theory and practice, together with only a limited evidence base, would appear to make them of potentially great interest to VBP.

1.3.3. Dementia and values-based practice

Until the publication of *The Dementia Manifesto*, one of the published works included in this thesis (Hughes and Williamson, 2019), there had only been limited discussion of dementia in the literature on VBP. The most explicit references to VBP and dementia have been made by Hughes, in several publications, although these did not attempt to critique VBP (Hughes, 2006; 2014; 2023; Hughes, *et al.,* 2013). Despite the international prevalence of dementia, with over 55 million people estimated by the World Health Organisation to have the condition worldwide (World Health Organisation, 2021), it does not feature in VBP's international text about mental health practice (Stoyanov *et al*., 2021). There have been a few publications that have drawn on VBP and were co-edited by key figures in VBP, which have involved broader discussions emphasising the importance of values in relation to the experience of dementia and dementia care. These considered philosophy and practice in relation to dementia (Hughes, 2013), dementia in relation to discourses about diseases of the psyche (Gillett & Harré, 2013), and ethical issues relating to dementia for both people with the condition (Hughes, 2015) and family carers (Hughes & Baldwin, 2015). Values in relation to the concept of 'personhood' and dementia also featured in a publication that drew on VBP (Morgan *et al*., 2015).

Hughes was also a member of the working party that produced the 2009 publication on ethical issues and dementia for the Nuffield Council on Bioethics where values featured prominently, although no reference was made to VBP (Nuffield Council of Bioethics, 2009). In systematic qualitative reviews of ethical issues in dementia care there has been no reference to VBP (Strech *et al.*, 2013; Johnson and Karlawish, 2015). There is also no substantive reference to social care in relation to dementia in the VBP literature.

The limited presence of dementia in VBP literature or reference to VBP in discussions about ethics and dementia is perhaps surprising for several reasons. Dementia has significant and progressively more severe effects on a person's ability to communicate their values and for others to understand their values, especially when the person is distressed, confused or behaving uncharacteristically as a result of their dementia. These situations may also be very challenging to values held by family carers and practitioners if they cannot understand why the person with dementia is behaving in particular ways. Important values associated with personal identity may be fundamentally challenged, for example, if the person with dementia no longer recognises family members, believes they are imposters, or thinks that staff or other people are family relations. The absence of any cures for the diseases that cause dementia and limited evidence base for medical treatments (almost exclusively confined to Alzheimer's disease) or other interventions clearly point to the important role that values play in care and treatment decision-making involving people with dementia. And as Kitwood pointed out, historically there has been a range of negative values associated with the care and treatment of people with dementia that he described as 'malignant social psychology' (Kitwood, 1997).

Similar values have been echoed in the negative ways dementia has typically been portrayed in the media and seen by the general public based on incorrect, pejorative or uninformed beliefs about the condition (Low and Purwaningrum, 2020; Alzheimer's Disease International, 2024). Negative values associated with stigma, including self-stigma, discrimination and exclusion are closely associated with dementia (*ibid.*; Milne, 2010; Nguyen 2020). Stigma and discrimination is commonly associated with other mental disorders (Fox *et al*., 2018), although this also does not feature significantly in the VBP literature. However, the symptoms of dementia, the disease pathway, and limited treatments can give rise to expressions of particularly morbid values rarely associated with other conditions (Low and Purwaningrum, 2020).

1.4. Dementia, legal frameworks, and values-based practice

A particular area that my publications focus on is the interaction of various legal frameworks with dementia and this thesis will explore the implications this has for VBP. Since VBP was first developed there has been a significant increase in legal frameworks in the UK which potentially affect people with dementia, family carers and practitioners.[2] In the late 1990s the main piece of legislation affecting people with dementia was the NHS and Community Care Act 1990 which made local authority social services departments responsible for providing care and support in the community to older and disabled people, including people with dementia.[3] To a lesser extent, the Mental Health Act 1983 (MHA) could be used to detain people with dementia in hospital if they were a risk to themselves or others and there was

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[2] It should be noted that some of the legal frameworks referred to in this thesis differ across the four UK nations, most notably mental capacity, mental health and social care legislation. These differences are summarised in Appendix A.

[3] See Appendix A for all references to statutes.

treatment available. However, the lack of treatments for dementia has meant that the MHA tends not to be used often for people with dementia compared to other mental health disorders; using older age as a rough proxy for dementia. For example, in 2023/24 less than 18% of all detentions under the MHA involved people aged 65 or over (NHS Digital, 2024b).

However, from the late 1990s new laws and legal frameworks came into force which had significant impacts in the provision of dementia care. These included the Human Rights Act 1998 (HRA), the Mental Capacity Act 2005 (MCA), the United Nations Convention on the Rights of Persons with Disabilities 2006, (UNCRPD), the Equality Act 2010, and the Care Act 2014. Appendix A briefly summarises these different legal frameworks. The relevance of them to this thesis lie partly in the proliferation of legal processes affecting people with dementia, family carers and practitioners. But also of relevance is the range of values expressed in those legal frameworks that could be involved in interactions in dementia care, the status those values have compared to other values, and the implications this has for VBP.

1.4.1. Mental Capacity Act 2005

To illustrate the impact this proliferation of legislation has had on people with dementia and those that care for them, and because of its particular relevance to this thesis, the MCA provides a good example. Dementia is a condition commonly associated with the MCA because of the effects dementia has on a person's ability to make decisions (Pennington, *et al.*, 2018).

Unfortunately, data showing how many people with dementia are affected by the MCA is limited. There is no national monitoring or data collection of, for example, capacity assessments or best interests decisions made under the MCA, and the

MCA does not require standard documentation to be used for either process (Parliament. House of Lords, 2014). Monitoring data about other aspects of the MCA and research indicates that dementia is a factor in 32%-53% of MCA-specific activities (Townsley and Laing, 2011; Care Quality Commission, 2014; Ruck Kean et al, 2019). Dementia is the main diagnostic reason for older people to be subject to the MCA's Deprivation of Liberty Safeguards (DoLS). DoLS are applied if a person needs detaining in a hospital or care home for the purposes of care in their best interests because they lack capacity to consent to this. In 2023-24 the number of individuals aged 65 and over subject to at least one application for DoLS in England was 226,620, or 85% of the overall total number of applications (NHS Digital, 2024c).[4] This suggests that large numbers of people with dementia are subject to DoLS, which require the application of other aspects of the MCA, including the five principles, mental capacity assessments, and best interests decisions. Therefore, despite the paucity of MCA data overall, the data that does exist appears to support the assumption that here is a big overlap between dementia and the MCA.

A simple and obvious yet very important observation about legal frameworks is that they require compliance, in ways that differ from other frameworks that should be taken into account or guide interventions in health and social care, such as evidence-based practice. Acting unlawfully carries sanctions; for example, the MCA includes a criminal offence of ill-treatment or neglect of a person who lacks capacity. Practitioners also risk being struck off from their profession and losing their job if their practice is not compliant with the law. Evidence about practitioners' adherence to legal frameworks is very limited. Only one reference could be found regarding the

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[4] It is worth noting that by comparison, in 2023/24 there were 50,434 detentions under the MHA, and some of these would be repeat detentions involving the same person (NHS Digital, 2024b).

MCA in this respect, relating to the number of criminal prosecutions involving staff under the Act in 2013-14 (McNicholl, 2014). The number was significant (349), but tiny given the numbers of people affected by the MCA. One might hypothesize that if practitioners had to make a choice, they would generally prioritise acting lawfully, over following the wishes and demands of service users and family carers for example, although no research could be found conducted in this area

However, as VBP asserts, values in the absence of evidence makes decision-making much more complicated and the MCA contains both explicit and implicit values which must be applied to ensure lawful practice. However, despite appearing to be reasonable and appropriate, several of those values are not supported by an evidence base that proves their efficacy.

The clearest example of explicit values in the MCA are the five principles that underpin it and are referred to as values in the MCA's Code of Practice (Office of the Public Guardian, 2005). Furthermore, according to section 4(6) of the MCA, any best interests decision made on behalf of a person who lacks capacity must take into account their “past and present wishes and feelings” and “beliefs and values” that might influence the decision if they had capacity (*Mental Capacity Act 2005*). The MCA's Code of Practice does not attempt to define what the Act means by ‘values’, although the suggestion is that values can be identified through people's “cultural background; religious beliefs; political convictions, or past behaviours or habits*”* (Office of the Public Guardian, 2005, p.83). However, as was argued at the time the MCA came into force, best interests was a legal concept that had its scope widened to apply to everyday health and social care decisions without any significant evidence base to support it (Dunn *et al.,* 2007; Hope *et al.,* 2009).

As well as values being explicitly referred to in the MCA they may also be applied implicitly when the Act is used. According to section 3(1)(c) of the MCA, part of the test of capacity is the person's ability to "use or weigh" the information required to make the decision (*Mental Capacity Act 2005*). Evaluating information in this way is likely to involve (and reveal) a person's values. It should be noted that the MCA's 'functional' capacity test, which includes the person's ability to use or weigh up information, has an evidence-base as it closely resembles an instrument known as the MacCAT-T, designed and successfully tested for clinicians to assess mental capacity (Grisso *et al.*, 1997).

Implicit values are also present in section 1(4) of the MCA which states that a principle of the Act is that someone should not be deemed to lack capacity merely because they make an "unwise" decision (*Mental Capacity Act 2005*). There is no detailed definition in the MCA Code of Practice for what constitutes an 'unwise decision', beyond suggesting they could include decisions that others thought to be unwise or were unhappy with, or put the person at "significant risk of harm or exploitation or…is obviously irrational or out of character" (Office of the Public Guardian, 2005, p.25), though these might also indicate a lack of capacity. The Code does not describe in any detail how to differentiate between an 'unwise' decision and a lack of capacity, nor is there an evidence base or NICE guidance for what constitutes an 'unwise' decision. An analysis of judicial determinations involving unwise decisions (and best interests) came to the conclusion that abstracted values played a very significant role in resolving these determinations (Coggon and Kong, 2021).

It is also worth returning to the point made earlier about practitioners ensuring their practice is lawful. In the case of the MCA it is fairly safe to assume that practitioners will want to decide on unwise decisions and best interests using what they perceive to be the ‘right’ values. If they use the ‘wrong’ values, it not only affects the person who may lack capacity but the practitioner could face legal sanctions as well. But in theory this appears to challenge VBP’s binary between values and evidence, and non-hierarchical approach to values. The values expressed in the MCA require compliance, almost as if they were evidence, but this then gives them a special status and appears to elevate them above other values, such as professional or personal values.

The interaction of the MCA in dementia care therefore requires having knowledge of how to apply values expressed in law, an understanding of the values of a person with dementia, as well as an awareness of how a practitioner’s values or a family carer’s values might affect that interaction. As a result, it would appear to be both an important and potentially very revealing area for VBP to explore.

Although decision-making is a key focus of VBP, there has been limited discussion about VBP in relation to issues of mental capacity and impaired decision-making in the context of the MCA. This is perhaps surprising as VBP has addressed the issues of conflicting values that arise in relation to compulsory detention and treatment for people with mental disorders and legal issues associated with informed consent (Molodynski *et al*., 2010; Dunn *et al*., 2018; Muir-Cochrane *et al*., 2018). As already mentioned, VBP has also been influential on mental health legislation in England and Wales.

Several publications that reference VBP have included discussion of issues concerning decision-making, mental capacity and values which referred to the MCA, although these have not focused specifically on dementia. These have included consideration of capacity in relation to consent (Fulford *et al.,* 2006; Van Staden, 2015), advocacy (Cowley, 2015), shared decision-making (Adshead *et al.,* 2018) and values associated with concepts of autonomy and rationality (Craigie & Bortolotti, 2015; Radoilska, 2013). In a publication edited by Radoilska, arguments are put forward about the value-laden nature of the MCA (Holroyd, 2012; Fistein, 2012), which is also commented on in Morgan *et al.* (2015) where VBP is proposed as a useful way of resolving conflicts that may arise when applying values contained in the MCA.

Hughes makes a closer connection between VBP, dementia and the MCA in his 2014 publication (Hughes, 2014). Hughes discusses values in relation to key processes contained within the MCA such as identifying an ‘unwise’ decision or determining a person’s ‘best interests’, particularly in relation to palliative care. He also discusses VBP in relation to mental capacity and dementia, and points to some VBP literature which pays much more attention to the concept of ‘mental disorders’ than it does to dementia in the context of mental capacity. The latter is seen as more ‘factual’ by virtue of its organic nature. However, he refrains from attempting a comprehensive application of VBP to the MCA or how values expressed through legal frameworks such as the MCA might pose particular challenges for VBP. Certainly nothing has been published to indicate that VBP has actively engaged with the Mental Capacity Act, its Code of Practice or practitioner training in the way VBP did with the Department of Health regarding changes to mental health legislation (Care Services Improvement Partnership and the National Institute for Mental Health in England, 2008). In a much later publication Hughes explores dementia, VBP and the MCA in more detail but still refrains from considering the implications for VBP of the interaction between dementia and the MCA (Hughes, 2023).

1.4.2. Disability and human rights legislation

The MCA therefore provides a good example of values expressed in law, interacting with dementia care and the yet to be explored implications this has for VBP. However, it is also relatively easy to spot explicit and implicit values in other legal frameworks relevant to this thesis, including disability and human rights. These include the 'wellbeing' principle that is central to the Care Act 2014, and the social model of disability (SMD) that underpins the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the Equality Act (see Appendix A). With a couple of exceptions (described in Appendix A), neither of the values-based concepts of 'wellbeing' and SMD use evidence-based practice to justify the legal requirements they underpin, but they still demand legal compliance. It is worth noting that SMD has been remarkably influential in both policy and practice, is based on values that in many ways stand in opposition to a biopsychosocial model of disease and disability, and that dementia friendly communities can partly be construed as an example of SMD (Shakespeare, 2017; Shakespeare, *et al.*, 2017).

Key VBP texts make only very limited reference to human rights and equalities legislation. Given the global status of human rights one might expect them to feature more prominently in VBP's recent textbook, *International Perspectives in Values-Based Mental Health Practice* (Stoyanov *et al.*, 2021). However, there is very little reference to them, and there is no reference to the UNCRPD. There is also no discussion of disability, although the Equality Act Is referred to in relation to a chapter on race equality and VBP training (Woodbridge-Dodds and Hunkins-Hutchinson, *ibid,* pp.379-389). Human rights also do not feature significantly in other key VBP literature, although they are mentioned in relation to the importance of practicing within the law (Morgan *et al.*, 2015) and in connection with universal morality

(Beauchamp, 2015). An argument is also put forward for a human rights-based approach to mental health, particularly in lower and middle income countries (Fernando and Sumathipala, 2015). It should also be noted that in three separate VBP texts Fulford favourably cites an interpretation of rights contained in the UK's Human Rights Act as a framework of values for decision-making, similar to VBP's framework of shared values, rather than a checklist of rights to be strictly adhered to (Fulford *et al*., 2012; Fulford, 2014; Sadler *et al.*, 2015). How far Fulford is suggesting that values expressed in human rights are of no more significance than any other values is not clear, but it might be argued that his interpretation of Woolf's position could lead to a misunderstanding of the legal status of values expressed in law. Despite searching the VBP literature, I found no reference to linking VBP, human rights, and equalities legislation with dementia.

Regarding the SMD, my search found no discussion of it in relation to VBP in the VBP literature. Although some of the case studies in *Essential Values-Based Practice* included descriptions of long-term health conditions which could lead to disabilities or impairments, these are only referred to in clinical terms, and there are no case studies that use the term 'disability' (Fulford *et al*., 2012). In literature associated with VBP through its online library[5] there are two references to disability studies, including one that considers a human rights-based approach for people with learning disabilities but neither make explicit links with VBP or SMD (Barnes, 2016; Roberts *et al.*, 2013).

Given the values contained in human rights and equalities legislation, the MCA, and in SMD, and their relevance to health and social care practice, they all appear to be

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[5] https://valuesbasedpractice.org/vbpreferencelibrary/

potentially fruitful areas for VBP to explore. To date, this has only been done sporadically, if at all.

1.5. Summary

Dementia is a major health condition affecting millions of people worldwide. As a progressive, terminal condition affecting the mind and brain, lacking a cure and with treatments of limited efficacy, it is unlike other major mental disorders. VBP is an important framework, both in theory and practice, that can help address fundamental problems where EBP is limited in both health and social care. Yet dementia has received scant attention in VBP literature. This thesis will suggest that there are unique and valuable opportunities for VBP to develop by looking at values expressed by people with dementia, and the interaction of dementia with values expressed or underpinning several important legal frameworks.

Chapter 2

Development of a narrative from my published works

2.1. Introduction

This chapter uses evidence drawn from twenty of my published works to show how they make an important and original contribution to knowledge, in terms of both the theory and practical application of values-based practice (VBP). This contribution is based on publications I authored or co-authored, focusing on various aspects of dementia, particularly people’s lived experience of the condition, and the interaction of legal frameworks with people with dementia, family carers and practitioners. Although only a minority of the publications refer explicitly to VBP, through a critical analysis of the publications the chapter demonstrates how personal, professional and legal values relevant to dementia care both challenge VBP’s existing framework while also giving it opportunities to develop.

The chapter is divided into four sections, followed by a summary of the chapter. The first two sections (2.2 and 2.3) consider seventeen of my published works that focus on particular aspects of dementia and the implications this has for VBP. Section 2.2 identifies evidence from eight of my publications about the values of people with dementia and the implications this has for VBP. Section 2.3 considers evidence from a further nine publications about values involved in the interaction of legal frameworks with people with dementia, family carers and practitioners, with a particular focus on social care, and the implications these have for VBP. Section 2.4 discusses two publications where VBP is explicitly referenced and applied to dementia. The final section draws on a published report from an international dementia research study on ‘dementia friendly communities’ (DFCs), to illustrate and summarise the original and important contribution that my published works make to the development of VBP.

2.2. Published works about the lived experience of people with dementia

The centrality of the service user and their values is fundamental to VBP and person-values-centred practice is one of the key elements of VBP's 'good process' for balanced decision-making within a framework of shared values (Fulford *et al*., 2012). It therefore seems appropriate to begin this chapter by considering the contribution my publications make in identifying the values of people with dementia and the implications this had for VBP.

2.2.1. The collective voice and values of people with dementia

Three of my published works were based on a research study and capacity-building project I led on that focused on a growing 'service user' involvement movement of people with dementia (Williamson 2012a; 2012b; Litherland and Williamson, 2013). The project became known as the Dementia Engagement and Empowerment Project (DEEP) and was the first UK-wide study of groups actively involving or led by people with dementia. As discussed in the previous chapter, studies had been published previously exploring the participation and involvement of people with dementia in particular areas such as training and education. However, there had been no research that looked more broadly at the nature and development of groups of people with dementia which aimed to collectively influence across a wide range of areas relevant to dementia.

The research study used a multi-methods approach (Lewis-Beck *et al*., 2003). This included a literature review, a questionnaire survey, and group interviews. The survey collected qualitative and quantitative data from both groups and individuals with dementia, and recorded 43 groups involving people with dementia. Data supplied by seventeen of the groups indicated they were ‘activist’ groups and people with dementia were involved substantially in the groups’ leadership. While two-thirds of the groups were in contact with twenty or less people with dementia, four groups stated that they were in contact with over 100 people with dementia. Caution should be exercised about self-reported figures, but it would appear that more than 500 people with dementia were involved across the various groups that took part in the study. Most of the participation studies cited in the literature review had much smaller samples or were focused on the lived experience of people regarding particular practice interventions rather than the active participation of people in wider involvement activities.

The subsequent growth and development of the DEEP network has not revealed any groups that existed at the time of the study which the research failed to identify or include. The study would therefore appear to provide a comprehensive overview of groups actively involving or led by people with dementia at the time the study took place.

Fifteen individual questionnaires were completed by people with dementia, and people with dementia participated in some of the group interviews. It was not reported in the publications how many people with dementia were directly involved in completing the group questionnaires or participating in group interviews, and I was not present at the time of the data collection. It was reported that staff involved in supporting several groups provided some of the responses, therefore this proxy reporting means that there needs to be some caution when interpreting the findings.

Findings from the research in the publications reported on the activities carried out by the groups, as well as how the groups were organised, their achievements, the challenges they faced, and their views on a national DEEP network of groups. All of these are good indicators of values important to people with dementia who participated in the study.

Activities carried out by the groups included sharing the lived experience of dementia for the purposes of staff training, service and policy development, and shaping research; challenging the general stigma associated with dementia; and providing peer support to others with lived experience. Activities such as these reflect values underpinning concepts such as empowerment, co-production, awareness-raising, and peer support, which are common features of similar initiatives involving people with other health conditions or disabilities (Fawcett *et al*., 2017). Sixty-eight percent of respondents to the survey said that people with dementia decided what activities their groups did. The significance of these findings is that they demonstrated that large numbers of people with dementia were not passive recipients of care but had real agency as individuals and collectively; they could express their values and be active participants in trying to shape the care and support that they and others needed.

People with dementia were also reported as believing that their active participation in the groups could help slow the progress of their dementia, through the cognitive stimulation provided by the activities and interactions that being part of the group involved. Participation therefore was seen to be a form of therapy, and the publications suggested this was based on a value of acceptance of a diagnosis of dementia. There was no evidence reported that people rejected dementia as a diagnosis, and this is consistent with evidence from other studies about the subjective experience of receiving a dementia diagnosis (Bunn *et al.*, 2012; Perry-Young *et al*., 2018; O’Malley *et al.*, 2021). This is in contrast to the mental health service user movement where people with mental health problems often expressed values which challenged the validity of psychiatric diagnoses (Lacey et al, 1993; Rogers and Pilgrim, 2014).

