School of Occupational Therapy, Social Work and Speech Pathology

Person-Centredness In Human Services: An Evidence-Based Conceptualisation To Inform Practice

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Author's Declaration

To the best of my knowledge and belief, this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007), updated 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Numbers #OTSW-12-2011, #HR147/2015, and Amendment Approval Number #HR147/2015-08 (Appendix A).

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Rebecca Adriana WATERS

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Statement of Contributors

This thesis includes one published paper of which I am the primary author:

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Thesis overview

Abstract

The term "person-centred" is increasingly used in human services to define desirable approaches to service delivery. There is, however, no consensus in the literature about the principles of person-centredness and its constituent characteristics, although contemporary government policies regarding service delivery for various groups of vulnerable people have been developed with this approach in mind. It has previously been impossible to define 'person-centredness' without being contextually specific, in fact, it is the very reason that this research was necessary. By drawing on the literature and the views of an expert reference group, this research develops a descriptive framework of person-centred principles and constituent characteristics as they apply to people with disability, elders and people with mental health issues. In addition, this thesis builds a conceptualisation of person-centredness by problematising the contested concepts across multiple contexts. Person-centredness across human services is explored and explained using a post-structuralist approach and addresses the applicability of the framework across policy, organisational and front-line practice contexts.

Research aims

This research aimed to investigate the existence of a shared knowledge of person-centredness across the disability, ageing and mental health sectors. The purpose was to establish a set of person-centred principles and associated attributes across human service sectors to potentially assist in providing consistency of understanding for service users, service providers, funders and policy makers. This study is significant as it is connected with promoting the interdisciplinary and intersectoral transfer of person-centred knowledge and practices.

This research commenced by questioning person-centredness as a magic concept [1] (Pollitt & Hupe, 2011). To meet the research aims, person-centredness was explored via a four-stage research process, informed by Bacchi's (2009; 2016) post-structuralist 'What's the Problem Represented to Be? (WPR) approach. Specifically, this research included (1) a

[1] Magic concepts share the following characteristics: (1) broadness (multiple overlapping definitions with large scope and valency); (2) normative attractiveness (overwhelmingly positive connotation and difficult to be 'against'); (3) implication of consensus (dilute, obscure and sometimes deny traditional social science concerns); and, (4) global marketability (used by many practitioners and academics, are fashionable and feature frequently in official policy documents and reform projects) (Pollitt & Hupe, 2011).

comprehensive review and thematic analysis of the data in the disability, ageing, and mental health literature to determine the characteristics, descriptors and uses of the term 'person-centred', (2) a survey of an expert group on the meaning of person-centredness as it applies in human services and subsequent thematic analysis, (3) the development of a descriptive framework of person-centredness consisting of key themes, characteristics and service expressions, and (4) a confirmation and extension of the service expressions and examples in the framework by an expert focus group.

The findings of the research stages are collated into a descriptive Framework of Person-Centredness in Human Services (FPCHS). This resultant framework is explained and discussed using a conceptual model and is considered in the light of street-level bureaucracy (Evans, 2011; Evans, Jordan, & O'Leary, 2010; Lipsky, 2010) and Nussbaum's (2011) capabilities approach.

Methodology and results

The first stage of the study aimed to mine data defining the characteristics, descriptors and uses of person-centredness from the disability, ageing and mental health literature. Data were extracted from the included literature (1996-2014) and thematically analysed using the six step process outlined by Braun and Clarke (2006). This stage of the study determined seven key themes of person-centredness.

The second stage of the study involved the recruitment of an expert group with significant experience in the area of person-centred approaches to participate in an electronic survey to provide further information about person-centredness from a community of practice perspective. Participants were personally contacted and invited to participate in an online survey. Participants provided demographic information and open, narrative responses to questions investigating their understandings and experiences of person-centredness in human services. Data were again extracted from the responses and once again thematically analysed using the same process as stage one (Braun & Clarke, 2006).

The third stage of the study drew together the data from the first two stages of the research to develop a descriptive Framework of Person-Centredness in Human Services (FPCHS) comprising of the key themes, characteristics and initial service expressions. The researchers conducted several iterations to develop and confirm the framework against the literature and survey results.

The final stage of the study involved consultation with an expert focus group to provide an extension of the service expressions of the descriptive framework in practice. These results provided further detail to the descriptive framework to illustrate the expression of person-centredness in human services.

Discussion

The discussion section reflects on the descriptive framework and the implications for policy, practice and service development in human services. Using a post-structuralist approach, the FPCHS informed the exploration of the problem representations of person-centredness and the resultant policy and practice solutions. These problem representations are considered in the light of magic concepts in government policy, street-level bureaucracy, and the Capabilities Approach. A conceptual model is used to explain the findings.

Conclusion and unique contribution of the PhD

This thesis concludes with a statement highlighting the unique contributions of this PhD to new knowledge in informing human service delivery. Specifically, this thesis uses a unique iterative methodology to execute a multi-level deconstruction of the concept of person-centredness. A descriptive framework of person-centredness for human services is developed comprising of key themes, characteristics and service expressions. A conceptual model is used to explain the commonalities and contestations of person-centredness between human service areas. Recommendations for future research studies are made.

Preface

I would like to preface this thesis with some background information to help contextualise the origin of this research and to provide some explanation for this particular research journey.

At the beginning of this research, I had been an occupational therapist for almost twenty years. I had worked in a variety of settings over the course of my career, most of them unexpected. My experiences ranged from direct service work in the early 1990s with adults with a severe intellectual and physical disability living in provided residential care, to children with intellectual disability and developmental delay living in the community. I worked a significant length of time on the then Local Area Coordination team at Disability Services Commission in Western Australia working with people with intellectual disability and their families to design supports that made sense to each person's situation. Promotions led to policy implementation positions where I got to better understand the bigger picture. Around 2004, life changes led me to work in my own private practice where I ended up back in direct service delivery, this time consulting in residential aged care, case managing with and for people with mental health issues, and working directly with children with significant behavioural problems. When I began working as an academic at Curtin University in 2009, my experience had been varied enough but similar enough to understand there was some commonality to what constituted good support for people.

By the time I had gathered enough belief in myself to commence a higher degree, a research project idea had been hatched by my original primary supervisor, Professor Errol Cocks, and the leadership and management of a human service organisation in Western Australia. That project idea was to become this research.

I began the research as a Master of Philosophy student, however, the scope and size of the research rapidly indicated that this was better suited to a Doctor of Philosophy. Conversion of the original candidacy to a Doctor of Philosophy candidacy occurred in December 2014. As such, there are two separate ethics approvals; one for the Master of Philosophy stage and one for the Doctor of Philosophy stage.

This research has occurred part-time for over approximately 8 years. Things have changed considerably over that time, including the retirement of my original supervisor, and significant change of management in the partner organisation such that that the partnership no longer exists. There have also been some attempts by other authors to consolidate the

knowledge about person-centredness and its representations in health care. Yet still, as far as I am aware, no one has attempted to draw together the aspects of person-centredness into an evidence-based framework. Despite these developments, the research continued and I hope that it offers a unique, evidence-based perspective of person-centredness that will inform policy implementation as major changes occur in the human service areas of interest.

Finally, due to the time limitations of having peer-reviewed publications accepted, and the evolving nature of this project, this research is presented as a hybrid thesis consisting of one accepted publication and a series of chapters explaining the remainder of the research process and the outcomes.

Acknowledgements

The task of completing this PhD has been one of nothing more than perseverance. I have juggled the roles of higher degree student with those of being a mother, daughter, wife, and full-time academic in a university. Completing this could not have been possible without the support of my primary PhD supervisor and long-time work colleague and friend, Angus Buchanan. Angus, I am grateful for your ability to know when to push me and to know when to leave well enough alone. It's been a long and rocky road, but we got there in the end.

I am grateful to Professor Donna Chung for stepping in and becoming my second supervisor halfway through the PhD process. I am grateful for your insights, your policy framework thinking, and your encouragement. You pushed me to think conceptually and to keep focused on the big picture. You made me feel like I could move mountains in my writing (even when the task seemed impossible), and you helped me realise my unique contribution to social policy (even as an occupational therapist).

I am thankful to Professor Errol Cocks for starting me on this project. Your history in human services and the stories you told resonated strongly with me and encouraged me to believe that this work was important to do. I am also grateful to the people who I have been privileged to work alongside in my various work incarnations as an occupational therapist or otherwise, who have each taught me something about the human condition, and about the importance of working with people who live on the margins of inclusion and acceptance. I am grateful to the participants who contributed to this research study as key informants or members of the focus group. Your contributions and insights from many years of practice in human services were hugely valuable. To Dr Lynelle Watts and Dr David Hodgson, thank you for your invaluable comments and final read-throughs of the thesis.

To my support team, Fiona Agostino, Emma Ashcroft, Anna Cain, Robyn Della Franca, Sally Hunter, Zona Rens, and David Waters… you all helped me to keep going in one way or another, whether by encouraging, proof reading, helping me problem solve, listening to my latest idea/iteration, making me a cup of tea, confirming the value of my work or loving me…. you have my deepest gratitude, you all rock!! To my other support team of Maxine and Reece and the gang at Dome Secret Harbour, thanks for the coffee – you can stop thinking about how to charge me for table space now!

To my son, Kane…. Little did you know just how important your 'how's it all going Mum?' questions about my day and my research were. You supported me through this

without even knowing you were doing it. I hope this achievement of mine goes some way to encourage you to know that anything is possible with a little bit of grunt and elbow grease, and a heck of a lot of grit. Love you heaps, buddy.

And to my Mum and Dad, thanks for everything. I can't begin to list all of the ways you have supported me, but you have, even when you didn't understand what I was doing! I love you.

Dedication

This thesis is dedicated to my parents, Ray and Jennie Brookes, who encouraged and continue to encourage me in my pursuit of education; and to the memory of my Oma, Adriana C.L. Husson Kuipers, who determined from my early age that I would become a strong, compassionate, educated and independent woman who could look after herself, and would, by choice, look out for others.

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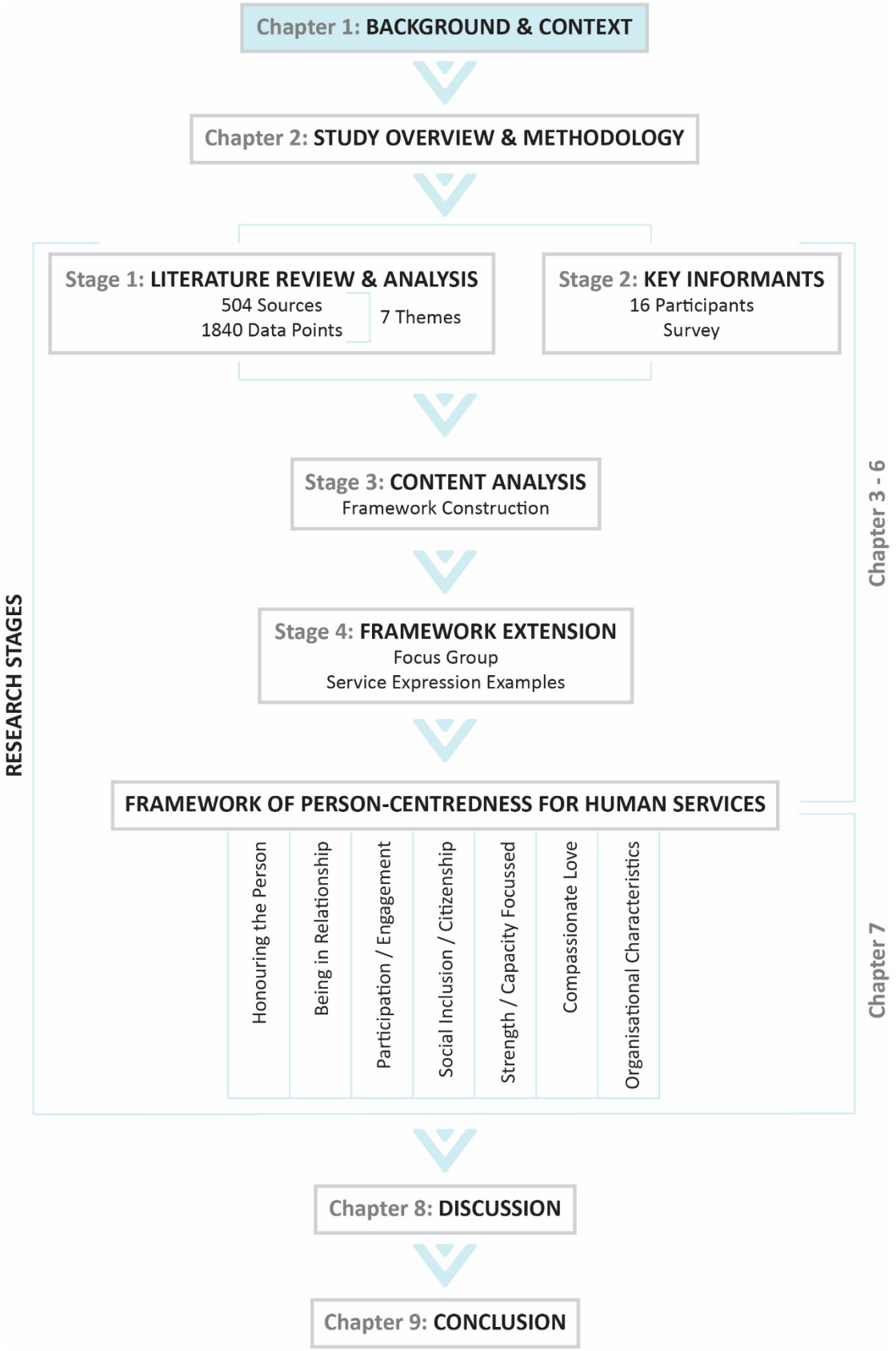
Chapter 1: Background and context



This chapter introduces the background and context of the research study. I introduce the theoretical framework and influencing bodies of knowledge and begin to frame the research problem to demonstrate the rationale for the study. Secondly, I introduce a background to person-centredness across three fields of practice: ageing, disability and mental health. I include a brief history of person-centredness which addresses how the concept is currently represented and employed in these Australian policy contexts. Finally, I describe the focus of this study, the methodological approach and provide an overview of the structure of the thesis.

1.1 Introduction

1.1.1 Person-centredness

'Person-centredness' and the use of the descriptor 'person-centred' before a service term (such as, 'planning', or 'approach', or 'therapy', for example), is considered highly desirable and synonymous with quality in human services. Despite featuring heavily in policy representations in Australia and other Western countries, person-centredness is elusively difficult to define, describe and evaluate in practice. The concept of being person-centred has been interpreted and implemented at every level from policy to practice, and across human service contexts including ageing, disability, mental health and medicine. Its interchangeable use with the terms 'client-centredness' and 'patient-centredness' in various settings ostensibly suggest a fundamental sameness. However, levels of confusion across contexts and policies about what being person-centred means contribute to disagreement. The concept is highly contested at multiple levels of implementation and although elusive, remains desirable in human service delivery. While there is no consensus in the literature about the principles of person-centredness and its constituent characteristics and attributes (Slater, 2006; Smith, 2017), it is held up as being an indicator of service quality in implementation, a desirable outcome of policy, and a positive way of working at the street-level. There is much to learn across and between human service areas as there is a huge diversity in best practice, however, it is this diversity of practice and understanding which has led to a fragmentation of innovation and research (Harding, Wait, & Scrutton, 2014).

Measurement and evaluation of person-centredness in human services are ultimately hindered because of the lack of understanding across fields (Harding et al., 2014). These conceptual debates are much more than a distraction from the hands-on implementation challenges. The challenges extend to barriers in aggregating research outcomes on effectiveness to impeding replications of innovations in service delivery, both of which are

perceived as being important in securing a commitment from policymakers (Harding et al., 2014).

Person-centredness, therefore, needs to be reviewed and understood from multiple perspectives. There are grounds for investigating person-centredness at multiple levels (from policy to practice) and across contexts in human services (ageing, disability and mental health). The development of a conceptual framework of understanding may assist in targeting research and practice evaluations. This thesis builds a conceptualisation of person-centredness by exploring, examining and discussing highly contested ideas, policies and practices across contexts. It is somewhat unique in its construction because it does not articulate these concepts in the beginning but rather builds the conceptualisation through the use of evidence derived from the research stages. To this end, I must ask the reader to hold this as the purpose of the thesis. Using multiple sources to inform the conceptualisation, this research provides a comprehensive starting point for further evaluation and measurement of person-centredness across human service delivery and aims to promote the intersectoral and interdisciplinary transfer of knowledge.

1.1.2 Who is the person in person-centredness?

The term 'person-centredness' by its very construction suggests an agent defined as 'person' at the middle or 'centre'. Determining who is a person is widely contested in many bodies of knowledge including moral philosophy, psychology, sociology, anthropology, and social, political and economic sciences. Beauchamp (1999) defines "the common sense concept of person is, roughly speaking, identical with the concept of human being" (p311), yet others, such as Singer (2010) suggest that species-membership is not sufficient for moral consideration. Arguments from cognitive theorists and moral philosophers suggest that to be considered a person one or all of the following characteristics should be present; "(1) self-consciousness (of oneself as existing over time); (2) capacity to act on reasons; (3) capacity to communicate with others by command of a language; (4) capacity to act freely; and (5) rationality" (Beauchamp, 1999, p. 311). At its most fundamental level, having a status of a person relates directly to the rights of moral consideration, including but not limited to, the right to life and the ethics of killing, especially for people who are positioned on the margins of moral personhood (Kittay, 2008). Being a person speaks not only to questions of life and death but also to the right to be 'treated as a person' when we are subject to the roles of patient, client or consumer in human services.

The arguments of moral philosophers and cognitive theorists in determining who is a person do not hold in the theorising of person-centredness across human services conducted in this research. For the domains of concern in this research, the people with whom we are concerned are variously positioned on the margins of moral personhood (Kittay, 2008), and from the moral viewpoint do not hold the status for moral consideration (Beauchamp, 1999). Morality, considered both as the ability to behave morally and to be the subject of moral treatment and consideration, are ideas which have perplexed society's thinkers as the markers of inclusion and exclusion. Using this construction of the person in person-centredness excludes people with disability, people with mental health issues and people who are ageing from consideration and "obscures the nature of our condition as needy, vulnerable beings, suspended between things as they are and as they might become, for better or worse, and as we need or want for them to become" (Sayer, 2011, p. 4).

In contrast, Post (1995) calls for a 'new moral solidarity' in the care of people with dementia, which could equally be applied to the care of other people who fall outside the traditional cognitive conceptualisations for moral consideration. This moral solidarity suggests that mental capacity and rationality cannot be the means by which we "divide humanity into those who are worthy or unworthy of full moral attention…" (p3). Instead, he argues that there is a need to develop ethics based on the essential unity of human beings (Post, 1995). Chappell (2011) states "In normal cases, we have already identified a creature as a person before we start looking for it to manifest the personal properties, indeed this pre-identification is part of what makes it possible for us to see and interpret the creature as a person in the first place" (p.1). Rather than using criteria as the means for excluding a creature from being a person, Chappell (2011) contends that we make the decision that someone is a person first and then look for the displays of sentience, rationality and self-awareness, therefore "we treat (someone) as a person *in advance of* any such displays" (Chappell, 2011, p. 7, italics in original).

Sayer (2011, p. 106) suggests "it is hard to say anything much about people or indeed interact with them without presupposing something about what they have in common. In everyday practice, ordinary people…rarely have any trouble distinguishing humans from non-human animals or objects". Post's (1995) call for a new moral solidarity is consistent with Rorty (cited, in Sayer 2011, p.107) who calls "for a transcultural solidarity based on the hope that suffering will be diminished, that the humiliation of human beings by other beings will cease".

This construction of the 'person' in person-centredness provides us with a very different starting point than that of moral philosophy. From this viewpoint, the person is a social and evaluative being who is capable and can flourish but is also vulnerable, susceptible to harm, and can suffer (Sayer, 2011). For Sayer (2011), "the most important functions people tend to face in their everyday lives are normative ones of what is good or bad about what is happening, including how others are treating them, and of how to act, and what to do for the best" (p.1). This research considers this construction of the person as the appropriate starting point. This construction of the person further points to significance of this study in understanding what being person-centred actually is and for whom.

1.2 Theoretical frameworks

Theoretical frameworks provide a contextual underpinning to research. This research study is influenced by several broad bodies of knowledge, and the results are discussed in relation to these in the discussion chapters. These influencing theoretical frameworks are; the role of magic concepts in policy construction (Pollitt & Hupe, 2011); post-structural policy analysis (Bacchi, 2009, 2012a, 2012b, 2016; Bacchi & Goodwin, 2016); the role of discretion in street-level bureaucracy (Hupe, Hill, & Buffat, 2015; Lipsky, 2010); and, the Capabilities Approach (Nussbaum, 2011). These theoretical frameworks are required to help understand the concept histories and explore the contested policy uses and practice applications. I have chosen to introduce these theoretical frameworks to the reader here, to further signpost the purpose of conducting the research.

1.2.1 'Magic concepts' in government policy

Pollitt and Hupe (2011) introduce a term in public policy discourse known as 'magic concepts'. Magic concepts are key terms which "seem to be pervasive amongst academics and practitioners" (p.641). The study of magic concepts is a study of words and how they are being used particularly in relation to the understanding and implementation of government policy. According to Pollitt and Hupe (2011), magic concepts share four characteristics; (1) broadness (they connect with many other concepts, have huge domains, and many definitions); (2) normative attractiveness (they are difficult to disagree with, are usually identified as being modern or progressive, and have an overwhelmingly positive connotation); (3) implication of consensus (they dilute, obscure or conflict with traditional social science); and, (4) global marketability (they are fashionable with academics, policy makers and practitioners alike) (p.643).

Carey and Malbon (2018) suggest that although Pollitt and Hupe (2011) discuss magic concepts at a high level of public administration, there is utility in the approach at a context level to identify magic concepts within a given program, reform, or set of practices. To this end, 'person-centredness' could be considered a magic concept, particularly as the term is used daily and globally (at least in Western countries), and seems to facilitate new orientations and understandings at a rapid rate. Magic concepts are, by their very nature, able to constitute multiple meanings and ambiguity, and are often perceived as succeeding one or more of their predecessors (Pollitt & Hupe, 2011). Carey and Malbon (2018) warn that it is "important to pay attention to where magic concepts emerge during policy implementation to alert us to problem areas" (p.12) as it is risky to trust something when the intricacies and details of its operation are not clear. Magic concepts can sometimes fulfil explanatory functions, but only, according to Pollitt and Hupe (2011), if they are accurately "positioned, specified, operationalised, and applied in systematic ways" (p.654).

Magic concepts are as much a part of political vocabulary as they are of technical or scientific vocabularies (Pollitt & Hupe, 2011), and this is certainly the case for 'person-centredness'. Person-centredness appears in policy, academic literature, grey literature, procedures and in the day-to-day language of human services. It has been held up as the indicator of quality in human services and as being the panacea and solution to the medical model (Lupton, 1997). From this perspective, the concept of 'person-centredness' appears to be a rightful candidate to explore, particularly in the light of its operationalisation in human services. This research considers person-centredness to be a magic concept, that to follow Pollitt and Hupe (2011), requires positioning, specifying, operationalising and application in systematic ways.

1.2.2 Post-structural policy analysis: "What's the Problem Represented to be?" (WPR) approach

Given that all policies aim to address certain problems, no policy works without first problematising its territory and considering the scope of its impact (Shao & Gao, 2019). Post-structuralism offers one approach to understanding problematisations. Whereas structuralism in sociology, anthropology and linguistics is a method of interpretation and analysis that considers structure more important than function, a post-structuralist approach contends that to understand an object or phenomenon, we must study both the phenomenon and the systems of knowledge that produced it (Downing, 2008). Problematisations are used in this sense to refer to the Foucauldian approach of questioning, analysing and classifying issues at specific times and under specific circumstances to understand how and why things become

problems and how they are shaped as particular objects for thought (Deacon, 2000, cited in Bacchi (2012b)). In this form of exploration, the historical process of the production of the problem is important and "involves 'standing back' from 'objects' and 'subjects', presumed to be objective and unchanging, in order to consider their 'conditions of emergence' and hence their mutability" (Bacchi, 2012b, p. 4).

Carol Bacchi's "What's the Problem Represented to be (WPR)?" approach offers one such post-structuralist framework to undertake this analysis (Bacchi, 2009, 2012a, 2012b; Bacchi & Goodwin, 2016). The aim of Bacchi's (2012a) approach is to "understand policy better than policymakers by probing the unexamined assumptions and deep-seated conceptual logics within implicit problem representations" (p.22). The WPR approach offers a methodology to scrutinise the forms of knowledge that underpin public policy representations and encompasses the place of experts and professionals. Specifically, the WPR acronym is intended to clarify that the purpose of the analysis is to begin with the postulated 'solutions' in order to make clear and examine critically the inherent problem representations (Bacchi, 2012a). Bacchi's (2012a, p. 22) investigative framework of problem representation assists by seeking the answers to a series of focus questions. These focus questions direct the investigation to address presuppositions and assumptions as well as questioning the multiple histories, contexts and applications of the concept.

In addition, Bacchi and Goodwin (2016) contend that attention to the heterogeneity and plurality of practices makes it possible to insist that the realities we live are contingent and open to challenge and change. A post-structural perspective highlights how our multiple understandings of a concept both directs and creates knowledge and practices (Bacchi & Goodwin, 2016). In the case of this research, I begin with the assumption that person-centredness is framed as a 'solution' to a myriad of human service 'problems' across the areas of ageing, disability and mental health. Many researchers, practitioners, theorists and policymakers have tried to pin down person-centredness to make it possible to evaluate it as a process, an outcome, a value, a policy and as a practice (Harding et al., 2014), however, this has remained elusive, perhaps as a result of its status as a magic concept. The investigation of person-centredness as a problematisation offers a comprehensive and complex perspective.

1.2.3 Street-level bureaucracy and front-line worker discretion in the implementation of person-centredness

To this point, I have introduced the idea of person-centredness as a magic concept having utility in human service delivery. I have also introduced the WPR approach which

suggests that our understanding of person-centredness may both inform, and be informed by, practice and policy. To add to this background, I introduce Lipsky's (1980, 2010) theory of street-level bureaucracy. Street-level bureaucracy is a term assigned to the front-line discretion of workers in welfare and human services (Lipsky, 2010). Lipsky's work has been used to examine and explain the complexities of policy implementation and organisational prioritisation at the street-level of front-line workers in public welfare and social service organisations (Evans, 2011). In particular, Lipsky (2010) provides an analysis of discretion in street-level bureaucracies (which human services are) and focuses on the continuing discretion that front-line workers have in policy implementation. Policy implementation can be explained by two approaches: top-down theorists (who see the policy as something to be implemented by an organisational bureaucracy) and bottom-up theorists (who consider a policy to be created by the tensions and demands of working on the front-line) (Evans, 2011).

Street-level bureaucracy interfaces well with the WPR approach. In the WPR approach, the policy is construed as a solution to a problem representation. In Lipsky's street-level bureaucracy, policy is both constructed by the front-line worker and implemented by the front-line worker, via a process of discretion. This discretion often occurs in a context of conflict, where any policy has to be understood and applied alongside other policies and resources within an organisational structure (Evans, 2011; Lipsky, 2010). Lipsky (2010) asserts the motivation of the street-level worker is directed towards maximising goals and outcomes for clients in the welfare state, rather than the organisation or the broader government. Other authors suggest that discretion is primarily used by practitioners to make their work easier and manage the everyday demands of operating at the front-line in an environment of reduced resources (Evans & Harris, 2004). The everyday work of policy implementation in human services is at the mercy of practitioner discretion which is influenced by professional practitioner knowledge and identity (Carson, Chung, & Evans, 2015).

1.2.4 The Capabilities Approach

A final theoretical lens to consider in this research is at the level of the person and is relevant to the most important elements of people's quality of life. To this end, I introduce Nussbaum's (2011) version of the Capabilities Approach regarding human development. Building on the previous work conducted by, and with, Amartya Sen (1992), Nussbaum (2011) provisionally defines "…the Capabilities Approach…as an approach to comparative quality-of-life assessment and to theorising about basic social justice" (p.18). Fundamentally, Nussbaum argues that the key question is 'What is each person able to do and to be?' when considering

societies and their basic decency or justice. Nussbaum's ten central capabilities[2] allow each person to be considered as an end with a priority on choice or freedom. Additionally, the Capabilities Approach is "concerned with entrenched social injustice and inequality, especially capability failures that are the result of discrimination or marginalization. It ascribes an urgent task to government and public policy – namely, to improve the quality of life for all people, as defined by their capabilities" (Nussbaum, 2011, p. 19). Broader than a conceptualisation of human rights, Nussbaum's ten Central Capabilities offer a way of thinking about the work of governments and public policy to secure a 'decent political order' for all citizens, and in the case of this research, including people who are ageing, have disabilities and / or have mental health issues. This version, over Sen's, attempts to operationalise the ideas in constructing a theory of basic social justice inclusive of human dignity (Nussbaum, 2011). This theoretical lens offers a way of considering the impact of public policy on the experiences of the subject of person-centredness (namely the *person*), and the extent to which human services are constructed to uphold human dignity.

1.3 Defining 'person-centredness': A note about semantics

Prior to continuing any further, it is important to introduce a reflection on semantics. It has been suggested that the nebulous nature of person-centredness and approaches that are defined as being person-centred, has in fact been one of the reasons for hindered implementation and evaluation (Harding et al., 2014). The term 'person-centred' is used a descriptor in many situations and is often used inter-changeably with terms such as 'patient-centred', 'client-centred' and 'consumer-centred', and as has been previously noted, is notoriously elusive to define. Some authors perceive that there is no difference in the use of the terms and they can be used interchangeably (Entwistle & Watt, 2013; Slater, 2006). Others are adamant that person-centred care should not be confused with patient-focussed or patient-centred care or other terms because of the association with the reductionist

[2] Nussbaum's ten central capabilities: (1) Life (being able to live to the end of a human life of normal length); (2) Bodily Health (being able to have good health, nourishment and shelter); (3) Bodily integrity (being able to move freely, be secure against assault, have opportunities for sexual satisfaction and choice in reproduction); (4) Senses, imagination, and thought (being able to use the senses, imagine, think and reason); (5) Emotions (being able to have attachments to things and people outside ourselves, love, grieve, experience longing and gratitude); (6) Practical reason (being able to form a conception of the good and plan one's life); (7) Affiliation (being able to live with and toward others, be in relationship, having the social bases of self-respect, treated as a dignified being of worth that is equal to others); (8) Other species (being able to live with concern for other species); (9) Play (being able to laugh, play and enjoy recreation); and, (10) Control over one's environment (both political and material) (Nussbaum, 2011, pp. 33-34)

patient – professional interactions that are counter-productive to care customised to a person's needs, values and preferences (Talerico, O'Brien, & Swafford, 2003). The proliferation of publications based on inter-related concepts of person-centredness (such as patient-centred, client-centred, consumer-oriented, and person-oriented) adds to the challenge of understanding how these concepts are comparable (Edvardsson, 2015). It also assumes that being person-centred is inextricably linked to the context of providing care. Literature in other fields suggests that both assumptions are incorrect given the use of the term as a descriptor in many varied applications outside of 'care', including action, advocacy, planning and therapy. Therefore, for the purposes of this research, I ask the reader to commence reading this thesis by holding the term 'person-centred' as a distinct and separate identity. I also ask the reader to overlook the lack of a definition of the concept at this stage, as the exploration and conceptualisation of these contested ideas form the basis of this research.

1.4 The emergence of person-centredness: Concept, policy and practice

A post-structuralist approach requires that we investigate both the phenomenon and the systems of knowledge which produced the phenomenon (Downing, 2008). This research investigates person-centredness across the three human service areas[3]. With this in mind, I identify the policy references to person-centredness across the sectors and provide an overview of the concept in each of these contexts with specific attention paid to the problem representations and histories of their development.

1.4.1 The Australian policy environment

The current socio-political context made it timely to investigate person-centredness for two major reasons. Firstly, there had been a period of significant proposed and actual policy reform in Australia in the disability sector (with the creation of the Commonwealth Government National Disability Strategy (Council of Australian Governments, 2010) and the National Disability Insurance Scheme (Government of Australia, 2013), the aged care sector (with the introduction of the Aged Care Reform and the focus on consumer direction in the Commonwealth Home Support Programme (Department of Social Services, 2014a, 2014b)) and in the mental health sector (as evidenced in The Roadmap for National Mental Health Reform (2012-2022) (Council of Australian Governments, 2012), the fifth National Mental

[3] The three human service areas addressed in this research are ageing, disability and mental health

Health and Suicide Prevention Plan (Australian Government Department of Health, 2017) and the Mental Health Commission of Western Australia Strategic Plan (Mental Health Commission of WA, 2012, 2015). Policy reforms influence the funding and prioritising of services and support to eligible groups. As a result, non-government, non-profit, and charitable organisations are increasingly providing supports across these human service areas. Secondly, policy reform in disability, ageing and mental health in Australia points to person-centredness as being concerned with consumer or self-direction in services or supports, and concepts of choice, control, flexibility and individualisation amongst others. This policy reform is occurring without a clear understanding of the problem representation and hence person-centred 'solutions' to the problems in human services are implemented without a clear framework underpinning what characterises this approach. Since the commencement of this research, there is now an acknowledgement at least, that person-centredness has evolved differently in different fields, and that research and innovation have been fragmented as a result (Harding et al., 2014). A continuation of the conceptual debate prevents the implementation and replication of innovation in person-centredness despite there being proof of concept (Harding et al., 2014).

1.4.2 The disability sector

Person-centred 'planning' developed in North America as a means to operationalise Wolfenberger's principle of normalisation[4] in order to improve service quality for people with developmental disability (O'Brien & O'Brien, 2000). The principles of normalization and social role valorization (SRV) have been described as the most influential works in the disability sector in terms of impact on practice in the area of mental retardation (intellectual disability) in the late 20th century (Flynn & Lemay, 1999). Many of the ideas underpinning normalisation and SRV were applied to other disability areas and to other marginalised and vulnerable groups of people (Wolfensberger, 1983) and "brought about an enormous change in services"(Flynn & Lemay, 1999, p. 3). O'Brien and O'Brien (2000) state "like other efforts for social change, person-centred planning (in disability) has been used and misused, complicated and simplified, lengthened and shortened, trivialised, legalized and lionized" (p.2). Their historical perspective uses 'person-centred' as a descriptor for a particular style of planning

[4] Normalisation: Largely attributed to Wolfensberger and Nirje. Replaced by the term 'social role valorisation' in 1983 (Wolfensberger, 1983). Wolfensberger's (1972) book *The Principle of Normalization in Human Services* was rated … "as the most influential work published in the field of mental retardation, in terms of its impact on practice" (Flynn & Lemay, 1999, p. 3). Gaining relevance in the era of deinstitutionalisation, "the highest goal of the principle of normalization (was) the establishment, enhancement, or defense of the social role(s) of a person or group, via the enhancement of people's social images and personal competencies" (Wolfensberger, 1983, p. 234).

approaches which were formatively developed between approximately 1979 and 1992. The overall intent of this group of planning practices was to provide "a systematic way to generate an actionable understanding of a person with a developmental disability as a contributing community member" (O'Brien & O'Brien, 2000, p.2). While person-centredness in developmental disability has its roots in planning, the conceptual frameworks of inclusion and citizenship[5] for the purposes of improved life outcomes for marginalised groups appear to have broadened their use in person-centred 'practice'.

Person-centred 'practice' is a contemporary method of working with people with disabilities and has its origins in the concepts of normalisation, the social model of disability, the closure of institutions and the inclusion movement (Kilbane & McLean, 2008). Person centred practice is defined as "pulling together the best of what we now know about ways of working that maximise the control individuals have to live their lives as citizens on their own terms" (Kilbane et al., 2008, p. 30). The core principles are hierarchically defined by the authors as listening, sharing power, responsive action, and connecting with citizenship. Although person-centredness has evolved over a number of years, it gained momentum in the United Kingdom with the establishment of the UK Department of Health '*Valuing People*' White Paper in 2001 (Kilbane et al., 2008) and the subsequent '*Valuing People Now*' in 2009. Person-centred care continues to appear in UK government discussion papers, such as the 2015 Green Paper '*Transforming Care for People with Learning Difficulties – Next Steps*' (National Health Service England, 2015).

In Australia, "person-centred approaches to planning, design and delivery of supports and services have emerged, and interest is growing in individualised, self-directed funding and supports" with a focus on achieving "full inclusion of people with a disability in everyday life" (Council of Australian Governments, 2010, p. 13). The subsequent implementation of the strategy has resulted in the National Disability Insurance Scheme (NDIS) which is frequently described as the biggest reform in disability service since deinstitutionalisation. Consistent with the United Nations Convention on the Rights of Persons with Disabilities (2006), the National Disability Insurance Scheme Act 2013 sets out a number of principles grounded in human rights which clearly articulate the goals of broader social inclusion, participation and citizenship for people with disability, all of which have been previously identified as

[5] Citizenship: In this context, citizenship is understood as "a central, organising principle that underpins the shift towards person-centred practice" (Kilbane, Thompson, & Sanderson, 2008, p. 35). This understanding of citizenship is informed by Duffy's (2003) Six Keys to Citizenship: (1) self-determination, (2) money, (3) direction, (4) home, (5) support, and (6) community life.

characteristics of person-centredness (Government of Australia, 2013). The lack of consensus about person-centred approaches has been noted as impacting the successful rollout of the NDIS in Australia (Green & Mears, 2014). In addition, the marketization of disability services in the NDIS era is creating competition and the impact on service delivery and care coordination is as yet unknown (Green, Malbon, Carey, Dickinson, & Reeders, 2018).

1.4.3 The ageing sector

Person-centredness in the ageing sector is largely concerned with the provision of services to those requiring dementia care. Authors lack agreement over the principles of person-centredness in this sector, although several acknowledge the roots of it were established in Rogerian psychotherapy (Bellchambers & Penning, 2007; Brownie & Nancarrow, 2013; Morton, 2000), and that much of the work builds on the principles outlined in Tom Kitwood's (1997) book, *Dementia Reconsidered: The Person Comes First*. The National Care Forum for Older People and Dementia Care Committee (2007, p. 2) stated that the emphasis should "always be on the person as an individual" and should take into consideration the unique qualities of the person as determined by their life history and experiences, and likes and dislikes. Citizenship of the person is considered fleetingly from a rights perspective.

A concept analysis of person-centredness conducted by Slater (2006) made no reference to any of the developmental work and research conducted within the disability sector over the previous 50 years. There is little communication across the sectors although similar principles are applied and usually with different terminology (Slater, 2006). Other literature reviews on person-centred approaches in aged care focus directly on person-centred care (Alzheimer's Australia, 2014). Slater (2006) stated that person-centredness is a term frequently used in relation to the care of the older person, and typically interchangeable with patient-centred or client-centred care. There is a lack of delineation of the clear differences between person-, client- and patient-centred approaches in the nursing and medical research literature focused on the aged care sector.

The delivery of services within aged care (both in- and out-of-home care), is being influenced by the Commonwealth Government's Aged Care policy reforms with specific directions to implement consumer-directed care and home care packages aimed at maintaining people in their homes (Department of Social Services, 2014a). Additionally, the Commonwealth Government released a discussion paper for community consultation which articulated an "increased focus of well-being and reablement" which "will be supported by a

standardised national assessment process that will include the development of goal orientated, person-centred support plans for clients" (Department of Social Services, 2014b, p. 8).

1.4.4 The mental health sector

Authors writing about the concepts of recovery following mental illness have used the Tidal Model of Mental Health Recovery and Reclamation as the underpinning rationale for promoting person-centred care (Barker, 2001; Buchanan-Barker & Barker, 2008). The Tidal model is primarily concerned with the person 'reclaiming' the personal story of their distress and difficulty as a mechanism to "get going again" (Buchanan-Barker & Barker, 2008, p. 171). The approach is grounded in the acute care setting and focuses on repair and recuperation in preparation for returning to everyday living. Buchanan-Barker and Barker (2008) postulated that the person's narrative of their story and their unique lived experience are of primary importance in advancing the voyage of recovery. There is some similarity with perspectives held in the ageing sector as the Tidal model is an approach to a particular style of caring or intervention which is concerned with the person's history of illness. Person-centredness, as described in the mental health literature, draws on elements of both the disability and ageing literature. For example, there are similarities in the acknowledgement of roots in Rogerian psychotherapy (as with the literature in ageing) (McKay, McDonald, Lie, & McGowan, 2012) and with the processes of person-centred planning (as in the disability literature) (Buchanan, Peterson, & Falkmer, 2014).

The policy framework for mental health services in Australia includes strategies at both a National and State level. Nationally, *The Roadmap for National Mental Health Reform 2012-2022* states that its first priority is to 'promote person-centred approaches' which allows "people flexibility, choice and control over their recovery pathway, and responds to each individual's unique needs, circumstances, life-stage choices and preferences" (Council of Australian Governments, 2012, p. 14). The *Fifth National Mental Health and Suicide Prevention Plan* (Australian Government Department of Health, 2017) prioritises "a holistic, person-centred approach to physical and mental health and well-being" (p.37) and commits all governments "to ensuring future mental health services are person-centred and meet the needs of people with mental illness and the community" (p.49). In Western Australia, the State Government's Mental Health Commission commenced a strategic plan which identifies key reform directions, the first of which is 'Person-centred supports and services' (Mental Health Commission of WA, 2012). This key reform is stated as "the unique strengths and needs of the person experiencing mental health problems and/or mental illness are the key

focus of individualised planning, supports and services" (Mental Health Commission of WA, 2012, p. 6). The resultant Mental Health Commission of WA Strategic Plan (Mental Health Commission of WA, 2015) makes several references to "access to an easy to navigate system where (people) can be provided with personalised, high-quality and safe treatment and support" (p.8).

Underpinning the review of policy in the mental health area in Australia is the recognition of a fragmented, unresponsive system resulting in inadequacies and inefficiencies experienced by people (Australian Government Department of Health, 2017). The foreword to the *Fifth National Mental Health and Suicide Prevention Plan* (Australian Government Department of Health, 2017) demands that "consumers and carers are central to the way in which services are planned, delivered and evaluated" while also recognising the tragic impact of suicide on Australians (p.v). Both of these statements suggest that the current system is, therefore, inefficient, inadequate and operates in a context that does not prioritise people with mental health issues and their carers. Interestingly, the Fifth Plan operationalises the next stage of the *National Mental Health Policy 2008* (Australian Government Department of Health, 2008). Ten years after the release of the original policy, the experiences of people have, at best, only minimally improved. One of the actions within the Fifth Plan is a review and renewal of the *National Mental Health Policy 2008* which is to include consumers and carers in policy and oversight, including co-design of models of care and service and program reform (Australian Government Department of Health, 2017). The inclusion of consumers and carers in the co-design of supports and centrally locating consumers in the planning, delivery and evaluation of services suggests that the move towards person-centred approaches is not only desirable but necessary in the sector.

1.5 Research aims

This research on person-centredness sits within historical problem representations that are viewed differently across human service contexts. Person-centredness, or one of its many variations in the nomenclature, is upheld as a solution to these problematisations. The conceptualisation of person-centredness is located within siloed histories and sits in a broader social policy context of marketization, individualisation and choice, and a weakening of the medical model (Carney, 2015; Lupton, 1997; Meagher & Goodwin, 2015a).

Policy representations of person-centredness across all three human service areas assume that the people who are subjects of the policy have agency and that their human rights can be upheld through the processes of agency engagement. However, as the above

identified policy approaches and literature reveal, there was, and continues to be, no unitary meaning of the concept of person-centredness. The use of person-centredness in policy domains varies, as well as how it is operationalised in daily practice. This warranted an exploration of the concept to facilitate understanding across the three human service areas.

Therefore this study focused on a critical analysis of the literature, policy and practice applications to develop an empirical, evidence-based framework of person-centredness. The purpose of this framework was to better understand the policy solution of person-centredness thereby allowing a critical analysis of the underpinning human service policy problem representations. This research draws together what is known about person-centredness across three human service domains to create an empirically-based framework and an evidence-based conceptualisation of person-centredness to inform practice and policy implementation. The research objectives were:

1. To conduct a comprehensive review of the ageing, disability and mental health literature, and extract data from the literature which reflect the characteristics, descriptors and uses of the term 'person-centred';
2. To consult an expert group on the meaning of person-centredness as it applies in human services for elders, people with disability and people with mental health issues to translate the theoretical evidence of person-centredness obtained from the literature;
3. To build a descriptive framework of person-centredness using the data from the literature and the expert group in an effort to inform practice and policy implementation;
4. To consider the framework and the findings using the identified theoretical frameworks; and
5. To critically analyse the conceptualisation and forms of the operationalisation of person-centredness.

These objectives were addressed through the study's four stages which are outlined below.

1.6 Overview of the thesis structure

This thesis is organised into nine chapters. Following this introductory chapter is an overview and rationale of the study design. As the study contains a number of stages, the thesis has been structured so that this chapter offers the reader an overview of research objectives and methods used. Chapters three to six give the detail of each of the four sub-

studies. In chapters seven and eight, the descriptive framework based on the research is presented and the findings from the study strands are examined in the light of other research and emerging policy and practice trends. The final chapter, nine, concludes the thesis. The structure of the thesis is outlined below:

Chapter 2 This chapter presents an overview and rationale of the study design and addresses ethics.

Chapter 3 This chapter describes Stage 1 of the research in which data was mined from the literature on the uses, definitions and characteristics of person-centredness across ageing, disability and mental health. It describes the process and results of the thematic analysis of the uses, definitions and characteristics of person-centredness. This chapter includes the one submitted and accepted publication from the research.

Chapter 4 This chapter describes Stage 2 of the research in which key informants' perspectives on person-centredness across ageing, disability and mental health were gathered. It includes the results of the extension of the themes, sub-themes and characteristics of person-centredness from an expert group.

Chapter 5 This chapter describes Stage 3 of the research in which data consolidation and interpretation occurred. It describes the process of content analysis, and the results of the descriptive characteristics and preliminary service expressions and examples of person-centredness in a draft conceptual framework.

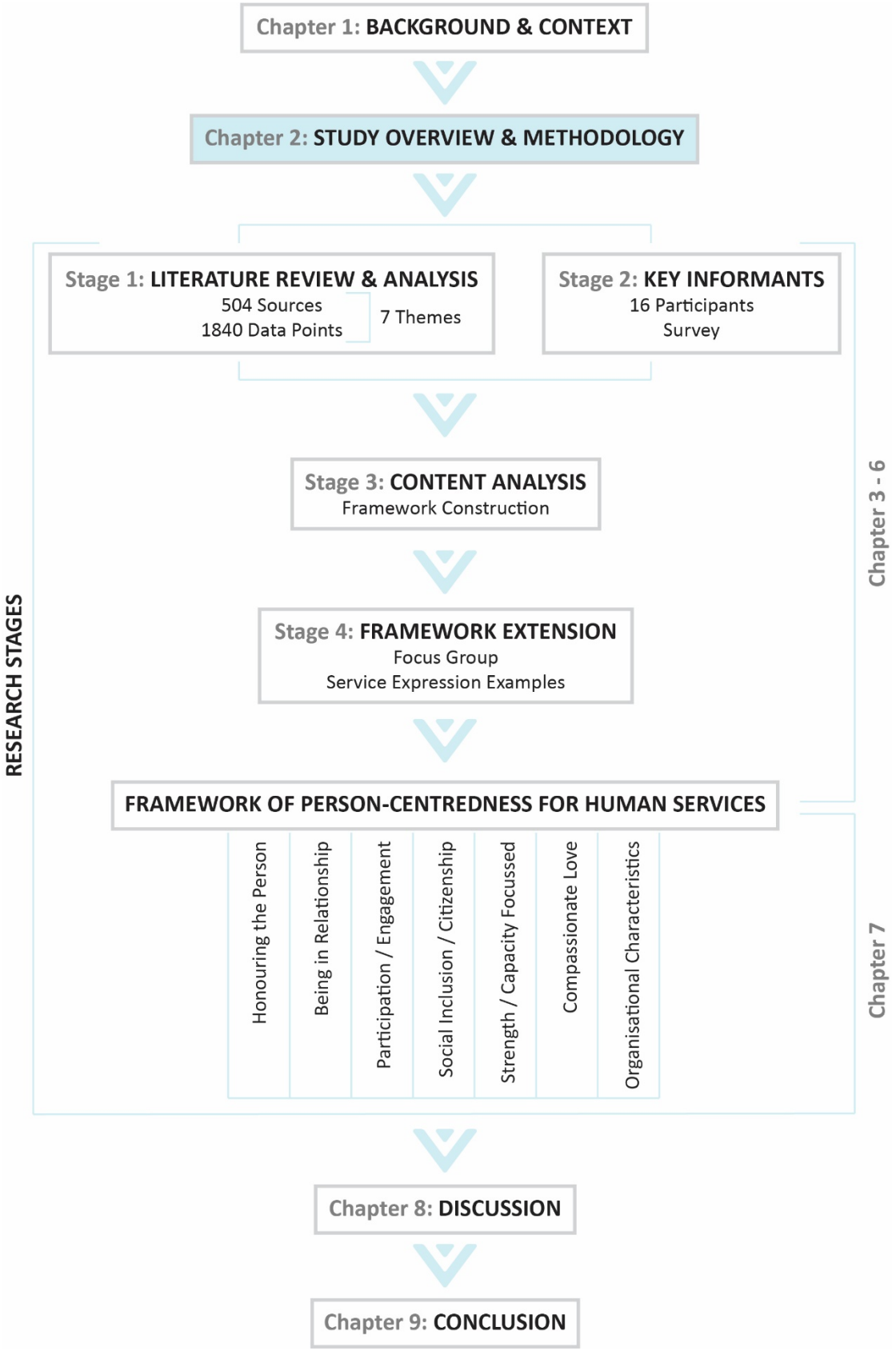
Chapter 6 This chapter describes Stage 4 of the research and includes the process and results of the extension of examples of service expressions of person-centredness using an expert focus group.

Chapter 7 This chapter presents the final descriptive framework of person-centredness across human services developed from the four research stages.

Chapter 8 This chapter discusses the overall research findings in the context of the identified theoretical frameworks and introduces a model to explain the problem representation of person-centredness.

Chapter 9 The final chapter concludes the thesis, explicitly articulates the contribution of the research to new knowledge, addresses the strengths and limitations of the studies, and presents the recommendations for further research.

Chapter 2: Study overview and methodology



This chapter introduces the research methodology and locates it alongside the theoretical frameworks introduced in the first chapter. The overall aim of this research was to explore person-centredness as a magic concept using Bacchi's WPR approach (Bacchi, 2009, 2012a; Bacchi & Goodwin, 2016) and Lipsky's theory of street-level bureaucracy (Lipsky, 2010) to expose the different levels of discourse. Each study in the research aims to progress the positioning, specifying, operationalising and systematic application of the concept of person-centredness to inform practice across the three human service areas (Pollitt & Hupe, 2011). I introduce the individual study methodologies here to provide the reader with an overview of the direction of the project. Finally, I address the ethical considerations of the research.

2.1 Research methodology

This research is comprised of four stages with each stage building an additional level of data to inform the development of an empirically-based conceptualisation of person-centredness. The research is highly iterative and comprised of a number of inductive and deductive processes with each building on the previous stage. Each stage is introduced below to assist the reader in understanding the project.

2.1.1 Stage 1: Content analysis of the literature on person-centredness in disability, mental health, and ageing.

Consistent with the WPR approach, Stage 1 of the research provides a place to begin the analysis and a way to open up for questioning something that appears obvious and natural (Bacchi, 2012). A modified scoping review methodology (Objective 1) and a subsequent thematic analysis (Objective 2) were used to identify the key uses, descriptors and characteristics of person-centredness in the literature (Arksey & O'Malley, 2005; Braun & Clarke, 2006). The results were used to develop a set of themes with constituent subthemes, characteristics and service expressions. The results of this stage provide an understanding of how person-centredness is constructed in academic and grey literature and in Australian policy documents, to inform front-line practice and expose the first level of the discourse.

2.1.2 Stage 2: Surveying of key informants (expert group) to extend understanding of person-centredness in disability, mental health, and ageing

Stage two employed an online survey technique to ascertain the perspectives of key informants to inform the results obtained in the first stage (Payne & Payne, 2011). Bacchi's WPR approach in the analysis of policy concepts asks what is left unproblematic in the policy representation (Bacchi, 2012a). Silences in the policy representation should be investigated

and attention paid to if the problem can be conceptualised differently (Bacchi, 2012a). This stage acts to expose professional discourse across multiple domains of human services. Key informants provide a unique perspective of the problem representation by virtue of their location (Payne & Payne, 2011).

The survey results were thematically analysed in the same manner as the first stage results and provided confirmation of the existing themes and extension to the subthemes, characteristics and service expressions (Objective 3). A new and previously unidentified sub-theme was revealed through this process which revealed what Bacchi terms a 'silence' or something that is perceived as 'unproblematic' in the problem representation (Bacchi, 2012a). The introduction of this new sub-theme brought into focus the impact of street-level discretion in the implementation of person-centredness in practice (Lipsky, 2010).

2.1.3 Stage 3: Modified content analysis to develop the Framework of Person-Centredness in Human Services

The next step in the WPR approach asks 'what effects are produced by this representation of the problem?' (Bacchi, 2012a). To further investigate the problem representation, this third stage of the research utilised a modified content analysis to develop a consolidated descriptive framework of person-centredness across disability, mental health, and ageing. This was named the Framework of Person-Centredness for Human Services (FPCHS). It identifies seven key themes of person-centredness, with constituent sub-themes, characteristics and service expressions, all of which were drawn from either the literature or the key informants or both. The FPCHS was developed by identifying the macro, meso and micro levels of expressions of person-centredness. The framework highlights a two-way model of development consistent with Lipsky's top-down and bottom-up influences on policy implementation (Lipsky, 2010). Each element within the framework has an audit trail back to its contribution source. In addition, the content analysis process identified a selection of service expression examples that inform the practical implementation of the framework, furthering the idea that street-level bureaucrats both interpret and direct the ground level experience of the policy (Evans, 2011; Lipsky, 2010).

2.1.4 Stage 4: Extension of the Framework of Person-Centredness in Human Services (service expression examples) by an expert group

This fourth and final stage of the research sought to extend the understanding of the street-level discretion of practitioners in the implementation of person-centredness across human services (Objective 5). It was clear from the previous three stages of the research that

practitioners utilise professional discretion in the implementation of the concept at the street-level (Lipsky, 2010). Stage 4 involved drawing together a cross section of key informants to participate in a focus group to extend the practical examples of service expressions of person-centredness in human services. In this sense, this stage of the research allowed me to understand how the person/ subject of the human service practice is constituted through the layers of policy and professional discourse (Objective 4). Consistent with action research, this approach was useful in exploring the theory in relation to practice by emphasising knowledge produced in the context of application (Eden & Ackermann, 2018). Street-level discretion of the front line worker influences how the discourse plays out in practice. The focus group provided an opportunity to understand how street-level bureaucrats use discretion to promote person-centredness, as they understood the concept. This process extended the detail in the descriptive framework by bridging the elements of the conceptual framework with practical implementation from a cross-section of disability, mental health, and ageing perspectives.

2.2 Ethics

This study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Numbers #OTSW-12-2011, #HR147/2015, and Amendment Approval Number #HR147/2015-08 (Appendix A). The research presented and reported in this thesis was conducted in accordance with the National Statement on Ethical Conduct in Human Research updated 2014 (National Health and Medical Research Council, the Australian Research Council and Universities Australia, 2007).

The information sheets and consent forms were provided to participants at the commencement of each stage of the study. In Stage 2, participants were provided with study information as an introductory component to the online survey (Appendix C). This included information about the aim of the research, the expected research process, what participants were being asked to do, and how confidentiality and privacy would be managed throughout the research process. Information was provided on data collection and storage. The participants were also provided with the researcher and the research supervisor's contact information. Consent was obtained via an explicit decision to continue with the survey. This consent included an acknowledgement of understanding of the research project process, confirmed their interest in continuing with the survey, confirmed that they could ask questions and/or withdraw from the study at any point without consequence, and agreed that their de-identified data could be used in publications about the research.

In Stage 4, participants were provided with information sheets and consent forms prior to the commencement of the focus group. This information sheet included information about the aim of the research project, the purpose of the focus group, what the participants were being asked to do, how private information and data collected would be stored and managed, as well as the researcher and researcher supervisor's contact details. The signing of the consent form ensured participant acknowledgement of the purpose of the research study, the ability to ask questions and withdraw from the focus group at any point without consequence. The signed consent form also formally acknowledged participant agreement to be involved in the focus group, and permission to use de-identified data in publications resulting from this study. The participants were also informed that the focus group would be recorded for the purposes of data checking.

Confidentiality of data was maintained at all times. Data from Stage 2 was identifiable by code only. The privacy of responses was ensured at all times. At no stage could participants be identified in the reporting of data. Data collected in Stage 4 of the research study was collected at the group level. All data collected for this research project is stored on Curtin University's password protected research network drive in accordance with The Australian Code for the Responsible Conduct of Research (Section 2), and will be retained for a period of seven years in accordance with the Western Australian University Sector Disposal Authorities (WAUSDA).

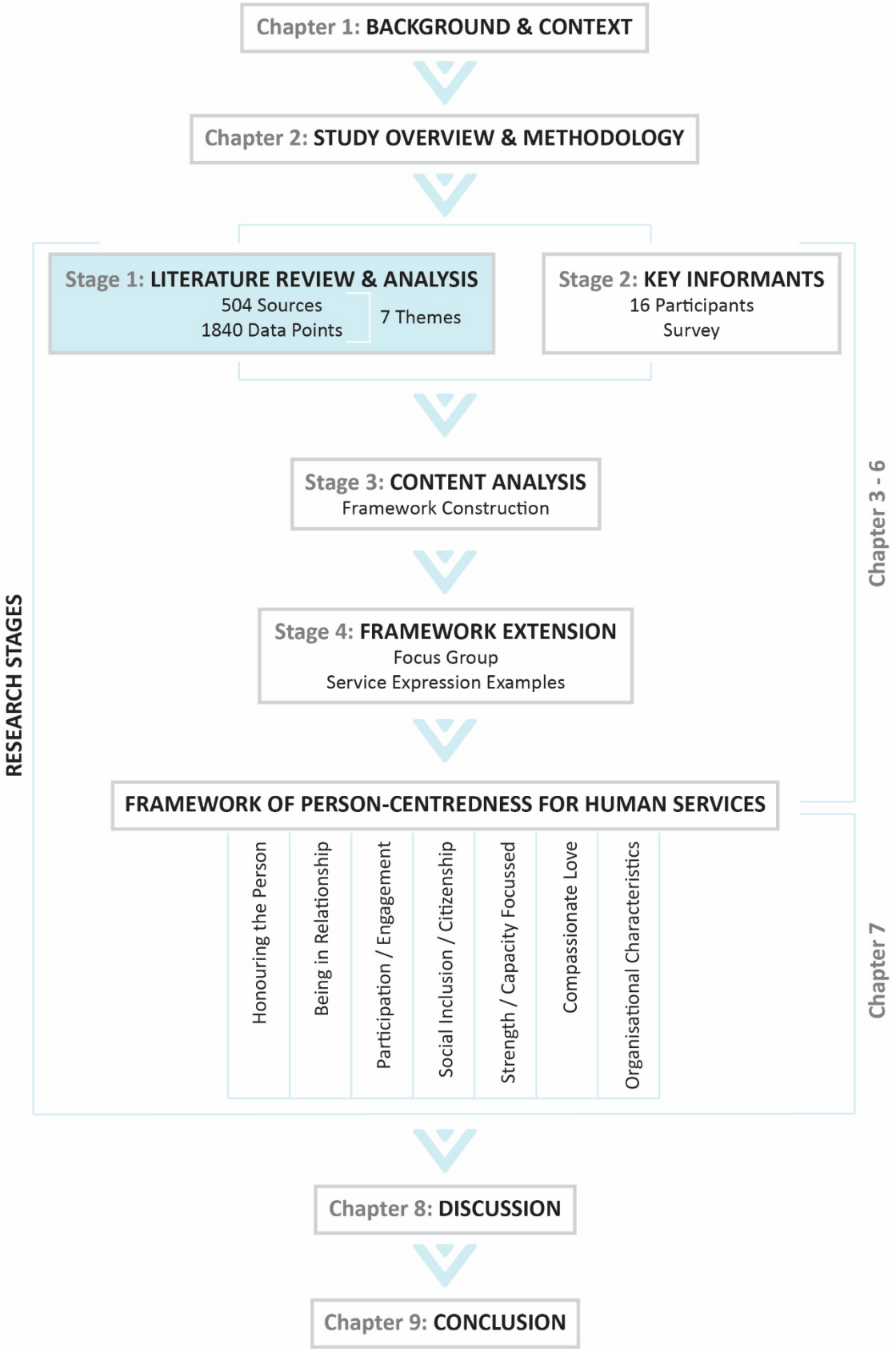
2.3 Project Participants: Key Informants and Focus Group

Throughout this project, key informants and a focus group were used to inform the street-level implementation of the concept in practice. The sixteen key informants provided comprehensive information for inclusion in Stage 2 of the research project and were representative of the three human service areas. Seven key informants (three of whom participated in Stage 2) also participated in a focus group in Stage 4 and provided both confirmations of the identified service expressions from the literature and extension of the service expressions as they applied in their practice contexts.

Maximum variation of purposive sampling (Dickerson, 2006) was used to ensure a breadth of responses to contribute to the research data in both Stage 2 and Stage 4. Participants were drawn from the three human service areas and included: People with lived experience of person-centred services and supports in one or more of the human service areas of interest; key staff and policy makers with expertise and more than 5 years'

experience working in the sector in a person-centred context; and national or local researchers published in person-centred approaches and/or related areas. Further details regarding participant demographics are provided in the results chapters for these stages.

Chapter 3: Stage 1: Person-centredness according to the literature



In this chapter, I contextualise this first stage of the research project by providing the rationale for investigating the literature in depth using Bacchi's WPR approach (Bacchi, 2012a; Bacchi & Goodwin, 2016). Following this, I provide the one published article submitted as a part of this research project. This article presents a review of the literature for the period 1996-2016 to explore the uses, definitions and characteristics of the term 'person-centred' as it applies to ageing, disability and mental health areas. This review considered all of the applications of the term 'person-centred' in the human services academic literature as well as in policy artefacts (such as policy documents, legislation and government documents). The data were used to complete a thematic analysis which formed the foundation for the remainder of the research project.

3.1 Background

Following Pollitt and Hupe (2011) and Carey and Malbon (2018), I am hypothesising that 'person-centredness' is a magic concept with utility in public policy and practice. Person-centredness shares the four characteristics of magic concepts being broadness, normative attractiveness, the implication of consensus and global marketability (Pollitt & Hupe, 2011). Magic concepts play a role in explaining and articulating government reforms and affect both academia and practice. They have utility when they can be used to fulfil explanatory functions when they are accurately positioned, operationalised and applied in a systematic manner (Pollitt & Hupe, 2011). Operationalising and systematically applying a magic concept can only be fulfilled once the policy representation is understood. To this end, it is important to conduct some form of analysis to scope and interrogate the policy.

The WPR approach is a form of post-structural policy analysis intended to facilitate critical interrogation of public policy (Bacchi, 2012a). In essence, the intent is to find a place to begin the analysis. Bacchi (2012a, p. 22) states that the WPR approach is "'looking for a way to open up questioning something that appears natural and obvious". Being person-centred does exactly that – appears natural and obvious. As a magic concept, it has broad application, it is difficult to argue against, elusive in definition and has normative attractiveness. From the perspective of Bacchi, it is exactly the reason examination of the deep-seated pre-suppositions and assumptions that underpin the representation of the concept are required (Bacchi, 2012a).

Bacchi and Goodwin (2016) contend that it is possible to work backwards from a proposal or concept to how a problem is represented and that it is possible to interrogate many kinds of material to critically reflect upon the deep-seated assumptions upon which the

concepts are based. Analysis of texts provides a starting point for questioning the concept of interest. Therefore, this first stage of the research interrogates how the person-centredness is constructed in the academic literature and policy artefacts (policy documents, legislation, government reports) across human services. This process is informed by the first three questions of the WPR approach to policy analysis: (1) what's the problem represented to be in a specific policy or policies, (2) what deep-seated presuppositions or assumptions underlie this representation of the problem (*problem representation*), and, (3) how has this representation of the policy come about? (Bacchi & Goodwin, 2016).

This literature review and thematic analysis provide a fused extension of the concept of person-centredness across the three human service areas of interest. By including a review of published papers, grey literature and policy documents, it includes writings by people who have gone on to be policy makers and inform service implementation. The literature review and thematic analysis was published in *Health Policy* in 2017 and is reproduced with permission below (copyright permission provided in Appendix F). Examples of the search strategy, the search results and the sample data extraction sheets are included in Appendix B.

3.2 An exploration of person-centred concepts in human services: A thematic analysis of the literature

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Review/Comparative article

An exploration of person-centred concepts in human services: A thematic analysis of the literature

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ABSTRACT

Being 'person-centred' in the delivery of health and human services has become synonymous with quality care, and it is a core feature of policy reform in Australia and other Western countries. This research aimed to identify the uses, definitions and characteristics of the term 'person-centred' in the ageing, mental health and disability literature. A thematic analysis identified seven common core themes of person-centredness: honouring the person, being in relationship, facilitating participation and engagement, social inclusion/citizenship, experiencing compassionate love, being strengths/capacity focussed, and organisational characteristics. These suggest a set of higher-order experiences for people that are translated differently in different human services. There is no common definition of what it means to be person-centred, despite being a core feature of contemporary health and human service policy, and this suggests that its inclusion facilitates further misunderstanding and misinterpretation. A common understanding and policy conceptualisation of person-centredness is likely to support quality outcomes in service delivery especially where organisations work across human service groups. Further research into the application and service expressions of being 'person-centred' in context is necessary.

1. Introduction

In Australia, many human services have strived to be identified as being person-centred in the delivery of their support services since the early 2000s [1–5]. The current implementation of the National Disability Insurance Scheme Act (2013) has person-centred approaches as a fundamental priority [6]. The policy drive to be person-centred has been mirrored in other Western countries including the United Kingdom [7,8], and in the United States of America ([9]; Patient Protection and Affordable Care Act [75]). The authors' own experiences were in the area of intellectual disability in the late 1990s and early 2000s where being 'person-centred' became a descriptor for providing positive, contemporary and desirable supports, and was linked to a planning process. As human service delivery has matured, there has been an increasing push towards services which are deinstitutionalised, flexible and responsive, and community-based. 'Person-centred' is now being used as an adjective to describe a number of approaches and processes including person-centred planning and person-centred thinking (in the areas of disability, intellectual disability and learning disability), person-centred care, person-centred therapy and person-centred nursing (in dementia care and ageing), and person-centred services and person-centred therapy (in mental health and recovery). Previous authors have attempted to define being person-centred however these have been limited to specific areas of service delivery [10–14]. Not surprisingly, applications of being person centred in the provision of services and supports to vulnerable people have traditionally been siloed, meaning that the viewpoint or understanding of the term has been assumed to be universally understood in the context of the discipline. There is little evidence to suggest that the development of the concept in each individual discipline shares a consistent historical theoretical base nor is there evidence to suggest that there have been points of mutual development of understanding over time. While some authors have attempted to review and synthesise understandings of the term, the work has still largely been located in specific disciplines' areas [13–15]. Equally scarce is contemporary research which defines the uses, meanings and characteristics of being person-centred in service delivery *across* human services. Given that there are now a number of service providers who support people across diagnostic groups and across human service settings, and given the proliferation of the concept in contemporary government policy, it is timely to determine what is really meant when services and sup-

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ports define themselves as being person-centred irrespective of an individual's diagnostic presentation.