Another difference that was reported by people with dementia concerned the value of interdependency, commonly expressed by people with other health conditions through peer support, service user groups. However, the publications reported that people with dementia emphasised the importance of family members and friends in supporting them to participate in the DEEP groups. Dementia services and practitioners were reported as generally being seen in a positive light, often playing important roles in supporting the groups. Again, this differs somewhat from the mental health service user movement where interdependency involving family members tends to feature less, and there is greater emphasis on individual autonomy, with professionals and services often being viewed with suspicion, fear or hostility (*ibid*).

The findings in these two DEEP publications are important for VBP in several ways. Firstly, they make it clear that a diagnosis of dementia does not render people ‘value-less’. The findings indicate that people with dementia continue to have values, and that large numbers of them want to be involved, both individually and collectively, in ways to improve their lives and the lives of others with dementia based upon their values. Secondly, the ‘research into practice’ element of the study was very successful (Byrne, 2011), as the DEEP network continues to this day and has over 80 groups with a significant legacy of work. This also includes ongoing activities, such as research led by people with dementia (Innovations in Dementia, no date(a);

Innovations in Dementia, no date(b)). This means that both symbolically and geographically, the values of people with dementia are ‘on the map’ for VBP in the UK and the groups in the DEEP network are potentially available for further research into VBP. The different views that some people with dementia expressed about the condition, compared to the views of many service users with mental health issues about mental disorders, also indicates that there may be important and interesting differences in values held by people with dementia that VBP could explore.

2.2.2. Values and the involvement of people with dementia in research

The values of people with dementia, and their ability to engage with values-based concepts through research, was a significant feature of two further publications I co-authored (Clarke et al, 2018; 2020). These papers, published in peer-reviewed journals, described a qualitative research study I was involved in where people with dementia were co-researchers, to support the analysis secondary data from a previous research study about the roles of ‘dementia advisers’ and ‘peer support network services’ that were set up under the first national dementia strategy for England in 2009 (Clarke et al, 2013).

The study (described in the papers I have included in this thesis) was based on a model of ‘participatory research’, a recognised model in research whereby research participants are also research ‘partners’, actively collaborating with the professional researchers and contributing to different aspects of the research process (Burns et al, 2021). Values such as empowerment, respect, and partnership were therefore key to the success of the study.

The papers acknowledged previous examples of participatory research involving people with dementia but made the point that this study was unique in its focus on people with dementia as co-analysts in the study, using a particular methodological approach. This approach required people with dementia to analyse the secondary data using two, values-based theoretical frameworks; Douglas's 'cultural theory of risk', and Tronto's 'ethic of care' (Douglas and Wildavsky, 1982; Tronto, 1993). A series of workshops were held to analyse the secondary data, some of which I facilitated, for four groups of people with dementia and family carers (recruited via the DEEP network of groups described above). In total, 34 people with dementia and family carers supported the analysis. The workshops presented the secondary data and the frameworks in ways that were accessible to the co-analysts.

The papers showed how people with dementia, individually and collectively could engage with, discuss and apply values as part of a research process, as well as identify and express values about care and support for people with dementia.

The first paper focused on the research methodology and the ability of people with dementia to act as co-analysts (Clarke et al, 2018). Initially their contributions were based mainly on their personal experience. However, as the relationships between them and the professional researchers developed, and the workshops were refined iteratively to enhance accessibility, the co-analysts were increasingly able to discuss the connections between their personal experiences, the secondary data, and the theoretical frameworks, and the values these entailed.

The second paper focused on the findings that came out of the participatory research process (Clarke et al, 2020). Analysis by the professional researchers attending the workshop discussions identified three processes that the co-analysts considered key to care and support of people with dementia. Rooted in the value of co-operation, these were co-operative communication, co-operative action, and co-operative care. As authors of the paper, we considered these to reveal more profound values of solidarity, inclusion and citizenship.

The importance of these two papers, however, is in the evidence they provide about the ability of people with dementia to engage, discuss and express values, including the use of values as part of a research methodology, rather than the specific values identified. Nevertheless, it is important to note that considerable effort was required to make the research methodology accessible for people with dementia. In addition, to gain ethical approval people with dementia being co-analysts were required to be defined as ‘research participants’ in the ethics application, rather than co-researchers. The papers acknowledged that the values of the professional researchers shaped and drove the project and it was a self-selected sample of people with dementia and family carers that participated.

Yet despite not mentioning VBP, the papers illustrate several aspects of VBP in action involving people with dementia, albeit, in a non-clinical setting. These include awareness, reasoning, knowledge and communication of values, being person-centred, partnerships and teamwork, and the importance of linking evidence with values. The papers provide further evidence that research into VBP could and should include people with dementia.

2.2.3. The values of people with more severe dementia

Evidence about the relevance of dementia to VBP in the publications discussed so far has involved people with dementia who were able to express or discuss their values as part of a research process. The final three publications to be discussed in this section that I authored or co-authored provide possible evidence about the values of people with dementia where the severity of their cognitive impairments made it difficult or impossible for them to express or communicate their values (Williamson and Kirtley, 2016; Williamson, 2018a; Kirtley and Williamson, 2016).

The publications describe a multi-methods research study that explored the experiences of people with dementia exhibiting particular effects seemingly caused by dementia, often referred to as behavioural and psychological symptoms of dementia or ‘BPSD’ (Colm *et al.*, 2024). Described in medical terms as delusions, hallucinations, confabulations and extreme confusion, these symptoms of dementia included the person believing and behaving as if they were living in a different time or place to where they actually were, not recognising family members or believing they were someone else, or behaving in ways that were completely different to how they behaved before developing dementia.

While the study focused on a topic which already had a considerable literature base, it had originality in elements of its methodology, and its focus on what experiences of different realities and beliefs meant to people with dementia. In addition to research methods including a literature review, survey, and focus groups, the study used an expert panel approach (Walker, 2023). The expert panel involved practitioners, academics, people with dementia and family carers and collectively interviewed participants, discussed the data collected, and gave feedback on the publications. Participants included practitioners as well as people with dementia and family carers. To encapsulate the multi-methods approach, the study was called an ‘inquiry’ and the expert panel was known as the ‘inquiry panel’ (see Chapter 3 for further details and reflections on the research methodology). The study aimed to explore was whether the BPSD experienced by people with dementia were more than just symptoms of dementia but were important and meaningful experiences for the person with dementia. To reflect this possibility, the study used the terms ‘different realities’ and ‘different beliefs’. In addition, the study aimed to explore the most appropriate responses by practitioners and family carers when people with dementia had these experiences.

If these different realities and beliefs were important and meaningful for the person with dementia, it would suggest that people with severe dementia continued to have values which could shape the way they behaved and responded to those experiences. However, in designing the study it was recognised that collecting data directly from people with dementia experiencing different realities and beliefs was very difficult. The publications acknowledged that this meant there was an element of speculation to the findings from the study. However, the publications emphasised that a benefit of using the inquiry research model was in the way it brought extensive experience from a range of experts and people with lived experience of dementia and different approaches to collecting, analysing and interpreting the data.

The findings reported in the publications led to the conclusion that in a large number of situations different realities and beliefs experienced by people with dementia were important and meaningful to the person with dementia, and should not just be considered as medical, psychological or behavioural symptoms of the condition. Explanations included the person ‘time shifting’ to an earlier stage of their life and acting on that basis, or using reference points from that stage of life to interpret their current situation. Another explanation involved the possibility that the experiences were expressions of need which might be social or emotional, but could also be psychological or physiological. Another suggestion was that the experiences might represent a coping strategy, or an effort to understand or retain a sense of identity in a situation they found difficult to understand. In some situations it seemed possible that people’s values had changed and a previously held belief was no longer important.

For the reasons already stated, caution should be exercised regarding the findings from this study but it is reasonable to conclude that evidence cited in the publications indicates that people with severe dementia can retain and express values, albeit in ways that may be difficult initially for practitioners and family cares to understand. VBP is therefore very relevant as a means of exploring these values and the often difficult situations they can give rise to.

Different realities and beliefs also have implications for VBP in how practitioners and family carers respond to people with dementia when having these experiences. The publications, and the inquiry’s literature review (Kartalova-O’Doherty, 2014), explored in detail the evidence collected in the study regarding interventions and responses to people with dementia having these experiences. People with dementia could become very distressed, paranoid, hostile or even physically aggressive but in most situations, there was very little evidence supporting interventions that could remove the different reality or belief, or reorientate the person to the actual reality they were in. Instead, most interventions were aimed at reducing distress and associated behaviours, including the use of anti-psychotic medication. Several interventions referred to in the literature review involved acknowledging or validating in different ways, the person’s reality or belief (*ibid.*). The three publications included in this thesis reported considerable evidence collected by the inquiry to indicate that acknowledgement and validation interventions were often very effective. However, all three publications went on to describe the complex ethical debate that this generated because all these interventions were based on varying degrees of dishonesty.

There is little discussion in the VBP literature about honesty, although where it is referred to it is presented as a virtuous and positive value (Tyreman, 2011). It is therefore easier to envisage VBP excluding dishonesty, in the same way as it excludes racism, rather than condoning it as a legitimate value to be considered. My three publications pointed out that honesty is a key requirement of practitioners, and included in professional codes of conduct. It is also deemed by many people to be a very important personal value. Trust lies at the heart of practitioner-client/patient interactions and therapeutic relationships (Taylor-Smith, 2023). But if VBP were to exclude dishonesty as a value then VBP cannot be operationalised in situations where interventions to alleviate the distress of a person with dementia which may involve an element of dishonesty are being discussed or debated. The publications described considerable differences of opinion on the issue of honesty, and while some people with dementia involved in the study were uncomfortable with being dishonest many practitioners and family carers took a more pragmatic view. Some degree of consensus was reported as being reached whereby the principle of ensuring the person's wellbeing (a value-based concept in its own right) should guide the response or intervention, even if this involved some degree of dishonesty.

While the values of people with dementia experiencing a different reality or belief may be difficult to discern, the findings of these publications that included evidence from people with the condition, indicated the possibility that their values may be playing an important role. The literature about BPSD frequently refers to the difficult situations that they may give rise to, which could lead to disagreements about the most appropriate response or intervention to use (Ostaszkiewicz *et al.*, 2015; Feast *et al.*, 2016). VBP is therefore clearly relevant but also faces the challenge of how it addresses dishonesty as a value where dishonesty informs or underpins those responses and interventions. The publications show how important it is for VBP to explore the experience of dementia in order for it to develop theoretically, but also for its practical application to be relevant to the condition.

2.3. Published works about dementia, legal frameworks, and values

This section considers evidence drawn from my published works regarding the implications for VBP when values expressed in law interact with the values of people with dementia, family carers and practitioners. As indicated in Chapter One, legal frameworks relevant to the care and support of people with dementia is an under-explored area in VBP literature. Laws such as the Mental Capacity Act 2005 (MCA) contain both implicit and explicit values that are fundamental to its use in practice. Other legal frameworks relevant to people with dementia, such as the Equality Act 2010, are under-pinned by the values-based social model of disability. Publications in his section include journal papers and reports that described research studies and other work which explored these laws in practice, including their use for people with dementia. I will particularly focus on findings that concern how the laws were used in social care for people with dementia, as social care is another area where VBP has only paid limited attention.

All the legislative frameworks researched and discussed in the publications included in this section came into force less than ten years before the publications were completed. In the case of the MCA, the publications researched areas of practice which had come into existence only five years before the first publication. Similarly, recent equalities legislation had not been explored in relation to dementia either at the date of the relevant publication. In this respect, the publications were based on important and original research when they were published.

2.3.1. 'Best interests' decisions under the Mental Capacity Act 2005 involving people with dementia

Four publications in this section concern the MCA (Williamson, 2011; Williamson *et al*., 2012; Williams *eta al*., 2012; Williams *et al*., 2014).

The first of these was a theoretical paper I authored for a peer-reviewed journal (Williamson, 2011). The paper was a commentary on another theoretical paper in the same journal that described an anthropological reflection on the concept of mental capacity, referred to by the author as mental 'competence' (Doorn, 2011). Doorn's paper referred to a range of values in their conceptualisation of mental capacity which differed significantly from how mental capacity was defined in the MCA. My commentary discussed some of the values Doorn referred to, particularly in relation to the MCA and the values it contained, and I raised some concerns about Doorn's conceptualisation of mental capacity. I concluded my paper by expressing reservations about introducing a new conceptualisation of mental capacity in England and Wales when the MCA had only just come into force and pointed to evidence indicating that the MCA's conceptualisation was still poorly understood (Department of Health, 2008; Myron *et al.*, 2008; Wearing and Lloyd, 2009) .

The significance of this paper was that it was my first publication where I linked dementia with values, including values expressed in law. My paper drew upon earlier research I had done involving people with dementia (Williamson, 2008a; Williamson, 2010; Levenson and Williamson, 2009), a peer-reviewed journal paper about VBP I had authored and research I had been involved with in relation to VBP (Williamson, 2004a; King *et* al., 2009), and research about the MCA (Myron *et al.*, 2008). The paper was an early indication of how dementia, and its interaction with the law, might have potential implications for VBP.

The other three publications concerning the MCA included in this section are two journal papers (one peer-reviewed) and a research report (Williamson *et al*., 2012; Williams *et al*., 2012; Williams *et al*., 2014). All three are based on a large research study I was involved with, including its design and analysis, that investigated best interests decision-making under the MCA in health and social care in England. It was a multi-methods study, using both qualitative and quantitative methods, involving focus groups, an online survey, telephone and face to face interviews. Interview participants were selected from the online survey which had 385 responses. Participants were health and social care practitioners from a range of disciplines working with people with different impairments, including dementia.

As discussed in Chapter One (Section 1.4.1), the MCA provides a rich source of both implicit and explicit values that VBP could consider, irrespective of the impairment a person may have to whom the Act is applied. However, the three publications describing the study provide a good basis for examining those values and the implications for VBP through the lens of dementia, particularly in relation to social care. The paper I was lead author on explicitly focused on findings from the study relating to dementia (Williamson *et al*., 2012).

The online survey collected mainly quantitative data from practitioners about decision-making situations (‘cases’) involving the MCA. Thirty-eight percent of the cases reported involved people with dementia, the largest impairment group in the study. Best interests decisions involving people with dementia concerning social care matters were reported as being almost as frequent as decisions involving health care issues. This was statistically significant compared to all the other main impairment groups where most best interests decisions involved heath care. Social care best interests decisions involving a move to or from a care home were much more common for people with dementia than other impairments groups. Changes in accommodation such as these are complex and life changing decisions, involving not only important values held by the person with dementia but also the values of family carers and practitioners. These values are therefore, in their own right, worthy of exploration by VBP. Social care practitioners also accounted for the largest single group of professionals who led best interests decisions on behalf of people with dementia (21% of cases reported in the online survey).

The publications also made the observation that people with dementia were somewhat disadvantaged in best interests decisions, and the assessment of capacity that preceded them, compared to other impairment groups. Evidence was provided in the publications to support this and values appeared to play an important role. Evidence was given of practitioners assuming a person with dementia lacked capacity because of their (old) age, diagnosis or particular symptoms of dementia, although deciding a person lacked capacity based on these grounds alone, ran contrary to the principles and processes of the MCA. There could be complex interplay between the values-based principle in the MCA regarding unwise decisions, and values-based concepts such as ‘risk’ and ‘insight’, in both capacity assessments and best interests decisions involving people with dementia. This was especially the case where a person with dementia wanted to remain in their own home but practitioners and / or family members believed they would be much safer living in a care home. It was noted that the MCA’s principle of always considering the ‘less restrictive’ care option rarely featured in cases involving people with dementia. Other evidence was cited of the disadvantages people with dementia experienced and the publications concluded that ageism, and rights-based approaches being less well embedded in dementia services compared to other impairment groups, were a significant part of the reason for this. The publications therefore indicate potentially fruitful areas for VBP to explore where the MCA was misapplied regarding people with dementia, especially in complex social care decisions. These include the challenge of discerning and respecting a person's values, applying values expressed in law correctly, and ensuring that other values-based concepts do not override the principles and processes of the law.

However, and somewhat contradictorily, the publications also provided evidence of good practice concerning people with dementia in the application of the MCA that involved values, which also provides important learning for VBP. Taking into account a person's values is an explicit requirement in the MCA of the best interests process and this was reported as being done in more cases involving people with dementia than any other impairment group. Even where there was evidence indicating the MCA had been incorrectly put into practice, this occurred very little in cases involving social care decisions involving people with dementia.

Two further areas of relevance to VBP that the publications pointed to concern the way practitioners made best interests decisions, and disagreements about best interests decisions involving people with dementia.

Compared to other impairment groups, the best interests decision-making process often took much longer in cases involving people with dementia. One reason given for this was that many of the decisions involved changes in accommodation which by their nature tended to have much longer timescales than a decision about medical treatment, for example. From VBP's point of view, decision-making processes taking place over days or weeks afford much more potential to explore the role values play, than a decision that might be taken in a matter of minutes. However, as a corollary to this, an important finding reported in the publications concerned who made the best interests decisions. According to the MCA there should be a single decision maker but findings based on the qualitative data (not broken down by impairment groups) indicated a strong preference among practitioners for shared responsibility for decision-making, based on principles of seeking consensus and multi-disciplinary working. While this approach might reflect elements of VBP's process, aiming at balanced decision-making within a framework of shared values, it is not consistent with the requirements of the MCA. This indication that professional values overrode values expressed in law, despite this leading to unlawful practice, would be another fruitful and important area for VBP to explore.

The publications considered disagreements about a person's best interests which were reported in 18% of the cases in the online survey. Sixteen percent (n=24) of these involved a person with dementia which was lower (though not significantly) than nearly all the other impairment groups. Disagreements involving people with dementia typically involved social care decisions where the person with dementia wanted to continue living at home but professionals and family carers believed they would be safer living in a care home. These decisions therefore involve plenty of scope for interactions between opposing values of safety versus autonomy. Where disagreements arose, the publications concluded that taking a person-centred approach that focused on the values of the service user was the most effective approach to take, which echos VBPs emphasis on the centrality of a person-centred approach and service user centrality.

A central aim of VBP is to help resolve disagreements involving values. The publications indicate that disagreements about social care best interests decisions concerning people with dementia often involved a complicated interaction of personal, professionals and legal values. These decisions therefore provide valuable opportunities for research that explores VBP in practice.

The publications pointed to the obvious importance of a rights-based approach in situations where the law clearly applied. Furthermore, the publications provided evidence of how the MCA had been broadly welcomed by practitioners because of the legal clarity it brought to professional practice, indicating a particular significance for values expressed in law. But the implication of this for VBP suggests that values expressed in law may have a different status to other values. One might expect compliance with the law to take priority over being led by a service user's values where the two were in conflict. One could therefore refer to values expressed in law as 'hard' values and those expressed by a service user or family carer as 'soft' values, but this suggests a hierarchy of values where, contrary to VBP's approach, the centrality of service user values are displaced by values expressed in law (Fulford, 2012). It is further complicated by practitioners applying professional values that are not in keeping with the law, such as multi-disciplinary, shared decision-making when making best interests decisions. But it is precisely these complications, evidenced in the publications, that demonstrate their importance to advancing VBP thinking.

2.3.2. Social care direct payments for people with dementia

A further example of the challenges that values involved in social care best interests decisions posed to VBP, involving people with dementia, is a feature of the fifth publication considered in this section (Laybourne *et al*., 2014). This paper, published in a peer-reviewed journal, described a research study I co-designed, that explored the use of social care 'direct payments' for people unable to consent to them, mainly people with dementia or learning disabilities. Direct payments are, in effect, a cash transfer from a local authority to a service user, to enable the service user to make decisions and exercise control over the services they use to meet their identified care and support needs. For someone who lacks capacity to make these decisions, a ‘Suitable Person’ (SP), such as a close family carer, can be legally authorised to make those decisions for the service user, providing they are in the service user’s best interests, as defined by the MCA (*The Community Care, Services for Carers and Children’s Services (Direct Payments) (England) Regulations 2009*).

The paper echoed the previous publications’ finding that despite expecting compliance with the values expressed in law, especially regarding the centrality of the wishes and feelings, beliefs and values of the person lacking capacity determining a best interests decision, other values that were not in keeping with the MCA often shaped the decision. In particular, it was often the values of the SP that determined what the direct payment was used for and it was not always clear that this was co-terminus with the best interests of the service user. The paper made the point that unless a family carer was very legal-minded it was perhaps understandable that they might have less understanding of the law than a professional but an important role for practitioners was to ensure that SPs understood the law, and this was not always reported as taking place.

However, the inclusion of the SPs’ values in best interests decisions also invites a reconsideration of the centrality given to service user values in VBP (and the MCA). Using a direct payment to obtain the services of a care worker to give the family carer a break could be in their best interests as well as the best interests of the person with dementia. This approach reflects shared values and values underpinning theories of relationship-centred care (Nolan et al, 2001; Reid, 2021) or the feminist-influenced, ethics of care (Gilligan, 1982: Tronto, 1993; Held, 2005), both of which draw attention to the role of family carers, especially women, as opposed to the focus on the individual service user in person-centred care.