2. Method

An adapted scoping review methodology was utilised for the initial purpose of identifying the current literature in relation to the concept of interest [16,17], in this case 'being person-centred'. The breadth and depth of literature available lent itself to further interrogation, and Braun and Clarke's [18] comprehensive steps for thematic analysis were followed after data extraction. Levac et al. [19] recommends considering the purpose of the study at the same time as determining the research question to help to provide a clear rationale for study selection. In this case, we were interested in identifying the breadth and depth of applications of the term 'person-centred' and its various synonyms in the disability, mental health, and ageing literature. The outcome of conducting such a review would provide evidence of a number of themes that represent the characteristics of person-centredness as it applies in these human service sectors which could have significant implications for policy development and human service design [19].

The first four stages of Arksey and O'Malley's [16] five-stage framework was followed for this exploration of person-centredness and included (a) identifying the research question, (b) identifying relevant studies, (c) study selection, and (d) charting the data. The fifth stage of the process, (e) collating, summarising and reporting the results in a meaningful way, was dropped to make way for a comprehensive thematic analysis [18]. There was no interest in assessing the methodological quality of the studies as the author was interested in gleaning the 'person-centred' descriptors and their attributes, which limited data extraction and synthesis [17].

2.1. Identification of the research question

The following research question was developed: What are the uses, definitions and characteristics of the term 'person-centred' in the existing literature applied to disability, mental health, and ageing? Armstrong et al. [17] suggest that this is then broken down into smaller components. The specific data of interest were: What contexts are the term 'person-centred' used in? What terms are used in conjunction with the term 'person-centred'? What characteristics are identified as evidencing 'person-centredness'?

2.2. Identification and selection of studies

Various search terms and Boolean operators were used to search three large databases, CINAHL, Proquest and PsychInfo, for peer-reviewed publications: person cent* (title) AND disabilit* (all fields) OR mental health (all fields) OR ageing (all fields) OR dementia (all fields) OR mental retardation (all fields). These three large databases were used as they predominately cover the human services literature. In addition, Google searches of key Australian government websites were conducted and grey literature which informed their services were included. While there was significant interest in the peer-reviewed literature, the grey literature was also perceived to be of benefit here as there are a number of influential authors in the field of person-centredness which influence human services in Australia. Government policy documents and position papers which referenced person-centredness were also included. These were collated from Australia, the United Kingdom and the United States of America. An additional number of articles were sourced using hand searching of the reference lists of articles identified in online databases. These searches elicited over 2000 source documents. Duplicate references were removed.

The retrieved articles were screened to identify those based on the following inclusion criteria: (a) journal articles using the term 'person-centred' as a descriptor in the title and appearing in conjunction with any of the additional search terms in the rest of the article, (b) published in English, and (c) published post-1995 to the current date of the search which was 2015. Articles were searched post-1995 as 'person-centred' is a relatively recent descriptor of services and approaches. All types of literature (i.e., quantitative and qualitative research studies, opinion pieces, policy documents, and literature reviews) were used. The exclusion criteria were: book reviews, and abstracts from conference proceedings (due to their brevity). Articles which were clearly outside the intent of the search were also excluded, for example, where 'person;' and 'centre' appeared in the title but were not adjacently located and therefore referred to a different concept than the concept of interest. A total of 504 documents were included in the review.

2.3. Charting and collating the data

Data were extracted using a narrative review approach. The headings used for data extraction allowed the author to identify the descriptors and characteristics in the content as well as the evidence for thematic analysis [17]. The data collection categories were: authors, year of publication, article title, context/human service area of concern, descriptors of 'person-centred' and approaches described as 'person-centred'. If authors had identified with a particular body of knowledge or theoretical framework which informed their writing, this was also noted. Both the primary author (RW) and the secondary author (AB), extracted data on the first 15 articles independently using text search on PDF documents and charted this data using an Excel spreadsheet focusing on the scoping question, to ensure consistency of identification of data. The primary and secondary authors met to compare extracted data and used a process of direct text comparison to ensure consistency in the identification of the core descriptors and characteristics. There was 100% agreement in the identification of the core descriptors between the authors. The primary author extracted the data from the remaining articles. Data were coded to allow the authors to quickly identify, cluster and categorise similar data chunks relating to the research question [20]. The authors used NVivo10 [21] to manage a large amount of data and a selection of codes was cross-checked by the second author to ensure consistency. Coding continued until saturation was reached.

2.4. Thematic analysis

The iterative process of selecting articles for inclusion, extracting data, and subsequent initial coding convinced the primary author that the process of further interrogating the data had merit. Braun and Clarke's [18] steps for conducting a thematic analysis were applied. These were (a) familiarising self with the data, (b) generating initial codes, (c) searching for themes, (d) reviewing themes, (e) defining and naming themes, and (f) producing the report [18]. The authors were familiar with the data due to the process of data extraction, and initial descriptive coding occurred as per Arksey and O'Malley's [16] process. Codes were sorted through a process of searching for points of commonality until consensus was achieved. Themes were reviewed by going back to a random selection of the raw data with the associated codes and ensuring there was a meaningful fit. Themes were refined using discussion and consensus to confirm naming and identifying the specific descriptors of each theme [18]. Given that thematic analysis may move beyond organising and describing the themes to interpreting, Braun and Clarke's [18] sixth step was applied to suggest some interpretation of the patterns and the significance of the data beyond a surface level. While a "good" thematic analysis should be

Table 1
Data sources by contexts.

CONTEXT	NUMBER
Gerontology/Dementia/Ageing	211
Disability/Learning Disability/Intellectual Disability	113
Medicine/Nursing/Occupational Therapy	80
Mental Health/Psychology/Psychiatry	66
Education/Special Education	16
Ethics/Bioethics	5
Other	13
TOTAL	**504**

systematic and analytic, the above steps were applied with flexibility to allow the researchers to be iterative and reflexive in making sense of the data [22]. Ultimately, we aimed to apply a process that permitted concept development and through the development of the themes and sub-themes revealed further depth to the understanding of person-centredness.

3. Results

Results are presented in a format that answers the research questions, recalling that the overarching intent was to explore *What are the uses, definitions and characteristics of the term 'person-centred' in the existing literature applied to disability, mental health, and ageing?*

3.1. What contexts are the term 'person-centred' used in?

Five-hundred and four documents were included in this study. The spread of source publications is displayed in Table 1.

By far, the most prolific writing in person-centredness is located in the ageing and dementia literature (211 documents), followed by the disability literature (113 documents). Documents that were coded in the medicine/nursing/occupational therapy category were related to person-centred approaches in those professions and although meeting our inclusion criteria were not immediately recognisable as falling into one of the human service areas of concern. Documents coded in the mental health category were related to person-centred approaches in psychology, psychiatry and behaviour management that did not focus on dementia or intellectual/learning disability.

3.2. What terms are used in conjunction with the term 'person-centred'?

The term 'person-centred' was used as an adjective in describing a service or approach in 54 unique occurrences across the identified contexts. The spread of the use of terms used in conjunction with the descriptor 'person-centred' is displayed in Table 2. The use of the term in more one context did not necessarily imply that the meaning was the same between contexts. For example, person-centred 'care' appears in the ageing, mental health, and medicine literature. Person-centred care in ageing relates to Kitwood's theory of dementia care and the related developments [23,24]. Person-centred care in mental health is used interchangeably with patient-centred care and appears to be related closely to the principles of recovery [25,26]. The review indicated that there is a prolific use of the descriptor 'person-centred' across a breadth of areas but the fundamental meaning of the term is elusively unclear.

3.3. What characteristics are identified as evidencing person-centredness?

The coding process utilised in this study allowed the identification of almost 200 separate characteristics from over 1800 pieces of descriptive information. A thematic analysis identified seven core themes of person-centredness: (1) honouring the person, (2) being in relationship, (3) facilitating participation and engagement, (4) social inclusion/citizenship, (5) experiencing compassionate love, and (6) being strengths/capacity focussed. The seventh theme identified organisational characteristics and values that overarched the service expression of person-centredness. The themes are presented with their component elements and referenced examples. Each of the themes and their sub-themes are specific answers to the original research question regarding the use of person-centredness across ageing, disability, and mental health. An overview of the thematic analysis results is presented in Table 3.

3.3.1. Honouring the person

This theme characterised the experience of the person-centred processes from the perspective of the person receiving the service. The first element of this theme strongly focussed upon individuality and acknowledging the person as an expert in their own life [27,28]. This builds further the idea of the person being central to the process of person-centredness. While it is common to state that person-centredness is characterised by placing the person at the centre, these clarifiers add some context to the meaning of that statement. In practice, it looks like individualised care [28], individualised planning processes [29] and services striving to respond to the person first with the system or organisation second [30]. The second element was choice and decision-making. Choice and decision-making were separately articulated in the literature as being fundamental to person-centred planning approaches [13], person-centred care [31] and person-centred thinking tools [32]. Love and Kelly [33] go as far as to say that being "person-centred "provides for individuals to make their own choices, even if those choices are not recommended. . ." (p.125). This is in stark contrast to traditional thinking in dementia, intellectual disability and mental health where people's cognitive capacity is frequently drawn into question and decision-making capacity questioned. Thirdly, knowing the person well, which allowed for understanding, active listening and valuing, was of great importance. This was often described as understanding a person's history or narrative [34–36] and focussed on the influence of people's life experiences and history of their choices. The fourth element was, allowing for as much as possible, self-determination and control over all aspects of life choices [37,38]. The primary underlying assumption of this approach was that, as a starting point, people have the capacity to self-determine and control what occurs in their lives irrespective of their diagnosis. Again, this appears in direct contrast to traditional, especially medical, service models. The fifth element was being respected [39–41]. This sense of being respected was often closely linked with choice, control, and individualised approaches. While this seems a desirable and sensible outcome, the element appeared to be most compromised when people chose to make decisions that others perceived as being negative or not in the person's best interests. The final element identified in this theme was the process of being reflective and exploring thoughts and feelings.

These sub-themes reflect some of the common statements used in conjunction with being person-centred such as, putting the person first [14], placing the person at the centre of all decision-making [42], and respecting each individual's history, abilities, tastes, preferences, strengths and needs [24,11,33].

3.3.2. Being in relationship

Theme two addressed the importance of relationships in being person-centred and confirmed the relevance of our human need to be social. Focus on relationships appeared as the most frequently occurring element of this theme. Relationships between the person and their family were seen as important as a means of being person-centred. For example, relationships between the service

Table 2
Situations where 'person-centred' is used as a descriptor of a service or approach in the literature by context.

	Context					
Term	ageing	disability	mental health	medicine	ethics	education
action		X				
active support		X				
activity	X					
advocacy		X	X			
approaches	X	X	X	X		X
assessment		X				
care	X		X	X	X	
communication	X					
coordinated care				X		
counselling		X	X			
culture			X	X		
dementia care	X			X		
dining	X					
education			X			X
ethics					X	
ethnography		X				
evaluation		X				
framework	X					
funding		X	X			
help			X			
integrative care			X	X		
integrative diagnosis			X			
interactions				X		
intervention	X		X	X		
medicine				X		
mental health care			X			
nursing	X	X	X	X		
organisation	X	X	X			
outcomes	X	X				
paradigm				X		
participation				X		
personality theory			X			
planning		X	X			X
play therapy	X		X			
practice	X	X	X	X		
program	X	X				X
psychiatry	X		X			
psychology			X			
psychopathology			X			
rehabilitation				X		
relationships	X		X			
reviews		X				
risk management	X					
services		X	X	X		
spirituality	X		X	X		
standards of care	X					
stepped care	X			X		
strategies			X			
supports	X	X	X			
teamwork	X					
therapy			X	X		X
thinking		X				X
transitions		X				X
ward climate	X			X		

provider and the person, and service provider and their family, were important in tailoring care rather than using a one-size-fits-all approach. There was a shared responsibility for staff to develop relationships with people and their families to better understand the physical and psychological needs of the person [38]. Terada et al. [36] stressed the importance of including family members and using relationships to individualise care. The development of a meaningful relationship (between the service provider and the person) was identified as being paramount in the process of defining life goals especially for people with IDs who have limited verbal communication [28].

Secondly, relationships were also considered a positive outcome of being person-centred further supporting the idea that people have an inherent need to be social. Kitwood [24] introduced being in relation as an important part of being person-centred and this has been developed further by other authors [23,12]. Regardless of cognitive impairment, each human being has a need and desire to be respected and connected with others in relationship [33]. People exist in a social, relational context and there is an understanding that positive relationships can enrich and prevent further disabling effects in dementia Stein-Parbury et al. [76]. Viau-Guay et al. [43] considered person-centred care to be a "set of practices aimed at helping the person with dementia enter into a relationship (with formal and informal caregivers, and with other residents)" (p.58). Being person-centred supports the maintenance of existing relationships and fosters the development of new ones [44,45]. In terms of importance, relationships in person-centred approaches should take as much priority as care tasks [46].

Table 3
Descriptive information about the themes from the literature.

	Frequency of appearance
Theme 1: Honouring the person	
Individuality/person as expert	***214***
individualised approach	*69*
personalised	*9*
personal preferences	*62*
person's perspective	*29*
person is central	*41*
expert	*4*
Choice/decision making	***105***
individualised decision making	*27*
choice	*52*
shared decision making	*26*
Knowing the person well	***87***
Knowing the person well	*27*
Narrative/personal history	*58*
Personal Profile	*2*
Self-determination/control	***51***
Control	*10*
Outcome – control	*17*
Self determination	*24*
Being respected	***34***
respect	*34*
Being reflective/exploring thoughts & feelings	***9***
being reflective	*1*
exploring thoughts and feelings	*8*
All appearances of codes for 'honouring the person'	***500***
Theme 2: Being in relationship	
Focus on developing relationships	***90***
Family relationships	***33***
Person – staff partnership	***13***
Being in relation with others	***11***
Positive & therapeutic relationship	***6***
therapeutic relationship	*3*
positive relationship	*3*
Natural or informal support	***6***
All appearances of codes for 'being in relationship'	***159***
Theme 3: Facilitating participation/engagement	
Meaningful activity/occupation	***32***
Participation	***14***
Facilitating independence	***10***
Engagement/involvement	***11***
engagement	*9*
level of involvement	*2*
Interests/Likes	***4***
All appearances of codes for 'facilitating participation/engagement'	***133***
Theme 4: Social inclusion/citizenship	
Social/community inclusion	***76***
community inclusion	*28*
community presence	*21*
social inclusion	*27*
Being part of the social world	***13***
Citizenship	***6***
Making a positive contribution	***5***
All appearances of codes for 'social inclusion/citizenship'	***100***
Theme 5: Strengths/capacity focussed	
Strengths/capacity focussed	***71***
strengths	*21*
capacities	*20*
assuming people's competence/abilities	*13*
having high expectations	*6*
without concern for limitations/barriers	*6*
commitment to positive outcomes	*5*
All appearances of codes for 'strengths/capacity focussed'	***71***

Table 3 (*Continued*)

	Frequency of appearance
Theme 6: Experiencing compassionate love	
Humanity	***19***
Comfort	***9***
Empathy	***8***
Hope	***6***
Compassion	***6***
Love	***5***
Belonging	***4***
Safety	***2***
Reassurance	***1***
All appearances of codes for 'experiencing compassionate love'	***60***
Theme 7: Organisational factors	
Staff attributes	***40***
staff attitudes	*12*
staff empowerment	*10*
staff satisfaction	*18*
Values-based/holistic	***25***
values – based	*9*
holistic	*16*
Flexibility/responsiveness	***13***
flexibility	*8*
responsiveness	*5*
Continuity/consistency of support	***5***
continuity	*2*
staff consistency	*3*
Other organisational factors	***55***
All appearances of codes for 'organisational factors'	***138***
Subtotal of appearance of codes for all themes	***1161***
codes related to context/strategies	679
Total codes	**1840**

3.3.3. *Facilitating participation and engagement*

Facilitating participation and engagement appeared as another of the major themes in the literature and was linked with positive behavioural outcomes for people. Participation in meaningful activities and occupations was a strong element of this theme. Seeking opportunities for people to be involved in activity, while acknowledging that people have differing needs to be engaged, is an important component of good socio-emotional care [47,48]. Meaningful engagement refers to activities that people choose for themselves and find satisfying, and are tied to individual's personalities and lifelong interests [35].

The elements of this theme also reflected people being both present and participating in community life [49,50], assisting people to achieve their desired lifestyle [51] and facilitating opportunities for people to live lives that give them meaning [27,38]. The theme included the importance of identifying and understanding personal preferences [52] and unique interests [53], and was considered to be a dynamic, flexible and responsive way of working with people [41].

3.3.4. *Committing to social inclusion and citizenship*

This theme related strongly to the concepts of being present and included in daily life, and being in a social world. This included maximising a person's potential [54], and providing supports that are focussed on community presence, community participation, positive relationships, respect, and competence [49]. Rae [55] identified some commonalities in person-centred approaches as identifying and working with the strengths of an individual, facilitating independence and building resilience, and offering choice and promoting inclusion into the mainstream and community at large.

While Kitwood [24] advocated for 'being in a social world' as one of the primary foundations of person-centred care, other literature builds on this and develops ideas that position being person-

centred as facilitating community presence [49,56,57]. For others, community presence was insufficient, and assumptions were made that community and broader social inclusion objectives were an important component of a person-centred approach [58–60,41]. Carnaby et al. [61] went as far as to suggest that the person-centred approach to meeting needs has 'social inclusion and citizenship at its heart' (p.44), while Borg et al. [62] stated that citizenship rights were an outcome of person-centred care for people with serious mental illness. In short, this theme advocates for people being present and included in the day-to-day fabric of life and their community.

3.3.5. *Being strengths/capacity focussed*

This theme focusses on being strengths-based and capacity focussed in the design of supports and services which are person-centred. This includes emphasising people's strengths and abilities [56,63,60], focussing on capacities as a part of the whole life experience [41,43], and assuming that people have competence [49,64]. These elements underpin the characteristics of having high expectations of people [30] and committing to achieving positive outcomes without concern for barriers or limitations [28]. Being strengths and capacity focussed requires that people working in services are relentlessly positive in their outlook for people irrespective of the level of support the individual requires.

3.3.6. *Experiencing compassionate love*

This theme captures significant but largely intangible elements of care that reflect the needs of being human and supports the sense of being cared for. Irrespective of the level of cognitive function of the person using the service or support, the level of support required or context of service delivery, this theme strongly reflected some fundamental characteristics of respecting humanity.

Elements included comfort [77,24], safety [78,42], reassurance [55], compassion [65,79], hope [39,40], love ([80]; Penrod et al., 2007), freedom [62,81], belonging [56,82], and empathy [83,66]. A number of the descriptive elements were used in conjunction with the purpose of acknowledging the person 'behind' the impairment or disease and facilitating personhood [84,85,24,11]. Some authors referred to the idea of there being a commonly shared humanity which people should be supported to maintain [62,86], and that using the term 'person' denotes a holistic humanness [81,82] and reflected human rights [87]. The elements were also related to ideas of being understood (especially in the circumstance where the person's cognitive function was questioned) [23], and where the provision of care or support should be inclusive of emotional needs and preferences [88].

3.3.7. *Organisational factors*

The final theme addresses the factors in contemporary person-centred organisational culture. Person-centred organisations were broadly characterised as having a vision reflecting the first six themes and grounded in a values-base that included being individualised, flexible, responsive [65], holistic [67], solution-focussed [68], and providing a continuity of care [38].

A significant element related to the role and experience of staff working in settings considered to be person-centred. Some authors suggested that adopting a person-centred approach to staff, as well as the people they serve, was an essential component of a person-centred organisational culture [69,24,59]. DeSantis [70], quoting a conference presentation by Sheard, stated that "for an organisation, being person-centred is about creating a culture where the (care) service brings out the best in individual staff and those receiving the service" (p.16). This included valuing staff [69] and providing staff with sufficient resources and support to do their job [65]. Leadership that modelled and practised person-centredness in the organisational culture was essential in demonstrating that this applied equally to staff before expecting it to be implemented in practice [59]. Where this was the case, it evidenced positive outcomes in increased staff job satisfaction [71]. Staff working in person-centred organisations, where the culture permeated all levels, were characterised as having permission to establish mutually positive relationships with people using the supports [72], being committed to the job [70], and were sufficiently flexible to accommodate people's individual needs [38]. Staff were able to concentrate on more than the tasks that needed to be performed which in turn enhanced positive outcomes and high-quality individualised supports [38]. Being person-centred was also considered an ongoing agency or organisational responsibility, because of the potential for neglect of people if personalised support arrangements are not done well [73].

4. Discussion

This thematic analysis extracted the key uses, definitions and characteristics of person-centredness as it appeared in the disability, mental health, and ageing literature. Over 500 articles were included in the analysis, resulting in over 1800 reference items and almost 200 individual codes evidencing a depth of exploration of the concepts. These codes were reduced to seven key themes reflecting elements of being person-centred.

Firstly, the results identify that the term person-centred is used a wide variety of contexts across human services. While there is a proliferation of literature in the ageing and dementia care fields, person-centred approaches are also widely addressed in both the disability and mental health areas, branching into associated contexts such as education and ethics. There is much confusion between authors about the fundamental roots of person-centredness and in some cases, the underlying philosophies are attributed in contradiction to each other in the same body of knowledge. For example, consider person-centredness as it applies in the field of intellectual disability. Person-centred planning in intellectual disability in the USA is attributed to a community of practice concerned with the process of deinstitutionalisation and the operationalisation of the normalisation movement [74], yet person-centred approaches to reminiscence work with people with intellectual disability is credited by other authors to Carl Rogers, with its roots in person-centred psychological therapy and counselling [66]. As a result, the set of assumptions and foundational knowledge underpinning the use of the term is not the same. With the progression in Australia at least, towards many human service organisations broadening their approach to supporting people from a breadth of backgrounds, this can contribute to a lack of understanding in the conceptual framework and therefore in the expectations that people can have of how they are served and supported.

Secondly, 'person-centred' is used broadly as a descriptor of a multitude of approaches, services, processes, and outcomes in human services. As much as there are points of commonality across human services, there are equally as many points of significant difference. For example, person-centred care appears in both the ageing, mental health, and medical literature, but not in the disability literature. Person-centred counselling appears in the mental health and disability literature but not in the ageing literature. It seems evident that using 'person-centred' as a descriptor seems to imply something desirable or of quality, although what that exactly is, is not clear. Again, this contributes to significant misunderstanding in the human services sector, and ultimately in what people can expect from services and supports.

The results suggest the characteristics of person-centredness can be viewed similarly to Fig. 1, where each human service perspective is grounded in different, although not mutually exclusive,

Fig. 1. Relationship of understandings of person-centredness between human service sectors.

understandings of the concepts. The understanding and the implementation of those aspects of person-centredness that sit outside of the common overlapping area seem particularly related to the service implementation and expressions that are unique to context. Human services are using the same language but the meaning and interpretation are not necessarily the same across sectors. From a policy perspective, the review indicates that person-centredness covers a wide terrain and this is because conceptualisation and developments in person-centredness have evolved in their policy spheres which have largely been siloed. This wide range of conceptualisations has made person-centredness resistant to narrowing understandings and subject to inconsistent measurement or operationalisation. Consequently, in each policy domain and related area of practice, person-centredness looks quite different as the setting or the context highly influences its presentation

Being person-centred is much more complex than 'putting the person at the centre' or 'providing individualised services and supports'. Where organisations are supporting one client group, this lack of common understanding is perhaps not as pressing. However, as organisations become more generic and broaden their service delivery models, a shared understanding of person-centredness is important for organisations to meet the mandated requirements of their service agreements that ultimately benefit the service user. Person-centredness looks different in different service contexts and these service expressions need to be further investigated. Otherwise, staff who work within a single organisation but across service contexts are at risk of implementing a watered-down version of person-centredness grounded in their own individual understanding. The unintended risk of this lack of clarity of the concept is that service implementation may ultimately be at best fragmented, and at worst, ineffective.

Policy is constructed with particular underpinning values and analyses of problems. In this research, what is important about the methodology is that person-centredness is not a policy problem but rather a value position on which policy and practice should be premised. Therefore, elucidating the meaning and conceptualisation of person-centredness in the scholarly literature and research is critical to understanding in what specific ways it has been taken up in the policy of government and the day-to-day practice of street-level bureaucrats, in this case, human service professionals.

5. Conclusion

This thematic analysis has confirmed a significant diversity of uses, definitions, and characteristics of person-centredness across the human services literature. Policies are requiring services and supports to be person-centred in their approach, yet a common framework is lacking. There is a raised imperative for a common framework of person-centredness given that person-centredness is appearing as an indicator of quality in human services, and that in Australia at least, some organisations are working across the three human service groups using a common approach. Further research needs to explore the interpretations of person-centredness across human service contexts, as there is a subsequent risk of service implementation being ineffective, especially where there is not a shared understanding.

5.1. Limitations

There were two perceived limitations to this study. Firstly, the literature was gathered from three large databases: CINAHL, Proquest, and PsychInfo. There is the possibility that some literature was missed in the search, however, these three databases cover a predominance of the human service literature, and it is anticipated that the volume of information included in the thematic analysis is likely to ensure that all key elements were captured. Secondly, one of the limitations of thematic analysis is that the three people coding and creating the themes do so from their individual perspectives. The researchers have tried to reduce this by seeking consensus and then cross-referencing to the associated coded text, to ensure accuracy.

Conflicts of interest

The authors report no conflicts of interest.

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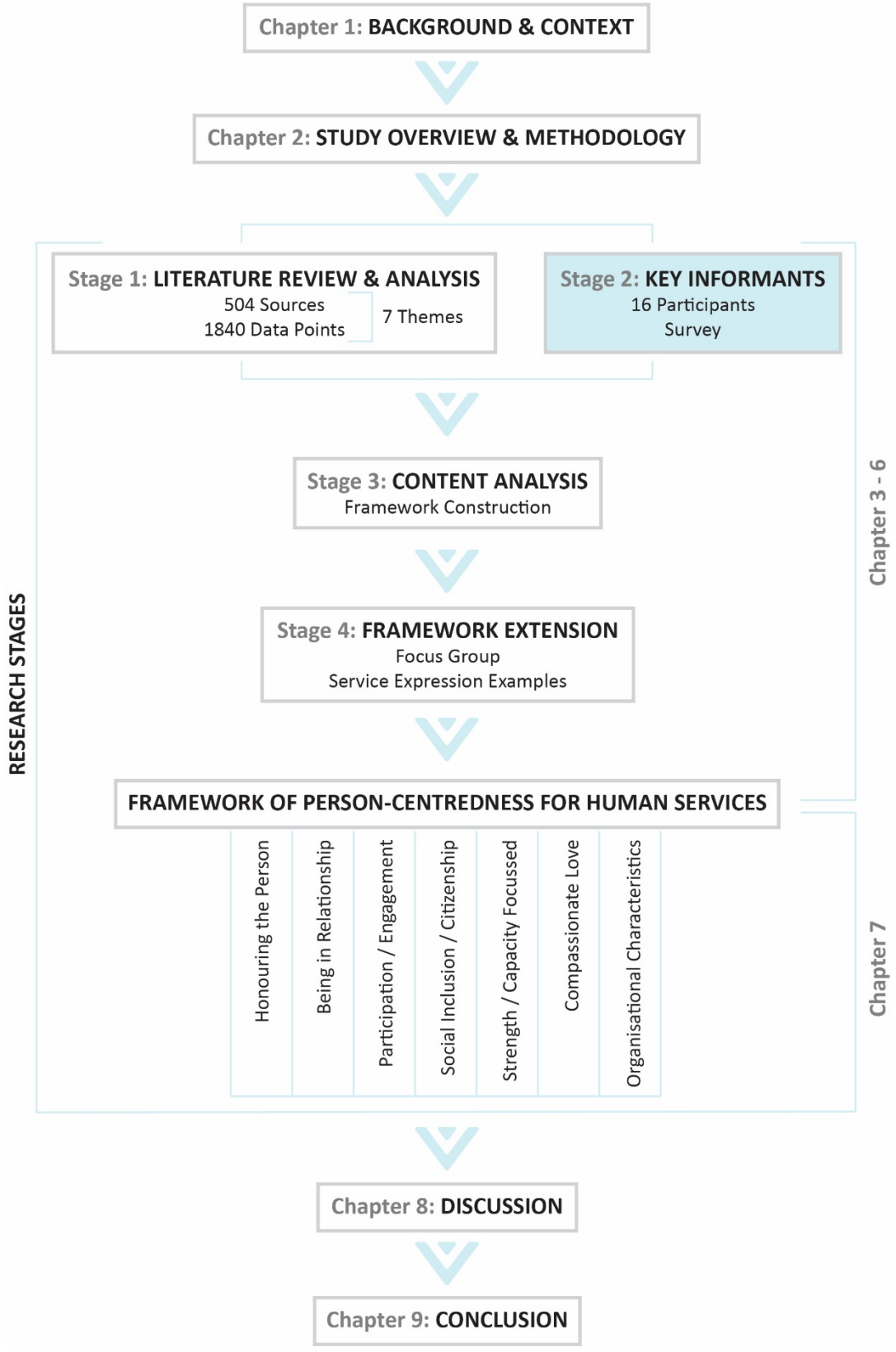
3.3 Gaps and silences in the literature review and analysis

This literature review and analysis is perhaps the most comprehensive conducted to attempt to understand the problem representation of person-centredness across human services. Bacchi (2012a) contends that careful scrutiny must also be paid to the gaps and limitations in this problem representation. A part of that scrutiny includes an inventive imagining of potential alternatives or viewing the problem from an alternate perspective. The focus of the process is to understand how "policies produce problems with particular meanings that affect what gets done or not done, and how people live their lives" (Bacchi, 2012a, p. 22).

In this case, there is plenty written about the nebulae that are person-centredness in published papers and policy artefacts. In probing the unexamined assumptions and deep-seated conceptual logics within these problem representations, it became apparent that an investigation of how the problem was constructed and experienced at the grass roots or front-line practitioner level was necessary. The gap between formal policy statements (or representations) and what implementation looks like on the ground is a persistent concern in human and social services (Carson et al., 2015). Therefore, to round out the problem representation of person-centredness, the next stage of the research addresses the perspective of key informants. This is a means of paying attention to other knowledge (in this case, practice knowledge) that underpin public policies producing a broad understanding of the concept that encompasses the place of experts and professionals (Bacchi, 2012a).

Chapter 4: Stage 2: Person-centredness according to key informants



In this chapter, I describe the second stage of the research; a survey of a purposively sampled expert group perceived by the research team as having expertise or knowledge in the area of person-centredness. I provide the background and rationale as to why this was conducted, outline the method and data analysis approaches undertaken, provide the results and discuss the significance of the findings. I conclude the chapter by linking this stage to the first stage of the research.

4.1 Background and rationale

Person-centredness is considered a multidimensional concept in health and human services and is interpreted in many different ways by many different people (Harding et al., 2014; Leplege et al., 2007; Waters & Buchanan, 2017). The 'family' of approaches, concepts and policies are situated in the context of a diverse and evolving community of practice (Harding et al., 2014). Concepts of person-centredness clearly have multiple meanings which can and have been interpreted in varying ways across many human service domains (Gzil et al., 2007). The research suggests that person-centredness can be considered from different perspectives, ranging from a conceptual framework debate or understanding to divergent perspectives about its practical implementation (Harding et al., 2014; Waters & Buchanan, 2017).

Bacchi's use of post-structural theory to understand policy analysis draws attention to discourse (Bacchi & Goodwin, 2016). The many representations and understandings of person-centredness reflect it being embedded within multiple discourses or multiple unexamined ways of thinking within problematisations (Bacchi & Goodwin, 2016). Using problematisation as a method involves studying the historical process of the production of the problematized 'objects' (Bacchi, 2012b, p. 4). "Examining specific policy interventions to see how the 'problem' is constituted within them opens up a critical space to reflect on how governing takes place and with what effects for those so governed" (Bacchi & Goodwin, 2016, p. 40). In this use, 'governing' means how person-centredness 'happens', and how it produces particular effects for the 'person' in person-centredness.

For example, the term person-centredness was initially used in a liberatory, radical way which rejected notions of passivity and aimed to challenge the one-dimensional user identity of the person seeking services or supports. User identity can now more adequately be described as patients, co-producers, citizens, consumers and community members in one person and at the same time (Ewert, 2016). Ewert (2016) proposes that "each facet of the user identity gains or loses relevance depending on health care contexts, health statuses,

personal values and the design of service arrangements" (p161). The use of the term 'person-centred' in neo-liberal welfare discussions and policies individualises 'choice' whilst also individualising social and public health problems.

To date, this thesis has mapped the use of the term 'person-centred' across domains of practice and levels of policy to practice. In this chapter, 'person-centredness' at the practice level is the focus. This will be interpreted by seeking the perspectives of key informants across the three human service domains of interest.

This stage of the research seeks to understand the construction of the concept by exploring the professional discourse by looking at practice (Bacchi, 2012b). Key informants in research are people "whose social positions…give them specialist knowledge about other people, processes or happenings that are more extensive, detailed or privileged than ordinary people, and who are therefore particularly valuable sources of information to a researcher" (Payne & Payne, 2011, p. 136). Key informants are considered to have different and additional information to impart as they often occupy formal positions of authority in social, political, or administrative realms (Lysack, Luborsky, & Dillaway, 2006) and can have a close view of how it occurs every day (Payne & Payne, 2011). Key informants offer a perspective on the problem construction of person-centredness that is closer to the front-line of services. By virtue of the key informants' location in human services, they can expose how person-centredness is constructed as they both reproduce and are subject to the discourse. In addition, it can potentially reveal some of the effects on the people who are subjects of the policy representation. The purpose of the survey was to elicit key informants' responses on their perception and interpretation of the concept of person-centredness from their knowledge and professional and/or personal experience. Participants who had knowledge and experience of service and supports described as being person-centred, or researching person-centredness in human services, were purposively sampled to provide rich study data.

4.2 Method

Potential key informants known to the researchers and their extended networks were identified, contacted by phone and/or email, and invited to participate in an electronic survey. Key informants included academics, service providers, service users and policy makers and were approached according to the following matrix:

Expert Group	Ageing sector	Disability sector	Mental Health sector
Service users	3	3	3
Service providers	3	3	3
Academics	3	3	3

Following the initial agreement, potential participants were sent a link via email to access an online questionnaire. In addition to demographic information, informants were asked to provide open-ended responses to the following questions: How would you describe person-centredness in services and supports for people who use human services? What do you think are the issues in relation to the application of person-centredness in health and human services? Informants were encouraged to provide as much detail as possible. The full survey questionnaire and the participant information sheets are included in Appendix C. Sixteen responses were received and their demographic characteristics are presented in table 1:

			n (16)
Sector:			
Academic			5
Non-Government Organisation			6
Government Organisation			2
Government Policy			3
Service User			2
Age (years):			
25-34 years			1
35-44 years			1
45-54 years			11
55-64 years			4
Years of experience with human services:			
	Working	*Teaching*	*Using*
never	3	8	14
less than 1 year		1	
1-2 years		1	
2-5 years			
5-10 years	2	1	1
10-15 years		2	
more than 15 years	11	3	1
did not state			
** Note: some participants identified as being involved in more than one sector*			

Table 1: Background characteristics of key informants

4.3 Data analysis

Data were entered into NVivo10 to facilitate data analysis (QSR International, 2010). Data were coded to allow the researchers to quickly identify, cluster and categorise similar data relating to the primary research question. A sample of the data was coded independently by two researchers to ensure the consistency of identification of data (Lysack et al., 2006). Data were analysed using a combination of inductive and deductive coding (Fereday & Muir-Cochrane, 2006). The analysis was guided, but not limited to the original set of codes developed in Stage 1 of the project. Codes were mapped back to the existing set of codes from the literature using a deductive approach (Fereday & Muir-Cochrane, 2006), and checked against the existing data set to ensure consistency of content. There were some instances where coded items did not correspond with any of the pre-existing literature categories, and in these cases, a new code was developed to reflect the response utilising an inductive approach (Fereday & Muir-Cochrane, 2006). Three researchers then met to determine the inclusion of the new codes into existing themes or to create new themes ensuring triangulation of data methods (Lysack et al., 2006).

4.4 Results

Sixteen of the 27 approached key informants responded to the survey and provided comprehensive narrative responses to the survey questions. Unsurprisingly, informant responses largely mirrored the existing codes from the literature and therefore contributed to the original themes. The majority of responses were consistent with 'honouring the person', 'being in relationship', having a 'strengths/ capacity focus' and 'facilitating meaningful activity/occupation'. Informants also identified characteristics of organisations that were necessary for person-centredness to be successfully implemented that were consistent with the literature. A new set of characteristics reflecting staff behaviour were identified from the survey responses that were not present in the existing literature.

4.4.1 Honouring the person

The data indicated that respecting individuality and making the person central to all processes was key to person-centredness. One informant confirmed that being person-centred is about "honouring the person" and "ensuring that their voice is heard and that responses and services are made accordingly to their individual need". Another provided an extension to this idea by stating they did not want "to be given support simply based on what my disability is …but support based on what I want and need as a person with a disability." In addition, several informants highlighted the importance of responding to a person's needs

and wants and enabling choice and control. This was evidenced by one informant's response to describing person-centredness in human services:

> *"Services that are individualised, responsive and enable people to make choices about their own lives….they respond to people's preferences and changing needs, choice and preference effortlessly."*

Another informant addressed the limitations of services, and human service workers, in being able to respond individually when there is a finite selection of service or support available:

> *"Some people can imagine new ideas and have an appetite to strive for a better life. Others have lived an impoverished life and do not know what is possible and will stick to the same menu of services "offered" – wherever the person is at is where we as service providers should start."*

Interestingly, one informant highlighted that having services tailored to the person did "not necessarily mean they are always delivered individually", suggesting that the existence of person-centred supports did not always translate into practice.

4.4.2 Being in relationship

Key informants identified aspects of being in relationship that was consistent with the literature. Responses clearly supported building a relationship with the person and equally addressed the importance of the relationship with family (where preferenced) as a part of the person-centred approach. Informants identified the relevance of recognising the wider familial and social context in which people live their lives, providing a service which actively engages with and welcomes the family's participation and involvement, and understanding the person and their family from their historical context. One informant also highlighted the significance of providing a "positive personalised environment (both physical and social) for both the person and their families", inferring that being person-centred involves creating environments where the person and their families may feel able to participate.

4.4.3 Organisational factors

Several organisational characteristics were described as being fundamental to the implementation of person-centred approaches. Informants reasoned that there needed to be a consistency of understanding of person-centredness throughout the organisation from the grassroots to management, underpinned by strong values and principles. However, the

existence of the strong values and principles does not necessarily translate into practice, as articulated by one informant:

> *"The 'how' of being 'person-centred' and translating this into practice is the challenge because of the many contributing factors to its implementation – it's not just about training, although an individual human services worker's mindset, attitude and skills are fundamental to person-centred practice, but how the system (funding and regulatory) supports and promotes person-centred practice… how human services organisational management systems, policies and processes understand and support it…and what the community at large understand and expect of person-centred human services practices."*

Some informants suggested that organisations were quick to identify as being person-centred in their approaches until such time as they were challenged to alter the way they operated. This was seen as being particularly relevant to large organisations that offered traditional services and programmes to people. Service driven approaches were perceived as being inflexible and unresponsive to people's needs. The whole system of the professionalisation of human service disciplines impedes some aspects of being person-centred, with one informant stating:

> *"Systems are not person-centred – they are bureaucratic-centred, doctor-centred and professional-centred… The whole system of professionalisation creates a power differential which legitimises the power of the professions."*

Another informant suggested organisations and professionals had difficulty validating the lived experience of people and that people's experiences were subsequently devalued and rated of lesser importance. This resulted in organisations having difficulty in realigning their service design to better 'fit' the needs of people. Even in circumstances where organisations professed to work from a person-centred values base, the responses of staff vary between rigidity and "interpreting/bending the criteria". Depending on the culture of the organisation, staff can be hesitant to "respond to novel requests in case they set precedents or break some rule".

Finally, informants addressed the disconnection between organisational policy and what occurs in practice, highlighting the need for congruence between the two. One informant eloquently described this as follows:

> *"It requires the whole organisation to operate in this (person-centred) way. The people engaged to provide the support really need to come from a strong values base. Sometimes organisations are not focussed on these elements as the crucial starting point. Being person centred is almost a process and style of approach. Organisations that don't understand this may develop policies but these don't necessarily mean there will be cultural changes within the organisation without investment, training and opportunities for all workers."*

4.4.4 Staff behaviours

A previously unidentified set of characteristics consistent with being person-centred that have been labelled as staff behaviours were highlighted. This new category of staff behaviour suggests the need for staff to deeply think about, and engage with, the essence of the concept of person-centredness. It highlights the requirement for staff to be highly adaptable in the employment context to adjust practice to operate with integrity and in coherence with the concept. While the literature identifies staff values and attitudes and the process of active listening, the informants identified additional desirable behaviours that both demonstrate being person-centred and allowing person-centredness to occur. These behaviours included the ability of staff to operate with a level of emotional literacy informed by the ability to be critically reflexive. Practitioner self-awareness was seen as being essential in providing person-centred support to people and working in a person-centred manner. One informant described this as follows:

> *"It means being willing to go beyond passively believing in the person, to actively mirror and demonstrate that I do… I will need to have good communication skills and a deep awareness of emotional literacy and a willingness to understand behaviour as language rather than pathology."*

Informants elaborated on emotional literacy by highlighting the importance of critical reflexivity in being person-centred. Critical reflexivity was seen as being aided by emotional literacy and as facilitating "self-awareness, regulation of feelings, insight, and interpretative capacities in practitioners". Another informant suggested, "to be able to hear and see in this (person-centred) way requires practitioners and agencies to commit to, and constantly enact, critical reflexivity".

The importance of being open, inquisitive, interested and non-judgemental was also described, particularly in situations where a person may appear resistant to support. Active listening by the practitioner was confirmed as a necessary staff attribute in being person-

centred. The positive response of staff to difficult situations is a large factor in being person-centred;

> *"This means that practitioners and agencies do not personalise what may appear to be a person's resistance to engaging in service delivery and instead adopt an open, curious, and interested stance, seeing each person as unique with a distinct set of life experiences inside and outside of the reasons they are seeking support."*

The ability of staff to 'get out of the way' was highlighted suggesting that staff behaviour has the potential to affect person-centredness. Staff needed to 'de-centre' themselves so that the person was able to communicate and express themselves without censor;

> *"It is about practitioners finding ways to 'get out of the way' and having a deep experiential understanding of what gets in the way of keeping the person at the centre – understanding and wrestling with disabling, disempowering patterns such as rescuing, needing to be right or justified, pathologising, paternalism, professionalism (status) and risk aversion and much more."*

Yet another informant supported this by stating it was important not to "take negative interactions personally".

4.5 Discussion

Key informants' responses demonstrate consistency with the literature in the most predominantly occurring areas of 'honouring the person' and 'being in relationship'. Person-centredness appears to be most often described in terms of knowing the person well (King, O'Brien, Edelman, & Fazio, 2011; Kirkley et al., 2011) placing the person at the centre (Gervey, Gao, Tillman, Dickel, & Kneubuehl, 2009; McKay et al., 2012), and taking an individualised approach, especially focussing on well-being and satisfaction (Argyle, 2012; Love & Kelly, 2011). Unsurprisingly, all informants reiterated this in their responses suggesting that the rhetoric of the most common parts of the approach is firmly entrenched and at least broadly understood.

Key informants did, however, offer a nuanced perspective on both organisational characteristics and staff behaviours. In the case of organisational factors, Love and Kelly (2011, p. 125) consider the 'person-centered operational system' to be gold standard where there is a focus on both the person's well-being and maintenance of humanity as well as the transforming of the operational structure to support these outcomes. Informants strongly

reiterated the importance of consistency in the understanding of person-centredness throughout the organisation from the grassroots to a managerial level. Having a responsive values-based organisation can go some way to the successful implementation of person-centred approaches, and a well-informed training and development program that underpins competence in a person-centred culture would be well placed. There was also a suggestion that being person-centred is somehow the antithesis of traditional service delivery, giving prominence to the inability of large organisations to operate in flexible and timely ways.

In the case of staff behaviours, informants have clarified that there are ways of implementing person-centredness that are the sole responsibility of the individual staff. This suggests that there are some aspects of person-centredness that exist independently of organisational structures and policy determinants. These aspects of person-centredness are 'created' by the problem representation. Emotional literacy and critical reflexivity are competencies that staff have or can develop and enact. The ability to acknowledge people, be non-judgemental and 'get out of the way' are approaches that recognise the value of the person. In addition, these aspects of person-centredness are at the professional discretion of the street-level bureaucrat or front-line worker (Lipsky, 2010).

The results suggest therefore that there may be a shift in methods of practice, an emerging area of person-centredness which is not currently appearing in the literature. The reality is that it is not easy for staff to translate policy into practice. Staff are required to have a flexible set of skills that rely on discretion in how practice is implemented, yet expect consistency in how people will experience the service. In this sense, staff are both reproducing the discourse but are also subject to the discourse (Bacchi & Bonham, 2014; Lipsky, 2010). There is a multiplicity and a depth to the concept of person-centredness but they are not inter-dependent parts. Person-centred policy can exist but that doesn't necessarily mean that an individual practitioner's practice expresses exactly the policy. Equally, the individual practitioner's practice can 'look' person-centred, and be called 'person-centred' but not be consistent with policy. Lipsky (1980, 2010) contends that 'the decisions of street-level bureaucrats, the routines they establish, and the devices they invent to cope with uncertainties and work pressures, (can) effectively become the public policies they carry out" (p.xii). There are many possible 'realities' in understanding what person-centredness is and in what it looks like in practice. Following Mol, what needs to be analysed and understood, therefore, are the practices; "the what is being done and the what, in doing so, is reality in practice made to be" (Bacchi & Bonham, 2014, p. 191).

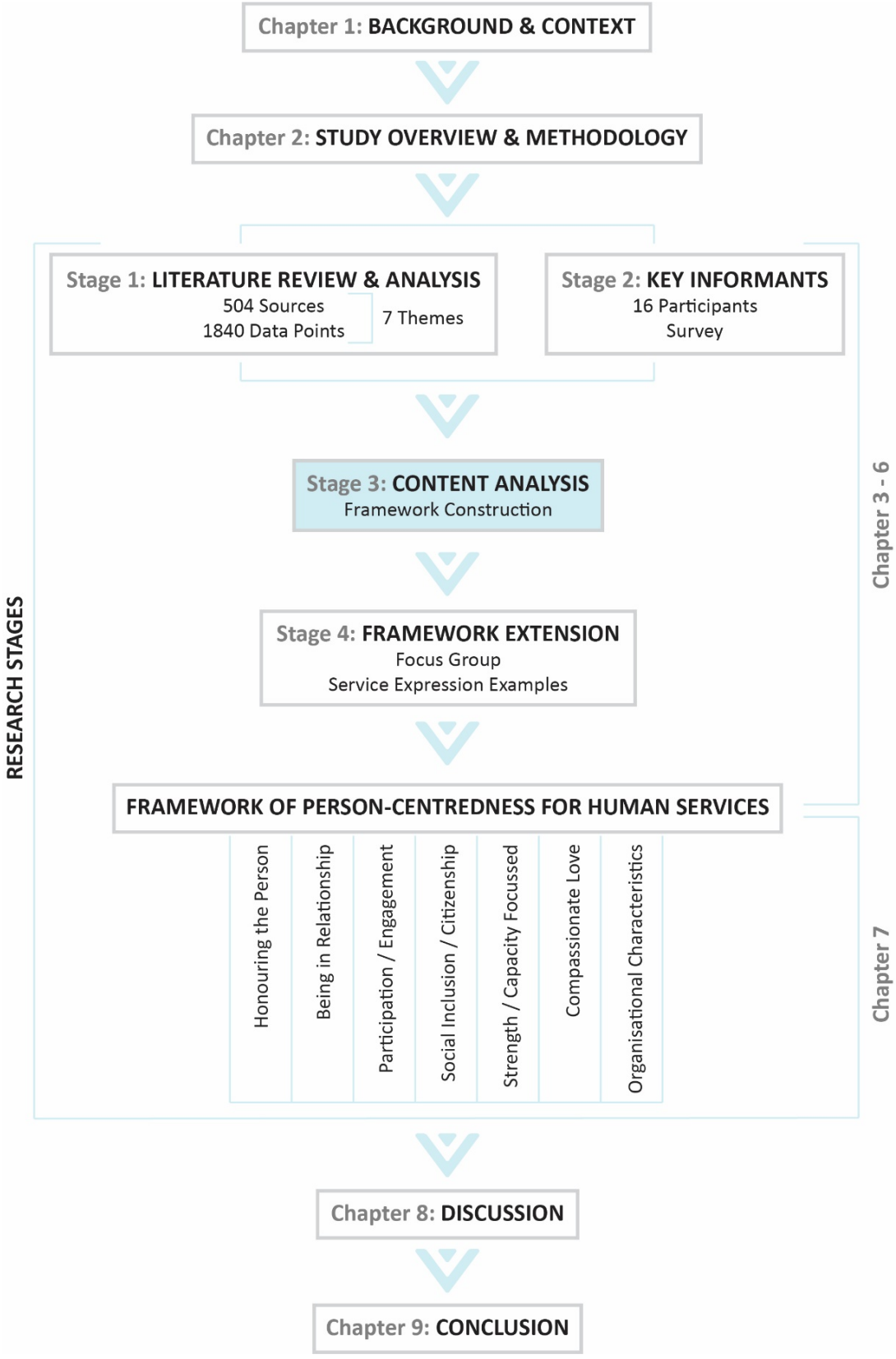
4.6 Conclusion

These results appear consistent with the some of the over-arching themes identified in the first stage of this research (Waters & Buchanan, 2017) and by Harding et al. (2014) insofar as there is a huge diversity in the understanding of person-centredness in human services. Equally, however, this research stage demonstrates that there is a large element of consistency with the descriptions and rhetoric of person-centredness identified in the first research stage, especially under the thematic headings of 'honouring the person' and 'being in relationship'.

The problematisation analysis which underpins Bacchi's WPR approach (Bacchi, 2009, 2012b) demonstrates the significance of the sector history in how person-centredness is translated into the everyday of practice. Consistent with Harding et al. (2014), the results also suggest that person-centredness is experienced differently on the ground depending upon the context and this is a product of evolving differently across these different contexts. The multiple histories and the inability to clearly define person-centredness across human services has led to disconnection in the translation of policy concepts (which have been influenced by a set of underpinning values and attitudes stemming from personhood) to practical, on-the-ground, ways of working. Whilst there were divergences in the survey results there were also some important common features which placed responsibility for professionally living and implementing person-centredness firmly with the practitioners, regardless of organisational context.

These results, combined with the results from Stage 1 of the research, formed the foundation for the content analysis in the next stage of the research.

Chapter 5: Stage 3: Creating the descriptive framework of person-centredness using content analysis



In stages 1 and 2 of this research, multiple understandings of person-centredness across human services were identified. This provides a foundation that may both direct and create knowledge and practice (Bacchi & Goodwin, 2016). In this chapter, I describe stage 3 of the research which is the creation of a descriptive framework of person-centredness drawn from the data gathered in the first two stages. The purpose of developing this framework is to use what is currently known about person-centredness to construct a meaningful and practical conceptualisation. The evidence-based conceptualisation can offer a framework to underpin the implementation of person-centredness in policy, practice and research between human service contexts.

I explain the choice of methodology, summative content analysis (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005), and demonstrate and describe the iterative analysis process of extension and confirmation of the themes and sub-themes to develop statements of characteristics and service expressions. I also describe the process of confirming this evidence-based conceptualisation via a data checking process with the literature and survey results and obtaining agreement with two other researchers. This chapter concludes by establishing the need for consultation with an expert group in the final research stage.

5.1 Background

This stage of the research involved the construction of the initial framework from the data and thematic analyses conducted over the two previous stages of the research. The intent was to define a framework that reflected the previously identified broad themes of person-centredness and the constituent sub-themes thus providing a clear structure to collate, record and review the data into a meaningful and practical format.

5.2 Method

A modified content analysis methodology was used to determine meaning and consensus of the conceptualisation of person-centredness across human services. I utilised a summative content analysis which built on the initial thematic analysis (where appearances of the data of interest were counted and compared) by using an iterative process, over several phases, to interpret and understand the underlying context (Hsieh & Shannon, 2005). The goal of the content analysis is primarily to develop a deep understanding of the phenomenon being studied by using a systematic classification process (Hsieh & Shannon, 2005) for the purpose of providing new knowledge or representation of facts or a practical guide to action (Elo & Kyngäs, 2008). During this process, I documented the evidence that currently existed and used the framework structure to track each individual piece of data into the final

descriptive framework. I describe the content analysis across three phases using a number of figures to visually represent the process. The methodology also provides an audit trail for the systematic process of considering all of the collected data (Lysack et al., 2006). Data collected from both the literature and the key informants were combined and analysed concurrently.

5.2.1 Phase 1

5.2.1.1 Determining a structure for data analysis

Data were organised for this stage of the process using the thematic analysis headings (themes) and sub-headings (sub-themes) from stage one and two of this research study. The table, using the thematic analysis headings, provided the structure for the transfer of the raw data from NVivo (QSR International, 2010). This data was presented in the first column of the table. An example of the structure for this stage of the data analysis is depicted in Table 2.

Data	Source
Theme 1: Honouring the person	Theme heading from Stage 1
Subtheme 1.1 Individuality /person as expert	Subtheme heading from Stage 1
Attribute 1.1.1 Individualised approach	Attribute heading from Stage 1 and 2
services are individualised; services must cater for each individual's varying needs and desires; about listening to what is important to the individual; services should be individually designed; an individualised rather than institutionalised philosophy of care; high quality individualised care; individualised interventions; incorporates the use of individually tailored psychosocial and complementary interventions; highly individual comprehensive approach to assessment and intervention; treating people as individuals; individualistic approach to social care; individualised programs; individualised activities; Individual self-directs care; recognising the individuality of people with dementia; individualised care planning; meets individual needs; requires staff to individualise the way they select, combine and implement the various elements of care; defined by the individual	Raw coded data from Stage 1 and 2: each piece of data can be directly linked back to a raw literature source or survey response from the first two stages of the research

Table 2: Initial structure for data analysis

5.2.1.2 Defining the characteristics statements

Content analysis requires a systematic and objective means of describing and quantifying phenomena, and to distil words into categories that share the same meaning (Elo & Kyngäs, 2008). Once all of the coded data was transferred into the table, I created statements that accurately reflected the terms. This involved not merely bringing together similar data, but conducting a process of classification to determine items that belonged together (Elo & Kyngäs, 2008). As the primary researcher, I methodically worked through the data sets to ensure that all coded data were incorporated into a statement. Each data were considered firstly on its own, and then in relation to other pieces of the data in the same coded set to draw together similarities in intent and description. Table 3 demonstrates an example of a part of the process. The first resultant characteristic statement was recorded in the column labelled 'First iteration'. As the process progressed, some statements required refining and the result was recorded in a second column to ensure transparency. Statements were also re-worded to focus on the person and demonstrate consistency with the intent of the project. The column labelled 'Second iteration' shows the result of the iterative process. The full results of this stage of the content analysis are included in Appendix D.

5.2.1.3 Consolidation and refinement of the characteristics statements

Following the completion of the second iteration, a review of the characteristics statements by the primary researcher suggested that there was overlap between some statements and that some were not really characteristics but rather service expressions of person-centredness. The primary researcher approached the two research supervisors to independently review the characteristics statements to determine the accuracy of the statement in reflecting the initial data and if there was an opportunity to consolidate and refine the statements. Each researcher independently considered the characteristics statements with reference to the data set. The three researchers then met to reconcile and refine the characteristics statements via a process of peer debriefing (Lysack et al., 2006). Where there was disagreement or controversy regarding the statement, the group went back to the original coded data set and source documents to confirm that the statement accurately captured the intent (Lysack et al., 2006). The coded data were re-read in the context of the original source document and the three researchers reconciled the final meaning as to whether the item was a service expression or characteristic through discussion. Peer debriefing served to clarify conflicting data via several iterations and ensure the resolution of

the data representation in the characteristics statements. This process resulted in a consolidation and distillation of the characteristics statements.

Theme 1: Honouring the person

Sub-theme 1.1: Individuality/person as expert (230)

	First iteration	*Second iteration*
Attribute 1.1.1 Individualised approach (80)		
services are individualised; **services must cater for each individual's varying needs and desires;** **about listening to what is important to the individual; services should be individually designed;** **an individualised rather than institutionalised philosophy of care; high quality individualised care;** **individualised interventions;** **incorporates the use of individually tailored psychosocial and complementary interventions;** **highly individual comprehensive approach to assessment and intervention;** **treating people as individuals;** **individualistic approach to social care;** **individualised programs; individualised activities;** **Individual self-directs care;** **recognising the individuality of people with dementia;** **individualised care planning;** **meets individual needs;** **requires staff to individualise the way they select, combine and implement the various elements of care; defined by the individual**	1.1.1 the person is treated as an individual 1.1.2 the service caters for the person's varying needs and requirements 1.1.3 the person has an individualised selection, combination and implementation of supports and/or care	1.1.1 the person is treated as an individual 1.1.2 the person's varying needs and requirements are catered for 1.1.3 the person has an individualised selection, combination and implementation of supports and/or care

Table 3: Phase 1 - First and second iteration of content analysis to develop characteristics statements

5.2.2 Phase 2

5.2.2.1 Construction of descriptive theme headings, creation of service expressions and third iteration of characteristic statements

Phase 1 of the content analysis identified aspects of person-centredness which were not easily converted into a characteristic statement and were better described as service expressions or examples of being person-centred in practice. Phase 2 of the content analysis process involved reviewing each second iteration statement alongside the initial data set, and determining if it was a characteristic statement, a service expression or a service example. As with phase 1 of the content analysis process, the primary researcher methodically worked through the data set to ensure that each piece of data was represented in the final framework. Each decision and refined statement was recorded in an expanded version of the original table utilised for data analysis. Finally, descriptive statements were developed that reflected the content of each of the framework sections by theme.

5.2.2.2 Confirmation of third iteration characteristic statements, service expressions and examples; removal of attribute statements; refinement of thematic descriptors

As with phase 1 of this content analysis, the primary researcher met with the research supervisors and repeated the process of triangulation of data methods to ensure integrity in the interpretation of the data using peer debriefing (Lysack et al., 2006). Once again, disagreement or controversy regarding the statements was reconciled by returning to the original coded data set and source documents to ensure that the statement accurately captured the intent (Lysack et al., 2006). Peer debriefing served to clarify conflicting data via several iterations and ensure resolution of the data representation in the third iteration characteristics statements, service expressions and preliminary service examples. The three researchers determined to remove the attribute statements at this point as they were not perceived to add value in either the presentation or understanding of the framework. As all researchers were in agreement with the content of the thematic descriptors, only minor editing for clarity and readability occurred at this point. An example of the result of this process is provided in Table 4.

Theme 1: Honouring the person

Theme: The person is understood, treated and supported in a holistic manner as an individual with a unique perspective, history, needs, strengths and preferences. The person is acknowledged and respected as an expert in their life. The person is placed firmly at the centre of any decisions and choices that involve them. The person is known well by the staff at the service. The person is assumed to have capacity to self-determine or is supported as much as possible to have control over their life. The person is respected and valued.

Sub-theme 1.1: Individuality/person as expert

second iteration statements	*third iteration statements*	*service expressions*	*preliminary service examples*
1.1.1 the person is treated as an individual	1.1.1 the person is treated as an individual	1.1.1.1 the person is treated as an individual	• the person is addressed by their name without exception
1.1.2 the person's varying needs and requirements are catered for	1.1.2 the person's varying needs and requirements are catered for	1.1.2.1 the person's varying needs and requirements are catered for	• the person is responded to individually taking into account their likes, dislikes, preferences and needs
1.1.3 the person has an individualised selection, combination and implementation of supports and/or care	1.1.3 the person has an individualised selection, combination and implementation of supports and/or care	1.1.3.1 the person is able to select, combine and have implemented supports and/or care that best meets their needs	• the person is able to select combinations of support that best meet their requirements, dependent on their personal circumstances
1.1.4 the person receives a personalised holistic approach to their needs	1.1.4 the person receives a personalised holistic approach to their needs	1.1.4.1 staff at the service demonstrate a willingness to discuss and where possible, within the constraints of resources, act to support the person in a holistic manner	• the person is considered in their entirety by the service (not just by their diagnosis)

Table 4: Example of framework following content analysis

5.3 Results

These results form the structure and content of the Framework of Person-Centredness for Human Services (FPCHS). The framework consists of seven themes: each theme is presented initially with an overarching descriptive statement. Following this, each theme is comprised of a set of sub-themes and constituent characteristics. Each characteristic has, where the data analysis indicated a close conceptual association, a paired service expression. Preliminary examples of service expressions have not been included at this stage. These were added to the framework, in conjunction with the focus group's examples, following the final stage of the research.

The data sets indicate that the themes of the FPCHS which are best understood are 'Honouring the person' (542 codes) and 'Being in relationship' (167 codes). The bulk of what is described in policy documents, literature and from the key informants support these most commonly understood and researched aspects of person-centredness across human services. However, these results also indicate that the remaining five themes of person-centredness are more difficult to describe and operationalise. In comparison to the first two themes, the data sets for the remaining five themes of the FPCHS have fewer codes and as a result, fewer constituent characteristics.

The results of this stage of the research are presented here in their entirety.

Theme 1: Honouring the Person

Theme: The person is honoured by being:

- ***understood, treated and supported in a holistic manner as an individual with a unique perspective, history, needs, strengths and preferences;***
- ***acknowledged and respected as an expert in their life;***
- ***placed firmly at the centre of any decisions and choices that involve them;***
- ***well known by the staff at the service;***
- ***assumed to have capacity to self-determine or is supported as much as possible to have control over their life; and***
- ***respected and valued.***

	Characteristics	Service Expressions
SubTheme 1.1: Individuality/person as expert		
1.1.1	the person is treated as an individual	1.1.1.1 the person is treated as an individual
1.1.2	the person's varying needs and requirements are catered for	1.1.2.1 the person's varying needs and requirements are catered for
1.1.3	the person has an individualised selection, combination and implementation of supports and/or care	1.1.3.1 the person is able to select, combine and have implemented supports and/or care that best meets their needs
1.1.4	the person receives a personalised holistic approach to their needs	1.1.4.1 staff at the service demonstrate a willingness to discuss and where possible, within the constraints of resources, act to support the person in a holistic manner
1.1.5	the person's preferences for daily living and routines are honoured	1.1.5.1 the person's preferences for support for daily living are clearly documented by the service
1.1.6	the person's perspective, needs and preferences are acknowledged and included in the establishment of a positive relationship with the service and implementing the appropriate supports	1.1.6.1 the person's perspective is considered and honoured in the design and development of supports 1.1.6.2 the person's needs and preferences are clearly documented 1.1.6.3 the provision of supports to the person are informed by and based on the documentation
1.1.7	the person's history, including significant life experiences inform interactions by staff with the person	1.1.7.1 the person's history, including significant life experiences, are respected in the establishment of a positive relationship with staff at the service
1.1.8	the person's gifts, strengths and dreams are included in implementing the appropriate supports	1.1.8.1 the person's gifts, strengths and dreams are clearly documented by the service 1.1.8.2 the person's gifts, strengths and dreams inform interactions by staff with the person
1.1.9	the person is firmly located at the centre of any process involving them including planning, action and decision-making	1.1.9.1 the person is treated as an equal expert and the focal point of a respectful and reciprocal service partnership
1.1.10	the person co-owns the support plan	1.1.10.1 the person is a participant in the design or development of the support plan

	Characteristics	Service Expressions
1.1.11	the person is at the centre of their own story, not their diagnosis or illness	1.1.11.1 the person is at the centre of their own process, including the design or development of any support or care plan 1.1.11.2 staff at the service avoid generalisations and subsequent decision-making about person's based on their diagnosis, illness, or disability
1.1.12	the person is supported to build an alliance of supporters by the service	1.1.12.1 the person's supporters are welcomed by the service in all aspects of the design, decision-making and provision of supports
SubTheme 1.2: Choice / Decision Making		
1.2.1	the person directs their own decision-making	1.2.1.1 the person directs their own decision making
1.2.2	Where shared decision making occurs. the person is an equal participant in a shared decision-making process	1.2.2.1 the person is an equal participant in shared decision-making involving them
1.2.3	the person is treated as having competence in decision-making	1.2.3.1 the person is treated as understanding and having competence in all decision-making processes
1.2.4	the person's autonomy in decision-making is supported	1.2.4.1 the person's autonomy in decision making is supported
1.2.5	the person is supported to make informed choices about their own lives including the dignity of risk taking and the right to failure	1.2.5.1 the person is supported to make informed choices about their own lives 1.2.5.2 the person's choices are acknowledged and supported even when they may be in conflict with the service (within the realms of duty of care)
1.2.6	the person is supported to make their own choices with the purpose of being empowered to achieve their aspirations and become more included	1.2.6.1 the person is supported to make their own choices with the purpose of achieving their personal goals 1.2.6.2 the person is supported to make their own choices with a primary focus of being included
1.2.7	the person's choices are respected	1.2.7.1 the person's choices are respected 1.2.7.2 where possible, the person's choices take priority over the organisational priorities
1.2.8	the staff use approaches that are open and inquisitive in determining appropriate supports	1.2.8.1 staff at the service pay attention to all of the ways that the person communicates with the aim of entering into a deeper understanding of the person's preferences for support
1.2.9	the service supports shared action through creative problem solving	1.2.9.1 the service supports shared action through creative problem solving

	Characteristics	Service Expressions
SubTheme 1.3: Knowing the person well		
1.3.1	the person is well-known by the staff at the service	1.3.1.1 staff at the service know the person well
1.3.2	the person's family, friends and significant others are well known by the staff at the service	1.3.2.1 staff at the service know the person's family, friends and others who are important to the person
1.3.3	the person's individual characteristics are understood by the staff at the service	1.3.3.1 staff at the service understand the person's individual characteristics
1.3.4	staff have time to get to know a person well	1.3.4.1 staff are permitted to spend time getting to know the person well
1.3.5	the person, their family and friends are able to share information regarding the person to develop a personal profile and vision for the future	1.3.5.1 the person's family members are encouraged and welcomed to share information about the person as a part of getting to know the person well 1.3.5.2 the person's friends are encouraged and welcomed to share information about the person as a part of getting to know the person well
SubTheme 1.4: Self-Determination / Control		
1.4.1	the person is supported to self-determine as a fundamental human right	1.4.1.1 the person is supported to self-determine as a fundamental human right
1.4.2	staff at the service deeply understand the complexities of self-determination	1.4.2.1 staff at the service deeply understand the complexities of self-determination
1.4.3	the person has power and control in their life	1.4.3.1 the person is able to control their environment to suit their preferences 1.4.3.2 the person is able to control their life experiences to suit their preferences 1.4.3.3 the person has the right to refuse
SubTheme 1.5: Being respected		
1.5.1	the person is respected and valued as being unique and their dignity, rights and responsibility is promoted	1.5.1.1 the person is valued as being unique 1.5.1.2 the person's dignity is respected 1.5.1.3 the person's privacy is respected 1.5.1.4 the person's rights are respected
1.5.2	the service is founded on mutual respect between all people and facilitates partnerships with people and their families that are both respectful and reciprocal	1.5.2.1 staff at the service act in a manner that is nurturing, empowering and respectful to people

Theme 2: Being in relationship

Theme: The person is:

- ***acknowledged as a relational being and as being in relationship with other people;***
- ***supported to establish, develop and maintain relationships as a strong component of being person-centred, including, but not limited to, relationships between the person and their family and friends, the person and staff at the service, and the person and other informal or natural networks of people.***

	Characteristics	Service Expressions
SubTheme 2.1: Focus on establishing, developing and maintaining relationships		
2.1.1	the person is acknowledged and actively supported to establish, develop and maintain relationships with others	2.1.1.1 supports are provided that acknowledge the importance of relationships in the person's life 2.1.1.2 the person is supported to have personal connections with others
2.1.2	staff at the service are aware and understand the importance of caring empathic relationships to quality of life, quality of care and quality of management	2.1.2.1 staff at the service are caring and empathetic towards the person 2.1.2.2 staff at the service are respectful of each other 2.1.2.3 staff and management at the service are respectful of each other
2.1.3	staff at the service support existing relationships and encourage the development of new relationships for the person	2.1.3.1 staff at the service work in ways that maintain the person's existing relationships 2.1.3.2 staff at the service work in ways that encourage the development of new relationships with the person
2.1.4	the person's family are welcome, involved and engaged in the service	2.1.4.1. the person's family are welcome, involved and engaged in the service
2.1.5	staff at the service acknowledge and encourage informal and natural relationships as a valuable component of the person's social network	2.1.5.1 staff at the service act in ways that facilitate natural, informal or unpaid relationships as a part of the person's wider social network
2.1.6	the person's wider social network are included and mobilised	2.1.6.1 where a person has a wider social network, the person is supported to maintain relationships 2.1.6.2 where a person has a wider social network, the network is encouraged and mobilised to be included in the person's life

	Characteristics	Service Expressions
SubTheme 2.2 Person-staff relationships		
2.2.1	the person and the staff at the service acknowledge the centrality of the professional relationship as a means of supporting engagement, advocacy, collaborative planning, and intervention	2.2.1.1 the person and the staff at the service are permitted to have strong caring relationships as a commitment to building a therapeutic alliance
2.2.2	the person and staff at the service are supported to have positive interactions in relationships	2.2.2.1 staff at the service foster a genuine engagement with the person
2.2.3	staff at the service encourage collaboration and partnerships between the person and others	
2.2.4	staff at the service have a sustained commitment to the person with a high degree of engagement and follow-up case management	2.2.4.1 staff at the service have a sustained commitment to the person with a high degree of engagement and follow-up case management

Theme 3: Facilitating participation and engagement

Theme: The person's preferences to participate and be engaged in activities of their choice is:

- ***validated;***
- ***acknowledged as being important to health and well-being;***
- ***supported by processes and procedures that promote their involvement.***

	Characteristics	Service Expressions
SubTheme 3.1 Meaningful activity/occupation		
3.1.1	the person's activities and occupations are individualised	3.1.1.1 the person has an individualised record of activities and occupation that they enjoy 3.1.1.2 the person has an individualised plan of activities and occupation that suits their likes and preferences 3.1.1.3 the person is supported to do the activities they enjoy and like 3.1.1.4 the person's history, health, needs, preferences, interests, routines and habits inform the type and level of support 3.1.1.5 the person's abilities, values and spirituality inform the type and level of support
3.1.2	the person is supported to be engaged in activities that are meaningful to them	3.1.2.1 the person is supported to be engaged in meaningful activity
3.1.3	the person is assisted to seek opportunities to engage in meaningful activity	3.1.3.1 the person is assisted to seek opportunities to engage in activities that they find meaningful 3.1.3.2 the person is supported to try new activities
3.1.4	the service acts to assist people to have something interesting to do during the day	3.1.4.1 staff at the service act to assist the person to have something interesting to do during the day
SubTheme 3.2 Participation		
3.2.1	the person's participation in a full life is encouraged	3.2.1.1 the service acts to encourage the person's participation in the full range of life activities

Theme 4: Social Inclusion

Theme: The person is supported as a valued community member in a way that is underpinned by the principles of rights, independence, choice and inclusion.