Cases involving people with dementia reported in the paper were in a minority compared to people with learning disabilities despite the former being a greater proportion of users of local authority social care services. Citing additional evidence, the paper makes the point that values of choice and control offered by direct payments appeared to be of less importance to older people compared to younger adults with disabilities. This raises interesting questions for VBP about different age cohorts having some shared ‘generational’ values which could be helpful when trying to discern the values of a person with dementia who was unable to communicate what was important to them. However, the onus should always be to identify the values of the individual first, rather than assuming their values based on generalisations about their age cohort.

2.3.3. Disability rights, the social model of disability, and dementia

The publications considered so far in this section indicate how social care best interests decisions under the MCA involving people with dementia provide new and valuable perspectives on VBP. The types of social care decisions considered, commonly for people with dementia involving changes in accommodation or less commonly the use of direct payments, are rich in values and there is no clear evidence base to indicate what constitutes the ‘right’ intervention. However, the studies described in these publications did not collect evidence directly from people with dementia. The discussion about their values and the implication this has for VBP therefore remains somewhat speculative. Furthermore, social care interventions such as direct payments are underpinned by a wider, values-based social model of disability (Glasby, 2005). The social model of disability (SMD) blurs the divide between values and evidence, and lies at the heart of other legal frameworks relevant to people with dementia. The next publications to be discussed in this section not only directly involved people with lived experience of dementia but also involved exploring their values in relation to SMD and the legal frameworks it underpins.

As discussed in Chapter One (Section 1.4.2), the evidence base for the development of SMD were the values of people with disabilities, rather than traditional medical research, but SMD has been very influential in shaping public attitudes, social care, and legal frameworks. However, prior to 2015 there had only been one academic article published that explicitly considered how SMD's conception of disability, and how disability was defined in law, related to dementia (Gilliard *et al.*, 2005).

Two of my published works describe a policy discussion project that explored the applicability of SMD, and legal frameworks that are based upon it, for people affected by dementia (McGettrick and Williamson, 2015; Williamson 2015a). The project incorporated an element of qualitative research, that included people with dementia in dialogue with activists with other disabilities, through an expert panel and a consultation event.

The publications demonstrate the relevance of values (referred to as 'principles') underpinning SMD, legal frameworks and a human rights-based approach (HRBA – Cahill, 2018) to dementia policy and practice, and the implications of this for VBP. The publications provided evidence of how and why dementia could be understood as a disability as defined by SMD, including examples of SMD and HRBA values in practice, such as the DEEP network, 'dementia friendly communities', and the Scottish national dementia policy (Scottish Government, 2010).

The publications acknowledged possible reservations about applying SMD and HRBA values to dementia, including views expressed by some people with dementia that they considered their condition as a disease, not a disability. However, the publications make the point that a self-definition of dementia does not preclude someone from the protections afforded by legal frameworks like the Equality Act and UNCRPD. Nevertheless, while endorsing the benefits of understanding dementia as a disability, the publications do this in the context of a model of SMD that allows for the individual's subjective experience of the condition. The publications conclude that legal frameworks based on SMD and HRBA would enable people with dementia to be, and be perceived to be, active citizens with the same rights as the rest of the population, rather than being treated as passive recipients of services with a disease 'victim' status.

The publications had an explicit aim of influencing policy and raising awareness about the relevance of disability rights to dementia. While research was used to support this aim, neither publication was a research paper *per se*, so a degree of caution needs exercising about the conclusions that can be drawn. Nevertheless, the publications clearly illustrated a meaningful interaction between dementia and the 'fact values' contained in or underpinning legal frameworks. Importantly, this included the endorsement by people with dementia of the values which activists with other disabilities had advocated for that led to the development of SMD, thereby further blurring the distinction between VBP and EBP.

Two further publications that I authored also allude to the relevance of dementia's interaction with concepts of disability and legal frameworks to values and VBP. The first of these (Williamson, 2015b), published in a peer-reviewed journal, drew attention to the relevance of notions of social inclusion and citizenship to dementia but also reported how there was a growing public health focus on dementia. The second publication (Williamson, 2015c), a book chapter, reiterated arguments for understanding dementia (as well as other mental disorders) in non-biomedical or biopsychosocial terms, and drew upon earlier research I had led on including, a small study looking into quality of life issues for people with dementia (Williamson, 2010). Of particular note, and by way of linking with the next section, the book chapter also made explicit reference to VBP as a significant approach that could challenge values associated with disease-focused models of dementia.

2.4. Published works about dementia and values-based practice

The two preceding sections have provided evidence from my published works of how values feature in various aspects of dementia in ways that provide unique and important contributions to the development of VBP. However, none of the publications described so far, explicitly reference VBP. The two publications in this section both refer to VBP and connect it with dementia. In this sense, they provide two important markers for the narrative in this thesis. The first publication provides an early indication of elements of that narrative. The second publication, which draws significantly on research findings from some of my other publications included in this thesis, encapsulates the key components of the thesis and shows why dementia offers unique challenges to VBP.

2.4.1. Law, Values and Practice in Mental Health Nursing

Although I did not envisage it at the time, the interplay of dementia, VBP and legal frameworks described in Williamson and Daw marked the beginning of the central narrative of this thesis (Williamson and Daw, 2013). The publication was a handbook designed as a practice guide to the Mental Capacity Act 2005 and Mental Health Act 1983 (which had recently been revised) for psychiatric nurses. It used VBP to explore situations where differences in values could be problematic when the MCA or the MHA processes needed to be used. The handbook included a chapter describing VBP and also referred to the Equality Act, Human Rights Act and the UNCRPD, as well as references to relevant research. Although the handbook presented VBP as a way of helping in situations where differences in values involved the law, it is important to note the legal frameworks the handbook referenced, all containing values, and all potentially relevant to dementia.

The handbook did not specifically focus on dementia but made frequent references to it and included several case studies involving people with dementia to illustrate where their values, the values of others, and values expressed in law could be in conflict, and how VBP could help in these situations. There was never an intention that the handbook would be an exploration of how values in relation to dementia and its interaction with the law might pose challenges for VBP; at the time of writing the handbook I regarded VBP as providing a potential solution to the kinds of conflicts the handbook described. However, several references to dementia in the handbook involved some of the unique aspects of dementia discussed in this thesis which raise questions for VBP, including how people with severe dementia were commonly perceived as lacking values, or having none worthy of serious consideration (Kitwood, 1997).

Of particular interest in relation to this thesis is a case scenario in the handbook involving a person with dementia living in care home whose mental capacity appears to be impaired, is very confused, and shouts racist abuse at other residents and staff. Although the scenario is described in the context of VBP excluding values such as racism, the scenario asks whether the person’s own experience of race and ethnicity (including an incident where she had her purse stolen by an Asian youth) should be explored to try and understand her current behaviour. As well as asking the reader to consider what legal aspects might apply to the scenario, they are invited to consider if their response might be different if there was no racist element involved. Although not originally intended to raise questions about VBP's excluded values, the scenario illustrates the difficulty VBP has in applying a prohibition on certain values in a situation like this involving dementia. Despite the racist abuse being offensive, the person could not be denied care and their dementia meant that a reasoned discussion with them about the offence they were causing could not take place. The suggestion therefore was that their racism should be explored in the context of their life story and dementia to try and find a solution, thereby taking a more nuanced approach to values that VBP excluded.

The handbook was not intended to take a critical approach to VBP in relation to dementia and values expressed in law. However, it can be seen as the first publication that explicitly indicated how dementia, and its interaction with legal frameworks offered both potential challenges but also opportunities for the development of VBP.

2.4.2. The Dementia Manifesto – Putting Values-Based Practice to Work

The second publication in this section is chronologically the most recent of my publications included in this thesis and is the most complete articulation of the central narrative in this thesis (Hughes and Williamson, 2019). The publication is a book I co-authored that aimed to apply VBP to dementia. It was part of a book series explicitly focused on VBP and its application in various fields of health care and health care thinking, including commissioning services and interprofessional collaborative practice (Heginbotham, 2012; Thistlethwaite, 2012). The book was the first time VBP had been comprehensively applied to dementia.

The book’s title gives some indication of its aspiration: *The Dementia Manifesto: Putting Values-Based Practice to Work.* It was intended both to make a statement about dementia using the lens of VBP, as well as “putting it to work” both theoretically and practically, as a way of introducing it to practitioners working in the field of dementia. But the book also showed how dementia presented challenges to putting VBP to work, drawing upon many of the publications already cited in this thesis.

The main structure of the book was built around the ten key elements of VBP’s ‘good process’ around balanced decision-making where there was tension or conflict involving values in practice or clinical situations related to dementia. In this respect the book was uncritical of VBP and could provide plenty of practice examples to illustrate how VBP could be of use.

But the book also included a chapter that was framed partly in terms of ‘enhancing VBP’. This chapter described how the progressive nature of dementia and its effect on functions such as cognition, memory, and communication, together with an absence of evidence for any condition-reversing treatments, posed unique challenges for VBP. The chapter also pointed to the proliferation of legal frameworks that had appeared since VBP was originally conceived and how their interaction with dementia illustrated the awkward status for VBP that values expressed in law occupied. This included reference to the relevance of the social model of disability to dementia, and the importance of understanding dementia as both a disease and a disability. These challenges, together with evidence about the values of people with lived experience of dementia, were supported by numerous references to the publications already cited in this thesis.

Of particular note was a case study that was included, which had similarities to the one contained in the previous publication (Williamson and Daw, 2013). This illustrated the difficulties for VBP that arose involving ‘excluded values’. The case study involved racist values being expressed by a man of Indian Hindu heritage with dementia, towards African-Caribbean people and Muslims. These views occurred because his dementia had caused him to ‘time-shift’, and he was re-experiencing from his past, discrimination at the hands of Muslims and Black African Ugandans. While posing challenges for VBP, as the chapter title suggested, they also provided new and original ways of developing VBP.

The book endorsed the benefits of VBP in dementia practice but emphasised how these benefits could only be reaped if VBP developed in response to the challenges that dementia posed, illustrated in the book. This included a reconsideration of the relationship between facts and values, the status of excluded values, embracing the duality of values involved in understanding dementia as both a disease and a disability, and replacing VBP’s two-pronged approach involving EBP, with a three-legged framework that works in partnership with a rights-based approach as well.

The book would therefore appear to be an obvious conclusion to this thesis because of how it drew various aspects of values in both the lived experience of dementia and dementia care together, to both challenge and show how VBP could develop. Yet although the book was the clearest articulation of the overarching narrative in this thesis, a reviewer commented that the book did not have an international perspective therefore the values that underpinned it were from an English / UK standpoint (Bartlett, 2019). This was a fair criticism and an important one given VBP’s international perspective.

2.5. A published work about European ‘dementia friendly communities’

My final publication to be considered in this thesis is a research report describing a study I was the lead researcher on that explored the development of ‘dementia friendly communities’ (DFCs) across Europe (Williamson, 2016). The study was commissioned and funded by the European Foundations’ Initiative on Dementia (EFID), a group of non-governmental, grant-making organisations from several European countries. EFID were aware of the development of DFCs in many European countries and wanted research to be undertaken about the extent and nature of DFCs in Europe, and to identify commonalities and differences in their development.

As previously discussed, DFCs are complex, values-based phenomena containing a multiplicity of collective and individual values but only have a limited evidence base regarding their efficacy as an intervention (Novak, L *et al.*, 2020). The study was one of the first international research projects that explored DFCs and therefore provided important and early insights regarding DFCs including their underpinning values and how these might vary across different countries. The study also provided an opportunity to explore the role of values associated with SMD and values expressed in the development of DFCs, therefore potentially offering international evidence and learning for VBP, about the range of values already discussed in this thesis.

It was a multi-methods study involving a brief literature review, online survey (available in eight European languages), and telephone interviews. The online survey was promoted via national networks of organisations known to EFID and the telephone interviewees were recruited via the survey. There were 194 respondents to the online survey, the overwhelming majority of whom worked in paid roles for health, social care, academic or community organisations, representing 19 different countries. Seventeen telephone interviews were undertaken with eight different countries represented. Although the largest proportion of respondents to the survey were from the four UK nations, over 50% of respondents were from other European countries, with significant contributions from Belgium, Germany, the Republic of Ireland, France, Italy and the Netherlands, giving it a clear international scope.

The study identified several common factors involving values that were seen as key to the development of DFCs, which have been echoed in more recent reviews (Shannon, et al, 2018; Hung, L et al, 2021). These included the need to challenge stigma and discrimination associated with dementia, the importance of partnerships and collaborations between a range of organisations, and the need to demonstrate commitment to the development of DFCs through providing the necessary resources.

Of particular importance also was the active inclusion and involvement of people with dementia, reflecting the theme discussed in Sections 1.3.1 and 2.2.1 earlier in this thesis, emphasising the need to include the values of people with lived experience of the condition. Many participants used the term ‘citizens’ to describe people with dementia, reflecting values associated with concepts of equality and citizenship (Bartlett and O’Connor, 2007). However, legal frameworks and rights were only mentioned occasionally by participants. The report noted, however, that Scotland had been explicit in adopting a human rights-based approach in its national dementia strategy and approach to service delivery, which subsequently included DFCs (Scottish Government, 2010; 2017). Although SMD was not referred to by participants the report inferred from the emphasis given to challenging discrimination, the inclusion of people with dementia, and use of the term ‘citizens’ that values inherent in SMD and rights-based approaches were beginning to feature in both dementia discourse and practice. The publication therefore identified values previously referred to in this thesis that were in effect, performing the role of evidence as being key drivers in the development of DFCs. This reiterates the important implications for VBP discussed previously, in the way dementia policy and practice is developed, and in its challenge to VBP’s binary division of facts and values.

The publication was also important because it offered a suggestion for where VBP might focus on in the future in order to explore some of the key challenges posed by this thesis. Based on the evidence collected, the study formulated a ‘taxonomy’ for dementia friendly community activity (Williamson, 2016, p. 45).

The taxonomy brought together the key features and values underpinning DFCs identified in the study to create descriptors of three different DFC models. Firstly, it described a ‘community support’ DFC model, where the focus of DFC activity was on providing community care and support for people with dementia. Secondly, it identified a ‘community involvement’ model, where the focus was on the wider community (not just health and social care services) being supportive towards people with dementia. The third descriptor was of a ‘whole community and citizenship’ model, where the focus was community partnerships co-ordinating a ‘whole community and citizenship’ approach with the active involvement of organisations, resources, and framing people with dementia first and foremost citizens.

Although the taxonomy could be used or seen as a developmental process, the study emphasised that this was not necessarily linear or a requirement for evidence of progress; various factors in different countries might influence the development of

DFCs and it was important not to make judgements about which was the correct or best model without taking into account these factors. In this sense, the taxonomy echoes the non-hierarchical approach to values taken by VBP: the values underpinning a ‘community support’ DFC model should not be seen as the ‘right’ or ‘wrong’ values compared to those values supporting a ‘whole community and citizenship’ DFC model.

What the taxonomy offers VBP is a basic ‘roadmap’ of a significant area for the development and expansion of VBP thinking that aligns with the narrative of this thesis. VBP has focused mainly on health care issues relating to the areas of ‘community support’ and sometimes ‘community involvement’ delineated by the taxonomy. These broadly relate to a biopsychosocial model of illness and disability, conventional service structures in health and social care, and involvement initiatives, all of which focus on treating or caring for the individual. However, VBP has not explored the area of ‘whole community and citizenship’ outlined in the taxonomy, and it is in this field where the evidence from my publications cited in this thesis most clearly points to challenges and opportunities for VBP. Seen through the prism of dementia, awareness of values expressed in legal frameworks, understanding values expressed through lived experience as evidence, and acknowledging how these values have become embedded into policy and practice (through rights-based approaches, the social model of disability, and DFCs), are all fundamental features of the ‘whole community and citizenship’ model. The approach would expose VBP to different evidence and ways of considering values that challenge some basic elements of VBP, such as the values / facts binary. It would also require VBP to reflect on how ‘values’ associated with shared subjective lived experiences of a health conditions such as dementia might be reconsidered as evidence on par with that used in evidence-based practice.

Some caution should be exercised about the conclusions drawn from this report. Trans-national research runs the risk of misunderstanding or misinterpretations of data because of language issues and different cultural norms (Stephens, 2009). The concept of a ‘friendly community’ could be seen as diluting more robust values of ‘accessibility’ and ‘inclusivity’ which underpin an SMD notion of community based on rights and equality (Shakespeare *et al.*, 2017), and the validity of the taxonomy was not empirically tested.

Nevertheless, this final publication provides an international perspective on values and dementia relevant to VBP. In its focus on DFCs, a phenomenon where nothing similar exists for any other health condition or disability, it draws together key values in dementia identified in my other publications such as the values of people with lived experience and values underpinning or expressed in law, that could help the development of VBP. The taxonomy provides an evidence-based framework to guide that development.

2.6. Summary

My publications that are included in this thesis provide evidence supporting a clear narrative that has significant implications for VBP. Although the majority of them do not explicitly reference VBP, by critically analysing them they offer a substantial range of perspectives concerning values and dementia that make new and important contributions to VBP.

The publications in the first section of this chapter provide evidence of people with dementia expressing and utilising values as service users, co-researchers, and as active citizens seeking to improve public awareness and service provision. This includes people with dementia where the severity of their dementia makes it difficult for them to communicate their values, or for others to discern them.

These publications illustrate unique aspects of dementia in relation to values, such as the values that appear to be important to a person with dementia as their condition becomes more severe. The publications about people with dementia as co-researchers, or involved in groups that were part of the DEEP network, offer evidence of the ability of people with dementia to be involved in values-based work. The DEEP network that the study helped create, provides VBP with access to a network of groups involving people with dementia that could be used to explore values in more depth. Some of the publications also raise challenging questions for VBP about honesty as a value, and how values that VBP might exclude, such as dishonesty, may be essential to engage a person with dementia in order to alleviate distress. Indirectly, the publications point to a further issue for VBP regarding how far research findings involving a consensus about values expressed by people with dementia could be considered as evidence to inform EBP, thereby potentially blurring VBP’s binary distinction between values and factual evidence.

The second section of the chapter focused on publications which provided evidence of how the values of people with dementia, and family carers and practitioners supporting them, interact with values expressed in different legal frameworks, and the implications this has for VBP. The publications indicate how this particularly applies to social care for people with dementia, where in many situations there is a very limited evidence base to draw upon. I suggest that values expressed in law, such as ‘unwise decisions’ or ‘best interests’ which are not evidence-based, can be seen to have a different status than personal or professional values, and this has important implications for VBP's non-hierarchical view of values. However, this perspective is complicated by evidence from some of the publications, which pointed to values that were not always consistent with those expressed in legal frameworks being used when applying the law, especially the MCA.

Some of the publications in this section point to the values-based concept of SMD and its relevance to dementia in policy and practice, and the application of legal frameworks. The publications illustrate how the values underpinning SMD led by people with lived experience, could become drivers of change comparable to EBP and the biopsychosocial model in dementia care. This further illustrates how values underpinning or expressed in law can blur VBP's distinction between facts, values and evidence.

The first two sections provide evidence from my publications of aspects of dementia and dementia care, hitherto unexplored by VBP, which VBP theory and practice would potentially benefit from considering. By doing this, VBP would not only be more inclusive of people with dementia, but also have the opportunity to develop through unique and important challenges posed by dementia.

The two publications in the third section explicitly refer to VBP. Although they do not overtly critique VBP, they draw attention to the important issues raised by the other publications involving VBP and dementia, especially in relation to their interaction with values expressed in legal frameworks. *The Dementia Manifesto* makes the argument that VBP needs to work in partnership with a rights-based approach and understanding of dementia as a disability, as well as evidence-based practice, for VBP to be fully relevant to health and social care practice.

The final publication draws on research using an international perspective DFCs. The publication includes a theoretical framework in the form of a taxonomy that outlines the principles and values for three different approaches to DFCs, based on the research findings. The taxonomy draws attention to key themes that I have identified in this thesis. These themes include the unique aspects of values and dementia, the values of people with dementia, the relevance to dementia of values expressed in legal frameworks and models of disability that pose new challenges to VBP. Furthermore, the taxonomy points to an area of theory and practice involving values associated with community, rights, inclusion, and citizenship relating to dementia which VBP has yet to explore, but would benefit greatly through such an endeavour.

Chapter 3

Autobiographical context and reflections about my professional development as a research practitioner

3.1 Introduction

This chapter places the published works in this thesis in an autobiographical context. I reflect on my professional development as a research practitioner before, during, and after the period covered by the published works. The chapter provides evidence of my contribution to multi-authored publications and the research studies they report on where relevant, as well as discussing methodological critiques of those studies. It also considers the significance and relevance of the publications that were not reporting on specific research studies. The section describes the contribution and impact the publications had to the subject area and my professional development as a research practitioner since the last publication included in the thesis was completed. This includes further publications that I have more recently written that build on or relate to themes in the thesis.

Appendix B provides more details of each of my publication included in the thesis in relation to my contributions, methodology, and impact, which are listed chronologically.

3.2. Autobiographical context

The origins of this thesis date back to the 1990s when, as a mental health practitioner, I became aware of the importance and challenges of working with values. At that time I worked with homeless people with mental health conditions and went on to manage one of the first mental health ‘assertive outreach’ services in the UK.

Assertive outreach was an evidence-based approach to working with people with severe and enduring mental health conditions (though not dementia), first developed in the United States (Stein and Test, 1980). The evidence supporting assertive outreach was reviewed and promoted in the UK as an effective way to work with people who were often excluded by mainstream mental health services, or were deemed ‘hard to engage’ such as homeless people (Centre for Mental Health, 1998). Assertive outreach became part of the national mental health service framework for England in 1999 (Department of Health, 1999).