	Characteristics	Service Expressions
SubTheme 4.1 Social/community inclusion		
4.1.1	the person is supported as a valued community member	4.1.1.1 the person is supported as a valued community member
4.1.2	the person is supported in a way that is underpinned by the principles of rights, independence, choice and inclusion	4.1.2.1 the person is supported in a way that is underpinned by the principles of rights, independence, choice and inclusion
4.1.3	staff at the service provide support to the person that promotes inclusion and inclusiveness	4.1.3.1 staff at the service provide support to the person that promotes inclusion and inclusiveness
SubTheme 4.2 Being part of the social world		
4.2.1	the person is supported to be in a social world	4.2.1.1 the person is supported to be in a social world 4.2.1.2 the person is able to be with other people, where chosen

Theme 5: Strengths / Capacity focussed

Theme: The person:

- ***is perceived in a positive and proactive manner focussing on strengths and abilities;***
- ***has unique capacities and contributions, not someone who needs to be fixed or managed; and***
- ***has competence that is acknowledged and assumed in the design and provision of services and supports.***

	Characteristics	Service Expressions
SubTheme 5.1 Strengths and capacities focussed		
5.1.1	the person is assessed using strengths-based assessment strategies	5.1.1.1 the person's strengths and capacities are assessed as a component of a full and comprehensive assessment
5.1.2	the person's unique strengths are recognised	5.1.2.1 the person is supported to utilise their capacities and assets rather than limitations or deficiencies
5.1.3	the person is supported to retain their capacities by enhancing their remaining strengths	5.1.3.1 the person is supported to retain their capacities by enhancing their remaining strengths
SubTheme 5.2 Assuming people's competence and abilities		
5.2.1	the person's competence is acknowledged and assumed in the provision of supports	5.2.1.1 the person is assumed to have competence irrespective of illness or disability
5.2.2	the person is supported by focussing on what the person can do rather than the abilities that have been lost due to disease or disability	5.2.2.1 the person's abilities are used in the design and implementation of their supports
SubTheme 5.3 Having high expectations		
5.3.1	staff at the service have high expectations of the person's development and capabilities	5.3.1.1 staff at the service assume that the person can learn 5.3.1.2 staff at the service have positive expectations of the person's capabilities
SubTheme 5.4 Without concern for limitations/barriers		
5.4.1	the person is encouraged to express their desires without concern for limitations or barriers	5.4.1.1 staff at the service are open, curious and inquisitive in supporting people to express their desires without concern for limitation or barriers

Theme 6: Experiencing compassionate love

Theme: The person:

- ***has absolute value and is respected within a culture of life;***
- ***is acknowledged and treated as a human being with needs of comfort, empathy, hope, compassion, love, belonging and safety.***

	Characteristics	Service Expressions
SubTheme 6.1 Humanity		
6.1.1	the person has absolute value and is worthy of respect	6.1.1.1 the person's humanity and everyday life are of primary and central importance 6.1.1.2 the person is of equal value to any other person
6.1.2	the person is related to as a human being	6.1.2.1 the person is related to a human being
6.1.3	the person is acknowledged in the emotional aspects of human existence	6.1.3.1 the person's emotional needs are acknowledged and responded to
6.1.4	the person's well-being and maintenance is central	6.1.4.1 the person's well-being and maintenance of their well-being is of primary importance
SubTheme 6.2 Comfort		
6.2.1	the person's needs for comfort are addressed	6.2.1.1 the person's psychological needs for physical and emotional comfort are addressed 6.2.1.2 the person has access to people, objects, items and activities that provide comfort
SubTheme 6.3 Empathy		
6.3.1	the person is understood through empathy	
6.3.2	the person is considered with unconditional positive regard	6.3.2.1 the person is considered with unconditional positive regard
SubTheme 6.4 Hope		
6.4.1	the person experiences a sense of hope and purpose in life	
6.4.2	the person is supported in a way that emphasises well-being and hope	
6.4.3	the person has a sense that their future is positive	

	Characteristics	Service Expressions
SubTheme 6.5 Compassion		
6.5.1	the person is responded to with compassion	6.5.1.1 the person has a compassionate understanding communicated to them by staff
6.5.2	the person experiences compassion as a part of caring, empathy, and sensitivity to needs and values	
6.5.3	staff at the service develop compassion through having mutually respectful relationships with people	
SubTheme 6.6 Love		
6.6.1	the person's need of being loved and recognised is met	6.6.1.1 the person's need of being loved and recognised is met
6.6.2	the person is supported to establish and maintain loving relationships	6.6.2.1 the person is supported to establish and maintain loving relationships
6.6.3	the person is loved for who they are	6.6.3.1 the person is loved for who they are
SubTheme 6.7 Belonging		
6.7.1	the person experiences a sense of belonging	6.7.1.1 the person experiences a sense of belonging
6.7.2	the person experiences a sense of togetherness with others	6.7.2.1 the person experiences a sense of togetherness
SubTheme 6.8 Safety		
6.8.1	the person's safety is protected while maintaining the essence of the person	6.8.1.1 the person's safety is protected while maintaining the essence of the person

Theme 7: Organisational characteristics

Theme: Person-centred organisations and services hold a strong holistic values-base underpinned by particular staff attributes, flexibility and responsiveness and continuity and consistency of support.

	Characteristics	Service Expressions[6]
SubTheme 7.1 Values-based / holistic		
7.1.1	the service has a value-base that respects and values the uniqueness of people and seeks to maintain and/or restore personhood	
7.1.2	the service values the person's subjective experience of illness or disability	
7.1.3	the service takes a values-based approach to thinking about, communicating with, assessing, and planning for, and supporting people	
7.1.4	the service values a holistic philosophy of care and support	
7.1.5	the person is treated as a 'whole person' and supports the consideration of the person's needs and preferences from a holistic perspective	
SubTheme 7.2 Staff attributes		
7.2.1	staff at the service genuinely relate to the person	7.2.1.1 staff at the service have positive attitudes and care practices
7.2.2	staff at the service work to satisfy the wishes and needs of people	7.2.2.1 staff at the service work to primarily satisfy the wishes and needs of people rather than the system
7.2.3	staff at the service are sufficiently flexible to accommodate individual conditions	7.2.3.1 staff at the service are sufficiently flexible to accommodate the needs of individual people
7.2.4	management staff at the service model being person-centred with staff and provides leadership	7.2.4.1 management staff at the service models being person-centred with staff as well as people who require support 7.2.4.2 management staff at the service provides leadership in person-centredness
7.2.5	staff at the service feel part of a team that has a sense of pride, passion and togetherness	7.2.5.1 staff at the service feel part of a team that has a sense of pride, passion and togetherness

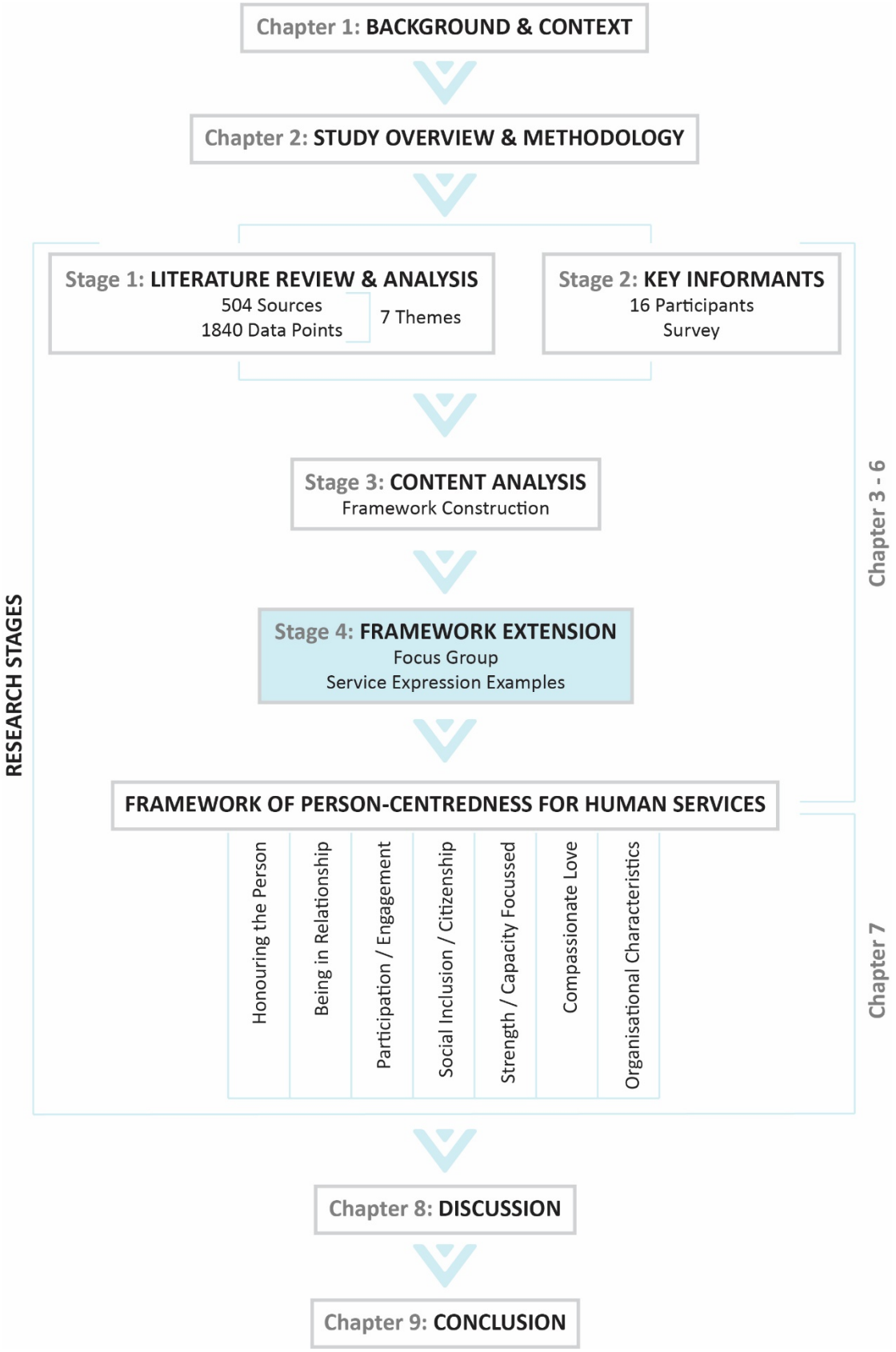
[6] Some sub-themes do not have service expressions here because they were not apparent in the content analysis.

	Characteristics	Service Expressions
7.2.6	staff at the service have excellent interpersonal skills and know themselves well	7.2.6.1 staff at the service have excellent interpersonal skills and know themselves well 7.2.6.2 staff at the service foster and grow feeling-based and instinctive care and support 7.2.6.3 staff at the service are well trained and engage in ongoing professional and personal development
7.2.7	staff at the service are empowered by staffing models	7.2.7.1 staff at the service are empowered by staffing models
SubTheme 7.3 Flexibility and responsiveness		
7.3.1	in order to be responsive, the service is timely and flexible	7.3.1.1 the service is timely and flexible in order to be responsive to people
7.3.2	the service is flexible in its practices	7.3.2.1 the service has flexible practices 7.3.2.2 the service works to reduce bureaucracy and red tape to promote flexibility
SubTheme 7.4 Continuity and consistency of support		
7.4.1	the person receives continuity of service	7.4.1.1 staff at the service are assigned to the same people for continuity and consistency of support

5.4 Conclusion

The contribution of the FPCHS lies in providing a structure to understand the commonality of purpose and values in human services practice. There are clearly common understandings of similar concepts across the human service areas. It appears, however, that the expression of the characteristics varies according to population group, sector and practice purpose. Interestingly, some aspects of the framework did not appear to lend themselves easily to a service expression example. The reasons for this were not clear and this conclusion led to the need for the final stage of the research which was to explore service examples of person-centredness in front-line practice with key informants.

Chapter 6: Stage 4: Exploration and identification of service expression examples of person-centredness



In this chapter, I present the final stage of the research where an expert focus group were asked to provide service expression examples to extend the Framework of Person-Centredness for Human Services (FPCHS). I describe the rationale, methodology, data analysis and discuss how the responses add to the overall framework structure and detail. I conclude the chapter by drawing the findings of the four stages of the research together.

6.1 Background and rationale

The previous stages of this research have led to the development of a framework with clear themes and sub-themes, statements of characteristics, service expressions and some service examples from the literature and key informants. These research stages have demonstrated a disconnect and a set of divergences between the concept, policy and practice of person-centredness, and that the implementation of the concepts and policies is largely left to the street-level workers as they attempt to bridge the concepts of person-centredness in policy and the reality of human service work (Lipsky, 2010). As has been previously identified, the concept, policy construction and subsequent practice interpretations are situated in a diverse and evolving community(s) of practice (Harding et al., 2014) and in utilised across multiple purposes (Waters & Buchanan, 2017), although it seems that most are concerned with the treating of people as 'persons' (Entwistle and Watt, 2013). In this stage of the research, a second group of key informants were recruited to participate in a focus group to provide examples of how and where the statements of characteristics and fundamental ideas were implemented in day-to-day practice. The intent was to test the descriptive framework by identifying how and where these concepts translated into practice. Given that person-centredness is a hotly contested and debated construct, could key informants offer a perspective that varied from the greater body of knowledge about the concept? Could key informants offer a nuanced understanding of the implementation of person-centredness that would indicate whether it may even be considered a magic concept?

The purpose of the focus group was to elicit key informants' examples of how the conceptual ideas identified in the characteristics statements of the FPCHS were being implemented based on their professional and/or personal experience and observations of others in practice. As has been previously stated, key informants in research are people "whose social positions….give them specialist knowledge about other people, processes or happenings that are more extensive, detailed or privileged than ordinary people, and who are therefore particularly valuable sources of information to a researcher" (Payne & Payne, 2011, p. 136). The use of key informants was important because the purpose was to explore

understanding and implementation amongst practioners known to be committed to working in a way that was person-centred. The focus group of key informants was a means of enabling a dynamic interaction between group members so that debates, consensus and ideas about person-centredness could emerge that were unlikely to do so with individual interviews where only single perspectives could be gained (Lysack et al., 2006). This was, therefore, more likely to give rise to applications of person-centredness that may or may not be accommodated within the framework. This method of interrogating the conceptual framework was intended to address two aspects: first, whether it was a rigorous conceptualisation of person-centred service expressions, and second, whether the framework was equally applicable across each of the three human service sectors. This is critical with a post-positivist study that is trying to capture the dynamic realities of service provision rather than a study focussed on measures and compliance. Post-positive approaches acknowledge that theory and practice are related and not binary opposites (Ryan, 2006).

6.2 Method

Potential focus group participants were approached based on their backgrounds and experience in the implementation of person-centred ways of working in human service organisations in Western Australia. Participants were invited by personal email or telephone to participate in a single focus group to provide examples of person-centred ways of working in their professional and/or personal experience. The focus group method was used because it was about responses to particular aspects of person centred operationalisation in organisations and practice, rather than a group interview where questions are exploratory and concerned with asking the same questions of all participants (Lysack et al., 2006). Purposeful sampling using theory-based selection was used (Dickerson, 2006) and participants were approached because they were known to the research team as having expertise or experience in the area.

A group of key informants was selected that included representatives across the human service fields of practice in ageing, disability and mental health. Participants were mostly street-level bureaucrats including service providers, service managers, service users and academics. Seven participants were approached and all agreed to participate in the focus group. Information sheets were provided at the time of approach by email (Appendix D1). Consent forms were signed at the commencement of the two-hour focus group (Appendix D2). All participants had more than 5 years' experience in human service delivery, including

service users, and were either currently working in one of the areas or had previous experience of working in or accessing services.

Participants were provided with a draft of the framework's characteristics statements developed in the first three stages of the research as foundational information for the group discussion at the beginning of the session. The focus group commenced with an overview of the research to date with the primary researcher explaining the development of the framework. Participants were asked to consider the characteristics statements as a foundation to identify service examples of person-centredness in their area of practice. While participants were able to contribute freely, the primary researcher monitored the time and facilitated the group to ensure that each section of the framework was considered equally. Responses were recorded by the two research supervisors. The primary researcher also made field notes during the focus group.

6.3 Data analysis

Data were entered into NVivo10 to facilitate data analysis (QSR International, 2010). Data were mapped back to the service expressions identified in the first three stages of the research project using the characteristics statements and field notes as indicators as to where the data most accurately aligned using a deductive approach (Fereday & Muir-Cochrane, 2006). The primary researcher then translated the focus group data into service example statements for inclusion in the FPCHS. The three researchers met to ensure the accuracy of the statements in reflecting the intent of the coded data via a process of peer debriefing (Lysack et al., 2006). Finally, the three researchers considered the focus group transcripts as a whole to look at how differing constructions of person-centredness were described by the key informants in different roles and across different fields of practice.

6.4 Findings and discussion

Participation in the focus group had three distinct outcomes; firstly, participants identified service examples that were consistent with those previously identified in the literature; secondly, participants' own understandings were broadened by participating in the focus group with the range of differing perspectives; and thirdly, the focus group confirmed that concepts of person-centredness clearly have multiple meanings that have, and continue to be, interpreted and implemented in different ways (Leplege et al., 2007). Focus group participants confirmed the framework's key components and provided examples of the operationalisation of the framework in their respective contexts. During the focus group, there was considerable discussion about what demonstrated evidence of the expression of

the characteristics in each human service context, and in some cases, participants examples highlighted the divergence in what was considered as person-centred across fields of practice. Examples of these instances are outlined in detail later in this chapter.

Participants were able to provide the most practical service examples in the aspects of the framework that was more comprehensively described in literature 'such as 'honouring the person' and 'being in relationship'. Key informants revealed that the extent to which service examples can be identified predominantly fall within the first two themes of the FPCHS. The less well-recognised service expressions, such as 'facilitating participation/engagement' and 'social inclusion/citizenship' had fewer identified examples. Some of the examples provided fit more than one theme and therefore were not mutually exclusive. Table 5 shows the number of responses provided by theme by the key informants, indicating that the first two themes are where people's applications predominate. These two areas are where person centredness is concerned with how people are treated when using services or when resident at a service.

FPCHS Thematic Heading	No. of service examples
Theme 1: Honouring the person	87
Theme 2: Being in relationship	44
Theme 3: Facilitating participation/engagement	16
Theme 4: Social inclusion / citizenship	17
Theme 5: Strengths/capacity focussed	23
Theme 6: Experiencing compassionate love	20
Theme 7: Organisational characteristics	30

Table 5: Key informant responses by theme

Table 5 highlights where key informants are most confident and familiar with person-centredness in practice. It was not intended as a measure of the extent and types of person-centredness occurring in the human services, but rather to provide a brief indication to the reader of which themes dominated in the practice description examples. The table highlights the match, or lack thereof, of the breadth of characteristics written about in the literature on person-centredness and what is focussed on in practice by the key informants.

6.4.1 Service examples: 'Honouring the person' and 'Being in relationship'

During the focus group, key informants emphasised service examples which were representative of the first parts of the FPCHS, 'honouring the person' (87 responses) and

'being in relationship' (44 responses). Some examples of these are included in Tables 6 and 7 to illustrate the relationship with the service expression.

Interestingly, some key informants described examples of person-centredness which could be attributed to practices that prioritised the person's wants and needs yet were outside traditionally accepted modes of service delivery. For example, key informants identified ways of working that enabled people to achieve their desired outcomes and prioritised individual dignity over risk, despite a clash with the organisational duty of care and even professional values. For example, under the theme of 'being in relationship', key informants identified service examples such as 'the person is supported to initiate and continue intimate and sexual relationships' and 'staff at the service act in ways to limit the negative aspects of regulatory bodies'. This suggests that the discretion employed by front-line workers who aim to be the most person-centred sometimes sits outside of expected organisational practice and procedure and is mediated by professional values, practice experience and resistance to gatekeeping on behalf of the organisation. This sits in tension with the need for street-level bureaucrats "to judge and control clients for bureaucratic purposes" (Lipsky, 2010, p. 72), and dictate the parameters under which the implementation of services will occur.

In some cases, representations of person-centredness conflicted between human service delivery areas. One example of this is in the case of the congregation of people with similar lived experiences. In the intellectual disability sector, the congregation of people with intellectual disability has traditionally been perceived as being negative, due to the negative social connotations (Wolfensberger, 2000). Yet, one key informant from a mental health service delivery background suggested that being in relationship with other people with similar lived experiences was a positive thing, and supported personal recovery. The conflict in opinion about 'congregation' can be argued from the perspective of the person. In intellectual disability, the argument against congregation is grounded in an ableist[7] privilege constructed by people, albeit well-meaning people, outside of the personal experience. In mental health, the argument for congregation comes from the perspective of choice and the lived experience of the person related to a history of stigmatisation. This suggests that the siloed histories of person-centredness cause a misinterpretation of practice across human services. This is of

[7] Ableism: "a network of beliefs, processes and practices that reduces a particular kind of self and body (the corporeal standard) that is projected as perfect, species-typical and therefore essential and fully human. Disability…is cast as a diminished state of being human" (Campbell, 2001, p. 44).

particular concern for organisations which are increasingly providing services to user groups across sectors. What is readily perceived as good practice in disability, may not be perceived as being good practice in mental health, for example. This both complicates and confounds the organisational interpretation and delivery of government policy and almost makes it impossible for the front-line worker, especially those working between and across domains, to translate into practice.

Therefore, some aspects of being person-centred, which are valued by the person, are only visible at the street-level and are not apparent at either the policy or organisational levels. Examples such as supporting intimate and sexual relationships between people with cognitive disabilities are rightfully fraught with all sorts of complications from a duty of care perspective, and even from a professional values viewpoint. Yet there is no denying that people continue to be sexual beings, despite their disabilities and health conditions, and there is some suggestion at least that the front-line worker may pursue the use of their discretion in choosing to facilitate this to occur. In the case of congregated services for people with disability, these also may not be visible at the organisational level but may become apparent at the street-level where discretion occurs and a more likely and flexible interpretation of policy may occur.

At the broadest level, practitioners seemed to describe examples of person-centredness that were familiar and consistent with the way services operate. None of the examples was disruptive or revolutionary or suggested new /or innovative ways of conducting human services. The examples did not suggest strong levels of disruption to service delivery relationships, existing power balances or even to professional values or ethics.

Theme 1: Honouring the person	
Service expression	Common service examples
1.1.7.1 the person's history, including significant life experiences, are respected in the establishment of a positive relationship with the staff at the service	• documentation at the service starts with where the person is and includes a narrative of the person and their story • staff training at the organisation is focussed on beginning with the person's story and facilitating assessment and planning within that context
1.1.10.1 the person co-owns the support plan	• the person is a part of a shared planning process where they participate in the design of the supports and are involved in writing the documentation • the person is involved in a planning process that requires them to be present and a part of the discussions and agreement to the outcomes (eg. PATH, MAPS)
1.2.5.2 the person's choices are acknowledged and supported even when they may be in conflict with the service (within the realms of the duty of care)	• the staff have a responsibility to advocate for the plan, even when the practitioner sees the world differently from the person or their family (the person's view takes priority) • the staff recognise that people are allowed to fail and can make alternate decisions (for example, a service may use treatment disclaimers evidencing people's dignity of risk) • the staff are willing to sit with the uncertainty of people's right to decide vs whether the staff think it is beneficial or not
1.2.8.1 staff at the service pay attention to all of the ways a person communicates with the aim of entering into a deeper understanding of the person's preferences for support	• the staff are able to spend the necessary time to get to know the person well • the staff use a variety of methods/strategies to get to know the person well (eg. planning cards, targeting language, visual cues, behaviour)

Table 6: Service examples 'Honouring the person'

Theme 2: Being in relationship	
Service expression	Common service examples
2.1.1.2 the person is supported to have personal connections with others	• the staff support the person to develop networks of both paid and unpaid supports in their lives • the staff work to develop support networks with the person that recognise the importance of being a part of society and not just having paid people providing support • the person is supported by people who want to be in their life, not just paid employees
2.1.6.2 where a person has a wider social network, the network is encouraged and mobilised to be included in the person's life	• the person is able to invite friends to their home and be supported to show hospitality (share meals, etc) • the person is encouraged to have inter-generational relationships (eg. In aged care, children are welcomed to visit)
2.2.1.1 the person and the staff at the service are permitted to have strong caring relationships as a commitment to building a therapeutic alliance	• role boundary documents at the organisation acknowledge the humanness of relationships • the staff at the service work in ways that support connection and sharing

Table 7: Service examples 'Being in relationship'

6.4.2 Service examples: Remaining themes

Key informants seemed less able to identify examples of service expressions related to the thematic headings of 'facilitating participation/engagement' (16 responses), 'strengths/capacity focussed' (23 responses) and 'social inclusion' (17 responses). Some of the service expression examples for these themes are provided below in Table 8, 9 and 10.

Theme 3: Facilitating participation/engagement	
Service expression	Common service examples
3.1.2.1 the person is supported to be engaged in meaningful activity	• the person is supported to engage in activities that have meaning to them and suit their interests • the person's support plan for participation and engagement is dynamic and easily altered when requested
3.1.4.1 staff at the service act to assist the person to have something interesting to do during the day	• staff at the service work to ensure that people have something to do during the day that is of interest to them
3.2.1.1 the service acts to encourage the person's participation in the full range of life activities	• the person is supported to participate in their community • the person is supported to participate in daily life activities and routines • the person is supported to participate in social activities and relationships • the person is able to attend places and activities of their choice

Table 8: Service examples 'Facilitating participation/engagement'

Theme 4: Social inclusion	
Service expression	Common service examples
4.1.3.1 staff at the service provide support to the person that promotes inclusion and inclusiveness	• staff at the service provide support that acts to promote inclusion and inclusiveness; for example, on a visit to the local coffee shop, the staff facilitate support to the person that enables them to conduct their own order, rather than ordering on behalf of the person • the person is supported to access settings, services, supports and routines available in the community at large • the person is supported to contribute and belong

Table 9: Service examples 'Social inclusion'

Theme 5: Strengths/capacity focussed	
Service expression	Common service examples
5.1.3.1 the person is supported to retain their capacities by enhancing their remaining strengths	• the service has procedures and policies in place that encourage the maintenance of a person's skills and abilities
5.2.1.1 the person is assumed to have competence irrespective of illness or disability	• the person is treated as understanding what is occurring in their environment without concern for their cognitive status • the person is treated as having capacity but requiring support

Table 10: Service examples 'Strengths/Capacity focussed'

The focus group participants were also less able to identify service expression examples for the final two thematic headings (20 responses for theme 6 and 30 responses for theme 7) across all domains of practice. This may be able to be explained by reflecting on the thematic analysis conducted in stage 1 of this research. In Stage 1, more than half of the identified codes appearing in the thematic analysis (659 of 1161 codes) represented the first two themes of 'honouring the person' and 'being in relationship', suggesting that person-centredness has been understood or translated to valuing the person and treating them as persons with agency. The results from this final stage of the research confirm that the aspects of person-centredness related to those two main themes are more readily and clearly understood across all areas of practice. They are also the aspects of person-centredness that are most commonly described and expanded upon in the literature.

The responses provided by the focus group are examples of the service expressions of person-centredness in the day to day practice. The findings do not suggest that the remaining five themes do not hold currency rather they highlight that the common rhetoric of person-centredness is much easier to articulate than the practicalities of what could be perceived as additional outcomes more than just what is required when working directly with people around core tasks required by the job.

6.4.3 Person-centredness: A 'magic concept'?

The findings from this stage of the research confirm that while the rhetoric of person-centredness appears relatively well understood between practitioners, the practice of person-centredness remains elusive and somewhat obscured both within and between service contexts. Following Pollitt and Hupe's (2011) four criteria[8] introduced in Chapter 1 of this thesis, there is much evidence to support person-centredness being a magic concept. Carey and Malbon (2018, p. 2) argue that Pollitt and Hupe's "magic concepts can be deployed on context-specific levels to avoid tackling challenging problems and further muddy already complex governance arrangements and policy challenges." In fact, person-centredness is so broadly used and applied, that it almost cannot be anything but magic and elusive. Using Carey and Malbon's (2018) framework for identifying and mapping magic concepts further supports this claim (table 11).

[8] Pollitt and Hupe's (2011) four criteria for magic concepts were (1) broadness, (2) normative attractiveness, (3) implication of consensus and (4) global marketability.

Criteria	Questions	Person-centredness
Broadness	Does the concept cover huge domains, have multiple, overlapping domains or connect with many problems?	This concept is applied in multiple human service contexts and settings and with an assumed consistency of meaning. It is most often attributed to a status of quality and is applied at all levels from policy to organisational culture to practice.
Normative attractiveness	Is the concept hard to argue against because of its perceived progressive values?	Person-centredness is fundamentally unable to be argued against because of its assumed priority on the individual and its strong links to concepts of choice, control and self-determination, all of which are perceived as desirable characteristics in contemporary human services.
Implication of consensus	Does the concept dilute or deny conflicting interests, logics or arguments about the best solution to the context-specific problem?	The evidence from the research indicates that none of the service expression examples is disruptive or revolutionary in human service delivery, in either the organisational context or at the level of professional values. None of the policy-level or organisational-level responses disrupts power balances or service delivery arrangements. In addition, the concept is not able to address the current issues of abuse, neglect and inadequate service delivery in human services. Concept retains layers of opaqueness in what it actually looks like in practice.
Marketability	Is the concept known and used by many practitioners and feature in new policy documents, titles and new units within the context?	The increasing use of the term in academic literature, policy documents and practice contexts evidences the marketability of the concept. The term is frequently used as an indicator of service quality and is constructed as both a desirable process and outcome of human service delivery. In fact, person-centredness is so 'fashionable' to coin Pollitt and Hupe's (2011) term, that it has been co-opted into government policy across multiple sectors.

Table 11: Identifying person-centredness as a magic concept

This is not to say however that the status of person-centredness as a magic concept is a negative thing. Pollitt and Hupe (2011) suggest that they can perform the functions of "focusing and legitimizing certain ways of looking at the world and recruiting support for broad lines of action" (p.653). They do however warn that in performing this role, they should not automatically be mistaken for "clear-cut scientific, technical or operational terms" (Pollitt & Hupe, 2011, p. 653). The evidence in this study suggests that this might be where person-centredness as a concept has come unstuck. The responses from the key informants indicate

that there is at least some clarity between front-line workers about the day-to-day practice of person-centredness *across* human services, but there are also some areas where this is not so clear. And between domains of practice, the context and history of human service delivery strongly influence practice.

Pollitt and Hupe (2011, p. 653) state "to regard magic concepts as offering sets of direct prescriptions for specific practices is to misinterpret their capacity". This constitutes a warning to policy makers that using person-centredness as a concept to prescribe practice is too abstract. Magic concepts somehow rise above previously described and implemented techniques, practices, processes and constraints because they are all substantially different in each new situation and to attempt to operationalise or standardise them is to invite frustration (Pollitt & Hupe, 2011).

Pollitt and Hupe (2011) describe the magic concept as a "quintessentially modernist narrative of progress" (p.653). Researchers and practitioners should pay attention to the theoretical constructions and methodologies that make a 'magic' concept operational. In this case, person-centredness has been scaled up from a value position in practice to a policy approach in an attempt to articulate 'quality' in human services. However, it seems in its escalation to an advocated policy position it will remain largely symbolic without the underpinning practices to support the 'how' of person-centredness. So the policy push towards more person-centred practice may be better oriented towards 'how do we provide better quality supports and services to people who require them?'

6.4.4 Implementing the magic concept and the contribution of 'street-level bureaucracy'

Importantly, these results also highlight the level of discretion front-line workers has in the implementation of person-centredness at the street-level. The previous example of the facilitation of intimate relationships is a demonstration. However, the types and extent of discretion are also shaped by the organisational context such as the number of cases allocated, and the financial or other resources available/allocated to individual service users. Consistent with Lipsky (2010), the results suggest that front-line workers have the ability to exercise discretion and mediate the experience of the service in the execution of their role. Front-line workers are the actors who have responsibility for both delivering the benefits of the service and subsequently "delimiting people's lives and opportunities" (Lipsky, 2010, p. 346). They mediate the relationship of the person to not only the policy but also the organisational culture and operations. The role of the front-line worker becomes pivotal to

the individual experience of the human service. “In short, they hold the keys to a dimension of citizenship” (Lipsky, 2010, p. 4).

In some settings and some organisations, participants described working collaboratively with their line managers within the organisational culture to ensure the provision of services and support to people. This is often influenced by the professional and personal experiences of the front-line worker and the managers. In other organisations, front-line workers described acting in ways that, while not in absolute conflict with the organisational procedures and policies, could be construed as ‘bending the rules’. This discretion was often exercised in response to a commitment to professional values and knowledge (Evans, 2011).

6.5 Conclusion

The four stages of this research have led to the development of the resultant descriptive FPCHS. This framework offers a useful structure for presenting how being person-centred has been described and operationalised by writers and practitioners across the three domains of human service, and between policy and practice. The seven thematic headings relate broadly to the macro level policy constructions of person-centredness found in Australian policies pertaining to mental health, ageing and disability. The constituent characteristics attempt to drill down to organisational culture or broad practice goals and outcomes are less frequently operationalised. The service expressions and the examples gathered through stage 4 of this research are the best current information we have to articulate the translation of the principles of person-centredness in direct service work.

What is apparent from this research process, however, is that there are layers of opaqueness in our understanding of what being person-centred actually means. I use the term ‘layers of opaqueness’ because depending on the context aspects of being person-centred are more or less visible. The visibility also varies on the standpoint of the actor, for example, whether a policy maker, senior manager or support worker. However, there are still clear areas of agreement between human service fields that were evident in the ‘honouring the person’ and ‘being in relationship’ sections of the framework, or at least, a common understanding of the language. This language has been readily co-opted into policy and practice documentation. It has been translated to mean choice, control, individualism and self-determination, uncomfortably accommodating both human rights and free market choice discourse which will vary in implementation. Little attention is paid to the *contents* of the choices, the *type* of control, the implications of self-determination where someone may not

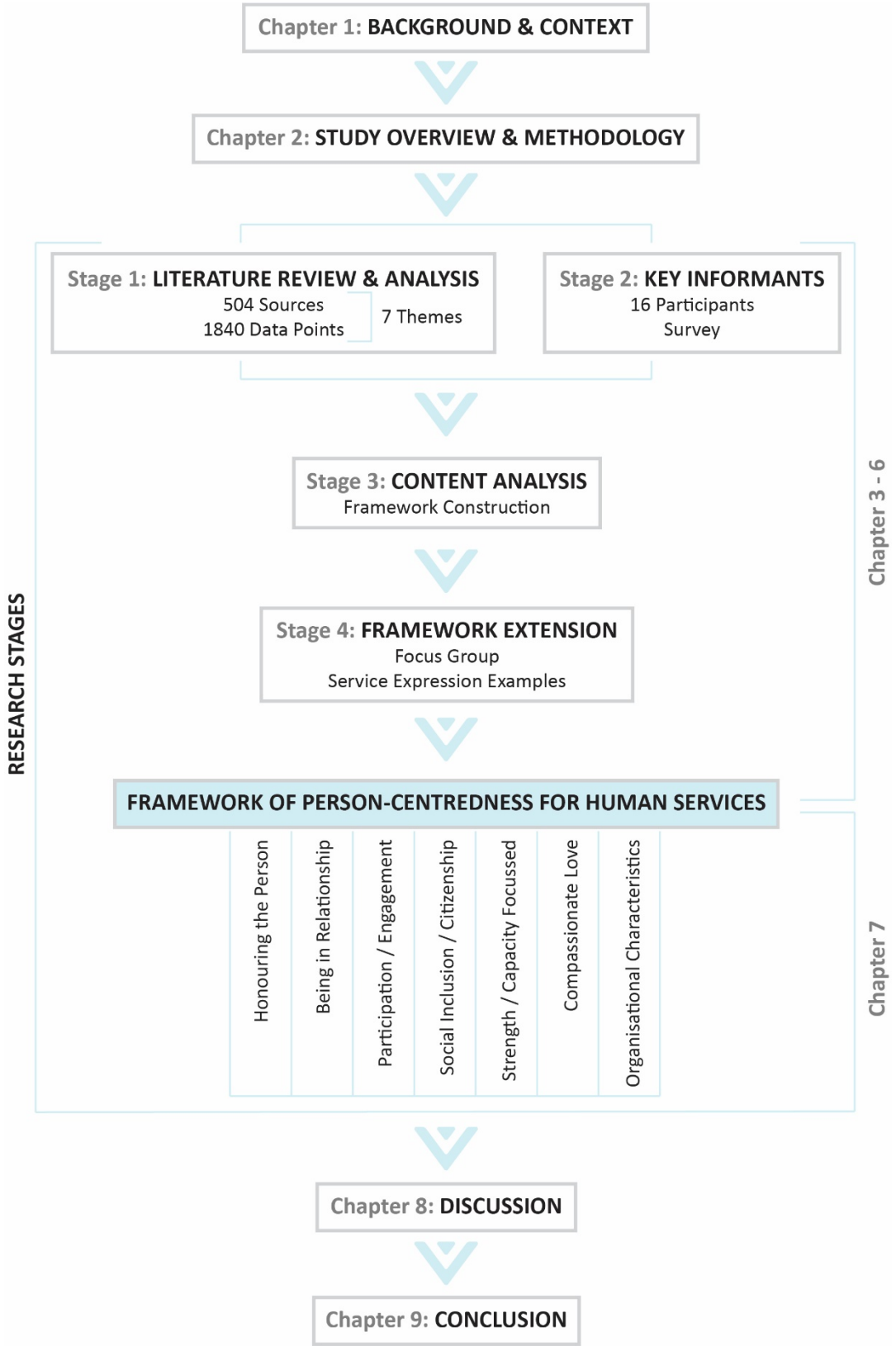
have *agency*[9], yet they exist in policy documentation, and are underpinned by the assumption that the market will self-adjust in a climate of supply and demand. In this case, proxy measures of choice, control and market dynamics replace the human rights oriented direct practices of person-centredness at the front line.

However, the closer we get to the front-line worker and the person, the more the experience of person-centredness is entirely obscured from both the organisation, the policy makers of government and even the market. What actually occurs between the front-line worker and the person, is known only to them and in some cases to immediate family who may also be present. The extent to which that interaction between the person and the front-line worker is person-centred is both contextual and individually determined. From the perspective of the front-line worker, it is mediated by values, professional knowledge, resources, resilience, compassion and care. And yet, the success of an interaction being considered person-centred is individually determined, informed by personal history and agency, and unique and changeable.

The next chapter presents the descriptive Framework of Person-Centredness in Human Services (FPCHS) based on triangulating of policy analysis, published literature and key informant data about practice.

[9] Agency: "the ability of people, individually and collectively, to influence their own lives, and the society in which they live" (Germov, 2009, p. 27)

Chapter 7: The Framework of Person-Centredness for Human Services (FPCHS)



This chapter presents the Framework of Person-Centredness for Human Services (FPCHS) in its entirety. The FPCHS consists of seven themes with descriptive thematic statements; constituent sub-themes, characteristics, service expressions and service expression examples. The full FPCHS is derived from and directly linked to the data collected and analysed in the four stages of the research project.

7.1 The Framework of Person-Centredness for Human Services (FPCHS)

Theme 1: Honouring the person

Theme: The person is honoured by being:

- *understood, treated and supported in a holistic manner as an individual with a unique perspective, history, needs, strengths and preferences;*
- *acknowledged and respected as an expert in their life;*
- *placed firmly at the centre of any decisions and choices that involve them;*
- *well known by the staff at the service;*
- *assumed to have the capacity to self-determine or is supported as much as possible to have control over their life; and*
- *respected and valued.*

SubTheme 1.1: Individuality/person as expert

	Characteristics	*Service Expressions*	*Service Examples*
1.1.1	the person is treated as an individual	1.1.1.1 the person is treated as an individual	• the person is addressed by their name without exception • the person is addressed with a sensitivity to language locating them at the centre of all interactions
1.1.2	the person's varying needs and requirements are catered for	1.1.2.1 the person's varying needs and requirements are catered for	• the person is responded to individually taking into account their likes, dislikes, preferences and needs • the person is communicated to using language which is understood • information is provided using a number of modalities which are sensitive to the person's capacities, eg. Easy read, COMPIC, speaking at a level for understanding, not outpacing

1.1.3	the person has an individualised selection, combination and implementation of supports and/or care	1.1.3.1 the person is able to select, combine and have implemented supports and/or care that best meets their needs	• the person is able to select combinations of support that best meet their requirements, dependent on their personal circumstances
1.1.4	the person receives a personalised holistic approach to their needs	1.1.4.1 staff at the service demonstrate a willingness to discuss and where possible, within the constraints of resources, act to support the person in a holistic manner	• the person is considered in their entirety by the service
1.1.5	the person's preferences for daily living and routines are honoured	1.1.5.1 the person's preferences for support for daily living are clearly documented by the service 1.1.5.2 the person's preferences for support are referred to and honoured by the direct support staff	• the person is able to determine their preferences for food • the person is able to determine the times for their meals • the person is able to determine their times for showering or bathing • the person is able to watch their favourite TV shows or participate in their favourite activities • the person is validated by support staff for their thoughts, ideas and concepts
1.1.6	the person's perspective, needs and preferences are acknowledged and included in the establishment of a positive relationship with the service and implementing the appropriate supports	1.1.6.1 the person's perspective is considered and honoured in the design and development of supports 1.1.6.2 the person's needs and preferences are clearly documented 1.1.6.3 the provision of supports to the person are informed by and based on the documentation	• staff at the service are open and inquisitive in determining the person's perspective, needs and preferences • the service has documentation that records the person's perspective, needs and preferences • the staff at the service refer to and honour the person's perspective, needs and preferences • the design of the person's supports reflect the documentation that records the person's history, life experiences, needs and preferences

1.1.7	the person's history, including significant life experiences, inform interactions by staff with the person	1.1.7.1 the person's history, including significant life experiences, are respected in the establishment of a positive relationship with staff at the service	• the person's history is documented and referred to in the establishment and provision of supports to the person • documentation at the service starts with where the person is and includes a narrative of the person and their story • staff training at the organisation is focussed on beginning with the person's story and facilitating assessment and planning in that context
1.1.8	the person's gifts, strengths and dreams are included in implementing the appropriate supports	1.1.8.1 the person's gifts, strengths and dreams are clearly documented by the service 1.1.8.2 the person's gifts, strengths and dreams inform interactions by staff with the person	• the service pays equal attention to the person's gifts, strengths and dreams as their needs in the design and implementation of supports • the person is supported to explore their thoughts and feelings
1.1.9	the person is firmly located at the centre of any process involving them including planning, action and decision-making	1.1.9.1 the person is treated as an equal expert and the focal point of a respectful and reciprocal service partnership 1.1.9.2 the person is the primary consideration of any planning, action or decision-making 1.1.9.3 the person is present, included and supported, where possible, to make decisions about any process, care, support, plan or action that concerns them	• the person, rather than the service or the system, is the primary concern of any planning, action or decision-making • the person is supported to make decisions about their care or support where possible • the staff at the service work to know the person well, and develop a positive relationship • supported decision making tools are made available and used
1.1.10	the person co-owns the support plan	1.1.10.1 the person is a participant in the design or development of the support plan	• the person is present at any meeting or consultation involving them • the person participates in a shared planning process that begins with who the person is, not what they need

			• the person participates in the process from assessment to the development of a community partnership plan • the person is a part of a shared planning process where they participate in the design of the supports and are involved in writing the documentation • the person is involved in a planning process that requires them to be present and a part of the discussions and agreement to the outcomes (eg. MAPS, PATH)
1.1.11	the person is at the centre of their own story, not their diagnosis or illness	1.1.11.1 the person is at the centre of their own process, including the design or development of any support or care plan 1.1.11.2 staff at the service avoid generalisations and subsequent decision-making about person's based on their diagnosis, illness, or disability	• the person is present and involved in the design and development of their support or care plan • staff at the service do not primarily make decisions about how to support persons based on diagnosis, illness or disability only • wellbeing mapping is used with a focus on the person participating in the process rather than the outcome • personalised recovery plans are used with people eg. Compass • personalised planning tools are used with people, eg. PATH • plans are readable, accessible and nuanced for the person especially for people with communication or reading difficulties
1.1.12	the person is supported to build an alliance of supporters by the service	1.1.12.1 the person's supporters are welcomed by the service in all aspects of the design, decision-making and provision of supports	• the person's family are welcomed by the service • the person's friends are welcomed by the service • the service acts in a way to maintain or establish supportive unpaid relationships for people

SubTheme 1.2: Choice / Decision Making

	Characteristics	*Service Expressions*	*Service Examples*
1.2.1	the person directs their own decision-making	1.2.1.1 the person directs their own decision making	• the person is regularly involved in decision making • the person is involved in the decision-making process of all aspects that concern them • the person is involved in decisions about all aspects of planning, review, support, care and other aspects of service delivery that directly impact their day to day life • the person is able to state 'this is what I want' and be responded to appropriately
1.2.2	Where shared decision making occurs. the person is an equal participant in the shared decision-making process	1.2.2.1 the person is an equal participant in shared decision-making involving them	• the person is an equal participant in shared decision-making • the person's perspective is considered equally in shared decision-making
1.2.3	the person is treated as having competence in decision-making	1.2.3.1 the person is treated as understanding and having competence in all decision-making processes	• the person is treated as being cognitively competent in all decision-making processes irrespective of disability
1.2.4	the person's autonomy in decision-making is supported	1.2.4.1 the person's autonomy in decision making is supported	• the person is supported to self-determine in decision-making processes
1.2.5	the person is supported to make informed choices about their own lives including the dignity of risk taking and the right to failure	1.2.5.1 the person is supported to make informed choices about their own lives 1.2.5.2 the person's choices are acknowledged and supported even when they may be in conflict with the service (within the realms of duty of care)	• the person is provided with, and supported to, make choices about their own lives • the person's choices are acknowledged and supported as much as is possible in the service delivery context

			• the service has, and uses, supported decision making processes with the person • staff at the service acknowledge and understand that the person has a 'right to fail', eg. Use of treatment disclaimers • the service has procedures for dealing with situations where the person makes decisions that challenge the organisational framework • the staff at the service have a tolerance for the dignity of risk (within the realms of duty of care) and this is evidenced in the documentation • the staff have a responsibility to advocate for the plan, even when the practitioner sees the world differently from the person or their family (the person's view takes priority) • the staff recognise that people are allowed to fail and can make alternate decisions (for example, a service may use treatment disclaimers evidencing people's dignity of risk) • the staff are willing to sit with the uncertainty of people's right to decide vs whether the staff think it is beneficial or not
1.2.6	the person is supported to make their own choices with the purpose of being empowered to achieve their aspirations and become more included	1.2.6.1 the person is supported to make their own choices with the purpose of achieving their personal goals 1.2.6.2 the person is supported to make their own choices with a primary focus of being included	• the person is encouraged to set and is supported to attain personal goals and aspirations • the person is supported to be included in their defined community • the person has a variety of inclusive experiences in their lives
1.2.7	the person's choices are respected	1.2.7.1 the person's choices are respected 1.2.7.2 where possible, the person's choices take priority over the organisational priorities	• the person's choices are respected • the staff are able to identify where there are gaps between their perception and what the

			person chooses, and are able to act upon it with the priority being on the person's choice
1.2.8	the staff use approaches that are open and inquisitive in determining appropriate supports	1.2.8.1 staff at the service pay attention to all of the ways that the person communicates with the aim of entering into a deeper understanding of the person's preferences for support	• staff at the service pay attention to all communication including verbal, non-verbal, behaviour, engagement, disengagement, coherence, non-coherence • staff at the service willingly use alternate communication methods and spend the time to elicit understanding of the person's preferences • the staff are able to spend the necessary time to get to know the person well • the staff use a variety of methods/strategies to get to know the person well (eg. planning cards, targeting language, visual cues, behaviour)
1.2.9	the service supports shared action through creative problem solving	1.2.9.1 the service supports shared action through creative problem solving	• staff at the service are willing and are encouraged to explore creative problem-solving processes • staff at the service are willing to 'think outside of the square' in their efforts to support the person

SubTheme 1.3: Knowing the person well

	Characteristics	*Service Expression*	*Service Examples*
1.3.1	the person is well-known by the staff at the service	1.3.1.1 staff at the service know the person well	• staff know the person's name • staff at the service address the person by their preferred name at all times • staff at the service do not refer to the person by diagnosis, behaviours, or other generalised labels or characteristics • staff at the service do not refer to person's by derogatory names or labels • staff at the service work in a way to build relationships with the person and get to know them
1.3.2	the person's family, friends and significant others are well known by the staff at the service	1.3.2.1 staff at the service know the person's family, friends and others who are important to the person	• staff at the service know the person's family, friends and others who are important to the person • staff at the service address the person's family, friends and others who are important to the person by name with acknowledgment of the relationship to the person
1.3.3	the person's individual characteristics are understood by the staff at the service	1.3.3.1 staff at the service understand the person's individual characteristics	• staff at the service understand the person's individual illness or disability presentation • staff at the service pay attention to the person's individual characteristics as a part of the service design and delivery process

1.3.4	staff have time to get to know a person well	1.3.4.1 staff are permitted to spend time getting to know the person well	• staff have time to get to know a person well • staff use conversation with the person and their significant others to deeply understand the person • staff utilise a depth and breadth of interpersonal communication strategies • staff are not reduced to only completing utilitarian tasks with or for the person
1.3.5	the person, their family and friends are able to share information regarding the person to develop a personal profile and vision for the future	1.3.5.1 the person's family members are encouraged and welcomed to share information about the person as a part of getting to know the person well 1.3.5.2 the person's friends are encouraged and welcomed to share information about the person as a part of getting to know the person well	• the person, their family and friends are able to share information to inform the service • documentation exists that uses information from friends, family and significant others in developing a personal profile and vision for the future and is informed by family and friends where appropriate • staff perceive family and friends as assets and central to decision making processes, including advocacy for the person

SubTheme 1.4: Self-Determination / Control

	Characteristics	*Service Expression*	*Service Examples*
1.4.1	the person is supported to self-determine as a fundamental human right	1.4.1.1 the person is supported to self-determine as a fundamental human right	• staff at the service work in ways that permit the person wherever possible to self-determine. this may include using different forms of augmentative communication; visual prompts or other forms of communication to facilitate choice

			• staff at the service use a variety of approaches and procedures to facilitate a person's self-determination
1.4.2	staff at the service deeply understand the complexities of self-determination	1.4.2.1 staff at the service deeply understand the complexities of self-determination	• staff at the service are well-trained in the complexities of self-determination • staff at the service provide opportunities for people to self-determine • staff at the service are able to respond appropriately around differing levels of risk in self-determination, eg. Every day choices vs life-altering decisions • there is evidence that staff are flexible and responsive to the person changing their mind
1.4.3	the person has power and control in their life	1.4.3.1 the person is able to control their environment to suit their preferences 1.4.3.2 the person is able to control their life experiences to suit their preferences 1.4.3.3 the person has the right to refuse	• the person's power and control over their environment is maximised by staff at the service • the person is able to adjust their physical environment • the person is able to decorate their physical environment to their tastes • the person has control over the temperature of their environment • the person has control over who enters their physical environment and when • the person is able to make choices and control their participation in anything that involves them; this may include everything from participation in community activities to attendance at medical appointments to having a haircut

SubTheme 1.5: Being respected

	Characteristics	*Service Expression*	*Service Examples*
1.5.1	the person is respected and valued as being unique and their dignity, rights and responsibility is promoted	1.5.1.1 the person is valued as being unique 1.5.1.2 the person's dignity is respected 1.5.1.3 the person's privacy is respected 1.5.1.4 the person's rights are respected	• staff at the service respect the person's privacy • staff at the service respect the person's confidentiality • staff at the service act with care towards the person
1.5.2	the service is founded on mutual respect between all people and facilitates partnerships with people and their families that are both respectful and reciprocal	1.5.2.1 staff at the service act in a manner that is nurturing, empowering and respectful to people	• staff at the service act in a manner that is nurturing, empowering and respectful to people • the service uses 'do not disturb' signs and pays attention to these

Theme 2: Being in relationship

Theme: The person is:

- ***acknowledged as a relational being and as being in relationship with other people;***
- ***supported to establish, develop and maintain relationships as a strong component of being person-centred, including, but not limited to, relationships between the person and their family and friends, the person and staff at the service, and the person and other informal or natural networks of people.***

SubTheme 2.1: Focus on establishing, developing and maintaining relationships

Characteristics	*Service Expressions*	*Service Examples*
2.1.1 the person is acknowledged and actively supported to establish, develop and maintain relationships with others	2.1.1.1 supports are provided that acknowledge the importance of relationships in the person's life 2.1.1.2 the person is supported to have personal connections with others	• staff provide support to the person to be in relationships with others • the person is supported to establish or maintain social relationships • the person is supported to be in relationship with others. this may include assistance to co-locate with others to enable a social connection for example, to provide physical support for people to share a meal, or to provide support to establish an internet connection to skype family or friends who live at a distance • the staff support the person to develop networks of both paid and unpaid supports in their lives • the staff work to develop support networks with the person that recognise the importance of being a part of society and not just having paid people providing support

			• the person is supported by people who want to be in their life, not just paid employees
2.1.2	staff at the service are aware and understand the importance of caring empathic relationships to quality of life, quality of care and quality of management	2.1.2.1 staff at the service are caring and empathetic towards the person 2.1.2.2 staff at the service are respectful of each other 2.1.2.3 staff and management at the service are respectful of each other	• staff show caring and empathy towards the person • staff, management and people who use the service are observed to interact with respect, care and compassion towards each other • staff at the service are able to have difficult conversations with people and tolerate discomfort in these
2.1.3	staff at the service support existing relationships and encourage the development of new relationships for the person	2.1.3.1 staff at the service work in ways that maintain the person's existing relationships 2.1.3.2 staff at the service work in ways that encourage the development of new relationships with the person	• staff allow visitors at times that suit the person • staff work in ways that support the person's rhythms of the year in that the person is encouraged to celebrate birthdays and other important events with family and friends • staff work in ways that support the person's rhythms of the day, week and month by encouraging connection with other people outside of the service in work and leisure • staff at the service act in ways to promote the establishment of new relationships for and with people • staff at the service have processes that involve the person and their family in activities that promote positive relationships • staff work in ways that promote unpaid relationships in the person's life, eg. Intergenerational groups, access to children, community comes into services • where chosen, the person is supported to be in relationship with other people with similar lived

			experiences, eg. Ghettos of Madness, drop-in centres, people come together out of choice • staff acknowledge pet ownership as a type of relationship • the person is supported to establish and maintain intimate relationships
2.1.4	the person's family are welcome, involved and engaged in the service	2.1.4.1. where it is the person's preference, the person's family are welcome, involved and engaged in the service	• the person's family are invited to events involving and concerning the person • the person's family are able to visit the person whenever they wish, without making an appointment • the person's family and friends are readily welcomed by staff if the person is in care
2.1.5	staff at the service acknowledge and encourage informal and natural relationships as a valuable component of the person's social network	2.1.5.1 staff at the service act in ways that facilitate natural, informal or unpaid relationships as a part of the person's wider social network	• the service has policies that facilitate natural, informal and unpaid relationships as a part of the person's wider social network • the service's existing policies and procedures do not act as a barrier to a person having a wider social network in place • the service works in a way that balances the presence of both paid and unpaid relationships in a person's life
2.1.6	the person's wider social network are included and mobilised	2.1.6.1 where a person has a wider social network, the person is supported to maintain relationships 2.1.6.2 where a person has a wider social network, the network is encouraged and mobilised to be included in the person's life	• staff at the service welcome members of the person's wider social network to be involved in the person's life (where chosen by the person) • the service's existing policies and procedures do not act as a barrier to a person connecting with their wider social network

		• there is evidence of critical reflection and self-awareness by staff as a means to encourage the mobilisation of a social network • the person is able to invite friends to their home and be supported to show hospitality (share meals, etc) • the person is encouraged to have inter-generational relationships (eg. In aged care, children are welcomed to visit)

SubTheme 2.2 Person-staff relationships

	Characteristics	*Service Expression*	*Service Examples*
2.2.1	the person and the staff at the service acknowledge the centrality of the professional relationship as a means of supporting engagement, advocacy, collaborative planning, and intervention	2.2.1.1 the person and the staff at the service are permitted to have strong caring relationships as a commitment to building a therapeutic alliance	• the person is able to establish a therapeutic relationship with staff at a service • the service has procedures and policies which respect people's relationships with caregivers, for example, staff are not rotated for administrative requirements only • staff work in ways that limit the negative effects of regulatory bodies • role boundary documents at the organisation acknowledge the humanness of relationships • the staff at the service work in ways that support connection and sharing
2.2.2	the person and staff at the service are supported to have positive interactions in relationships	2.2.2.1 staff at the service foster a genuine engagement and collaboration with the person	• the relationships between the person and staff are characterised by good rapport, trust and engagement
2.2.3	staff at the service encourage collaboration and partnerships between the person and others		

2.2.4	staff at the service have a sustained commitment to the person with a high degree of engagement and follow-up case management	2.2.4.1 staff at the service have a sustained commitment to the person with a high degree of engagement and follow-up case management	• Staff at the service have regular contact with the person and their family at a mutually determined frequency • Staff at the service follow through with commitments made to the person and their family • Staff at the service readily and independently initiate communication with the person and their family

Theme 3: Facilitating participation and engagement

Theme: The person's preferences to participate and be engaged in activities of their choice is:

- ***validated;***
- ***acknowledged as being important to health and well-being;***
- ***supported by processes and procedures that promote their involvement.***

SubTheme 3.1 Meaningful activity/occupation

	Characteristics	*Service Expressions*	*Service Examples*
3.1.1	the person's activities and occupations are individualised	3.1.1.1 the person has an individualised record of activities and occupation that they enjoy 3.1.1.2 the person has an individualised plan of activities and occupation that suits their likes and preferences 3.1.1.3 the person is supported to do the activities they enjoy and like 3.1.1.4 the person's history, health, needs, preferences, interests, routines and habits inform the type and level of support 3.1.1.5 the person's abilities, values and spirituality inform the type and level of support	• documentation exists that provides a record of the person's preferred activities and occupations • documentation exists that records the person's interests and likes • staff at the service refer to the documentation about the person's interests and likes and use this to inform the design, development and implementation of supports • staff at the service support people to do activities they like • people are not forced to fit into pre-determined activity programmes • staff at the service act to individualise the person's activities based on the person's preferences, interests and likes • staff at the service refer to the documentation about the person's abilities, values and spirituality to inform the design, development and implementation of supports

3.1.2	the person is supported to be engaged in activities that are meaningful to them	3.1.2.1 the person is supported to be engaged in meaningful activity	• the person is supported to engage in activities that have meaning to them and suit their interests • The person's support plan for participation and engagement is dynamic and easily altered when requested
3.1.3	the person is assisted to seek opportunities to engage in meaningful activity	3.1.3.1 the person is assisted to seek opportunities to engage in activities that they find meaningful 3.1.3.2 the person is supported to try new activities	• the person is supported to explore and pursue their interests, desires and goals • the person has the opportunity to try activities that interest them, and continue or cease those activities as they choose
3.1.4	the service acts to assist people to have something interesting to do during the day	3.1.4.1 staff at the service act to assist the person to have something interesting to do during the day	• staff at the service work to ensure that people have something to do during the day that is of interest to them • staff at the service work to avoid life-wasting for people

SubTheme 3.2 Participation

	Characteristics	*Service Expression*	*Service Examples*
3.2.1	the person's participation in a full life is encouraged	3.2.1.1 the service acts to encourage the person's participation in the full range of life activities	• the person is supported to participate in their community • the person is supported to participate in daily life activities and routines • the person is supported to participate in social activities and relationships • the person is supported to participate in education • the person is supported to participate in work and economic life • where required, the person is funded to participate and engage • the person is able to attend places and activities of their choice

Theme 4: Social inclusion

Theme: The person is supported as a valued community member in a way that is underpinned by the principles of rights, independence, choice and inclusion.