Assertive outreach services were community-based, multi-disciplinary teams that provided health and social care, and often support around issues such as housing as well. Many people who were referred to assertive outreach teams had experienced periods of compulsory detention and treatment in hospital under the Mental Health Act 1983. Often, they actively tried to avoid contact with mental health services, frequently denied they had a mental health problem, and had very different explanations for the distress and difficulties they encountered. Assertive outreach teams also often adopted a ‘whole team approach’ to working with people referred to the service, which involved very close working by team members from different disciplines and professions. All of these features were part of the team that I managed and I subsequently went on to train other assertive outreach teams that were being set up round the country. An unusual feature of the assertive outreach team I managed was that it was based in the voluntary sector, at Hammersmith & Fulham Mind in London. However, the service also undertook a number of tasks associated with the statutory sector, including the provision of treatments and Mental Health Act assessments, consequently the service reflected both statutory and non-statutory values.

My experience of the assertive outreach approach raised profound questions in my mind about many of the issues I have subsequently published on. A basic principle of health and social care is that people exercise their autonomy in choosing to seek help, and one would expect that if a person has a health condition that causes problems or distress, they would do this. Yet people referred to assertive outreach services frequently decided to do the opposite because their lived experience of their situation and explanation for their mental distress was very different to how mainstream services perceived them. This led to service users trying to exercise agency by rejecting help or having particular criteria for the type of help they wished to receive, resulting in the service having to partly accept the person's own explanation for their situation in order to engage with them. This meant that the service had to work with the person's beliefs, values, and expressed wishes, even if they appeared quite eccentric or to be the result of the person's mental health problem.

The assertive outreach service therefore had to develop quite unusual ways of engaging with people, and often focused on issues of social care and inclusion rather than mental health care and treatment. The mainstream 'biopsychosocial' model of mental illness often proved of limited use for people who rejected the notion they had a mental illness. Evidence-based practice which underpinned mainstream treatment interventions for mental health problems was also challenged by experiential "evidence" that informed service users' own beliefs, values, and attitudes towards their mental health / distress, and general living situation. However, this could lead to dilemmas in the team, reflecting the different professional (and sometimes personal) values of team members. Occasionally these turned into disagreements, especially where issues of risk arose, or there were differences of opinion about how far the team should collude with the person’s values or beliefs if these were seen to relate directly to the person’s mental health condition. Furthermore, team members struggled at times to understand what values could justify intervening in a person’s life when they clearly expressed their wish to be left alone. Of course, in certain situations the Mental Health Act could be used, but the values underpinning this were often seen by both team members and clients of the service to be coercive and negative, at least in the short term.

These dilemmas were amplified at times because the service was based within Mind, which considered the right of service users to choose whether or not they engaged with a service to be paramount. Yet this clearly could be in tension with the basic premise of the service and its statutory responsibilities.

Practical and ethical problems of what was the ‘right’ or ‘wrong’ thing to do, whose values were ‘right’ and whose were ‘wrong’ and when and how legal rights needed to be applied were therefore frequent occurrences in my experience of assertive outreach. These problems were also reflected in the literature about assertive outreach that was emerging at the time. This led to my first publication in 2002 on the ethics of assertive outreach which reviewed the literature that existed at the time on this topic (Williamson, 2002).

The publication of my paper on assertive outreach coincided with my first encounters with values-based practice (Woodbridge and Fulford, 2004; Fulford *et al.*, 2012). At the time I was designing and delivering training for staff newly recruited into assertive outreach teams around the country for an independent research and development organisation called the Sainsbury Centre for Mental Health.[6] Professor Bill Fulford

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[6] The ‘Sainsbury’ in the organisation’s name was dropped in 2010.

became associated with the Centre and introduced me to values-based practice (VBP) which was something of a revelation to me. We both recognised that the inclusive approach to values used by VBP, including where there were fundamental differences of values, closely reflected the practical and ethical challenges posed by assertive outreach. I also saw how VBP provided both a conceptual framework as well as practical tools and processes that could be used to address those challenges.[7] This led to another early publication of mine, a commentary I wrote on a VBP paper (Fulford and Colombo, 2004), where I used issues arising from assertive outreach to reflect on VBP (Williamson, 2004a).

In 2002 I moved jobs and started working at the Mental Health Foundation (MHF), a UK-wide research and development charity, where I was responsible for the work they did concerning adult mental health. MHF carried out social research, workforce and service development projects, and policy and public affairs work on issues affecting people with mental health problems, dementia, and learning disabilities, as well as work promoting good mental health and wellbeing for all. Shortly before joining MHF I had completed a social policy post-graduate diploma at Masters level which included a research methods module.

In my new post I was responsible for a variety of projects led by or actively involving people with personal experiences of mental health problems and services, including service user-led research, known as the Strategies for Living project (Faulkner and Layzell, 2000; Faulkner and Nicholls, 2001; Wright *et al.*, 2004). Many of their experiences echoed those of service users I had known through working in assertive outreach; disagreements with medical or biopsychosocial explanations for their

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[7] I reflected on the role that values and VBP (and dementia) played in practice development and training in two podcast interviews (Morgan, 2014).

mental distress, and experiencing mental health services as unhelpful, coercive or actively oppressive. Many people chose to describe themselves as “survivors” to denote that not only had they survived (or were surviving) their mental health problems, but also that they had survived negative experiences of using mental health services.

Findings from the research (both qualitative and quantitative) included different experiences and perspectives from survivors and service users on the mental health system, ranging from a complete rejection of it through to a broad acceptance, and the importance of issues such as stigma and discrimination, relationships and practical and emotional support. This reinforced further how people’s values might be considered as evidence, especially when they differed from the values of professionals and services when offering or promoting evidence-based treatments and interventions. Issues of human agency, inclusion, and subjective experiences of mental health problems and service user / survivor values were explored in three publications I authored or was involved with at that time (Williamson, 2004b; McCulloch *et al.*, 2005; Williamson and Crepaz-Keay, 2006).

My new post at MHF also enabled me to explore and research VBP further. I was particularly interested in developing and expanding on VBP by asking questions about the original thinking behind its conceptual framework, and the ‘value of values’ more broadly in policy and practice. In 2003 I played a key role in bringing key individuals (including Professor Fulford) and national mental health organisations together to participate in an online conference focused on values and VBP in mental health which attracted over 500 delegates. A subsequent online conference I helped organise on mental capacity in 2005 attracted a similar number of delegates and I was a co-author on an article about the conferences (Woodbridge *et al.*, 2005).

Further work I undertook concerning VBP was generated from my 2004 commentary paper where I posed questions about the explanations (“models”) of mental distress and disorder that had been used in developing the VBP framework (Williamson, 2004a). This subsequently led to me co-authoring a research report published by MHF describing an online pilot study exploring these models in more detail and suggesting other possible explanations (King *et al.*, 2009). One implication of the pilot study was:

> “the importance of policy and practice in mental health being based on robust ‘evidence of values’ rather than presuppositions, however reasonable these may seem” (King *et al*., 2009, p.36).

Alongside the research work I was doing involving people with lived experience and VBP I was also becoming involved in issues related to dementia. In 2004 I became Head of Policy at MHF and this led to me co-chairing the Making Decisions Alliance, a coalition of over 40 regional and national non-profit organisations that were campaigning in support of mental capacity legislation, resulting in the Mental Capacity Act 2005 (MCA). Because the MCA was so relevant to people with dementia, as well as practitioners and family carers supporting them, my leadership of this campaign brought me into frequent contact with organisations such as the Alzheimer’s Society. It also led to my first regular contact with people with dementia, who supported the campaign for the MCA, most notably, the late Peter Ashley (Dening, 2021). I subsequently worked temporarily on secondment for the Ministry of Justice (MoJ) as part of the Mental Capacity Act implementation programme where I maintained my interest and contact with the dementia sector.

When I returned to MHF from the MoJ in 2007 (the same year the MCA came into force) I was appointed as Head of Later Life, responsible for a programme of work on mental health in later life, including dementia (and mental capacity issues). This was a significant point in my professional development as a research practitioner. Not only was there a significant increase in the volume and scale of research studies I was responsible for, compared to my previous research role when I first joined MHF, but it also was my first substantive involvement as a research practitioner working in the field of dementia.

My appointment as Head of Later Life also coincided with dementia increasingly becoming a national policy and research priority, as signalled by the publication in 2009 of England's first national dementia strategy (Department of Health, 2009). These developments occurred at the same time as there was an increased legal focus on dementia as a result of the MCA. The explicit and implicit values contained in the MCA were areas where I had experience and expertise, and I was now in a position to investigate in more depth. Because of my previous focus on people's values and lived experience of mental health problems, it therefore seemed both important and timely to use research to explore the lived experience (including values) of people affected by dementia, particularly in the context of new legal frameworks affecting their lives and the care they received.

Out of this intersection of policy and practice and in the period prior to the publication date of the first paper featured in this thesis, my professional experience as a research practitioner in the field of dementia therefore started to grow. During this period I was responsible for developing proposals, securing funding, and leading on thirteen major projects about dementia (including several of the studies referred to in this thesis). In total, the funding I secured for these projects was over £900,000, the majority of which came from the Joseph Rowntree Foundation, Department of Health, and the Alzheimer's Society. The majority of the projects were research projects, or service development projects with an evaluation element. In addition to twelve publications included in this thesis, I was author or co-author on nine other publications associated with these projects, or about dementia more generally (Williamson, 2008a; 2008b; 2009a; 2009b; 2010; 2014; Levenson and Williamson, 2009; Mapes *et al.*, 2016; Morgan and Williamson, 2014).

In 2007 the Alzheimer's Society approached MHF to undertake research on their behalf focused on the lived experience of people with dementia and family carers. This resulted in three, qualitative research studies that I led on, exploring people's experience of dementia, the diagnostic process and care they received, and wider quality of life issues (Williamson, 2008a; 2010; Levenson and Williamson, 2009). Quotes from one of these publications were used extensively in the 2009 national dementia strategy (Williamson, 2008a; Department of Health, 2009). At the same time I was responsible for or involved with several studies and papers on decision-making and mental capacity (Myron et al, 2008; Williamson, 2006; 2007). Though not explicitly focused on VBP, it was clear to me that values were important features in several of these projects. This included the effect dementia could have on the values of people with dementia, and the interaction of their values with those of family carers and practitioners.

Aware of the role VBP had played in helping shape the principles in the revised Code of Practice for the Mental Health Act (Department of Health, 2015a). I also saw potential implications for VBP created by the interaction of dementia with values expressed in law, an area that, hitherto, VBP had not considered in any detail. Opportunities to explore this further were enhanced because I continued to remain directly involved with VBP. I had remained in contact with Professor Fulford and VBP's Collaborating Centre at St Catherine's College, Oxford University (in 2015 I became a project partner at the Collaborating Centre[8]). Through this contact, in 2012 and 2013 I co-led the organisation of a series of seminars with the Faculty of Philosophy at Oxford University, in partnership with MHF and several key individuals from the Collaborating Centre (including Professor Fulford), to explore possible topics for research collaborations. Consideration of the role values could play were central to these seminars, one of which was titled, ‘The Virtues of Ageing – Mental Health and Later Life’, at which I co-presented with a person with dementia (see Appendix C).

This early work I led on at MHF involving dementia and legal frameworks, as well as ongoing engagement I had with VBP, gave me the research experience to undertake the studies and other related work which are represented in the publications included in this thesis.

3.3. General reflections on becoming a doctoral researcher

My ambition as a research practitioner to study for a PhD by Publication did not arise until after the publication of the last paper included in this thesis, in 2020. The narrative described in this thesis that links my published works together and contributes to the development of VBP in important and original ways was not something I envisaged when the first paper included in the thesis was published in 2011. As has been pointed out elsewhere, the selected publications for a retrospective PhD by Publication are not usually planned or written to be part of a doctoral submission (Peacock, 2012). Although a research practitioner may identify a narrative linking some of their publications before they undertake a PhD by Publication, it may still involve applying this retrospectively to other publications to

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[8] https://valuesbasedpractice.org/who-are-we/project-partners/individual-partners/toby-williamson/

identify if they contain evidence to support it. In turn, this may lead to the narrative being revised or refined. This certainly reflects my experience.

In my case, it was not until I co-authored *The Dementia Manifesto* (Hughes and Williamson, 2019) that I clearly articulated the links between dementia and VBP, and some of the implications dementia had for VBP, especially in the context of legal frameworks and people's lived experience, which forms the central narrative of this thesis. The conclusion in *The Dementia Manifesto* about the need for VBP to work in partnership with a rights-based approach to be relevant to dementia care clearly suggested that VBP needed to be broader in its formulation to be relevant in both theory and practice. The status of values expressed in law, and evidence in earlier research I had done relating to values expressed by people with dementia also appeared to ask questions about how VBP conceptualised values and the relationship between values and evidence. This provided a hypothetical narrative for a PhD by Publication thesis. The challenge for me as a research practitioner has been to reanalyse my published works to identify originality in thinking and evidence to support this narrative, including in publications where VBP was not directly referenced.

A further challenge for me was working as a research practitioner in a non-university environment, and consequently having a more diverse portfolio of research projects and publications than a situation where I might have been able to focus on more specific research topics. This reflected my role at MHF where I had responsibility for a wide range of work, including research and some educational activity as one might find in a university, but also including policy, public affairs and media work, and non-research projects. This meant that there was less priority given to publishing in peer-reviewed journals at MHF, compared to a university, particularly because MHF's existence and funding were not linked to the Research Evaluation Framework (REF). However, in order to maintain a national profile and influence, it was important for MHF to publish and promote its own work. This resulted in my portfolio of publications being quite diverse, which is reflected in this thesis.

In the next section I reflect on my professional development as a research practitioner in relation to the publications and the work they describe included in this thesis.

3.4. Reflections on my published works

The publications included in this thesis are a mixture of primary and secondary research studies, books and book chapters, and commentary articles. Seven are publications in peer-reviewed journals (Williamson, 2011; 2015b; 2018a; Clarke *et al.*, 2018; 2020; Laybourne *et al.*, 2016; Williams *et al.*, 2014). Details of each publication, including more detailed methodological reflections and evidence of impact are contained in Appendix B.

3.4.1. Building and enhancing my existing research skills

Fifteen of my publications were based on six research studies I either led or had substantial involvement with as a co-researcher (Williamson, 2012a; 2012b; 2015a; 2016; 2018a; Williamson and Kirtley, 2016; Williamson *et al.*, 2012; Clarke *et al.*, 2018; 2020; Kirtley and Williamson, 2016; Laybourne *et al.*, 2016; Litherland and Williamson, 2013; McGettrick and Williamson, 2015; Williams *et al.*, 2012; 2014 . The publications include four papers in peer-reviewed journals, research reports, and papers in non-reviewed journals. Two of the publications exist only in electronic forms and are not currently publicly accessible (although available on request and attached via Appendix D), but have been included because they provide detailed research data on which other publications are based.

I was the principal investigator (PI) for three of the research studies (Williamson, 2012a; 2012b; 2016; 2018a; Williamson and Kirtley, 2016; Kirtley and Williamson, 2016; Litherland and Williamson, 2013). As PI I was responsible for developing and designing the research proposal including the key research questions and most appropriate methodologies. My duties also included securing funding, co-ordinating the studies, managing research assistants, liaising with research partners and key stakeholders, managing research budgets, undertaking different aspects of the data collection, drafting or co-drafting the research reports and articles, and dissemination. All three studies used multi-methods approaches involving the collection of both qualitative and quantitative data through semi-structured face to face and telephone interviews and focus groups, paper and online questionnaires, and rapid literature reviews.

In the three other studies, where I was co-researcher (and co-applicant for funding on two of them), I undertook various tasks including identifying the research topic and questions, helping design the study, recruiting participants, data collection, recruiting advisory group members (including service users and family carers), chairing advisory groups, helping to draft research reports and articles, and dissemination. In one of these studies I was responsible for the production of the final MHF report and organising a national dissemination event (Williams *et al.*, 2012).

Although I already had experience of all the tasks described from other research studies I had undertaken over the previous nine years, the six studies enabled me to further build on and develop my experience and expertise in many of these areas. This included designing studies on a larger scale than I previously had experience of, and working in close partnership with several universities. Having a small research capacity compared to universities, MHF benefited from collaboration and partnership working with larger institutions and this enabled me to learn and broaden my research perspective. However, the aims, structure and culture of voluntary sector research organisations like MHF was very different to higher education academic institutions; MHF had policy, influencing, and public information functions in addition to its social research role, whereas universities primarily have an academic focus. This meant there were variations in working styles and approaches to some of the research studies reported on in my publications. This particularly occurred where my role involved engaging people with dementia as participants or co-researchers in studies involving complicated theoretical or methodological elements such as secondary data analysis using conceptual frameworks. While the academic partner considered these essential to the study, they were challenging to explain to participants and co-researchers with dementia who did not have previous research experience (Clarke *et al.*, 2018; 2020). The next section includes a discussion of my role in resolving these issues of inclusion and participation involving people with dementia in research.

3.4.2. Engaging, recruiting and supporting the participation of people with dementia in research

A particular area where I was able to develop my research skills was the involvement of people with dementia in various aspects of the studies reported on in the publications. My own values as a research practitioner and the values of MHF emphasised the importance of meaningful participation involving people with lived experience in research. This meant that by the date of the first publication included in the thesis I already had a range of good contacts with many groups involving people with dementia, and individuals with the condition. I was able to utilise these to engage and recruit people with dementia into some of the studies included in this thesis. At the same time, I recognised that there were significant challenges in successfully doing this regarding issues such as consent, appropriate methods of data collection and accessibility of information about the research.

Although there was considerable diversity in the research topics and methods used in the different studies described in the publications, I fully recognised the importance of consistently maintaining professional standards regarding research ethics (Wiles, 2012; Social Research Association, 2021). This was particularly important where people with dementia were involved as participants and co-researchers. Issues such as ensuring information about a research study and the research methods used would be appropriate and accessible for people with dementia, and capacity to give informed consent is properly assessed, are widely recognised as requiring careful attention (Rivett, 2017; Götzelmann *et al.*, 2021). As well as taking these into account, my research practice involving people with dementia also adhered closely to ethical standards for research proposed by people with dementia themselves, in a publication I advised on, although it was published later (Innovations in Dementia, 2023).

One study was explicitly designed with elements of an action research approach. The study not only involved people with dementia as research participants but also aimed to create and support collective opportunities for them to have influence more widely regarding policy, services, education, training and public awareness (Williamson, 2012a; 2012b; Litherland and Williamson, 2013).

Significant numbers of people with dementia were research participants in two of the studies reported on in publications included in this thesis (Williamson, 2012a; 2012b; Litherland and Williamson, 2013; Williamson, 2018a; Williamson and Kirtley, 2016; Kirtley and Williamson, 2016). Again, I had to ensure research methods and tools were accessible for people with dementia and their participation met ethical requirements, especially if the topic was potentially distressing. The large amount of data that was collected from people with dementia in these studies, and the high quality of the data, indicated that this was done successfully and there were no negative experiences reported.

I also developed my research skills in the involvement of people with dementia in co-designing research studies. This included people with dementia being consulted about questionnaire design as part of a reference group (Williamson, 2012a; 2012b; Litherland and Williamson, 2013), being members of research advisory groups (Williamson, 2015a; McGettrick and Williamson, 2015; Laybourne *et al.*, 2014), and co-analysts (Clarke *et al.*, 2018; 2020). One study that I co-ordinated, which used an innovative ‘inquiry panel’ approach (see below) involved me supporting a person with dementia to co-chair the panel. I found it very rewarding to support this active involvement and empowerment of people with a condition that historically had meant their exclusion from this kind of research participation. However, it could prove time-consuming designing and producing methodological tools and other research materials in formats that were accessible to people with dementia. The involvement of people with dementia could also be challenging when they expressed reservations about fundamental aspects of particular studies, such as defining dementia as a disability (Williamson, 2015a; McGettrick and Williamson, 2015).

One study used a participatory research approach involving people with dementia as co-analysts of secondary data (Clarke *et al.*, 2018; 2020). It succeeded in maintaining the engagement of the co-analysts and enabled them to make meaningful and positive contributions. However, the study used a complicated research methodology involving theoretical frameworks, and was still largely led by the professional researchers. The complexities of enabling people with dementia to participate in this study were commented on in the published papers. The study illustrated the challenges of collaborative research involving university and non-university partners, and people with dementia as co-researchers undertaking data analysis (Drahota, 2016; Rivett, 2017; Nolte and Turker, 2023). It demonstrated to me the need to balance different priorities in order to successfully complete a research study.

Nevertheless, part of the purpose of the involvement of people with lived experience in research is to question, challenge and offer different perspectives to professional researchers. Where people with dementia were involved in the studies described, the design of the study generally meant they were able to contribute in these ways. On all the occasions when I had direct experience of this, their contributions enhanced both the research and the resulting publications.

The biggest challenge regarding the involvement of people with dementia in the research studies included in my publications was the difficulty of including people with more severe dementia who would be unable to give their consent to participate, or respond to conventional research methods such as interviews or focus groups. As I was drawn to researching areas where these difficulties were likely to arise, such as best interests, and different realities and beliefs arising from dementia, there was little or no involvement of people with dementia who had direct experience of those phenomena in the research. This was partly compensated for by the involvement of family carers who could report on those experiences by proxy. It was also possible to gather the views of some people with dementia who were able to consider the experiences hypothetically, as ones they might have in the future. This was valuable in terms of knowing people's advance wishes and preferences, although it had to be done with great sensitivity as the topic could potentially be distressing. However, the challenge remains for myself and other researchers to find approaches to research that can gather the views and experiences of people with more severe dementia, while maintaining ethical fidelity and consistency with the research aims (Phillipson *et al.*, 2018; Collins *et al.*, 2022).

3.4.3. Using different methodologies, engagement, dissemination, and impact

The studies also enabled me to enhance and develop new skills as a research practitioner. I gained valuable experience in survey and questionnaire design, one to one interviewing and group interviews using semi-structured approaches, and qualitative data analysis using methods such as thematic analysis and a constant comparison approach (Braun and Clarke, 2006; 2013; Glaser, 1965).

One of the studies where I was the PI used an innovative 'inquiry' approach (Williamson, 2018a; Williamson and Kirtley, 2016; Kirtley and Williamson, 2016). This was a research method that MHF had successfully used for other research projects (Mental Health Foundation, 2006a; Mental Health Foundation, 2006b). The approach involved bringing together a group of experts in the topic, ranging from academics and professionals through to people with lived experience, who formed an expert 'inquiry' panel (Walker, 2023). This panel met regularly throughout the course of the study to share their own expertise and views, consider evidence collected as part of the study, collectively interviewed participants ('witnesses') with expertise in the topic using a semi-structured approach, and agree the key themes and conclusions from the research that would be included in the research publications. The ‘dementia truth’ inquiry was the first time this had been attempted to consider the topic in question. The panel had twenty-one members, including three people with dementia (one of whom was also co-chair) and met ten times during the study. Although logistically challenging to manage, the commitment and attendance of members was excellent, and through informal feedback, the approach was deemed a success by members. However, one factor I had not anticipated was the sheer scale of primary data the study produced (over 500 pages of transcripts from the panel meetings) and together with the complexity of the topic, this resulted in the analysis and write up of the final report taking much longer than planned.

Another area where I acquired new skills as a researcher was in developing different ways of engaging research participants, disseminating research findings, and using research to instigate action. Appendix B provides more detail about my role in disseminating the research findings from the studies and other measures of impact, such as the number of citations. Examples of dissemination included: organising large national dissemination events to report on the findings; being invited to give conference presentations; designing practitioner training specifically based on reported research findings; and, incorporating research findings into higher education teaching, including the MSc in Dementia Care at the University of West London.

In two of the studies I developed, in collaboration with co-researchers, online tools for practitioners that aimed to incentivise recruitment and be used as data collection tools. These tools also automatically provided learning and feedback to practitioners using them to enable reflection on their professional practice (Williamson *et al.*, 2012; Williams *et al.*, 2012; 2014. Laybourne *et al.*, 2016). This required extremely careful design, to ensure the tools were appropriate for both purposes, confidential, and technically feasible. The approach proved very successful in the case of the best interests research study where the tool, which doubled up as the online structured survey, was used by almost 400 participants.

Developing methods of disseminating findings from the DEEP research project also enabled me to develop new skills. Not only did the methods need to be accessible to people with dementia but an explicit element of the project was ‘research into practice’: the research could stimulate and support the growth of an ‘involvement network’ of groups led by or actively involving people with dementia across the UK. As a result, I was actively involved in organising two national dissemination events co-produced with people with dementia and partner organisations which aimed to be as accessible and inclusive as possible (Williamson, 2012a; 2012b; Litherland and Williamson, 2013). Feedback from the events was very positive and 46 people with dementia attended, from ten different DEEP groups. I also led on commissioning a short film made about the research and the dissemination events, as another way of making the research accessible to people with dementia (the film is currently unavailable – see Williamson 2012a, Chapter 4). In terms of research into practice, DEEP was a great success: the DEEP network received funding for a further ten years after the research was complete and continues to this day with 80 active groups and a significant legacy of work and resources.[9]

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[9] www.dementiavoices.org.uk

3.4.4 Other publications

Seven of the publications included in the thesis were commentary papers, including three in peer-reviewed journals. All of these drew upon research I had previously been involved with, including several studies reported on in publications included in this thesis. The publications all show evidence of original thinking using research I had undertaken and the knowledge I had developed. As has been widely pointed out, theoretical thinking constitutes a valid and important part of research processes, particularly in disciplines such as philosophy, which VBP is partly based on (Russell, 1912; Loughlin, 2002; 2024; Mitchell and Loughlin, 2023; Williamson, 2018c; 2021). VBP itself, in a large part has its origins in this approach (Fulford, 1989).

All seven of the publications were written by invitation from the journal editor or publisher, including the two books. In terms of my professional development as a research practitioner this required me to develop my writing skills and ability to present research evidence to engage different audiences, especially health and social care practitioners. This represents another aspect of ‘research into practice’, and one of my books was included in UWL’s dementia education and training programmes (Hughes and Williamson, 2019). A webinar in 2021, hosted by VBP’s Collaborating Centre, was entirely focused on the book and had almost 100 attendees (Collaborating Centre for Values-Based Practice, 2021). The book is on the Centre’s website (Collaborating Centre for Values-Based Practice, no date). Reviews of both books were very favourable (Bartlett, 2019; Kontos, 2020).

At times it was challenging to continue developing as a research practitioner while finding time to produce non-research publications, but the latter became easier after I left MHF in 2016, because research opportunities were less available to me. It is possible I would not have been able to find the time to co-author *The Dementia*

Manifesto had I not left MHF. Taken together with the other publications, these publications form an integral part of this thesis and make an important contribution to the potential development of VBP.

3.4.5. Strengths and limitations to my professional development

The diversity of roles and activities I undertook in the research studies featured in my publications enabled me to enhance and develop my knowledge, skills and experience across a range of research topics, questions, methods, and collaborations. Particular strengths I have already highlighted have been in qualitative research methods, and supporting people with dementia as participants and co-researchers. In addition to strengths such as these, my work has provided me with an increasing range of professional experiences that I can use to reflect on the research studies and publications included in this thesis.

One important reflection for me as a research practitioner is that participants in all the studies were self-selecting. I was aware that this meant some degree of caution had to be exercised regarding the conclusions that could be drawn from the research. However, there are several reasons for believing the conclusions were credible. These included: good response rates to online surveys used, with significant variations in responses (Williamson *et al.*, 2012; Williams *et al.*, 2012; 2014); studies being more exploratory in nature and not aiming to be definitive in their findings (Williamson, 2018a; Williamson and Kirtley, 2016; Kirtley and Williamson, 2016); other data existing at the time of the study or subsequently which gave validity to the scope of the study and its findings (Williamson, 2012a; 2012b; Litherland and Williamson, 2013; Laybourne *et al.*, 2016); or, using a methodology where the representativeness of the sample group participating was not a key factor (Williamson, 2015a; McGettrick and Williamson, 2015; Clarke *et al.*, 2018; 2020).

The hardest study to reflect on in terms of my development, regarding the issue of self-selection as well as other matters, was the European study of dementia friendly communities (DFCs). Because of my very limited knowledge of DFCs in other countries, and different countries' understanding of what DFCs were, it was very difficult to know how representative respondents were of DFC development across Europe, and nearly 50% of the participants were from the UK. This raised questions about the validity of the data collected. A separate piece of research published in the same year identified DFC activity in 31 countries in Europe, twelve more than in my study. However, it contained similar findings about the importance of involving people with dementia in the development of DFCs and also referred to the importance of rights and citizenship, as did a follow up report (Alzheimer Europe, 2015; Alzheimer Europe, 2021). This would therefore appear to provide significant endorsement of the findings reported in my study which were used to develop the DFC 'taxonomy'. Furthermore, the taxonomy was not an attempt to build a definitive model of DFCs, but to use the findings to create a conceptual framework for understanding some key similarities and differences in the principles that underpinned DFCs. As such, the elements that made up the framework would therefore appear to broadly reflect generic policy and practice in dementia, irrespective of country.

The DFC study also made me more aware of different attitudes and legal frameworks across different countries, regarding data privacy, ownership and confidentiality, which led to some misunderstandings between myself and some of the funders from outside the UK, although these were resolved through negotiation. I had to develop an understanding of political sensitivities as well, and incorporate these into how the taxonomy in the final report was presented. This was in order to avoid potentially offending some countries by suggesting their development of DFCs was inferior compared to other countries.

One area where I had less opportunity to develop as a research practitioner was in the field of quantitative methods and data analysis. This partly reflected my particular interest in research methods that were suited to more in depth explorations of the issue being investigated, such as interviews, focus groups and expert panels (Okoko *et al.*,2023). I also felt that qualitative methods provided more sensitive ways of engaging people with dementia in research than quantitative approaches which could be more impersonal. Furthermore, as I often managed or worked as part of a research team where different research skills were represented, I could draw on the skills of others and base my contribution on the areas where I already had expertise and experience (Mulvihill and Swaminathan, 2022).

Overall, therefore, the publications based on research studies built on and enhanced my professional development as a research practitioner. This particularly involved engaging, recruiting and supporting participants especially people with dementia, interview and facilitation skills, collaborative working and report writing, dissemination, putting research into practice, and trying to maximise impact. Partnership working, especially with universities, also came with some challenges, as did international research, and reflecting on the issue of self-selection that was used in all the studies.

3.5. General reflections on my published works

In order to fully reflect on my professional development as a research practitioner in relation to the specific published works included in this thesis, it is also important to consider the backdrop of the work environments I was in during the period the publications cover.

As a research practitioner with a wide brief to cover in my role as Head of Later Life at MHF, I had to balance my research work on dementia, and issues such as people’s lived experience of the condition or its interaction with legal frameworks, with other research and organisational responsibilities. Although at times this presented challenges in sustaining a consistent focus in the areas described in this thesis, it also provided me with opportunities to raise my profile and the work I was responsible for to different audiences and settings. As my profile and output increased over time, there was a corresponding increase in organisations approaching MHF interested in collaborating with or funding further work in the areas I was responsible for. Successful partnership projects with universities such as Bristol and Edinburgh were undertaken (Williamson, 2012; Williams *et al.*, 2012; 2014; Laybourne *et al.* 2016). I also secured funding from the Joseph Rowntree Foundation for six separate dementia-related projects Williamson, 2012a; 2012b; 2015; 2018a; Litherland and Williamson, 2013; McGettrick and Williamson, 2015; Morgan and Williamson, 2014; Chakkalackal, 2014). MHF’s status as a voluntary sector organisation with national reach, inclusive values, and a good track record of positive engagement and social research with people with dementia that I had established, were all factors in supporting the development of these partnerships.

I attended national events and conferences where I presented the findings from all the research studies featured in the publications in this thesis, or actively participated in discussions about them. I was invited to present some of the studies on several occasions, at national conferences attended by academics, policy makers, service managers, commissioners and practitioners, and people with lived experience. This included the annual UK Dementia Congress, attended by over 250 people every year, where I presented papers and chaired sessions, including conference plenary sessions, every year for the last fifteen years.[10] Similarly, I presented at and chaired meetings of the National Dementia Action Alliance (NDAA). For ten years the NDAA was a partnership between government and statutory bodies, and non-statutory organisation, and established to support the implementation of successive national dementia strategies in England (Department of Health, 2012; 2015b).

The publications included in the thesis concerning dementia, human rights and equalities also informed work I undertook to help establish the Dementia Alliance for Culture and Ethnicity, a coalition of almost 30 key organisations and individuals, aimed at raising awareness of the impact of dementia on minority ethnic communities.[11] Formerly known as Race Against Dementia, the Alliance was referenced in the implementation plan for the Prime Minister's 2020 Challenge on Dementia (Department of Health, 2016).

However, over time the priorities of MHF shifted away from dementia. In terms of staff numbers and finances, MHF was very small compared to a university; year on year, average staff numbers never exceeded one hundred, and expenditure in 2016 was less than £5 million (Mental Health Foundation 2016). This meant that MHF had to be very focused, and I left the organisation in 2016, although the work I led regarding dementia was acknowledged in MHF's annual reports at the time Mental Health Foundation 2015; 2016).

After leaving MHF I became an independent consultant, initially with no organisational affiliation, which meant that research opportunities were more limited

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[10] https://journalofdementiacare.co.uk/events/uk-dementia-congress

[11] https://www.demace.com

for a couple of years and I was unable to develop my research skills in significant ways or use them to explore dementia further. However, I was invited to do several pieces of consultancy based on the work featured in my publications in this thesis (see Appendix B). This included building on my work associated with DEEP, establishing an organisational advisory panel made up of people with dementia and family carers for a national charity, Dementia UK, and designing and delivering training for over one hundred Admiral nurses (specialist dementia nurses) based on the findings from the dementia national 'truth inquiry' (Williamson, 2018a; Williamson and Kirtley, 2016; Kirtley and Williamson, 2016). I also continued to have papers published and advised on publications, in addition to those included in this thesis. Several of these publications related to aspects of the thesis, especially dementia in relation to disability and human rights (Alzheimer Europe, 2016; All Party Parliamentary Group on Dementia, 2019;

In 2017 I joined the University of West London as an hourly paid lecturer, teaching on its MSc Dementia Care course. This subsequently led to being employed as a researcher on a study exploring the impact of arts and creative engagement interventions for people with dementia living in a care home (Williamson, 2018b; Williamson, 2019a). The study had full ethical approval from UWL and was done jointly with an art gallery who funded the study. The research enabled me to re-engage with research practice and dementia, including conducting non-participant observation for the first time, using an adapted observational arts tool and several one-to-one interviews with people with dementia.

3.6. Postscript

Since starting as a doctoral researcher in 2021 I have continued to work as an independent consultant although I no longer teach at UWL. I have been able to maintain and develop as a research practitioner, particularly in the areas of arts, heritage, mental health and wellbeing, and community development, as well as designing a research and evaluation framework for and anti-gambling charity.

As a freelance consultant I have also undertaken several paid projects which have drawn on findings from the published works included in this thesis. This has included applying elements of the dementia friendly community approach, and involving people with dementia in service development work for care homes and supported housing for people with dementia in London. I have also authored book chapters, reports and articles which refer to or are based on publications in the thesis. These have included a chapter about VBP and dementia in *The Practical Handbook of Living with Dementia* (Williamson, 2022), a ‘Socratic dialogue’ debating the relevance of human rights to dementia (Jenkins and Williamson, 2024), and a forthcoming chapter referring to values and VBP in multi-disciplinary teams (Williamson, forthcoming).

The human rights focus in my published works has resulted in me being invited to undertake work on the relevance of equality, diversity and inclusion (EDI) issues to dementia. During the COVID pandemic I drafted a funding application that secured almost £½ million for the UK’s Race Equality Foundation for a programme supporting people with dementia from minority ethnic communities affected by the pandemic and I was also asked to be a consultant on the actual programme (Race Equality Foundation, no date). I authored a book chapter on human rights in relation to minority ethnic communities, as well as an article in a special EDI edition of the Journal of Dementia Care (Williamson, 2019b; Williamson, 2023).

3.7. Summary

Becoming a professional researcher in an independent research charity gave me a breadth of experience that informed my professional development, drawing on my other responsibilities as well. This built on and utilised my previous experience as a practitioner and manager in mental health services, together with my prior knowledge of VBP. It also had its challenges. My development as a research practitioner before, during and after the period covered by the publications in this thesis, was perhaps less typical and more varied compared to a more conventional research pathway based mainly in a university. The time span of publications included a period when I was an independent consultant, while being affiliated to UWL as an hourly paid lecturer and a researcher. This also had a significant impact on my professional development as a research practitioner.

My career as a research practitioner involved a wide range of research activities including research design, forming research partnerships with universities, recruitment of people with lived experience of dementia as participants and co-researchers, facilitation of advisory groups, different methods of data collection, analysis, writing up and dissemination. Findings from the studies included in my publications had a significant impact on the empowerment of people with dementia, such as the DEEP network, and professional training and higher education in dementia care, through incorporating them into the MSc in Dementia Care at UWL, and training for Admiral nurses, for example.

The requirements of my job at MHF and the funding criteria of grants I secured meant that I developed a portfolio of work that was diverse in content, including the research studies I led or was involved with, and this was reflected in my publications. Research studies carried out in partnership with other organisations meant I was able to develop my experience of many aspects of research methodologies and differences in approaches.

My professional development as a research practitioner also benefited from a degree of autonomy in the programme of work that I developed at MHF. This allowed for quite ground-breaking policy research projects exploring issues such as dementia and the social model of disability and opportunities to accept invitations to write books, book chapters and commentaries, as well as doing more substantive research projects.

Sustaining my professional development as a research practitioner after leaving MHF allowed me to continue to use research skills in terms of writing, publishing and dissemination of my work in the publications included in this thesis, This was partly addressed thanks to the opportunity to work at UWL which led to me becoming a doctoral researcher. This posed the final challenge to my development as a research practitioner: critically reanalysing the publications included in this thesis to identify and present evidence of a clear narrative based on values in dementia and its interaction with legal frameworks that makes an original and important contribution to the development of VBP.

Chapter 4

Conclusion

This thesis set out to critically analyse and evaluate twenty of my published works. The thesis aimed to identify a narrative involving values associated with the lived experience of dementia and its interaction with values expressed in law. The thesis has contended that this narrative makes an original and important contribution to the development of the theoretical and practical framework of values-based practice (VBP).

There is no reported study on the overall impact of values-based practice. However, as an international network of collaboration in the form of exchanges of ideas, online and in-person events, and publications, involving academics, practitioners, and people using health and social care, the ongoing events and other work announced by the VBP Collaborating Centre show how VBP continues to grow and develop. At the same time, the dominant model that guides and informs health and social care is still evidence-based practice (EBP).

The contention of this thesis is that dementia, especially in its interactions with legal frameworks, challenges VBP, but perhaps also is an illustration of the limits of EBP. The thesis does not focus on EBP but it is important to note that evidence of efficacy for both pharmacological and non-pharmacological interventions for dementia remains very limited; there are currently no cures or condition-reversing treatments (Pepper, *et al.*, 2024). This means that a key aim of health and social care policy, and services for people with dementia (and their families), focuses on maximising people's wellbeing and quality of life (Department of Health, 2009; Gaulthier *et al.*, 2022; Martyr *et al.*, 2018). As a result, dementia would appear to be an ideal candidate for VBP to consider, but to date, this has not occurred in any substantial way compared to other health conditions that VBP has focused on. This is particularly surprising because of the large numbers of people living with dementia, and the progressive nature of the condition meaning they need substantial support from health and social care services, especially the latter. Situations and decisions involving values therefore arise frequently in dementia care. These often involve several parties, difficulties discerning the needs and values of the person with dementia, and disagreements about the most appropriate course of action to take.

The publications in this thesis focus on the values of people with dementia, and values expressed or underpinning legal frameworks that affect people with dementia. Particular attention is given to decisions involving values and social care for people with dementia and their interactions with legal frameworks, as these are often complex decisions and illustrate a complex range of personal and professional values as well as those expressed in law. The thesis does not attempt to consider all aspects of values associated with dementia in relation to VBP because this would not reflect the focus of my publications and research.

The focus on the values of people with dementia in the thesis speaks to VBP's emphasis on the centrality of service user values in its 'good process', aimed at balanced decision-making based on mutual respect for differences of values. Several publications included in the thesis highlight people with dementia expressing values and being able to work with values, in research studies for example. (Williamson 2012a; 2012b; 2018a; Williamson and Hughes, 2019; Williamson and Kirtley, 2016; Kirtley and Williamson, 2016; Litherland and Williamson, 2013). However, this exploration of values and the lived experience of dementia has not yet featured in VBP literature. Other publications indicate that even people who are severely cognitively impaired by dementia should still be considered to retain values, even though it is challenging for them to communicate these or for others to discern them. However, the onus is on others to try and identify the person's values, rather than assume they are not important or do not exist. Given dementia's progressive and terminal nature and the limited evidence base for interventions, a situation unique to such a prevalent health condition, consideration of the values of people with dementia and how the condition affects those values would potentially take VBP into new areas of theory and practice.

Chapter two (Section 2.3.) of the thesis also explores the application of values expressed in, or underpinning legal frameworks of dementia care, especially in relation to social care decisions. Important terms, explicitly used in law, such as 'unwise decisions', 'best interests', and 'wellbeing' are clearly values-based and are not defined in terms of an evidence base. The MCA explicitly requires decision-makers to take into account a person's values when making best interests decisions. Irrespective of illness or disability, the MCA would appear to be an important and highly relevant piece of legislation for VBP to consider but this has not happened in a significant way compared to mental health legislation. My publications relating to legal frameworks such as the MCA also provide evidence of the complex interaction between personal, professional and legal values involving people with dementia, especially regarding decisions about social care. The publications reveal that other values, such as risk, insight or shared decision-making which are not part of the MCA, may be the key factors in driving decisions under the MCA. While compliance with the law would suggest that values expressed in law might have a higher status than other values almost akin to evidence, the research reported in my publications indicate that practice involving people with dementia and social care decisions is often unlawful. When the difficulty of discerning the values of some people with dementia who are severely cognitively impaired is added into this complex interaction, it shows there is a rich and important area in both theory and practice for VBP to explore further.

My publications also considered legal frameworks in relation to dementia which are underpinned by a social model of disability (SMD). SMD is a values-based framework developed by people with disabilities and when applied to dementia requires the condition to be seen through a lens involving citizenship, inclusion and equalities. This is a very different compared to a biopsychosocial perspective of dementia. Although it has not become a dominant paradigm in dementia, several publications of mine have discussed it, and pointed to examples of a rights-based approach to dementia that draws on SMD, such as dementia friendly communities.