SubTheme 4.1 Social/community inclusion

	Characteristics	*Service Expression*	*Service Examples*
4.1.1	the person is supported as a valued community member	4.1.1.1 the person is supported as a valued community member	• the person is supported to participate in community life in the same manner as any other person; this may include examples such as, being able to work in typical employment; attend churches that match their spirituality; attend community events and activities; shop at typical stores; or join typical groups. • the person is supported to establish and maintain a community presence • the person is supported to share in everyday life • staff at the service act to build capacity to support the person in their community
4.1.2	the person is supported in a way that is underpinned by the principles of rights, independence, choice and inclusion	4.1.2.1 the person is supported in a way that is underpinned by the principles of rights, independence, choice and inclusion	• staff at the service prioritise typical life opportunities and experiences over specialised activities, groups and experiences; for example, the person is supported to participate in community life in a way that is typical for all other people rather than segregated or congregated services

4.1.3	staff at the service provide support to the person that promotes inclusion and inclusiveness	4.1.3.1 staff at the service provide support to the person that promotes inclusion and inclusiveness	• staff at the service provide support that acts to promote inclusion and inclusiveness; for example, on a visit to the local coffee shop, the staff facilitate support to the person that enables them to conduct their own order, rather than ordering on behalf of the person • the person is supported to access settings, services, supports and routines available in the community at large • the person is supported to contribute and belong

SubTheme 4.2 Being part of the social world

	Characteristics	***Service Expressions***	***Service Examples***
4.2.1	the person is supported to be in a social world	4.2.1.1 the person is supported to be a social world 4.2.1.2 the person is able to be with other people, where chosen	• the person is encouraged to participate in social activities • the person is supported to be with other people (if it matches their choices) • the environment is set up to support the establishment and maintenance of social relationships

Theme 5: Strengths / Capacity focussed

Theme: The person:

- ***is perceived in a positive and proactive manner focussing on strengths and abilities;***
- ***has unique capacities and contributions, not someone who needs to be fixed or managed; and***
- ***has competence that is acknowledged and assumed in the design and provision of services and supports.***

SubTheme 5.1 Strengths and capacities focussed

	Characteristics	*Service Expressions*	*Service Examples*
5.1.1	the person is assessed using strengths-based assessment strategies	5.1.1.1 the person's strengths and capacities are assessed as a component of a full and comprehensive assessment	• staff at the service identify capacity in the person rather than limitation only
5.1.2	the person's unique strengths are recognised	5.1.2.1 the person is supported to utilise their capacities and assets rather than limitations or deficiencies	• staff at the service work to determine a person's strengths and abilities and where those contributions make sense • the person is assumed to have gifts and contributions to make
5.1.3	the person is supported to retain their capacities by enhancing their remaining strengths	5.1.3.1 the person is supported to retain their capacities by enhancing their remaining strengths	• the service has procedures and policies in place that encourage the maintenance of a person's skills and abilities

SubTheme 5.2 Assuming people's competence and abilities

	Characteristics	*Service Expressions*	*Service Examples*
5.2.1	the person's competence is acknowledged and assumed in the provision of supports	5.2.1.1 the person is assumed to have competence irrespective of illness or disability	• the person is treated as understanding what is occurring in their environment without concern for their cognitive status • the person is treated as having capacity but requiring support, rather than being someone who is fully dependent on the support and without any capacity
5.2.2	the person is supported by focussing on what the person can do rather than the abilities that have been lost due to disease or disability	5.2.2.1 the person's abilities are used in the design and implementation of their supports	

SubTheme 5.3 Having high expectations

	Characteristics	*Service Expressions*	*Service Examples*
5.3.1	staff at the service have high expectations of the person's development and capabilities	5.3.1.1 staff at the service assume that the person can learn 5.3.1.2 staff at the service have positive expectations of the person's capabilities	• staff at the service have a commitment to positive outcomes for the person

SubTheme 5.4 Without concern for limitations/barriers

Characteristics		*Service Expressions*	*Service Examples*
5.4.1	the person is encouraged to express their desires without concern for limitations or barriers	5.4.1.1 staff at the service are open, curious and inquisitive in supporting people to express their desires without concern for limitation or barriers	• staff at the service act in ways that encourage people to explore the types of things that might be necessary from the service to best suit their requirements

Theme 6: Experiencing compassionate love

Theme: The person:

- ***has absolute value and is respected within a culture of life;***
- ***is acknowledged and treated as a human being with needs of comfort, empathy, hope, compassion, love, belonging and safety.***

SubTheme 6.1 Humanity

	Characteristics	*Service Expressions*	*Service Examples*
6.1.1	the person has absolute value and is worthy of respect	6.1.1.1 the person's humanity and everyday life are of primary and central importance 6.1.1.2 the person is of equal value to any other person	• the person has absolute value as being born human and can reasonably expect the same life conditions of any other person in the cultural context • the person can expect the same level of care and support as others • the person is respected within a culture of life
6.1.2	the person is related to as a human being	6.1.2.1 the person is related to a human being	• the person is treated as human • the person is related to as someone who is aware, has feelings, and insight into how they are treated
6.1.3	the person is acknowledged in the emotional aspects of human existence	6.1.3.1 the person's emotional needs are acknowledged and responded to	• the person is shown care, empathy and affection when distressed • the person is able to experience joy and happiness

6.1.4	**the person's well-being and maintenance is central**	**6.1.4.1 the person's well-being and maintenance of their well-being is of primary importance**	• **the person receives timely and responsive medical care** • **the person has a diet and an opportunity to exercise with a focus on well-being (if they so choose)** • **the person has access to low level medical 'maintenance' care** • **the person has access to specialist care when necessary**

SubTheme 6.2 Comfort

	Characteristics	***Service Expressions***	***Service Examples***
6.2.1	the person's needs for comfort are addressed	6.2.1.1 the person's psychological needs for physical and emotional comfort are addressed 6.2.1.2 the person has access to people, objects, items and activities that provide comfort	• staff at the service act in a manner that conveys comfort. for example, staff may touch the person on the arm or give a reassuring hug when the person shows distress • staff respond appropriately to signs of distress. for example, people's distress is not dismissed as 'difficult behaviour' or 'having no meaning' or being labelled as 'they always do that, don't worry about it' • the person has access to people, objects, items and activities that provide comfort. for example, the person may like to display photographs that provide comfort, or they may have a favourite rug or staff ensure that the person's family are called when the person shows distress

SubTheme 6.3 Empathy

	Characteristics	*Service Expressions*	*Service Examples*
6.3.1	the person is understood through empathy		
6.3.2	the person is considered with unconditional positive regard	6.3.2.1 the person is considered with unconditional positive regard	• the person is treated positively • the person is considered with unconditional positive regard; for example, the person is treated and understood positively at all times; diagnosis, behaviour, illness or disability have no impact on the perception of the person by others

SubTheme 6.4 Hope

	Characteristics	*Service Expressions*	*Service Examples*
6.4.1	the person experiences a sense of hope and purpose in life		
6.4.2	the person is supported in a way that emphasises well-being and hope		
6.4.3	the person has a sense that their future is positive		

SubTheme 6.5 Compassion

	Characteristics	*Service Expressions*	*Service Examples*
6.5.1	the person is responded to with compassion	6.5.1.1 the person has a compassionate understanding communicated to them by staff	
6.5.2	the person experiences compassion as a part of caring, empathy, and sensitivity to needs and values		
6.5.3	staff at the service develop compassion through having mutually respectful relationships with people		

SubTheme 6.6 Love

	Characteristics	*Service Expressions*	*Service Examples*
6.6.1	the person's need of being loved and recognised is met	6.6.1.1 the person's need of being loved and recognised is met	• the person is supported to connect with people who them regularly • the person is treated with affection
6.6.2	the person is supported to establish and maintain loving relationships	6.6.2.1 the person is supported to establish and maintain loving relationships	• the person is supported to establish and maintain loving relationships
6.6.3	the person is loved for who they are	6.6.3.1 the person is loved for who they are	• the person experiences agape or love in the non-sexual sense that is commensurate with being understood and valued

SubTheme 6.7 Belonging

	Characteristics	*Service Expressions*	*Service Examples*
6.7.1	the person experiences a sense of belonging	6.7.1.1 the person experiences a sense of belonging	• the person experiences a sense of belonging and feels included in the residential service
6.7.2	the person experiences a sense of togetherness with others	6.7.2.1 the person experiences a sense of togetherness	• the person experiences a sense of togetherness with others in the residential service

SubTheme 6.8 Safety

	Characteristics	*Service Expressions*	*Service Examples*
6.8.1	the person's safety is protected while maintaining the essence of the person	6.8.1.1 the person's safety is protected while maintaining the essence of the person	• staff at the service act in ways to keep the person safe while maintaining the essence of the person; for example, staff may implement least restrictive practices

Theme 7: Organisational characteristics

Theme: Person-centred organisations and services hold a strong holistic values-base underpinned by particular staff attributes, flexibility and responsiveness and continuity and consistency of support.

SubTheme 7.1 Values-based / holistic

	Characteristics	*Service Expressions*	*Service Examples*
7.1.1	the service has a value-base that respects and values the uniqueness of people and seeks to maintain and/or restore personhood		
7.1.2	the service values the person's subjective experience of illness or disability		
7.1.3	the service takes a values-based approach to thinking about, communicating with, assessing, and planning for, and supporting people		
7.1.4	the service values a holistic philosophy of care and support		
7.1.5	the person is treated as a 'whole person' and supports the consideration of the person's needs and preferences from a holistic perspective		

SubTheme 7.2 Staff attributes

	Characteristics	*Service Expressions*	*Service Examples*
7.2.1	staff at the service genuinely relate to the person	7.2.1.1 staff at the service have positive attitudes and care practices	• staff at the service are sensitized to the person's unique personality
7.2.2	staff at the service work to satisfy the wishes and needs of people	7.2.2.1 staff at the service work to primarily satisfy the wishes and needs of people rather than the system	• The service prioritises work to satisfy the wishes and needs of people • The service has systems in place that maximise the time and capacity of staff to provide direct support • The service works to reduce unnecessary paperwork and administrative requirements to maximise care and support for people • staff at the service are available and present for people rather than just focussing on tasks that need to be performed
7.2.3	staff at the service are sufficiently flexible to accommodate individual conditions	7.2.3.1 staff at the service are sufficiently flexible to accommodate the needs of individual people	• The service is staffed at ratios that can adapt to changes in individual needs quickly • Staff at the service are sufficiently flexible in managing their own workloads to accommodate individual conditions
7.2.4	management staff at the service model being person-centred with staff and provides leadership	7.2.4.1 management staff at the service models being person-centred with staff as well as people who require support 7.2.4.2 management staff at the service provides leadership in person-centredness	• Staff at the service are treated with the same principles of respect, autonomy, individuality etc as the people who use the service

7.2.5	staff at the service feel part of team that has a sense of pride, passion and togetherness	7.2.5.1 staff at the service feel part of a team that has a sense of pride, passion and togetherness	• The service has policies and procedures that foster a sense of pride, passion and togetherness. For example, when staff are valued and feel connected to a work environment, this may be evidenced in staff retention rates, a willingness to be flexible, a commitment to change processes for the greater good. There may be processes which support and facilitate service improvement such as time allocated to personal critical reflection, supervision, targeted staff development, a stable workforce.
7.2.6	staff at the service have excellent interpersonal skills and know themselves well	7.2.6.1 staff at the service have excellent interpersonal skills and know themselves well 7.2.6.2 staff at the service foster and grow feeling-based and instinctive care and support 7.2.6.3 staff at the service are well trained and engage in ongoing professional and personal development	• Staff at the service are supported to engage in critical reflection/reflexivity • Staff at the service demonstrate emotional literacy • Staff at the service are commended for excellent interpersonal skills • Staff at the service are supported in ongoing professional and personal development

7.2.7	staff at the service are empowered by staffing models	7.2.7.1 staff at the service are empowered by staffing models	• staff at the service are able to be flexible in their working conditions to primarily meet the needs of the person, and secondly meet their own personal requirements where there is not a disadvantage to the person being supported • staff at the service have continuity with people as a way to promote therapeutic relationships • staff at the service have energy, motivation, sufficient resources, training and reinforcement to be person-centred • staff at the service have job satisfaction • staff at the service are satisfied with their work conditions • staff at the service are able to initiate, become involved in, and take ownership of changes in practice to support being person-centred • staff at the service experience a culture that brings out the best in them and those receiving the service

SubTheme 7.3 Flexibility and responsiveness

	Characteristics	*Service Expressions*	*Service Examples*
7.3.1	in order to be responsive, the service is timely and flexible	7.3.1.1 the service is timely and flexible in order to be responsive to people	• the service uses flexible routines adopted to suit people's needs rather than staff needs • the service is responsive to the people
7.3.2	the service is flexible in its practices	7.3.2.1 the service has flexible practices 7.3.2.2 the service works to reduce bureaucracy and red tape to promote flexibility	• the service is able to easily adjust its supports for people if the person's needs change • the service has a minimal level of red tape and processes that allows supports to be flexible

SubTheme 7.4 Continuity and consistency of support

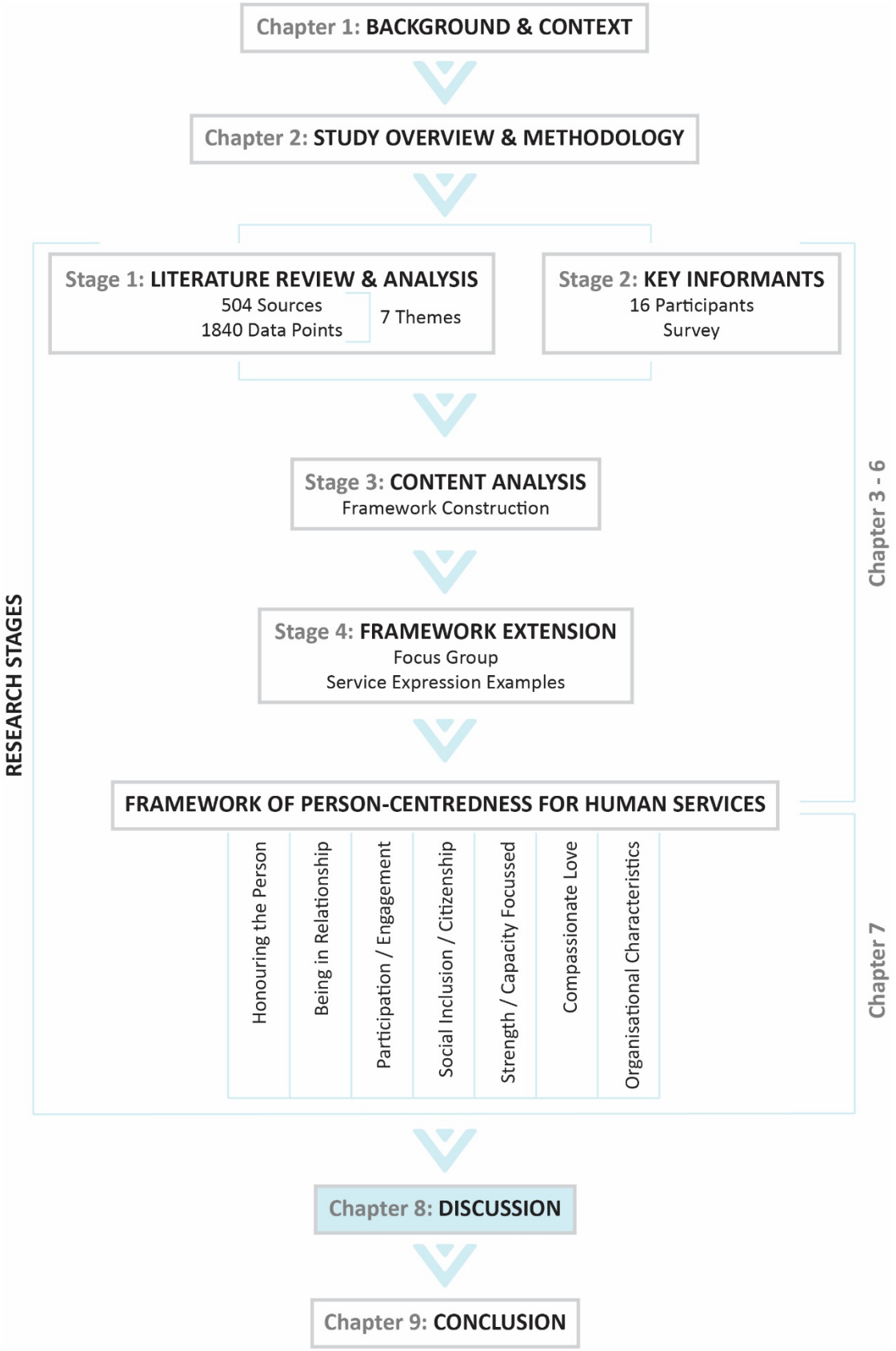
	Characteristics	*Service Expressions*	*Service Examples*
7.4.1	the person receives a continuity of service	7.4.1.1 staff at the service are assigned to the same people for continuity	• staff at the service have continuity with people as a way to promote therapeutic relationships

7.2 Conclusion

The FPCHS represents the outcomes of the four stages of data collection and analysis. The FPCHS describes person-centredness as it applies to the three human service areas of concern. These research processes have permitted interrogation of the problematisation[10] of person-centredness across policy and practice contexts and have revealed both commonalties and areas of continuing contestation. Some aspects were easily understood and translated into practice, whereas other aspects of the framework appeared to be understood yet were not readily translated to practice examples by participants. The discussion chapter that follows draws together and extends current conceptualisations about person-centredness in human services. The resulting conceptual model uses the findings from the process of creating the FPCHS to explain the representations of person-centredness as they apply to the various sectors of human services.

[10] To remind the reader, problematisations have been used in this sense to refer to the Foucauldian approach of questioning, analysing and classifying issues at specific times and under specific circumstances to understand how and why things become problems and how they are shaped as particular objects for thought (Deacon, 2000, cited in Bacchi (2012b). Policy, practice and history are all important in the understanding of the problematisation.

Chapter 8: Discussion



In this chapter, I draw together the results of the four research stages and the resulting FPCHS to explain the multifaceted concept of being person-centred in human services. Firstly, I begin by summarising the research stages. Secondly, I introduce a conceptual model to underpin the explanation of the problem representations (Bacchi, 2009, 2012a; Bacchi & Goodwin, 2016) of person-centredness. The conceptual model offers a way of understanding the inter-related aspects of the FPCHS, including those that have previously been either unexplored or had limited exploration, by framing person-centredness as both a 'means' and an 'end'. Finally, I reflect upon the implications of these problem representations for practice across human services.

8.1 Summary of the study

This study was completed in four stages. Stage one utilised an adapted scoping review methodology to review the literature on person-centredness across three human service areas. This stage interrogated how person-centredness is constructed in the academic literature and policy artefacts (policy documents, legislation, and government reports) across human services. A subsequent thematic analysis identified seven themes of person-centredness with several sub-themes and characteristics.

Stage two investigated the representation of person-centredness from the perspective of key informants using a survey methodology. A replication of the thematic analysis conducted in stage one, using stage two data, further confirmed several aspects of the original themes and identified a new sub-theme of staff behaviours, highlighting a previous unclear aspect of person-centredness specifically focused on the front-line worker.

Stage three involved a comprehensive modified content analysis using the data sets and thematic structure obtained in the first two stages. This iterative process led to the development of the draft FPCHS consisting of the seven themes, constituent characteristics and associated service expressions.

In the final stage of the study, stage four, a focus group of purposively selected front-line workers (including managers, practitioners and academics) were approached to confirm and extend service examples of person-centredness and test the usefulness of the framework in describing the practice. The results from this stage highlighted the complexity of person-centredness at the front-line where discretion and application are influenced by historical context, the sector of application, personal values of the worker, and the market of operation.

8.2 Conceptualising person-centredness: Understanding multiple problem representations

In this section, I present a conceptual model of person-centredness for human services to discuss and explain the results of the research. According to Berman (2013), conceptual frameworks can assist in supporting the definition of the research problem, in establishing the theoretical coherence (articulating and drawing together multiple theoretical perspectives and providing a basis for theorising generated by the study), supporting the practical aspects of the study and framing the conceptual and practical conclusions of the study (Berman, 2013).

Figure 1: Conceptual model of person-centredness

This conceptual model was constructed to assist in explaining the implications of this research study into person-centredness (Figure 1). As evidenced by the thesis to date, the process of developing this conceptualisation of person-centredness across human services has been comprehensive. The post-structural WPR approach (Bacchi, 2009; Bacchi & Goodwin, 2016) required the researcher to pay attention to not only the obvious representations of the problem but to also consider the less obvious histories underpinning the expression of the phenomenon in practice, and in the service expressions at the level of the front-line worker. This revealed several influences on how person-centredness is both constructed, understood and implemented which warrant discussion. These multiple

representations conflate our understandings of the concept yet most can be defined as having utility as a 'means' or as an 'end' of being person-centred.

8.2.1 History of person-centredness: Understanding person-centredness from the viewpoint of multiple histories and siloed concept development

During the stages of data analysis, the history of the concept in each individual sector became increasingly significant in understanding the variations in person-centredness. Investigating the historical origins that lie behind the everyday use of concepts as associated discourses can give us a glimpse of a past conceptual world (Goehring, 2013) and can assist us in constructing knowledge that informs the current state. Whilst there is much continuing debate about the concept of person-centredness, there is a consensus amongst writers, researchers and practitioners that the historical intention of the approach is to minimise the impact of dehumanising or depersonalising practices on vulnerable people (Entwistle & Watt, 2013). It can be concluded that being person-centred is varyingly experienced by people depending on the importance placed upon preventing these practices on the front-line.

Person-centredness has been described in human service delivery and literature since the early 1990s, yet variations of the theme exist in multiple human service areas since the 1960s, and in the case of the mental health area, since the 1940s in Rogerian psychotherapy. While this research only included literature which explicitly used the term 'person-centred', and excluded other associated literature such as 'patient-centred' and 'client-centred', there is without a doubt overlap with these concepts at both policy and practice levels. There are specific histories and developments in each of the human service contexts studied yet they all share a history of resistance to the medical model which gained momentum in the 1970s (Lupton, 1997). Despite there being similarities in conceptual understandings across human services, practical implementation of the concepts is tied to siloed histories of service user liberation which differed across the three contexts.

8.2.1.1 History of person-centredness in ageing

Person-centredness in ageing (figure 2) is perhaps the most well-known application of the concept in human service delivery and seems largely related to nursing care as a process. Kitwood (1997) introduced person-centred care as a way of thinking and working with people with dementia and introduced the idea that the social circumstances of the person with dementia had an impact on the experiences of the symptoms of the disease. By acknowledging and working with a person's history, likes, dislikes, preferences and strengths,

it was considered possible to keep personhood intact, despite a progressive disease which altered the person's identity. Personhood was defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood and the failure to do so, have consequences that are empirically testable" (Kitwood, 1997, p. 8).

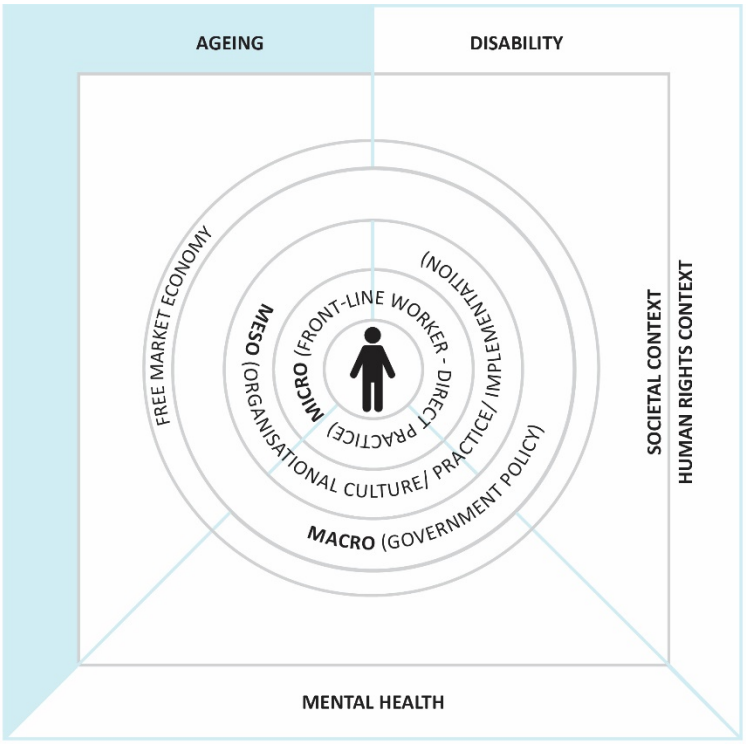


Figure 2: History of person-centredness in ageing

Kitwood (1997) further elaborated that staff behaviours and practices in the care environment could influence people's negative experiences of dementia. Malignant social psychology referred to a set of practices in the care environment that are deeply damaging to personhood and could undermine physical well-being (Kitwood, 1997). The recognition of these practices in the 'old culture of care' led to an understanding that they contributed to deeply depersonalising ways of working with people and fundamentally undermined personhood. At their core, they were considered to have the potential to be disabling and actively disempower vulnerable people. Examples of these disempowering and depersonalising ways of working included treachery (including forms of deception to distract or manipulate for compliance), infantilisation (treating a person patronisingly as a young child), intimidation (inducing fear in a person, through the use of threats or physical power), and objectification (treating the person as a lump of dead matter, without reference to the fact that they are sentient beings) (Kitwood, 1997, pp. 46-47). Person-centred care, therefore,

was seen as a 'means' of promoting personhood and extinguishing disempowerment and depersonalisation. As it was conceptualised in this context, person centredness represents a 'means' to attempt to control both the care relationship and the resulting impact ('ends') of care on personhood.

Kitwood attributes the work of Carl Rogers and his person-centred therapy used in humanistic psychology in the United States in the 1950s as laying the historical foundation for contemporary person-centred practice approaches. The key elements of this approach that Kitwood translated for use in person-centred dementia care were empathy, unconditional positive regard, and congruence on behalf of the therapist or carer towards the person (Kitwood, 1997; Rogers, 1957). Brooker (2004) and others have built significantly upon Kitwood's work focussing on the practical care of people with dementia. Approaches utilising the VIPS (Valuing, Individualised, Perspective, Social) framework are considered to be gold standard in dementia care (Brooker, 2007), and the subsequently developed Dementia Care Mapping attempts to operationalise and quantitatively measure the impact of staff practices on the person with dementia's behaviour (Brooker & Surr, 2006). Concurrently, a concept analysis of person-centredness contextualised the use of the term to older people. Slater (2006) identified that the literature interchanged terms of 'patient' and 'client' with 'person' in defining care, and this suggested an ongoing relationship with medical treatment and interventions. Interestingly, Slater (2006) did not discuss how person-centredness as a broader concept was applied in any other fields of practice and the interchangeable terms were not perceived to be problematic.

The results of this research identify the problem representation of person-centredness in ageing, and primarily dementia care, as being concerned with the maintenance of personhood. The development of person-centredness in ageing has been driven by a concern about the loss of personhood. Specifically, it reinforces the idea that the progression of dementia symptomatology can be slowed by including *practices of care* aimed specifically at opposing malignant social psychology. In this research project, service expression examples provided in both the literature and the focus group supported the principles of person-centred care as introduced by Kitwood (1997), and further developed by Brooker (2007), emphasising communication and relationships.

8.2.1.2 History of person-centredness in disability

Person-centredness in disability (figure 3) owes its history to a community of practice that aimed to operationalise aspects of social role valorisation (SRV) and normalisation

(Wolfensberger, 1983) at a period in time when deinstitutionalisation was occurring (O'Brien & O'Brien, 2000). Wolfensberger (1969, cited in O'Brien & O'Brien, 2000) specifically considered how society viewed people with disability, the structure of services and supports to people, the role of professionals in providing those supports, and most importantly, the impact on the lives of people who rely on services. Wolfensberger's work in SRV became a response to what he termed the typical negative life experiences of "people who are devalued by others, and especially by major sectors of their society" (Wolfensberger, 2000, p. 105). It is no surprise perhaps, that there are significant similarities between Wolfensberger's 'typical negative life experiences of devalued people' and Kitwood's (1997) malignant social psychology.

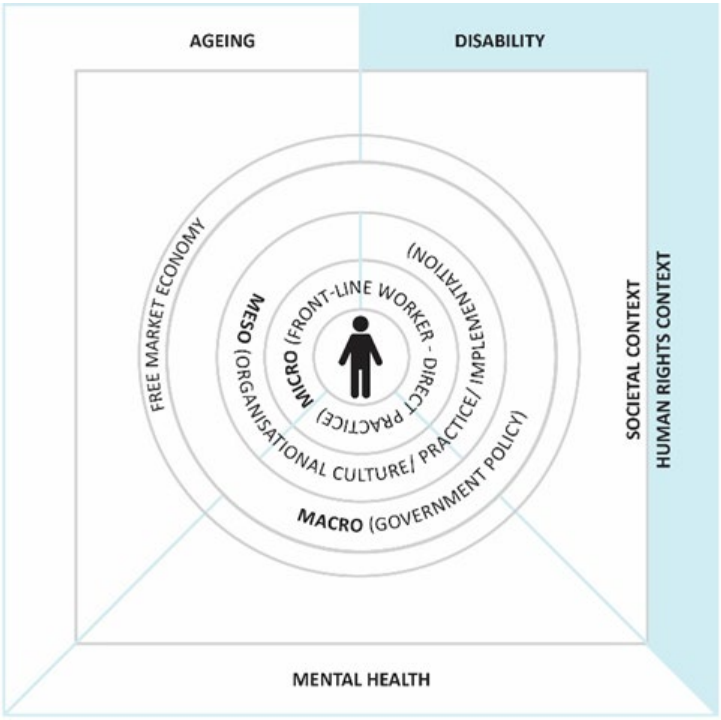


Figure 3: History of person-centredness in disability

Wolfensberger (2000) built his SRV schema on social role theory suggesting that devalued people would be less likely to be treated badly or have bad things happened to them if they held socially valued roles. In this sense, the responsibility does not rest on the front-line worker to be person-centred, but rather to adjust the external environment and the social roles of the devalued person, to make it less likely that the devalued person will be treated badly. Given that Wolfensberger himself did not have a disability, this approach could

in today's terms be considered a form of ableism[11]. It follows the traditions of functionalism with its strong emphasis on normative social roles and locates the problem of disability internally, and the solution, externally (Merton, 1949).

Many approaches in the communities of practice developing and implementing variations of person-centred planning were ultimately concerned with improving the lives of people with disability by "emphasising personhood, citizenship and developmental potential" (O'Brien & O'Brien, 2000, p.5). While 'personhood' is not defined in the disability literature (as far as I could find), the conceptual understanding appears similar to that used in Kitwood's work on dementia. This work in person-centred planning occurred at the same time as legal cases were mounted to resist institutions. People with disability were acknowledged as a segregated and disadvantaged minority and the push commenced for the development of comprehensive services in local communities. O'Brien and O'Brien (2000) describe the impact of the work of research-practitioners like Marc Gold, Lou Brown, and Tom Bellamy who 'demonstrated that people with severe disabilities were habitually, reflexively, and profoundly underestimated by almost all professionals who assessed their capacity to learn and to work" (p.7).

Over several years, social activism from both people with disabilities and their supporters gave momentum to the development of ways of working which became collectively known as person-centred planning. There are two key differences in the emergence of person-centredness in disability when compared with ageing: the focus was on demanding and acquiring personhood not the loss of personhood; and the reforms were driven by activists with disability and their supporters, not professionals and researchers as were the drivers in ageing. O'Brien and O'Brien (2000) state that the work in the disability area flowed from a common agenda including "themes of increasing choice, avoiding de-personalizing labels and difference-making procedures, honouring the voices of the person and those who know the person best, building relationships, individualizing supports based on high expectations for the person's development, and demanding that agencies adopt new forms of service and organization" (p.14). Social activism and a push against dehumanising practices and debunking of medical paternalism (Lupton, 1997) combined to give momentum to person-centred planning as a means of helping people with disability access better lives. In

[11] Ableism: "a network of beliefs, processes and practices that reduces a particular kind of self and body (the corporeal standard) that is projected as perfect, species-typical and therefore essential and fully human. Disability…is cast as a diminished state of being human" (Campbell, 2001, p. 44).

this sense, person-centred planning became a set of techniques to enable humanising practices with the aim of the person being treated positively. In this way, for people with disability, advocating for practices of person centredness was a 'means' to an 'end'.

Many authors have described elements of the planning approach focusing on the practical aspects of listening to the person, sharing power (between the person with disability and the professional therapist, care worker or otherwise), being concerned with citizenship and facilitating practical action (O'Brien & Pearpoint, 2002; O'Brien, Pearpoint and Kahn, 2010; Thompson, Kilbane & Sanderson, 2007). These pragmatic approaches have been grounded in action that resulted in the deinstitutionalisation of a group of people who had traditionally been marginalised and segregated into care settings. These processes were subject to many of the common difficulties associated with the implementation of person-centredness, where a virtual 'toolbox' of techniques were perceived as a way of practising without an appreciation of the implications of context (O'Brien & O'Brien, 2000).

Therefore, the policy problem representation in disability is that block funded, group-provided, congregated and segregated approaches to supporting people with disability do not best meet people's needs. The problem solution of person-centredness in disability, therefore, could be framed as a series of strategies aimed at ameliorating the effects of congregation and segregation (including where people could be subject to neglect or abuse (Blatt & Kaplan, 1966; Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004)). These have included multiple techniques known as person-centred planning and thinking which focus on individualisation and personalisation (Thompson et al., 2007). In Australia, the most recent change in social policy in disability (via the National Disability Insurance Scheme) is prioritising the *individualisation* of services and the *individualising* of subjects of the welfare state within a broader marketization agenda (Meagher & Goodwin, 2015a). While individualisation is perceived as desirable in the disability rights movement, and meaningful choice is an important policy goal (as a means of expressing and maintaining identity, dignity and autonomy (Meagher & Goodwin, 2015a)), this does not necessarily account for how personhood may be maintained, nor address how the person experiences the relationship with the front-line worker as the face of an organisation.

8.2.1.3 History of person-centredness in mental health

Person-centredness in mental health also developed from a siloed perspective (figure 4). The impact of social activism and the rise of the consumer led movement in the mental health sector had a significant impact on how people with mental health issues are

conceptualised, problematized and treated (Onken, Craig, Ridgway, Ralph, & Cook, 2007; Ralph, 2000; Schmoike, Amering, & Svettini, 2016). The reframing of mental illness to the notion that mental health and well-being exists on a spectrum and the contemporary principles of mental health recovery which do not assume the complete absence of mental ill health have challenged the previous medicalisation of mental health care (Amering & Schmoike, 2009; Onken et al., 2007). Historically, mental illness has been perceived as something undesirable even when some aspects of being mentally unwell fall on a neuro-typical spectrum. The stigma and negative connotations of mental ill health have typically resulted in medical responses seeking to ameliorate symptomatology through the use of medication. The reframing of psychiatric disability as something that is able to be recovered from (based on the testimonies of people with lived experiences) has been largely ignored by a mental health system focussed on a deficiency orientation and where the diagnosis is destiny (Ridgway, 1999, cited in Onken et al. (2007)). Concurrent with the continuing critique of the medicalisation agenda which started in the 1970s, mental health is now more successfully being represented as a state of well-being attainable through person-centred elements of recovery and as a result of interactions with family, friends and/or mental health professionals (Onken et al., 2007), allowing people to move beyond the role of patient (Amering & Schmoike, 2009).

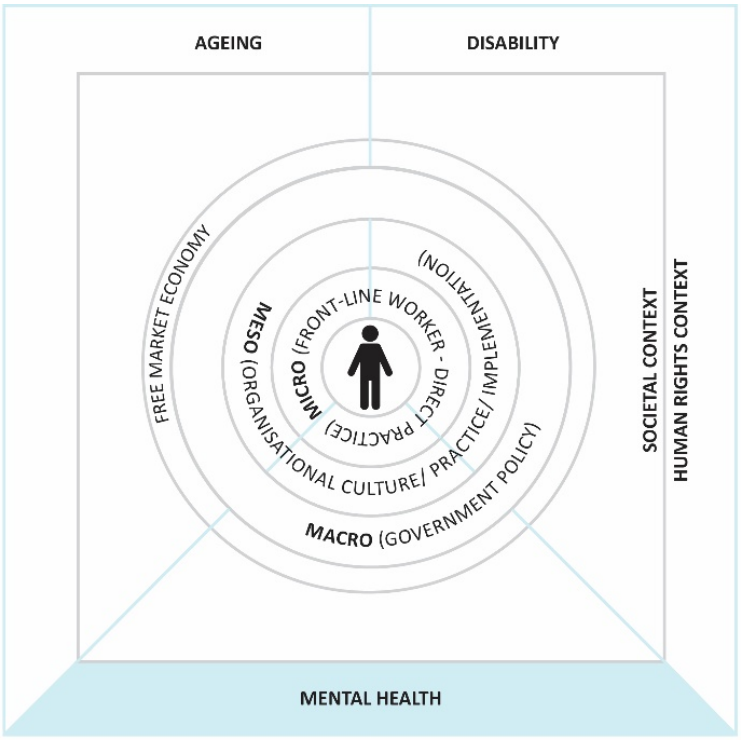


Figure 4: History of person-centredness in mental health

The representation of psychiatric disability and mental ill health as a solely medical problem no longer holds true, and as a result, a raft of processes, treatments, and ways of working with people have been identified as being central to the recovery agenda. Person-centred elements of recovery challenge the othering practices of medicalisation associated with the dominant discourses of the deviant 'other' which have traditionally objectified, subjugated, stigmatised and oppressed people (Foucault, 1980; Onken et al., 2007). It is premised on a shift in service user role from passive client to active participant (Mancini, 2011). Service examples provided by front-line workers are consistent with this, and at many levels, represent one aspect of support (within a holistic approach that includes medical responses). As with disability and ageing, the approaches labelled as being person-centred act at their fundamental level to prevent and mitigate dehumanising and marginalising practices (Amering & Schmoike, 2009).