I also make the observation of the influence that SMD has had over policy and practice more widely, despite it having no substantial evidence base beyond the expressed views of people with disabilities. Referring back to my publications that consider the research about the views and values of people with dementia (Chapter two, Section 2.2.1.-2.2.4.), I raise the question of when values might be considered as evidence that could shape policy and practice as much as EBP. If a consensus developed among people with dementia, based on evidence about their views, regarding the need for an SMD, rights-based approach in dementia care, this would pose a significant challenge for the biopsychosocial, conventional EBP paradigm which currently shapes policy and practice. This question goes beyond the scope of my thesis, but as with values expressed in law, would appear to significantly blur VBP’s binary distinction between facts based on evidence, and values.

These challenges and opportunities for VBP to develop are captured in the two books I co-authored included in the thesis which also make explicit reference to VBP. *The Dementia Manifesto* applies VBP to dementia care but proposes a rights-based approach that should work alongside VB and EBP to address some of the key issues raised in my other publications. The two books also point to how dementia raises particular complexities around VBP's notion of excluded values. The final publication in the thesis, though not focused on VBP, uses a taxonomy of dementia friendly communities based on a European research study. The taxonomy reflects a range of values affecting dementia policy and practice, including listening to and involving people with dementia, and a possible rights-based approach using SMD's focus on inclusion, equalities and citizenship. This captures the key themes and overarching narrative of the thesis, about what dementia offers for the development of VBP, and I identify on the taxonomy where VBP could usefully focus its attention.

In my reflections on my professional development as a research practitioner I identify my contributions to the publications and how they have enabled me to develop my experience and expertise. I point to the impact the publications have had on the subject areas, both academic and in the development of policy and practice, and how I have continued to contribute to the subject areas more recently. I also acknowledge where opportunities for my development were more limited, as well as addressing methodological critiques of my publications and the research they were based on, where relevant.

At the time of my first publication, I did not set out with the aim of creating the central narrative of this thesis about dementia and VBP. Through retrospective critical analysis and evaluation, I have been able to identify how the publications provide evidence of this narrative. Caution should therefore be exercised in the weight one places on it. However, there remains a significant absence in VBP concerning dementia, as well as values expressed in or underpinning legal frameworks, and the publications in this thesis provide clear indications of how VBP could benefit from exploring those areas further.

More specifically, VBP could use dementia as a lens to reflect in more detail about the implications that values-based concepts issues such as ‘unwise decisions’ and best interests under the MCA, honesty, SMD, and concepts of citizenship and inclusion may have for VBP’s theory and practice. Research could identify what similarities and differences might exist regarding the different issues identified in this thesis about values in dementia care with other health conditions. VBP’s Collaborating Centre has an ongoing programme of events including advanced studies seminars and a summer school, together with a commitment to co-production and more than a dozen interdisciplinary stakeholder networks focusing on VBP in different settings, though none since 2021 involving dementia. This thesis presents enough evidence to suggest that it is time for VBP to build a long-term engagement with dementia through activities such as these. Networks such as DEEP provide a rich source of people with dementia who could be invited to be part of this engagement, share their views about values, and be supported to co-produce this new area of work for VBP.

It is perhaps slightly ironic that this thesis draws significantly on evidence to raise questions about values, given how VBP tends to distinguish between the two. Yet VBP recognises the importance of evidence and empirical enquiry, as well as more theoretical thinking about values. My thesis draws on publications involving both, to make an original and important contribution to future research, policy and practice concerning VBP, the lives of people with dementia, their family carers and practitioners.

[*29,926 words (excluding title page, acknowledgements, abstract and contents page)*]

Appendix A

A summary of legal frameworks and the social model of disability

This appendix summarises the main legislative frameworks referred to in this thesis. It also summarises the social model of disability (SMD) which underpins two of those frameworks, the United Nations Convention on the Rights of Persons with Disabilities and the Equality Act 2010.

The appendix only summarises legal frameworks that apply in the UK and it should be noted that there are variations and differences across the four UK nations.

Mental capacity legislation

Many countries have legal frameworks for decision-making involving people who lack mental capacity to make decisions for themselves. The Mental Capacity Act 2005 (MCA) came into force in England and Wales in 2007 (*Mental Capacity Act 2005*). Scotland and Northern Ireland have different legal frameworks for mental capacity. The MCA provides a legal framework that supports people aged 16 and over to make decisions for themselves wherever possible, contemporaneously and in the future. It also sets out the legal processes and protections when people are unable to make a decision because of some form of impairment caused, for example, by dementia or a learning disability. The MCA covers all decisions including those in health and social care. It requires a functional assessment of mental capacity which must be time and decision-specific. The MCA has five key principles including an assumption of capacity, ensuring support is provided to help people make decisions wherever possible, and not deeming a person lacks capacity just because they make an ‘unwise’ decision. If a decision is made on behalf of someone it must be in their ‘best interests’ but minimise any restrictions placed upon them. A Code of Practice provides guidance on how the MCA should be applied on a day to day basis (Office of the Public Guardian, 2013).

Although the MCA has brought clear benefits to an area of practice which had previously lacked a clear legal framework for both people at its receiving end as well as practitioners but it has also brought challenges in terms of awareness and applying the legislation correctly in practice (Wilson, 2017; Scott et al, 2020). Certain sections of the Act that cover people who lack capacity to consent to situations where care deemed to be in their best interests require them to be deprived of their liberty in hospitals and care homes have also been criticised for being overly complex, insufficiently comprehensive, and often used inappropriately (Parliament. House of Lords, 2014). Known as the Deprivation of Liberty Safeguards (DoLS), with their own Code of Practice, amendments to the MCA were passed by Parliament to simplify them as well as to revise and amalgamate the two Codes of Practice (*Mental Capacity (Amendment) Act 2019*). However, in April 2023 the Government announced implementation of these were postponed indefinitely (Parliament. Joint Committee on Human Rights, 2023).

Mental health legislation

Like many other countries, the UK has separate legislation from mental capacity laws for the assessment, compulsory detention and treatment of people with mental disorders who pose a risk to themselves or others. England and Wales are covered by the Mental Health Act 1983 (MHA), although it has been subject to significant reform since (*Mental Health Act 1983*). Scotland and Northern Ireland have their own mental health legislation.

Unlike the MCA, the MHA has no test of mental capacity so people can be detained and treated involuntarily, even if they have capacity to refuse consent. If they are being detained in hospital beyond a period for assessment, appropriate medical treatment must be available. A Code of Practice provides guidance on how the MHA should be applied on a day to day basis (Department of Health, 2015a).

Human rights

The international legislative framework for human rights is the United Nations Universal Declaration of Human Rights (UDHR), an international document adopted by the UN's General Assembly in 1948 (United Nations General Assembly, 1948). The Declaration consists of 30 written 'articles'[12] detailing an individual's "human rights and fundamental freedoms". Although deemed to be inherent, inalienable and applicable to all human beings the Declaration is not legally binding.

In Europe the UDHR inspired the 1953 European Convention on Human Rights (Council of Europe, 1950). The Convention (ECHR) was also a reaction to the gross, state-sanctioned violations to human rights which had occurred prior to and during the Second World War, as well a response and defence against communism in the Soviet Union and Eastern Europe. In the UK human rights acquired legal force with the Human Rights Act 1998 (HRA) which incorporated the ECHR into UK law (*Human Rights Act, 1998*) for the whole of the UK. The HRA makes it unlawful for

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[12] The term 'article' used in this legal context refers to a specific section or provision in a legal document such as a statute, outlining a particular rule, right or responsibility.

any public body to act in a way that is incompatible with the ECHR so all laws and policies must be compatible with the Convention.

The ECHR contains 18 main articles which provide legal safeguards and protection for the freedom of individuals, such as the right to life, liberty and security, privacy and family life, political and religious freedom, and prohibition of torture and discrimination. Rights such as these are referred to as ‘negative’ rights as they largely prohibit unlawful interference in the lives of individuals. While some of the articles are absolute (i.e. have no conditions) others are conditional; Article Five concerning the right to liberty and security allows, for example, the lawful detention of persons of “unsound mind” (Council of Europe, 1950). Mental disorders including dementia fall under the category of “unsound mind”, which therefore allows lawful deprivations of liberty under mental health and mental capacity legislation. However, it should be noted that the term “unsound mind” is problematic because it is not congruent with current medical or diagnostic terminology but is a translation of the Latin, *non compos mentis*, and was used as a legal term I England, dating back to the seventeenth century (Burdzik, 2023).

The UK has also ratified the UN Convention on the Rights of Persons with Disabilities (United Nations General Assembly, 2006). The Convention (UNCRPD) is an international treaty which applies the principles of the UDHR to the position of persons with disabilities. The UNCRPD contains similar safeguards and protection to the ECHR, but specifically for persons with disabilities. However it goes further than the ECHR as it also includes ‘positive’ rights; rights of accessibility, independent living, education, work, health and rehabilitation services, and participation in community and public life. The UNCRPD defines disability in Article One as follows:

> “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers hinder their full and effective participation in society on an equal basis with others” ((United Nations General Assembly, 2006).

As well as ratifying the UNCRPD the UK is also a signatory to the Convention which means that laws and policies should be compliant with its Articles. However, the values underpinning the Convention are based on the ‘social model of disability’ (see below) which avoids diagnostic categories because these are seen as leading to stigma and discrimination. This creates a tension between the UNCRPD and the ECHR with its (problematic) category of “unsound mind”, and with laws such as the MCA and MHA which are based on the concept of mental (and cognitive) disorders (Martin *et al.*, 2014; Szmukler, 2019; Szwed, 2023).

There is also a tension of values between the UNCRPD and the MCA as Article 12 of the UNCRPD, concerning ‘equal recognition’ before the law, states that “persons with disabilities enjoy legal (mental) capacity on an equal basis with others in all aspects of life” (United Nations General Assembly, 2006). The UN Committee responsible for the UNCRPD interpreted that as meaning that irrespective of the severity of the person’s impairment, it must always be their “will and preference” which determines the decision to be made (United Nations Human Rights Office of the High Commissioner, 2014). This interpretation prohibited substitute decision-making, that is, someone making a decision on behalf of a person, as the decision should be based on their will and preference, although this may require a third party such as an advocate to help them express this. By this interpretation, ‘best interests’ decisions under the MCA are not compliant with the UNCRPD.

Equality Act 2010

The Equality Act 2010 covers the whole of the UK. It prohibits discrimination based on a range of ‘protected characteristics’, such as age, race, and gender, and includes disability (*Equality Act 2010*). Like the UNCRPD, the Act defines disability according to impairment and the interaction with wider society rather than by diagnosis. The Act requires employers and the providers of goods and services (including health and social care) to make ‘reasonable adjustments’ to prevent this discrimination occurring and to ensure accessibility and inclusivity.

The Equality Act is enforced by a statutory organisation, the Equality and Human Rights Commission.[13]

Social care legislation

The NHS and Community Care Act 1990 (*NHS and Community Care Act 1990*)

The Care Act 2014 is a legal framework that sets out how social care and support for disabled and older adults (including people with dementia) should be provided in England (*Care Act 2014*). Scotland, Wales and Northern Ireland have their own legal frameworks for social care. It applies mainly to local authority adult social care departments and covers topics such as assessment of care and support needs, eligibility for care, safeguarding and carers’ needs. A general duty of a local authority is the ‘well-being’ principle; when carrying out its responsibilities under the Act the local authority should always be seeking to promote the well-being of the individual. ‘Well-being’ is defined using a number of parameters including personal dignity, physical, emotional and mental health, protection from abuse and neglect, individual

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[13] https://www.equalityhumanrights.com

agency, suitability of accommodation, and the ability to participate, contribute and benefit from inter-personal relationships, community activities and opportunities. Statutory guidance explains how the Act should be used on a day to day basis (Department of Health & Social Care, 2014).

Social model of disability

Neither the UNCRPD or the Equality Act use diagnostic categories to define disability because they are underpinned by a conceptual framework known as the 'social model of disability' (SMD). SMD is based on values that intentionally challenge and differentiate it from a biomedical or biopsychosocial model, including the view that defining a person by their diagnosis leads to discrimination. For the purpose of this thesis it is important to briefly summarise the social model of disability.

SMD was initially developed in the 1970s by people with physical disabilities as a civil rights movement to challenge the institutionalisation of people with disabilities which it deemed as oppressive and a violation of people's rights to be able to live independently in the community (Watson *et al.*, 2019). SMD challenged a biomedical view that viewed disability as a problem residing with the individual; SMD focused instead on attitudes, behaviours, and physical barriers created by wider society as being the problem, preventing the person with the disability from participating in society as an equal citizen. In this sense, SMD draws upon a long history of evidence indicating the obvious physical barriers to inclusion for people with mobility and sensory impairments, as well effective solutions, such as Braille which dates back to the early 19th century (Braille, 1829). But SMD also drew attention to the extent and effect of stigma and discrimination experienced by people with disabilities (Watson *et al.*, 2019).

Over time SMD was adopted by many people with learning disabilities and people with mental health problems and this partly led to the development of a variant model of SMD where there was acknowledgement that experience of mental distress for example, was very real for some people and could not be resolved entirely by making wider society more inclusive and accessible (Hogan, 2019).

SMD is also closely associated with particular approaches and tools that help put it into practice, through the application of legal frameworks, especially human rights. The most well-known of these is the human rights-based approach (HRBA) which is a conceptual approach based on international human rights standards and aims to use these to redress issues of inequalities, discrimination, exclusion and unjust distributions of power (United Nations Sustainable Development Group, 2023). More practical tools have been developed to apply the HRBA in public policy making and practice. These include two that are known by their acronyms which represent the principles they are based on: FREDA (fairness; respect; equality; dignity; autonomy) and PANEL (participation; accountability; non-discrimination and equality; empowerment; legality) (Curtice and Exworthy, 2010; Scottish Human Rights Commission, 2024). Both tools are clearly values-based and their purpose is to provide a set of principles that can be used to guide and evaluate policy and practice that aims to be compliant with the HRBA. FREDA has tended to be more focused towards health care, although it should be noted that the regulator of both health and social care services in England, the Care Quality Commission has adopted it to guide it’s inspection and assessment framework.[14] The PANEL principles have been more widely applied in public

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[14] https://www.cqc.org.uk/guidance-regulation/providers/assessment/single-assessment-framework/importance-human-rights-our-approach

policy; for example the Scottish Government has for several years been committed to the HRBA and use of PANEL in several areas of policy including its national dementia strategy (Scottish Government, 2023).

It might be argued that SMD is more values-based than biomedical or biopsychosocial models because it comes from the activism of people with lived experience, rather than a model of disability and disease which is facts-based, drawing on research evidence demonstrating the existence of different health conditions and effective interventions.[15] Yet SMD does not deny the existence of a disability or disease. Instead it challenges a set of values which direct interventions to focus on treating or curing the individual, concentrating instead on interventions to make society more accessible and inclusive. It therefore points to potential choices in policy and practice about what type of interventions are provided to people with disabilities, between those that 'fix' the individual and those that 'fix' society.

It could also be argued that SMD has produced tangible results in policy and practice, although evidence supporting this is more limited in the academic literature. Disability activists were certainly influential in advocating for SMD to underpin equalities legislation in the UK that led to changes in physical environments, employment practices, and customer / service user experience for people with disabilities (Shakespeare, 2017). This may have also helped increase awareness and more positive public attitudes towards people with disabilities. SMD also appears to have played a role in policy and service development

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[15] The evidence base for a 'biopsychosocial' model is broader than a biomedical model as it draws on psychology and social sciences research. However, the 'social', at best, only implies a partial overlap with SMD as social difficulties experienced by the individual and social interventions aimed at rectifying these tend to focus on the individual rather than at a societal level (Engel, 1977; Wade and Halligan, 2017).

shifting away from institutional care towards more personalised support for independent living in communities, especially for people with physical impairments and people with learning disabilities (Glasby and Littlechild, 2009; Sims and Cabrita Gulyurtlu, 2013). Furthermore, SMD is explicitly referenced as underpinning a recent integration of the UK's National Disability Strategy (Department for Work and Pensions, 2021).

Although one might argue that SMD is more values-based than a biomedical or biopsychosocial model, it would appear there is evidence to show that SMD is associated with positive changes in policy, law, services and practices affecting the lives of people with disabilities. Whether or not these changes would have been generated by an evidence-based biomedical or biopsychosocial approach is unknown. However it would be fair to say that values, rather than evidence, were the key drivers for the changes that SMD have produced.

Although SMD has helped shape policy and practice it is interesting to note that it does not so clearly underpin the Care Act 2014 as it does the UNCRPD and Equality Act 2010. Assistance with care and support needs under the Act do not necessarily require a formal diagnosis although there needs to be evidence that there is some form of disability or illness and the Act is focused on the individual, rather than making community or societal changes.

Appendix B

Details of my published works included in this thesis

This appendix describes in chronological order all the publications I have included in my thesis. Each publication is summarised and, where applicable the research study it is based on. For multi-authored publication I identify my contribution, including to the research studies they report on, where relevant. I also critique and identify key limitations of the publications and the studies where relevant, reflect on my professional development as a research practitioner, and provide evidence of impact since the publication date, including examples of research into practice, conference presentations, and use in education and training.

Where available, I have included impact metrics such as citations, downloads, and book sales for each publication, as of the 14 November 2024. Citation data is taken from my profile on Google Scholar. Data on views, downloads and impact factor scores are from the journal publishers' websites.

Some publications were based on the same research study and in these cases I have referred back to the first relevant publication relating to the study.

1) Williamson, T. (2011) 'Running before we can walk: Do we have the capacity? *Philosophy, Psychiatry, & Psychology*, 18(2), pp.147-150.

I was invited to write this paper by Professor Bill Fulford, the founding editor of the peer-reviewed journal, *Philosophy, Psychiatry & Psychology*. It was a theoretical paper written as a commentary on another paper in the same edition of the journal (Doorn, 2011). The paper also applied evidence from research studies about mental disorders to support my argument, including a study I had been involved which explored aspects of VBP (King *et al.*, 2009). However, as a research practitioner I had limited understanding and awareness of practice and research involving dementia to be able to use dementia in my argument, nor was I well-versed in in applying philosophical thinking to practice which probably placed some limits on the contribution made by my paper. Nevertheless, it helped develop my ability to combine theoretical thinking with the use of research data to formulate arguments about values relevant to mental health conditions and VBP.

Impact

The same edition of the journal included a response from Doorn to my commentary and another commentary (Doorn, 2011; Shah, 2011). Doorn was complimentary about my commentary, describing it as “subtle and nuanced” (*ibid.* p.154) and concluded by saying, “I think the commentaries…have already advanced the discussion, for which they are greatly acknowledged” (*ibid.* p.155).

Citations - 6

2) Williamson, T., Boyle, G., Heslop, P., Jepson, M., Swift, P. and Williams, V. (2012) ‘Listening to the lady in the bed: The Mental Capacity Act 2005 in practice for older people’, *Elder Law Journal*, 2, pp. 185-192.

This publication was based on a large 18-month research study that I collaborated on as a co-researcher. The study was an investigation into best interests decisions under the Mental Capacity Act 2005 (MCA) and was funded by the Policy Research Programme (PRP) in the Department of Health. It was the first large scale piece of research I had been part of involving a partnership with two universities (Bristol and

Bradford) and the organisation I worked for, the Mental Health Foundation (MHF). I was invited by this law journal to be lead author of the publication so I was responsible for drafting it, and making amends as appropriate, based on comments from the other named authors. Two other publications included in this thesis were based on the same research study (Williams *et al*., 2012; Williams, *et al*., 2014).

The research study used a multi-methods approach, with a sequential methodology involving four phases (focus groups; online survey; telephone interviews; face to face interviews), with each phase generating data in its own right, but also informing the next phase in terms of areas of inquiry and recruitment of participants. The study had full ethical approval and permissions from participating organisations (mainly statutory health and social care providers). There were almost 400 individuals who participated in the study, most of whom were health and social care practitioners. People with dementia accounted for 40% (n=154) of the cases discussed in the online survey and there were similar proportions of cases involving people with dementia in the telephone and face to face interviews.

I made several key contributions to the study which developed or enhanced my skills as a research practitioner. I co-designed the research proposal that successfully secured funding for the study, as well as the research questions for all its four phases. Through my professional contacts I had made in my previous work on the MCA I was able to bring together a range of experts from national organisations to form an advisory group for the study. I also co-chaired the advisory group and it played a key role throughout the study. I led on developing the online survey, which we designed as an online resource as well, for practitioners to be able to reflect on their practice, based on an innovative resource I had developed for a previous project. This helped incentivise practitioners to participate. I was the first author on this publication as well as being co-author on the other two publications associated with the study (Williams *et al*., 2012; Williams *et al*., 2014). My knowledge of mental capacity legislative and policy issues enabled me to lead on drafting policy recommendations based on the study. I organised a national dissemination event launching the findings attended by nearly 100 people, and presented findings from the study at numerous conferences. These activities helped develop my research skills in designing methodologies for large scale research studies, especially online surveys, my writing and presentation skills, my ability to facilitate and collaborate with research partners (including co-authoring papers), experts in the field, and key stakeholders, and use research to influence policy and practice.

Although I was involved in discussions about the data generated through the different data collection methods, I was not directly involved in the actual data analysis process. With the benefit of hindsight, I would have liked to have played a more active role in the data analysis not only to have been able to explore the data in more detail, but also to develop my research skills.

As the focus of the study was on best interests decisions which affected several impairment groups only limited attention could be given in the analysis to people with dementia. Consideration of VBP was not part of the study, and analysis of the role values played in best interests decisions, or the values underpinning ‘unwise decisions’ for example, was also limited; the aim of the study was on practical aspects of implementing best interests decisions, not the theoretical or philosophical concepts that the MCA was based on.

Participants in the study were self-selecting so one has to exercise caution when exploring the implications of the findings. They were also recruited from specific organisations in specific geographical areas. Their knowledge and experience of the MCA may have partly reflected a particular interest or aptitude towards the MCA, or particular organisational policies and processes for documenting and recording that was designed to ensure legal compliance. Although it was emphasised that all research data collected was treated confidentially, practitioners who were less familiar with the MCA may still have been concerned that participation in the study might reveal their practice to be unlawful. Nevertheless, the good response rate to the online survey and the variation in practice that the study revealed provides one with a reasonable level of confidence about the credibility of the reported findings.

There was also no direct participation of service users or family carers in the research (or the advisory group), because of issues of consent and limited time, but this meant their experiences (and values) were largely excluded, or reported on by proxy. Again with hindsight, I would have liked to have explored how their participation could have been incorporated in the study. Nevertheless, the study not only developed my skills and profile as a research practitioner, but also added to my interest in exploring further the implications of values expressed in law for dementia, and what this might mean for VBP.

Impact

I was invited to present the findings from the study at several national conferences aimed at practitioners including Mental Health Today and Learning Disability Today in 2013/14. The publications and findings were also referred to on the University of West London's MSc in Dementia Care from 2018-2021.

Citations - 4

3) Williams, V., Boyle, G., Jepson, M., Swift, P., Williamson, T. and Heslop, P. (2012) ***Making Best Interests Decisions: People and Processes.*** **London: Mental Health Foundation.**

As part of the best interests study referred to in the previous publication, MHF agreed to publish this research report, as well as appendices (See Appendix B – the appendices exist only in electronic form and are not currently publicly accessible but available on request from MHF, from where a copy was obtained) containing more detailed analysis of the research data. I was not responsible for drafting the report but commented extensively on it before it was submitted for publication.

Impact

See publication 2) above.

Citations – 46

4) Williamson, T. (2012a) ***A stronger collective voice for people with dementia.*** **York: Joseph Rowntree Foundation.**

This publication reported on a 12-month research study investigating the extent and nature of groups in the UK led by or actively involving people living with dementia that were seeking to raise awareness about the condition and influence dementia policy, practice and research. The study was funded by the Joseph Rowntree Foundation (JRF) and was the first time any such study about these groups had been undertaken. As part of the study, I was required by JRF to produce this research report. Two other publications included in this thesis were based on the same research study (Williamson, 2012b; Litherland and Williamson, 2013).

The study involved a rapid literature review, a questionnaire survey to collect quantitative and qualitative data about the groups, and follow-up semi-structured interviews (telephone and face to face) involving people with dementia, family carers, and professionals that were supporting the groups. Ethics was approved internally by MHF. There was also a ‘research into practice’ component to the study, in that it aimed to stimulate and encourage the growth of existing groups and development of new ones and a possible network that linked them together. This involved holding two national events for groups identified in the study, and the production of a film about groups in the study.

I led on designing the research proposal that successfully secured the funding, overall co-ordination of the study, overseeing the literature review, developing the questionnaire survey, designing interview questions and supporting colleagues to undertake these, and some analysis of the results. I authored this research report and a second one about the study (Williamson, 2012b), as well as co-authoring a journal article about the study (Litherland and Williamson, 2013). I also brought together and facilitated an advisory group of national organisations, that worked closely with some of the groups the study focused on, to help guide the study. In addition to this group there was a loose, reference group network of individuals with dementia that were consulted on aspects of the study, such as the questionnaire design. There were 97 responses to the survey and 20 interviews were carried out.

As a research practitioner I already had experience of the research tasks involved in the study. The only analysis required of the quantitative data from the questionnaire survey was to report the numbers of responses to each question with no cross tabulation, and a thematic analysis was undertaken of the qualitative data (Braun and Clarke, 2006; 2013). However, the experience of involving people with dementia, albeit fairly informally, in helping design aspects of the study was new to me. Their feedback identified inaccessible aspects of the questionnaire which led to its redesign and developed my skills in ensuring research methods and tools were accessible to people with dementia.

As all the research participants were self-selecting and the study concerned a previously unresearched area it was difficult to know how representative the responses were at the time although the subsequent growth of the network of groups did not reveal any groups that existed at the time of the study which were omitted from it. Staff supporting the different groups helped to complete many of the questionnaires, therefore the responses may not have fully represented the views of people with dementia, but this was always a risk with any individual responding on behalf of a group. The role and commitment of staff towards empowering people with dementia to form such groups can give one a fair degree of confidence that they would aim to report the views of the groups as honestly as possible.

Because it was an unresearched area I felt it important, with the permission of participants, to include some primary data in an appendix to the main report so it could be used as both an archive and a resource for future research (Williamson, 2012b). The study involved me in new activities less familiar to me as a research practitioner, such as accessible event organisation for people with dementia, and film commissioning. As a research practitioner hoping to see tangible benefit and impact from a study I had successfully co-ordinated, it was extremely gratifying to see the subsequent growth, longevity, and success of the DEEP network that the study initiated (see below).

Impact

I was invited to report the findings at the UK Dementia Congress in 2012. The publications and findings were also referred to on the University of West London's MSc in Dementia Care from 2018-2021.

Since the original research study was completed, it is reasonable to say that the 'research into practice' element has continued to succeed. In 2012 DEEP received over half a million pounds additional funding from the National Lottery Community Fund and Comic Relief to continue for another 10 years, supported by Innovations in Dementia CIC, and the DEEP network of involvement groups created with that funding continues to this day (Innovations in Dementia, no date(a)). There are now over 80 influencing and campaigning groups across the UK which are part of the DEEP network. DEEP provides an extensive range of guides and resources about the involvement of people with dementia (*ibid*). DEEP is regularly represented at national conferences as well as featuring in other published studies (Beesley, 2018; Parveen et al, 2018; Sampson et al, 2019; Mathie et al, 2022). DEEP has supported and generated numerous initiatives, including the 'Dementia Enquirers' research programme that started in 2018 where research projects are led and controlled by people with dementia (Innovations in Dementia, no date(b)).

Citations - 41

5) Williamson, T. (2012b) *Ripple on the pond. DEEP: the engagement, involvement and empowerment of people with dementia in collective influencing. Appendix to main report – A stronger collective voice for people with dementia.* London: Mental Health Foundation.

As part of the DEEP study referred to above, I wrote this appendix published by MHF (See Appendix B – the appendix exists only in electronic form and is not currently publicly accessible but available on request from MHF, from where a copy was obtained) , containing the full literature review, data tables from the survey questionnaire, a selection of responses from the questionnaires and interviews, and transcripts of the groups interviews (all with the permission of participants).

Impact

See publication 4) above.

Citations – n/a

6) Litherland, R. and Williamson, T. (2013) 'DEEP: the engagement, involvement and empowerment of people with dementia in collective influencing' *Working with Older People,* 17(2), pp.65-73.

Also as part of the DEEP study I was invited to be co-author of this article in a non-peer reviewed journal. I wrote sections of the article and commented extensively on the complete draft before it was submitted for publication.

Impact

See publication 4) above.

Citations - 6

Downloads - 541

7) Williamson, T. and Daw, R. (2013) *Law, values and practice in mental health nursing. A handbook.* Maidenhead, UK: Open University Press McGraw-Hill Education

Aa a result of having co-authored chapters about the MCA and Mental Health Act 1983 (MHA) in a textbook for nurses (Fennell *et al.*, 2009; Williamson and Lawton-Smith, 2013), I was invited to author this entire handbook on the same topic. As a research practitioner I felt that my professional development had been boosted significantly with this invitation. However, I also recognised that my knowledge regarding the MHA was much more limited compared to the MCA, hence my decision to ask an associate with more expertise in the former to be a joint author. I wrote the introduction, five chapters (out of eleven) and an extensive appendix, as well as commenting extensively on the other chapters before it was submitted for publication.

The handbook also provided me with an opportunity to explore how VBP could support the correct application of the law and to develop my writing skills for a non-academic audience. The handbook required me to develop my knowledge about the Human Rights Act 1998, the Equality Act 2010, and the UN CRPD as well, as these were necessary to reference, and this provided me with the theoretical foundations for future research in these areas in relation to their impact on people with dementia.

The handbook did not require any substantial referencing or analysis of relevant literature, research studies or theoretical thinking, as it was very much intended as a practical guide to the legislation for nurses. Nor was the book solely focused on people with dementia. It was also a salutary lesson for me regarding new case law changing legal practice; the ruling in a Supreme Court case in 2014 regarding the Deprivation of Liberty Safeguards rendered certain sections of the book obsolete (‘Cheshire West and Chester Council v. P’, 2014). . Yet in terms of my expertise in the field of VBP, writing the handbook enabled me to reflect in detail on the relationship between legal frameworks and VBP, and the particular challenges dementia posed within that interaction.

Impact

The book received three favourable reviews (Cornock, 2013; Buswell, 2014; Chaloner, 2014), including the following comments:

> “This handbook stands out from others in the field. The content is clear, authoritative and accessible, with the concepts and practice explained in a straightforward manner” (Cornock, 2014, p.30).
>
> “This book is to be welcomed because it presents a comprehensible account of how the concepts of law and values are assimilated within mental health nursing” (Chaloner, 2014, p.10).

Citations - 4

8) Williams, V., Boyle, G., Jepson, M., Swift, P., Williamson, T. and Heslop, P. (2014) ‘Best interests decisions: professional practice in health and social care’, *Health and Social Care in the Community,* 22(1), pp. 78-86.

This article in a peer-reviewed journal reported on the best interests research study referred to above (Williamson, *et al*., 2012; Williams, *et al*., 2012). I was not responsible for drafting the paper but commented extensively on a complete draft before it was submitted for publication.

Impact

See publication 2) above.

Citations – 39

9) McGettrick, G. and Williamson, T. (2015) ***Dementia, rights and the social model of disability.*** **London: Mental Health Foundation.**

This publication reported on a 12-month policy discussion project that I led on, which explored the applicability of a human rights-based approach (HRBA), the social model of disability (SMD) and associated laws and policies for people affected by dementia. The project was not designed as a research study but it did include some qualitative data collection. The project was funded by the JRF and I commissioned and contributed several sections included in this report published by MHF, as well as commenting extensively on the complete draft before it was submitted for publication. I also authored a journal paper about the project which is included in this thesis (Williamson, 2015).

The project originated from a conference I attended where people with dementia connected with the DEEP network talked about their dementia as being a disability, and the rights associated with this. This seemed like an important area to explore that was relatively unexplored and I successfully obtained funding for the project from the Joseph Rowntree Foundation (JRF).

The project used a deductive approach, presenting SMD and associated legal frameworks for discussion and debate about their relevance to dementia, to people with dementia and family carers, professionals, academics, legal experts, and disability activists. The project did not use a formal research method but notes were collected from an expert advisory group and a consultation event which were subsequently analysed and used as the basis for the report. People with dementia and disability activists participated in both the advisory group and consultation event and the latter had over 40 participants. The report included notes taken at the consultation event recording people's responses to questions about the relevance of rights-based approaches and SMD to dementia.

In terms of my professional development the project built on my knowledge of dementia and legal frameworks (and the values they contained). I initiated the project, drafted the successful funding proposal to JRF, co-ordinated and facilitated the advisory group and consultation event, and co-authored the report as well as authoring the journal article (*ibid*). The project illustrated the development of my ability to respond as a researcher to investigating topics that were relevant to current policy and practice: the Scottish Government had adopted HRBA as a framework for their national dementia policy (Scottish Government, 2010); and the development of 'dementia friendly communities', which contained elements of SMD, that were increasing rapidly in the UK (supported by government policies) and internationally (Department of Health, 2012; Alzheimer's Disease International, 2016a; 2016b.

The project also further developed my skills as a research practitioner in public and patient involvement (PPI). It was important that I successfully enabled people with dementia, family carers and people with other disabilities to participate and contribute their views as evidence for the report. Partly in order to do this I involved an organisation that specialised in participatory work with people affected by dementia in the project; they supported people with dementia to contribute and produced a version of the project report that was fully accessible for people with dementia.[16] However, this also posed challenges, such as finding ways to explain concepts like SMD and HRBA in accessible ways to people with dementia. In this sense, the project was an important reminder to me of the challenges of doing research involving complicated legal frameworks with people with dementia or other lived experiences who were not familiar with those frameworks. The project also required me to develop my theoretical knowledge of concepts such as HRBA and SMD, as well as practical skills in ensuring it was accessible for disability activists with non-cognitive impairments.

In the context of this thesis and with hindsight, I would have liked to have explored values expressed in law in more detail in the report. The publication reflected a tension I had to manage between being a research practitioner while working for an organisation (MHF) that also aimed to use research to influence policy and practice on issues that were felt to be important. In this case, the starting point of the project was the hypothesis that disability rights were relevant to people with dementia so there were leading questions used in the deductive approach supporting the hypothesis. The project was therefore not strictly impartial, although the report did acknowledge that some participants, including some people with dementia, were uncertain about the applicability of SMD to dementia, for example. Furthermore, the project was constructed as a policy project with a research component, rather than a research study that had policy implications. Participants were small in number and

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[16] Innovations in Dementia CIC: www.innovationsindementia.org.uk. Unfortunately, the accessible version is no longer available.

self-selecting. Caution therefore needs to be exercised in the weight given to the reports’ findings. However, the report was not designed to offer a definitive view on the topic but to raise awareness and stimulate discussion about the issues raised, based on a credible position supported by the views of experts and people with lived experience.

Overall therefore, the report was a further stage in the development of my skills and knowledge and an important stepping stone to subsequent publications I authored on the topic.

Impact

The reported findings received considerable attention. I was invited to present the findings from the study at several national conferences aimed at practitioners including national dementia conferences in Birmingham and Salford in 2015. The publications and findings were also referred to on the University of West London’s MSc in Dementia Care from 2018-2021, and a specialist course in dementia for senior health practitioners commissioned from UWL in 2018-19. When the report was published, I received personal thanks from the Chief Executive of the Alzheimer’s Society for raising issues of human rights in relation to dementia and led to me advising on a Parliamentary report on the topic of dementia as a disability (All Party Parliamentary Group on Dementia, 2019).

Citations - 12

10) Williamson, T. (2015a) 'Dementia, rights and the social model of disability', *Journal of Dementia Care*, 23(5), pp. 12-14.

I was the sole author of this (non-peer reviewed) journal article that summarised the previous report (McGettrick and Williamson, 2015).

Impact

See publication 9) above.

Citations – 13

11) Williamson, T. (2015b) 'Dementia, public health and public policy – making the connections', *Journal of Public Mental Health*, 14(1), pp. 35-37.

This was the first paper I had published about dementia in a peer-reviewed journal where I was the sole author. Although it was not based on a particular research study the paper required me to make important connections between public policy and dementia, legal frameworks and disability, values-based concepts such as citizenship and social inclusion, and evidence from people with lived experience of dementia through networks such as DEEP. As a research practitioner, it represented another stage in my ability to write to a standard required by peer-reviewed publications.

Impact

Citations – 8

Downloads – 324

12) Williamson, T. (2015c) ‘From diagnosis, disease and disorder to decision making, disability and democratic rights – time for a paradigm shift?’ in D. Crepaz-Keay (ed.) *Mental Health Today…And Tomorrow.* pp.55-66. Shoreham-by-Sea, UK: Pavilion Publishing and Media Ltd.

This publication was one of two chapters I contributed to an edited collection. I drew upon research studies referred to in this thesis as well as other studies I had led on or been involved with, including a small study looking into quality of life issues for people with dementia (Alzheimer’s Society, 2010). The chapter discussed dementia in the context of the Mental Capacity Act 2005, other legal frameworks and SMD. The chapter explicitly referenced VBP as an approach that complemented evidence-based models of dementia, as well as challenging some of the values associated with biomedical and biopsychosocial models of illness and disease. Along with previous publications, the chapter signified my increased maturity as a research practitioner in my ability to marshal evidence and theory to make concise and effective arguments involving concepts and practice about dementia, values and legal rights.

Impact

Citations – n/a

13) Laybourne, A., Jepson, M., Williamson, T., Robotham, D., Cyhlarova, E. and Williams, V. (2016) 'Beginning to explore the experience of managing a direct payment for someone with dementia: The perspective of suitable people and adult social care practitioners', *Dementia*, 15(1), pp. 125-140.

This paper in a peer-reviewed journal concerned a research study I was actively involved with.

The paper reported on a research study exploring the use of direct payments in social care for people who lacked capacity to consent to the payments and manage them to pay for the care they received. Direct payments legislation had only been amended shortly before the study took place to allow people who lacked capacity to consent to direct payments to still be able to receive them, managed on their behalf by a 'suitable person' (SP), such as a family relative. As this linked directly with the Mental Capacity Act 2005 this provided me with a further opportunity in my professional development to build upon my research knowledge and skills in this area.

The study was led by MHF but done in collaboration with Bristol University, funded by the School for Social Research (SSCR) that was part of the National Institute for Health Research (NIHR). The study had ethical approval from the Social care Research Ethics Committee, as well as permissions from the participating organisations (local authorities). Data was collected through semi-structured interviews involving local authority social workers with experience of DPs for people who lacked capacity to consent (people with dementia or learning disabilities) and SPs. A thematic analysis was used to identify its findings (Braun and Clarke, 2006; 2013). The paper considered a sub-sample involving nine social care practitioners specialising in older adults social care and seven SPs from the five different local authority areas in England that had agreed to participate.

Although I led on initiating the idea of the study and was involved in its design, I was not the study's principal investigator (PI). This partly reflected MHF's structure, which had a separate research team from the later life programme I led. Senior researchers from that team had PhDs and it was therefore deemed more appropriate for one of them to be the PI. Although this meant I was not directly involved in data collection or analysis I chaired the study's patient and public involvement (PPI) advisory group and co-led on designing a tool for practitioners to help their understanding of direct payments. I was not responsible for drafting the paper but commented extensively on the complete draft before it was submitted for publication (I was also a joint author on another peer-reviewed paper that came out of the project (Jepson *et al*., 2015). Participants in the study were self-selecting, small in number and from organisations in specific geographical localities. However, evidence from elsewhere indicated that the uptake of direct payments for people with dementia who were unable to consent was generally very low, reflecting the low take-up in the study (Bartlett, 2009).

This study had great potential for both my own career and the development of MHF because it was the first time the organisation had secured funding from SSCR, a major academic research funder, and the successful completion of the study gave us confidence to submit another research proposal about the MCA to SSCR. From SSCR feedback this was initially very well received but changes in key personnel at MHF resulted in the application being rejected at the final stage and I left MHF shortly afterwards.

Impact

Citations – 16

Total views and downloads – 1118

Impact factor – 2.4 / 5-year impact factor: 2.6

14) Kirtley, A. and Williamson, T. (2016) *"What is Truth?" An Inquiry about Truth and Lying in Dementia Care*. London: Mental Health Foundation.

This publication reported on an 18-month, multi-methods research study into the experiences of people with dementia when they believe they are in a different reality as a result of their dementia. The focus of the research was to gain greater understanding of people with dementia who experienced different realities or beliefs caused by or associated with their dementia, usually as it becomes more severe. Rather than use medical terms such as delusions, the report reflected the inquiry's preference for non-medical terms, to make them more accessible to a lay audience. The inquiry also aimed to explore ways that practitioners and family carers could respond when people with dementia had these experiences.

I was the principal lead for the study, designing, securing funding and co-ordinating it, as well as co-authoring this report, and two other related publications that form part of this thesis, including a peer-reviewed journal article that drew on the inquiry's findings (Williamson and Kirtley, 2016; Williamson, 2018a). This report provided a summary of the key findings, themes and practical guidance that came out of the inquiry. It was based on a more detailed review of the evidence that I drafted and is also included in this thesis (Williamson and Kirtley, 2016). I was not the first author because I had left MHF when it was written, but I commented on a draft before it was submitted for publication.

The term ‘inquiry’ was used to denote a research study involving a multi-methods approach but also to describe a particular structure for considering the data collected. This structure had been successfully used on previous occasions by the Mental Health Foundation to explore other topics (Mental Health Foundation, 2006a; 2006b). The structure involved bringing together a diverse range of people with expertise and experience in the topic being explored, including professionals, researchers, service users and carers, to form an inquiry panel which could collectively listen to and discuss existing and new data that was collected, without being too constrained by a specific research question. The intention of the inquiry process was not only to increase knowledge and understanding of the topic but also to generate useful guidance for practitioners, service users and carers.

The inquiry panel was made up of 21 people including psychiatrists, psychologists and nurses, as well as academics, and people with lived experience of dementia, all of whom had expertise, experience or intertest in the topic, and met ten times. The panel listened to evidence given by 18 experts in the field, including professionals and practitioners, as well as voluntary sector representatives, a police officer, a philosopher and a poet. A rapid literature review was conducted by a colleague and I also managed a research assistant who supported the study (Kartalova-O’Doherty, 2014). Three focus groups were held involving people with dementia, family carers, and frontline staff from a day centre and care home, and an online survey open to the general public was carried out that had 415 responses (respondents were mostly practitioners or family carers). The key findings from the study reported in the publications represented the views of the inquiry panel based on the evidence collected in the study.

My skills at managing research studies developed significantly as a result of co-ordinating this multi-methods study involving a large number of individuals (including all the panel members) contributing to different elements of the research process. Although challenging at times in terms of practical organisation, the inquiry panel meetings proved very successful as a way of collecting and discussing data, with all the panel members remaining engaged throughout the study and being able to contribute.

Having involved people with dementia in previous research I was also keen to develop my research practice to explore ways in which research could explore the experiences of people with more severe dementia, including those who had experienced different realities or beliefs. However, I recognised that the practical and ethical challenges of collecting data from people with dementia who had those experiences were too great for this study which had limited resources, apart from possible survey responses (of which there were a small number). Nevertheless, I did everything possible to enable the active involvement of people with dementia as panel members (including one who co-chaired the panel) and research participants, ensuring information was accessible and they had support from family members and staff to fully participate. With this support, people with dementia who took part were able to reflect and express their views about different realities and beliefs, including the possibility that they might have these experiences themselves in the future. I had to ensure these discussions were facilitated very sensitively because of the potential for causing emotional distress when people with dementia considered this possibility.

All the participants were self-selecting but the study was wide ranging in scope and not designed to provide definitive answers about the complicated issues involved. However, it did aim to raise awareness and understanding of the issues, particularly among practitioners and family carers, and offer them practical advice and guidance. In this respect, the large number of responses to the online survey together with the more in-depth expertise and experience provided through the other research methods used, gave the findings and guidance a reasonable level of credibility.

As a research practitioner I found collating, analysing and identifying key themes and findings from the inquiry exceptionally challenging, especially while managing other research studies at the same time. There were over 500 pages of transcripts from the inquiry panel meetings and the other data collection methods used. With the benefit of hindsight I had clearly underestimated the amount of time this would take, I had not been trained in the use of qualitative research software such as NVivo, and there were insufficient resources to employ a researcher with these skills. A lot of my time was taken up with co-ordinating and supporting the panel, especially people with dementia.

The final report not only needed to be an accurate representation of the findings in relation to the original questions posed to the panel but also reflect where there was consensus among panel members. The diversity of expert witnesses meant that the final report spanned issues and disciplines including philosophy, ethics, personal morality, poetry, policing, psychiatry, psychology, nursing, social care, end of life care, policing, and alternative, non-biopsychosocial approaches to understanding and responding to different realities and beliefs. As a result, the study overran and the I had left MHF before the report was completed so it was agreed that it would be jointly authored. In some respects therefore the difficulties one can face as a research practitioner of taking on such an ambitious project.

Impact

The two co-authored reports were received with great interest and I was asked to do numerous conference presentations, including UK Dementia Congress in 2014 and 2019. It led to me being invited to author the third publication included in this thesis, in a peer-reviewed journal (Williamson, 2018a). The study also aimed to provide practical guidance for family carers and practitioners in how they responded to people with dementia experiencing different realities or beliefs. As a result, I was asked to run training workshops for Admiral Nurses (specialist dementia nurses) focusing on this aspect of the study, and over 100 nurses attended these workshops that took place between 2017-2018. The publications and findings were also referred to on the University of West London's MSc in Dementia Care from 2018-2021, and a specialist course in dementia for senior health practitioners commissioned from UWL in 2018-19. As a research practitioner, it was extremely gratifying to present findings reported in the publications to inform professional practice.

Citations – 29

15) Williamson, T. and Kirtley, A. (2016) *Dementia Truth Inquiry. Review of Evidence*. Mental Health Foundation report.

This report provided a detailed review of the evidence collected by the inquiry (See Appendix B – the review exists only in electronic form and is not currently publicly accessible but available on request from MHF, from where a copy was obtained). I provided the first draft of this report and was used to produce the summary report above. The final version was jointly authored as I had left MHF before it was completed.

Impact

See publication 14) above.

Citations – n/a

16) Williamson, T. (2018a) ‘Commentary on the paper ‘Dementia diagnosis and white lies: a necessary evil for carers and dementia patients?’. *International Journal of Care and Caring*, 2(1), pp. 139-144.

I was invited to write this paper for a peer-reviewed journal as a commentary on an article about the dilemmas of caring for someone with dementia experiencing different realities and beliefs (Russell, 2018). The paper made several references to, and drew heavily on the reported findings from the two publications above from the dementia truth inquiry.

Impact

See publication 14) above.

Citations – 1

Full text views – 196

PDF downloads - 112

17) Williamson, T. (2016) *Mapping dementia friendly communities across Europe*. Brussels: European Foundations' Initiative on Dementia.

This publication was an international research report I authored about a study I led on that investigated the development of 'dementia friendly communities' (DFCs) across Europe. It was an 18-month, multi-methods study, funded by the European Foundations' Initiative on Dementia (EFID), a collaboration of non-statutory funding organisations including the UK's Joseph Rowntree Foundation.

The study's methodology used a multi-methods approach; a brief literature review; an online survey; and, a series of telephone interviews. The survey was both qualitative and quantitative, and was available in eight different European languages. Recruitment to the study was via 900+ contacts through the different NGOs that made up EFID, the Mental Health Foundation, and the pan-European organisation Alzheimer's Europe although all participants were self-selecting (interview participants were selected from survey respondents who indicated they were willing to be interviewed). Qualitative aspects of the survey and the interviews were analysed thematically and coded using a constant comparative method (Braun & Clarke, 2006; 2013; Glaser, 1965), and the frequency of quantitative responses was recorded but no cross-tabulation was conducted. I designed the research proposal which secured funding for the project, co-ordinated the data collection, managed a research assistant supporting the project, analysed the data, wrote the final report and liaised regularly with EFID, including attending meetings and presenting the findings at EFID events in several different countries.

There were 194 respondents to the online survey, representing 19 different countries. Seventeen telephone interviews were undertaken with eight different countries represented. As the study was based in the UK the largest proportion of respondents as one might expect were from the four UK nations (just under 50% of the survey respondents), although one finding from the study was that there were notable differences in approach and practice to DFCs in England compared to Scotland in particular. However, there were significant contributions from Belgium, Germany, the Republic of Ireland, France, Italy and the Netherlands. Participants were self-selecting, recruited through 900+ contacts of the NGOs that made up EFID. Having very little prior knowledge of DFCs outside the UK, I had no way of knowing if the sample were representative of DFC activity across Europe. However, the findings appeared to be valid as another report about DFCs in Europe published at the same time included similar findings, as did a follow up report (Alzheimer Europe, 2015; Alzheimer Europe, 2021).

The study was my first, and to date, only international research study. Although DFCs were a recognised international phenomenon, almost inevitably there was considerable variation in the understanding and application of DFC theory and practice across different countries, affected by factors such as national and local dementia policies, services, and cultures. Furthermore, there were variations in terminology associated with DFCs between different languages. Furthermore, EFID were keen that the report should not appear critical of countries where DFCs were less prevalent or developed than other countries as this might inhibit DFC development in the future. All these factors made the process of analysing the data collected very challenging. Because data privacy laws differed in the countries where the funding organisations were based, there were some misunderstandings about confidentiality and ownership of the primary data which required careful and diplomatic communication on my part. However, all these factors were also extremely valuable learning for me as a research practitioner and EFID's concerns about how the findings were presented helped shape my thinking about the DFC 'taxonomy' in the final report.

Impact

I have presented the findings reported in the publications at several national conferences including the UK Dementia Congress. The publication and findings were also referred to on the University of West London's MSc in Dementia Care from 2018-2021.

Citations - 15

18) Clarke, C., Wilkinson, H., Watson, J., Willcockson, J., Kinnaird, L. and Williamson, T. (2018) 'A Seat Around the Table: Participatory Data Analysis with People Living With Dementia', ***Qualitative Health Research,*** **28(9), pp. 1421-1433.**

This paper, published in a peer-reviewed journal, reported on a research study led by Edinburgh University that involved people with dementia and family carers as co-analysts undertaking secondary data analysis. The study took place while I still worked at MHF who were research partners in the study and I led on this partnership, although the papers were published after I left MHF. Another published paper about the study is also included as one of my publications in this thesis (Clarke, *et al*., 2020).

The study used a qualitative methodology involving a series of workshops facilitated by professional researchers. The workshops were designed to enable the co-analysts with lived experience to analyse data collected in a previous study about the roles of ‘Dementia Advisers’ and ‘Peer Support Network Services’ that were set up under the first national dementia strategy for England in 2009 (Clarke et al, 2013). The methodology used in the study for the secondary data analysis involved using two theoretical frameworks: Douglas’s cultural theory of risk, and Tronto’s Ethic of Care (Douglas and Wildavsky, 1982; Douglas, 1992; Tronto, 1993). The analysis was done through a cyclical process of presenting and re-presenting the secondary data to the co-analysts in the workshops, asking questions of them based on the two theoretical frameworks, and recording their responses. These responses were then analysed and interpreted by the professional researchers and discussed further with the co-analysts. The study had full ethical approval though significantly, this approval required the co-analysts to be considered as research participants, rather than researchers. This was a good example for me of the difficulty of involving people with dementia in research roles as equals with professional researchers.

All the information given to the co-analysts, and workshop formats were designed to be as accessible and inclusive as possible for people with dementia to maximise opportunities for them to contribute. 34 people with dementia and family carers participated as co-analysts (some recruited from the DEEP network) in four different groups in England and Scotland.

My role in the study involved recruiting some of the co-researchers with lived experience via the DEEP network, having some input into designing the process by which the secondary data could be presented and discussed in the workshops, a number of which I facilitated, writing up workshop notes, and commenting on the paper before it was submitted for publication.

This paper described and discussed the process of involving the co-researchers in the methodological process used in the study. It therefore merits some careful consideration as it relates closely to my development as a research practitioner.

Although the co-analysts with lived experience were able to make meaningful contributions in the workshops, the paper acknowledged that the participatory approach that was used was challenging for both the co-analysts and the professional researchers involved. The paper made the point that approaches to participatory research involving people with disabilities generally did not take into account people with cognitive impairments such as dementia. Nevertheless, the workshops maintained the engagement and participation of the co-analysts who, as the paper pointed out, became more able over the course of the study to explore the secondary data not only from their own lived experience but also from more theoretical perspectives. Participants in the study were self-selecting and the paper acknowledged that the methodology might not suit some people with dementia or be accessible for people with more severe dementia. However, as one aim of the study was to test out the methodology, which was neither designed or intended to be provide definitive answers to the research questions, the findings can be treated with caution but still seen to be indicative and relevant for the purpose of this thesis.

I contributed to several discussions with the other professional researchers about the complexity of the task the co-analysts were being asked to do. The participatory aspect of the research did not extend to any of the co-analysts being named as authors on the paper. While the workshops were reported in detail, the interpretation of the co-analysts' views, and the findings based on these, were those of the professional researchers. As one of the authors I therefore tried to ensure the papers reflected the potential risks and biases that could result from our interpretation of the views expressed by the co-researchers. At times therefore I felt a tension between the academic aims of the research and the meaningful involvement of the co-analysts. This was also reflected in a tension I felt as a research practitioner working for MHF, having been involved in initiatives such as DEEP that promoted the involvement of people with dementia, while balancing this with my role in supporting a research study led by a university that posed significant challenges to the involvement of people with lived experience.

It should be stressed however that very careful planning was given to the methodology used in the study to try and ensure the meaningful participation and contributions by the co-analysts. The co-analysts remained actively engaged in their research role the full cycle of sixteen workshops was successfully completed. Similar numbers of people with dementia participated in the final round of workshops as did in the first workshops; on average fifteen people with dementia attended each round (range 13-17). In this respect, the methodology proved successful.

As I had not been involved in the original design of the study and having committed to the partnership it was therefore a reminder to me as a research practitioner of the need to make some compromises in order to collaborate positively and ensure the study was successfully completed while at the same time trying to ensure accessibility and inclusivity. In this respect, the challenges of the study were extremely beneficial to me as a research practitioner because of the learning I derived about using participatory research approaches with people with dementia, especially where they involve complex theoretical tools and methodologies.

Impact

Citations – 73

Total views and downloads – 2144

Impact factor – 2.8 / 5-year impact factor: 3.8

19) Hughes, J. and Williamson T. (2019) *The Dementia Manifesto – Putting Values-Based Practice to Work.* Cambridge: Cambridge University Press.

This publication is an academic textbook I co-authored with Professor Julian Hughes, an old age consultant psychiatrist and leading expert on ethics and dementia. I had known Professor Hughes since the mid-2000's through our shared interest in VBP and its application to older people and people with dementia. The book was part of a series on VBP published by Cambridge University Press (CUP). It originated from a suggestion I made in 2013 to Professor Bill Fulford, who was an editorial advisor for the book series, that to date dementia was largely absent in the VBP literature and including a book in the series about dementia and VBP would help to rectify this. This subsequently led to Professor Hughes and I being invited to write a book proposal that was accepted by CUP.

Although I had already co-authored a book, in terms of my professional development as a research practitioner this opportunity came at a better time because I was able to utilise a much greater range of research studies I had been involved with and enhanced knowledge of dementia, VBP and legal frameworks that I did not have when I co-authored my previous book. The book was also part of a prestigious series on VBP and aimed partly at a more academic audience than my previous book. I authored six of the book's chapters and the introduction. The book was subject to peer review.

The book was not intended simply as a handbook or guide to applying VBP to dementia and it allowed us to explore with some freedom how aspects of dementia, including its interaction with legal frameworks, posed challenges for VBP but also afforded opportunities for VBP's development. As the title indicates, we had bold ambitions for the book to change both theory and practice about dementia, people living with the condition, and dementia care, using VBP to do this.

Impact

The book has had two favourable reviews (Bartlett, 2019; Kontos, 2020). Reviewers comments included:

> "This is a welcome addition to new thinking in dementia studies…Overall, I think this is a very useful text for anyone in need of inspiration for adopting a values-based approach when supporting people with dementia and their families…it is an excellent new resource" (Bartlett, 2019, p.37).
>
> "[E]thically compelling and clinically useful…[it] takes on very difficult issues and offers concepts and methodology to fill a growing void in not just psychiatric practice but also in medicine, society, and family writ large. It is a worthy read for anyone working in geriatric or neuropsychiatric practice, performing capacity evaluations, or interested in ethical dilemma resolution methods. Whether taken as a blueprint for action or a stimulus for more and differently informed debate and brainstorming, "The Dementia Manifesto" lives up to the ambitiousness of its title" (Kontos, 2020, pp.869-870).

However, Bartlett (*ibid*) made the observation that the book was written from an English / UK point of view so lacked a global perspective. Kontos (*ibid*) also questioned how far the issue of autonomy for people with dementia could be aligned with the UNCRPD as the book suggested, and also thought that some of the case studies would have benefitted from less harmonious endings to illustrate the difficult issues involved.

The book was the focus of a webinar hosted by the Collaborating Centre for Values-based practice in health and social care on the 3 February 2021 (Collaborating Centre for Values-Based Practice, 2021). As well as presentations by myself and Julian two people with lived experience of dementia also spoke and the webinar had almost 100 attendees. The book is included on the Centre's website (Collaborating Centre for Values-Based Practice, no date). It was also included on the reading list for the University of West London's MSc in Dementia Care from 2018-2021, and was referred to on a specialist course in dementia for senior health practitioners commissioned from UWL in 2018-19.

Impact

Citations – 17

[17]Hard copy sales – 235

eBook sales – 64

Total number of full text HTML views – 690

Total number of full text PDF views – 2508

Total number of book summary page views – 9190

Altremetric attention score (news outlet, blog, X mentions and Mendeley readers) – 19

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[17] All sales data and metrics apart from citations provided by Cambridge University Press.

20) Clarke, C., Willcockson, J., Watson, J., Wilkinson, H., Keyes, S., Kinnaird, L. and Williamson, T. (2020) 'Relational care and co-operative endeavour – Reshaping dementia care through participatory secondary data analysis', *Dementia,* 19(4), pp. 1151-1172.

This was the second paper that came out of the study involving people with dementia as co-analysts referred to above (Clarke, *et al*., 2018). The paper was published in a peer-reviewed journal. I was not involved in drafting the paper but commented on it before it was submitted for publication.

The paper explored the views of the co-analysts about the secondary data presented to them and discussed using the two theoretical frameworks in the workshops. The findings were presented in the paper partly through interpretations by the professional researchers of what the co-analysts said in the workshops. Like the first paper, none of the co-analysts were authors so in my view, there were similar issues about potential misinterpretation and bias by the professional researchers, and how far the co-analysts might recognise and agree with the findings based on the interpretations of the professional researchers. However, these views were not reflected in the paper. The paper did acknowledge that the co-analysts were people who were willing and able to participate in the research process. The paper therefore concedes that there were methodological challenges to involving people with dementia as co-analysts who might have different views who could not or would not participate in this type of research process. Nevertheless, the care and attention given to ensuring that the methodology enabled meaningful participation by the co-analysts in the workshops, which seemed to be successful, meant that the findings can be considered as valid and significant.

Impact

See publication 18) above.

Citations – 28

Total views and downloads – 1408

Impact Factor – 2.4 / 5-Year impact factor: 2.6

Appendix C

‘Therapeutic conflicts’ inter-disciplinary seminars 2012-13

Attached documents:

1) Programme from Seminar 2: ‘The Virtues of Ageing – Mental Health and Later Life’

2) Seminar series report: *Therapeutic Conflicts: Co-producing meaning in mental health. A report*

Appendix D

My published works not currently publicly accessible

Attached documents:

1) Williamson, T. (2012b) *Ripple on the pond. DEEP: the engagement, involvement and empowerment of people with dementia in collective influencing. Appendix to main report – A stronger collective voice for people with dementia.* London: Mental Health Foundation.

2) Williams, V., Boyle, G., Jepson, M., Swift, P., Williamson, T. and Heslop, P. (2012) *Making Best Interests Decisions: People and Processes. Appendices A-F.* London: Mental Health Foundation.

3) Williamson, T. and Kirtley, A. (2016) *Dementia Truth Inquiry. Review of Evidence*. Mental Health Foundation report.

My published works references

Clarke, C., Wilkinson, H., Watson, J., Willcockson, J., Kinnaird, L. and **Williamson, T.** (2018) ‘A Seat Around the Table: Participatory Data Analysis with People Living With Dementia’, *Qualitative Health Research,* 28(9), pp. 1421-1433. Available at: https://doi.org/10.1177/1049732318774768.

Clarke, C., Willcockson, J., Watson, J., Wilkinson, H., Keyes, S., Kinnaird, L. and **Williamson, T.** (2020) ‘Relational care and co-operative endeavour – Reshaping dementia care through participatory secondary data analysis’, *Dementia,* 19(4), pp. 1151-1172. Available at: https://doi.org/10.1177/1471301218795353.

Hughes, J. and **Williamson T.** (2019) *The dementia manifesto – putting values-based practice to work.* Cambridge: Cambridge University Press.

Kirtley, A. and **Williamson, T.** (2016) *“What is Truth?” An Inquiry about Truth and Lying in Dementia Care*. London: Mental Health Foundation. Available at: https://www.mentalhealth.org.uk/sites/default/files/2022-09/MHF-dementia-truth-inquiry-report.pdf (Accessed: 30 November 2024).

Laybourne, A., Jepson, M., **Williamson, T.**, Robotham, D., Cyhlarova, E. and Williams, V. (2016) ‘Beginning to explore the experience of managing a direct payment for someone with dementia: The perspective of suitable people and adult social care practitioners’, *Dementia*, 15(1), pp. 125-140. Available at: https://doi.org/10.1177/1471301214553037.

Litherland, R. and **Williamson, T.** (2013) ‘DEEP: the engagement, involvement and empowerment of people with dementia in collective influencing’, *Working with Older People,* 17(2), pp. 65-73. Available at: https://doi.org/10.1108/13663661311325481.

McGettrick, G. and **Williamson, T.** (2015) *Dementia, rights and the social model of disability.* Mental Health Foundation report. Available at: https://www.mentalhealth.org.uk/sites/default/files/2022-09/MHF-dementia-rights-policy-discussion.pdf (Accessed: 30 November 2024).

Williams, V., Boyle, G., Jepson, M., Swift, P., **Williamson, T.** and Heslop, P. (2012) *Making Best Interests Decisions: People and Processes.* Mental Health Foundation report. Available at: https://research-information.bris.ac.uk/ws/portalfiles/portal/190241961/Final_Report.pdf (Accessed: 30 November 2024).

Williams, V., Boyle, G., Jepson, M., Swift, P., **Williamson, T.** and Heslop, P. (2014) ‘Best interests decisions: professional practice in health and social care’, *Health and Social Care in the Community,* 22(1), pp. 78-86. Available at: https://doi.org/10.1111/hsc.12066.

Williamson, T. (2011) ‘Running before we walk: Do we have the capacity?’, *Philosophy, Psychiatry & Psychology*, 18(2), pp.147-150. Available at: https://doi.org/10.1353/ppp.2011.0027.

Williamson, T. (2012a) *A stronger collective voice for people with dementia.* Joseph Rowntree Foundation report. Available at: https://www.jrf.org.uk/sites/default/files/migrated/migrated/files/dementia-groups-influence-policy-summary.pdf (Accessed: 30 November 2024).

Williamson, T. (2012b) *Ripple on the pond. DEEP: the engagement, involvement and empowerment of people with dementia in collective influencing. Appendix to main report – A stronger collective voice for people with dementia.* London: Mental Health Foundation.

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