These conceptual histories not only reconstruct how the siloed development of the concepts came together, they also justify and enable different claims and historical processes (Goehring, 2013). To follow Goehring (2013), "…taken together, the histories of all concepts also elicit temporal patterns of historical development that otherwise remain hidden if one simply describes features of successive events. By retracing the historical trajectories of concepts, (this) can not only tell us the history of different interpretations of historical realities, they also reconstruct the representations of historical reality that are contained within concepts themselves" (p.433).

8.2.2 Preventing dehumanising ways of working: Understanding person-centredness as a response to dehumanisation (human rights)

The results of this research suggest that person-centredness has been constructed as a response to dehumanising practices historically used with people in the three human service areas. "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood" (United Nations, 1948). The experiences of persons who are ageing, have a disability or mental health issue have not always been, and in many cases still aren't, consistent with this declaration.

Prior to this research, the different interpretations of being person-centred across human services were already obvious. In fact, the concept appeared not only contested but in

conflict, because the histories appeared disparate and disconnected from each other. Additionally, there appeared to be few common threads in the service expressions. In contrast, the review of the historical contexts in this chapter points to commonalties. While the concept has developed separately across human services, each silo of development has fundamentally grown from the same intent to reduce dehumanising approaches and practices with people who are vulnerable, marginalised and otherwise reliant on services to live their lives. People with disabilities, people who are ageing and people with mental health issues have now perhaps repositioned themselves as valuable and valued members of society entitled to rights and resources (Keith & Keith, 2013).

The first three stages of the research show that there are significant areas of overlap and similarity in the construction of the concept. It would seem that the development of a common understanding has been impeded largely by the siloed history of concept development and the expression of the concept at the front line service level. Person-centredness has developed in silos in each of the human services as a part of a liberatory resistance of the medicalisation agenda and against broader societal devaluation, but the practice examples appear different in each area because of its history, how personhood and citizenship was constructed within the three identified categories and who took part in the resistance. To refer to the conceptual model, the impact of the siloed histories experienced by the person can be understood through a human rights context (figure 5).

The extent to which people have been othered and devalued speaks directly to the definition of who is considered a ‘person’, and therefore, for whom ‘person-centredness’ applies. While there is much conflict between authors in moral philosophy about who constitutes a ‘person’ (Beauchamp, 1999; Singer, 2010) and whether persons with cognitive disability or dementia are moral agents, in broader Western society it is reasonable to contend that these persons are still social and evaluative beings and are therefore rightly able to demand to be treated with dignity and respect (Sayer, 2011). From this perspective, our commonalities as persons are more important than our differences (Sayer, 2011). The expectation of treatment with dignity and respect is not only related to autonomy “but with exercising the kinds of powers we associate with flourishing human beings” (Sayer, 2011, p. 199).

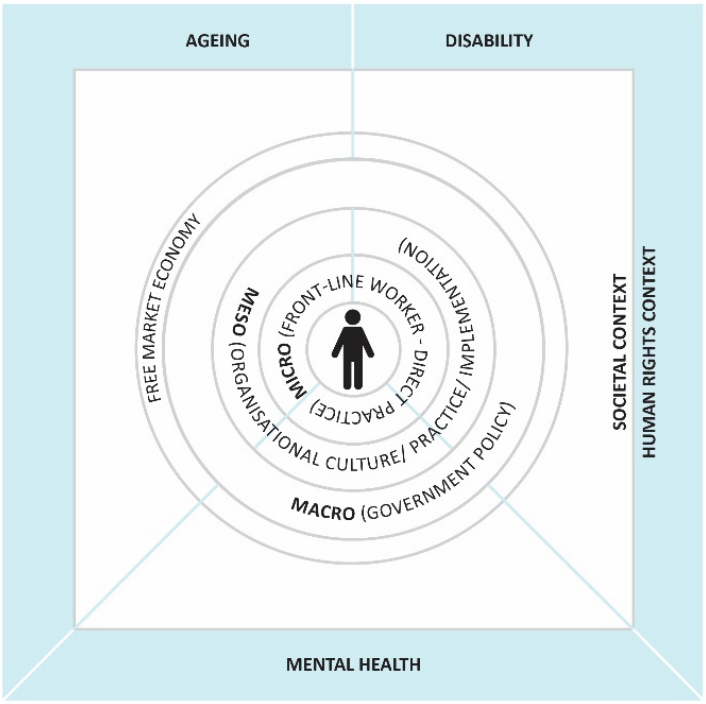


Figure 5: History of person-centredness filtered by a human rights context

There is evidence in each human service history that person-centredness is an effort to qualify the relationship between the person and the front-line worker. In fact, the importance of this relationship "highlights the deeply evaluative character of the human experience, and its relation to human vulnerability" (Sayer, 2011, p. 1). To follow the writing of Martin Buber (Wodehouse, 1945), practices aimed at reducing dehumanisation are inherently focussed on encouraging the front-line worker to interact with the person as '*I-Thou'* rather than '*I-It'*, that is, with dignity and respect in a manner that upholds personhood. This is consistent with Kitwood's (1997) practices aimed at reducing the likelihood of being treated like a lump of dead matter, or Wolfensberger's (2000) life wasting and death making.

8.2.3 User identities: Understanding person-centredness from the perspective of being made a subject

It is acknowledged throughout the findings of this research that person-centredness has been an important shift across various human service sectors to emphasise a focus on people's right to be treated respectfully and not objectified. However, this thesis points to the importance of recognising that a service user identity ought not to be totalising, as their service user identity is only acquired/imposed once they access services or are subject to human service intervention.

The term 'user identity' both locates and complicates the parameters within which people are treated (Ewert, 2016). Ewert (2016, p. 161) contends that each facet of the user identity "gains or loses relevance depending on the health care contexts, health statuses, personal values and the design of the service arrangements". Equally, the user identity of 'person with disability', 'person with dementia' or 'person with mental health issue' fits within this premise. Ewert (2016) identifies aspects of integrated health care which are consistent with similar aspects of quality identified in this research, such as being people-centred and responsive to service users. Mechanisms for achieving these ideals include considering users' perspectives, providing opportunities to increase self-management, respecting self-determination, maintaining ongoing patient-provider communication, and taking into account cultural and personal values (Ewert, 2016). Ewert's argument highlights how a limited and unidimensional representation of a person as a patient, or client, or consumer, can become 'front and centre' potentially erasing the other multiple identities an individual possesses when they are not in receipt of services, thus obscuring the identity of 'person'.

Laden's (2001) practical identity can assist in clarifying this understanding. Laden (2001) contends that practical identities have both a personal and a social aspect. The personal side of identity includes those aspects that "are particular... things that serve to differentiate and thus individualize us" (Laden, 2001, p. 88). Watts and Hodgson (2019) use an example of being a spouse of someone, or a child of a specific person, as situating us in relation to another and therefore in a reciprocal relationship. Reciprocal relationships can have a public and private aspect, and it is suggested that it is in the private aspect where social workers engage, relate and communicate with the person with reciprocity (Watts & Hodgson, 2019). The social aspect of the practical identity, according to Laden (2001), "is better thought of as arising from membership in various and sundry socially salient groups: being of a particular gender or race or religious group or profession" (p.88). Watts and Hodgson (2019, p. 163) contend that this aspect of identity is non-reciprocal and "indicates where we stand in relation to each other in *salient* social structures or groups." This representation of social identity is, in some ways, a short-hand for understanding how and where people are located and how they should be treated. It is familiar in the context of this research as membership in our human service groups of interest have historically resulted in marginalisation or oppression. Social workers, among other professions, are privy to the consequences of stigma, discrimination and violence that such group membership effects (Watts & Hodgson, 2019).

One potential way of thinking about person-centredness is to position it in relation to the personal aspect of Laden's (2001) practical identity. Person-centredness informs the quality of the reciprocal relationship between the person and the front-line worker. By taking this approach, the personal aspect of the practical identity becomes the space where the experience of person-centredness is located (Laden, 2001). To follow this, the person holds a fundamental position as a relational being which affords them unalienable rights. The other user identities are constructed relevant to the social aspect of practical identity; they infer membership of particular human service groups. And this is not to say that such group membership is negative, but rather that group membership on its own should not be the only determinant of how someone is treated. Therefore, the user identities of subject-patient (in a health care setting), or subject-client (in a community health care service), are nuanced and have relevance to the service setting but should be considered in relation to the personal aspect of the person's practical identity (Laden, 2001). On the journey to person-centredness, the person has to first be made a subject of intervention and is perceived as then having user identity as well as bringing their the other 'social group characteristics' into the interaction with the practitioner, just as the practitioner brings their professional identity, professional values and social context into the encounter. Therefore person-centred practice is not something that is applied in the same way by the practitioner in every encounter as all of these contexts mediate the encounter.

User identities that are relevant to context (for example, patient or client) prioritise certain areas of importance. For example, as a patient admitted to an emergency department fighting for life after a stroke, the immediate concern should be for life-saving intervention, not whether that intervention will help achieve social inclusion, as one of the lesser thematic headings identified in this research. Either way, the patient should be able to expect that they are treated with respect and dignity as a human *'Thou'* rather than a non-human *'It'* (Wodehouse, 1945), and that attention should be paid to the 'things that matter' to each person (Sayer, 2011). When the terms 'patient-centred' and 'client centred' are used in literature and practice, writers appear to be privileging the aspects which relate to the personal aspect of Laden's (2001) practical identity and result in outcomes which are evaluated by the person as being dignified and respectful. It also suggests that there are similarities between human service areas where dialogue and practice at the levels of 'honouring the person' and 'being in relationship' are most easily understood as being concerned with maintaining/developing or preserving personhood.

8.2.4 Cultural relevance: Understanding person-centredness as a Western socio-cultural construction

Based on the historical review provided in this thesis and consistent with Leplege et al. (2007), person-centredness as a socio-cultural construction firmly has its roots located in the Westernised social democratic traditions such as in the United Kingdom, North America and Australia. This construction of person-centredness locates the individual as having priority in social policies when viewed through a human rights lens and underpins Western health care policy positions and strategic developments (Bing-Jonsson, Slater, McCormack, & Fagerström, 2018). "The individual is a person with rights to autonomy and participation in their personal, social and political worlds, and choice is one means through which each person can enact self-determination" (Meagher & Goodwin, 2015a, p. 19). Other cultures, particularly socialist and communitarian cultures, do not place the same level of importance on individualisation, and therefore person-centredness has not evolved in those countries. Person-centred approaches to counselling, for example, have been considered largely inappropriate for use in non-Western contexts due to the collectivist and hierarchical nature of these societies (Hett, 2014). This is evident in the source documents reviewed for this research being 'western-centric'.

8.2.5 Person-centredness at the macro level: Understanding person-centredness as a policy construction

The conceptual model of person-centredness locates government policy as being subject to human rights and the Western societal context while being heavily constrained by the free market economy (figure 6). The policy construction of person-centredness is complex across human service areas, yet becomes increasingly complicated where the concept interfaces with the marketization agenda of broader conservative governments in neoliberal capitalist societies. The administration and implementation of person-centredness have become increasingly located within a market logic of choice and control and occurs in the shadow of political neoliberalism[12] in Western cultures (Davidson, 2015) which has led to a strong focus on marketization. Within this policy environment, the promotion of the economy and markets is central. There can then be slippage in the ideology whereby person-centredness and the promotion of choice become collapsed into consumerism in the market.

[12] Neoliberalism: "a theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong property rights, free markets, and free trade." (Harvey, 2005, p. 2)

Such a shift erases the focus on personhood and citizenship associated with the development of person-centredness.

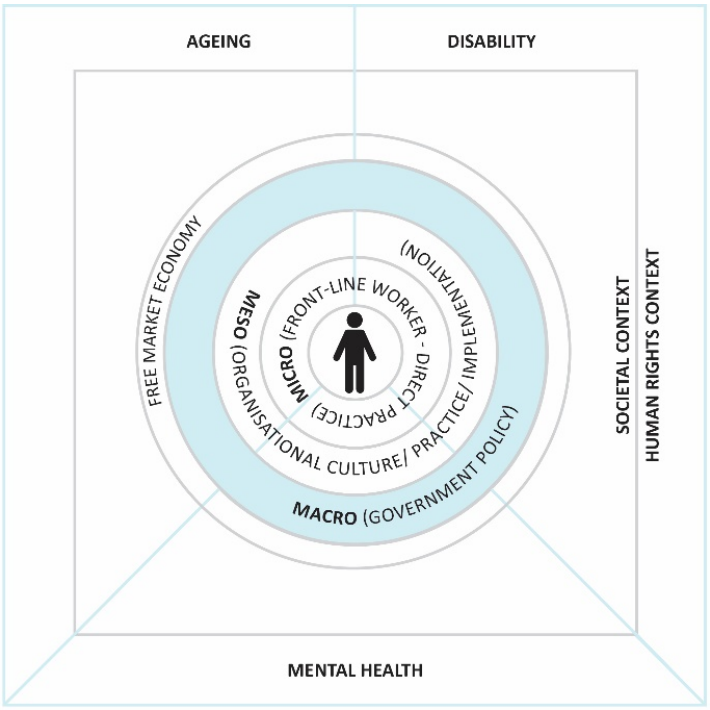


Figure 6: Person-centredness at the policy level (macro)

Across the human service areas of concern in this research, government policy has been reformed to 'place the person at the centre' resulting in initiatives such as 'My Aged Care' (a platform for applying for and managing supports and funding), 'My Health Record' (a centralised individual digital health record), and 'My Gov' (a centralised digital access point for government services). In these and other circumstances in government policy, the individual is assumed to be agentic and in a position to navigate and interact with management systems.

In Australian aged care policy, person-centredness and the personalisation of supports are further underpinned by the struggle of the aged care system to meet the demand for residential care or diversify sufficiently enough to meet the expectations of ageing Australians to tailor their own care (Carney, 2015). Following the Productivity Commission's (2011) proposed package of reforms, a number of these were partially adopted by the Australian Government to progress the "personalisation of support through a more consumer-directed, person-centred residential aged care system offering greater choice" (Carney, 2015). Additionally, the development of the National Disability Insurance Scheme (Commonwealth of Australia, 2013) focusses on the delivery of services and supports to

people with disability where choice and control are paramount in the 'how' of how this is attained. Choice is a very powerful concept in a free market economy, individual choice is a means of meeting wants (driving market competition). Aggregated individual choice, via market competition, is a means of distributing resources, theoretically enhancing quality and improving efficiency (Meagher & Goodwin, 2015a). To this end, it is understandable that person-centredness is reduced to technologies of consumer-directed and/or self-managed budgets, or choice of organisation to provide services or supports from a pre-determined set of options. The implementation of both of these options makes no reference to the quality of those choices – there is a choice, that is certain, but the contents of the choices are largely obscured from the policy construction. In this way, the commercialisation of choice in organisations self-defining as providing person-centred services does little to confirm the extent to which Nussbaum's (2011) capabilities are addressed.

Neoliberalism has had significant impacts on the type of providers who have both stayed or entered the markets in service delivery. In Australia, the biggest providers of services and supports in the human services areas of concern for this research, are non-profit organisations or organisations with a religious or charity background. There is some suggestion that the imperative of profit-making and therefore practices which result in economic efficiencies and the best use of available resources, may be incompatible with services of high quality and responsiveness (Davidson, 2015). In many ways, the capacity of social policy to respond to the requirements of addressing the conditions for citizenship and human dignity is unknown. There is not much concern for the contents of what happens in the choice and control, just that it occurs (Meagher & Goodwin, 2015a). If the Capabilities Approach is concerned with the individual experience and the conditions to create the opportunities or freedoms to realise individual capability, the marketization of person-centred human services does not address these conditions (Meagher & Goodwin, 2015a; Nussbaum, 2011). In this sense, the contents of human service delivery are only considered at a systems-level, based on the assumption that the sum of individual choices drives choice, competition and quality in markets (Meagher & Goodwin, 2015a). This speaks to the dangers in 'commodification of care' where personal values are replaced by procedures of care as a product to be traded in the market (Davidson, 2015).

8.2.6 Person-centredness at the meso level: Understanding person-centredness as organisational design and culture

The conceptual model of person-centredness locates organisational design, culture and procedures between the policy level and the front-line (figure7). Organisations hold the

responsibility and the imperative to translate social policy to front-line practice. Whilst fundamental organisational values drive service delivery, the interpretation of government social policy is strongly linked to the reporting of outcomes measures such as key performance indicators (KPIs), and demonstrating value for money. The content of the outcomes can be strongly influenced by organisational culture. For example, non-profit organisations with histories of charity or religious affiliation often deliver services in a manner which is reflective of their histories of service. However, in a market economy and consistent with Meagher and Goodwin (2015a), there is little attention paid outwards to the contents of social policy measures, other than the measures of numbers of people supported, the average cost of support packages, etc.

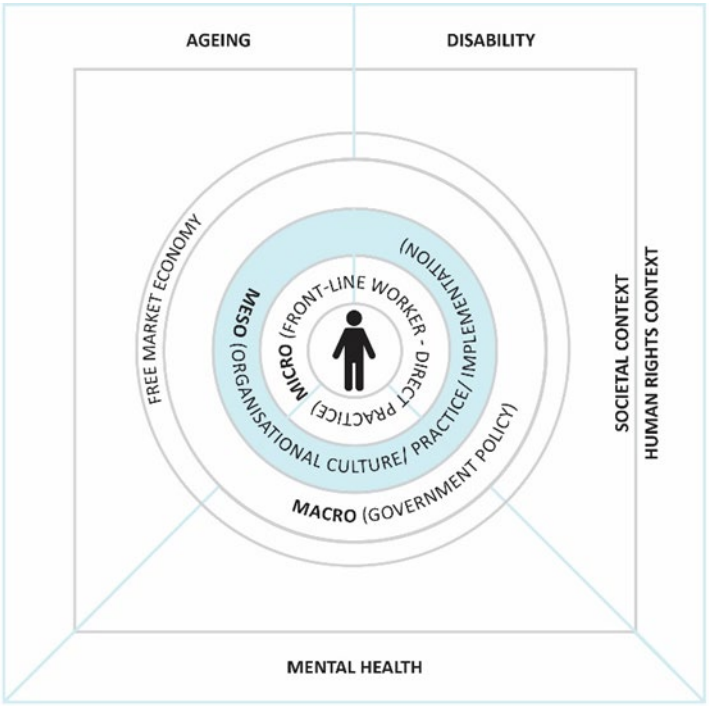


Figure 7: Person-centredness as organisational culture and practice (meso)

Within organisations, however, the 'what' of the choices and the 'how' of the implementation becomes increasingly important, the closer one gets to the end service user or 'person at the centre'. Depending upon the organisational culture and values, person-centredness is interpreted as either 'means' (via 'planning', 'therapy', 'budgets') or as 'ends' (as a state of interacting at the front-line). This second way of conceptualising person-centredness as an 'ends' respects the freedoms and opportunities that Nussbaum (2011) prioritises in the Capabilities Approach. In this way, organisations and their constituent workers become responsible for creating the conditions for the capabilities to be effected, or

from Sayer's (2011) point of view, the conditions for human flourishing. The extent to which this is achieved remains aspirational and elusive within the government constructed market agenda operationalised in neoliberalism. Front-line workers become agents of the State in being responsible for enacting social policy.

8.2.7 Person-centredness at the micro level: Understanding the concept as front-line practice

Finally, this model conceptualises person-centredness at the micro level as a relationship between the person and the front-line worker. Both the conceptual model and the FPCHS offer a perspective of the concept as a front-line practice where the multiple policies, practices and procedures are implemented. At this level, person-centredness is about the service expressions of the FPCHS. There is evidence in the FPCHS to suggest that person-centredness is both a means and ends for human services. As a means, person-centred approaches offer sequences of 'steps', 'processes' or 'tools' that should support being person-centred. However, the use of these is not, in themselves, the solution to the ends of being person-centred. What has become evident is that the experience of being person-centred can only be described and defined by the person who is deemed the one 'at the centre' of the human service. This experience remains a first person evaluation of the services and the supports and the impact of these on how one is treated. "When social science disregards this concern, as if it were merely an incidental, subjective accompaniment to what happens, it can produce an alienated and alienating view of social life" (Sayer, 2011, p. 2). This raises a fundamental difficulty in that there is rarely agreement on the picture of reality from the perspective of the person and the front-line worker (Lipsky, 2010), yet it highlights the "deeply evaluative character of human experiences, and its relation to human vulnerability" (Sayer, 2011, p. 1). The interpretation of this phenomenon is a result of the interaction between the front-line worker and the person at the centre.

As a result, it is not surprising that person-centredness is described in less detail in the themes defined as 'experiencing compassionate love' and 'being strengths/capacity focused'. There is also less complexity in the section that highlights staff behaviours, suggesting that there is an intangible quality in the delivery of what it means to be person-centred at the front-line. Both Lipsky (2010) and Evans (2011) agree that discretion at the front-line occurs in a context of conflict generated by the operationalisation of policy and front-line resistance to it. Not only does the front-line worker becomes responsible for enacting policy via organisational practice and procedure but their determination of how that happens is subject to personal and professional values. In the delivery of non-material policy outcomes, such as

'care', 'therapy', or 'assessment', the nature of these outcomes can only be seen fleetingly, if at all, at the policy level.

Figure 8: Person-centredness as front-line practice (micro)

Symonds, Miles, Steel, Porter, and Williams (2019) identify tension in implementing person-centredness for front-line workers. Using the example of social work assessment, they identified a tendency by managers to draw an equivalence between the process of assessment and person-centredness, that is, a good assessment and being person-centred are one and the same thing (Symonds et al., 2019). Once again, the concept of being person-centred is confused and conflated by the multiple interpretations at the policy, organisational and front-line levels. The fact that managers can draw the conclusion that a good assessment (that includes getting to know someone), and enacting the statutory agency requirements on behalf of the policy constructions are equivalent, ensures that person-centredness will continue to be misunderstood. "The influence of the institutional process in this…account placed constraints on the extent to which the assessment could be 'person-centred' throughout as required in the statutory guidance, producing a tension between the pursuit of person-centred practice in their assessments and the practical accomplishment of them within a statutory context" (Symonds et al., 2019, p. 9).

8.3 Implications for policy and practice

Given the multiple assumptions, definitions and representations of person-centredness across human services and between policy and front-line practice, this thesis demonstrates that the concept is highly contested across multiple sites that include policy, practice, sector/field of practice and academic literature. Therefore, it is not surprising that the service expressions and examples in front-line practice are also contested and in some cases in conflict with each other across contexts. The results of this research suggest that person-centredness can be described as a practice, a process and a policy. In the final section of this chapter, I position person-centredness as a concept in these three contexts.

8.3.1 Person-centredness as *practice*

In this thesis, person-centredness describes a value position underpinning practice that promotes the importance of the qualitative experience of human services from the perspective of the person. In practice, being person-centred focuses on the person's experience of their interaction with the front-line worker and is consistent with 'honouring the person' and 'being in relationship' with others. It is aimed at creating the conditions for human flourishing in the presence of experiences which can also have the potential to cause human suffering. In human service delivery, person-centredness as a *practice* is concerned with creating the conditions for human flourishing for people who have traditionally been positioned on the margins of moral personhood by virtue of their health, illness or disability status in the case of topics reviewed in this thesis. These conditions are most commonly understood across human services, are widely articulated, and can be broadly described by front-line workers in terms of what it looks like in day to day service delivery. This style of practice is most readily recognisable by the person because it is evaluated by the person as being respectful and dignified (Sayer, 2011). This representation of person-centredness is expressed when responses to the person are evaluated *by the person* as being highly personal, respectful and dignified. The success of the concept at this level is subject to the front-line worker discretion in the context of organisational culture, professional and personal values. This representation of person-centredness is mostly hidden from the other applications of person-centredness. These expressions of person-centredness at the level of individual interaction are mostly obscured from other levels of organisations and governments. It is life-giving and concerned with reducing the negative impact on, and the dehumanisation and suffering of, vulnerable people who are ageing, disabled or mentally unwell.

8.3.2 Person-centredness as *process*

Person-centredness as a *process* broadly uses the descriptor 'person-centred' as a way of 'doing' with people who have been positioned on the margins of moral personhood by virtue of their health, illness or disability status. This descriptor encompasses approaches or methods including 'care', 'therapy', 'counselling', 'assessment', etc. Person-centredness as a process is defined by the service or organisation, and includes ways of working that attempt to address the priorities of the person at the centre but are strongly mediated by the organisational contexts as existing literature and evidence from this research reveal. These strategies are the service expressions and examples employed by organisations to facilitate the outcomes evaluated by the person as being respectful and dignified, and aimed at promoting human flourishing and reducing suffering. They are experienced and interpreted by the person, and they are often implemented and mediated by front-line workers in rationed and under-resourced environments (Meagher & Goodwin, 2015b). At their best, they facilitate the central capabilities required for functioning (Nussbaum, 2011), and respect the person as a social being. At their worst, they are unrecognisable in comparison to any other human service. It is this meaning of person-centredness that authors confuse with ideas such as 'treating patients as persons'. The hope for organisations is that they will result in ways of working that are holistic and are expansionist rather than reductionist to a medical condition or illness. It is the component of patient centredness or client centredness that they are attempting to connect with in their service delivery models.

Person-centredness as a *process* addresses the multiple uses of the term as a descriptor of services identified in stage one of this research. The implementation of the processes is subject to organisational procedures and practices and front-line discretion. The *how* of the implementation can be influenced by training and the use of processes and techniques but the *experience* of the implementation, that is, how person-centred it was, remains subject to evaluation by the person in receipt of services/care/therapy.

Person-centred ways of working occur mostly in private, front-line, obscured settings. An example may prove useful in establishing this delineation. Consider the case of a visiting home care worker tasked with showering an older adult in their home following major hip surgery. Organisations employ people who have various levels of training and experience to perform this task. Organisations typically utilise what is perceived as quality safeguarding procedures ensure that the front-line worker is suitable to do the job and these may include evidence of a police clearance, maybe professional or work-related references, and consideration of training and /or employment history. The home care worker arrives at the

person's home and assists them to undertake the intimate task of showering and personal care. One might expect in this scenario that the performance of the task is respectful, conducted to a level of personal hygiene considered appropriate by the person, and that there is some appropriate care taken in the administration of the task like drying between the person's toes and under the armpits, etc. The experience of determining whether or not the task was completed in a person-centred manner lies with the person requiring the service, not with the front-line worker. Organisational procedures may demand that the front-line worker address the person using their name as a process of demonstrating person-centredness, yet the person may evaluate the tone that the worker used as being disrespectful or offensive, and therefore not person-centred. The quality of the interaction, the extent to which the front-line worker as a representative of the person-centred organisation is 'honouring the person', can only be determined by the person.

8.3.3 Person-centredness as *policy*

Person-centredness as a *policy* may be the most highly contested conceptualisation. Through top-down policy implementation, person-centredness as a policy construction aims to assert particular values and priorities to impact upon both organisational culture and front-line practice. This intention and logic make a number of assumptions. The first of these assumptions is that practice change can be directed and driven from the top-down, that is, the policy can direct and determine front-line practice (Lipsky, 2010). The second assumption is that the existing good or even best practice can be supported or directed from the top. The intent is that policy can bring about organisational change, and/or compliance from the manager down to the front line worker. In a number of settings, this is certainly possible, where there are material outcomes, such as payments (that is, in deciding who gets an income support payment for example) or in the case of immunisations (in that children must be immunised before attending school). In these cases, there is a product which can be provided or withheld, and these can also be at the discretion of the front-line worker.

Yet in the case of person-centredness, the policy intent is to attempt to direct both the organisation and the front-line worker to provide support in a certain way that reflects a particular set of values about how humans ought to be treated. The means of attempting to influence organisational culture and practice is somewhat flawed. In fact, the attempt to influence and systematise person-centredness through policy is paradoxical. Person-centredness is a non-material policy output; a way of being and doing and relating. It cannot be given and taken away like a welfare payment. The evidence in this research demonstrates that person-centredness is a desirable output but it cannot be forced into action via a policy

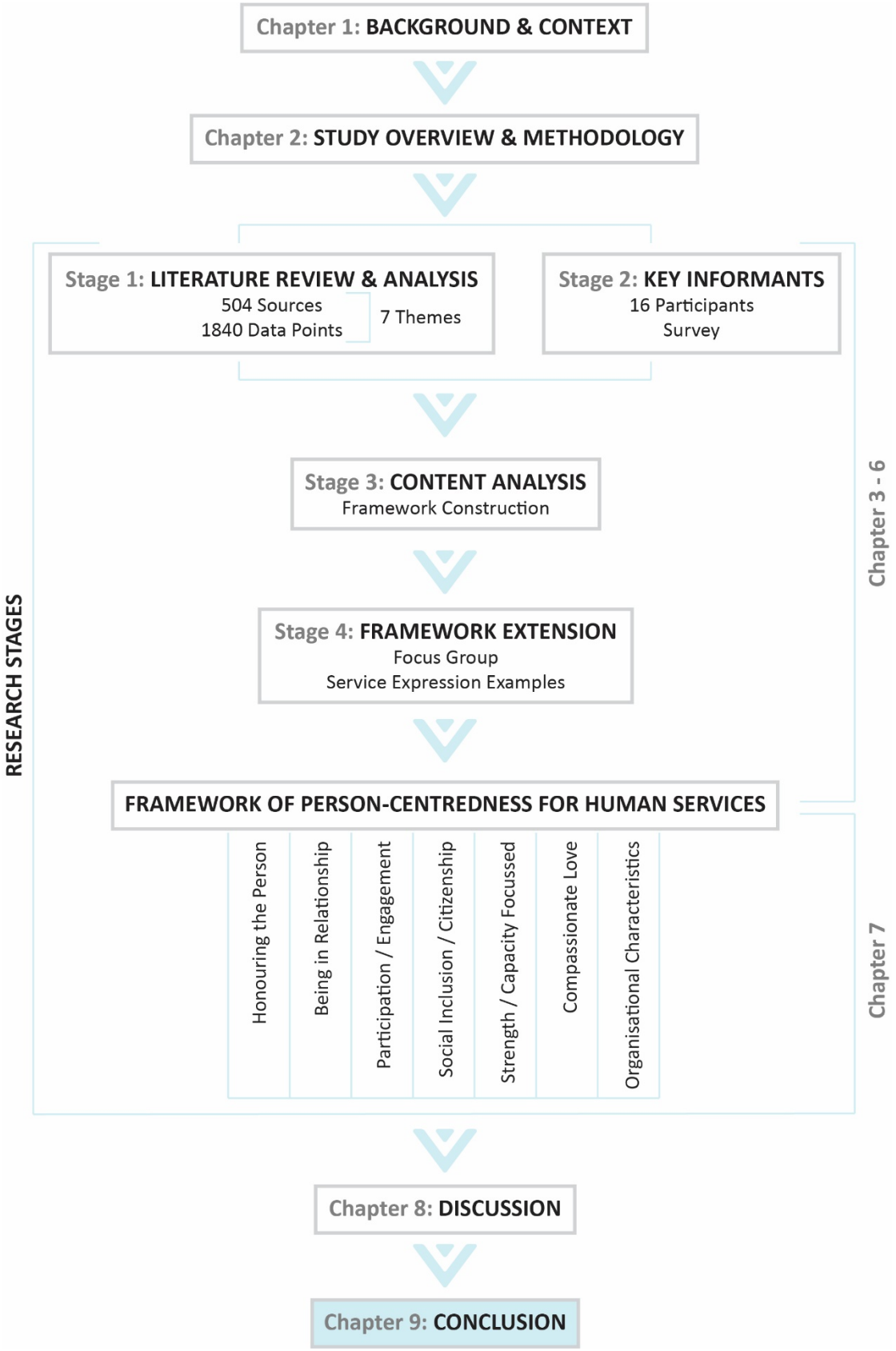
construction. Despite Lipsky's (2010) claim that front-line workers create policy via street-level discretion, the experience of person-centredness cannot be directed into existence by the government or even organisations, because it is a person's evaluation of the experience.

Person-centredness in policy is an attempt by governments to enforce the conditions, which are evaluated by the person in the context of front-line practice as being dignified and respectful, to policy constructions. The characteristics that are recognisable at the front line are not able to be automatically extrapolated to the policy level. They are aspirational rather than prescriptive, subject to competing policy demands, and impacted upon by the unique and competing siloed histories and multiple discretions of front-line workers. As a result, the descriptions of person-centredness as they appear in policy documents are consistent with being a magic concept (Pollitt & Hupe, 2011). At their best, they are translated to mean choice and control for the person in a neoliberal market, but even in this situation, the types of choices and the extent of control and autonomy are contested and co-exist with multiple other social policy pressures and demands. Person-centredness as a policy is influenced by social, political and economic agendas and as such is watered down in multiple constricted settings. The problem representation of person-centredness is evaluated as being positive in front-line practice whilst being largely obscured at this level and still highly contested.

8.4 Conclusion

In this chapter, I have discussed the results of the research and the FPCHS by using a conceptual model of person-centredness, and in doing so, have explained the multiple problem representations of person-centredness across human services and between levels of application, while highlighting the significance of the sector histories. I have concluded the chapter by identifying the implications for policy and practice. The next chapter concludes the thesis and articulates the unique contributions of this research to knowledge. I finalise the thesis with some final recommendations for further research.

Chapter 9: Conclusion



I finalise the thesis by articulating the outcomes of the research, significant contributions to knowledge, and recommendations for future research.

9.1 Outcomes of the research

Being person-centred is concerned with creating conditions that permit human flourishing in response to multiple histories of human suffering. Across human services, person-centredness is most commonly understood and translated into practice as 'honouring the person' and 'being in relationship' with others. The concept is underpinned by assumptions about persons that acknowledge our commonalities rather than our differences for the purposes of exclusion. These are constituted from a starting point of recognition of the dignity of persons and attempting to privilege the things that matter to them.

Being person-centred requires a willingness of behalf of the front-line workers to use discretion to facilitate the capabilities or conditions through which functionings can be realised (Nussbaum, 2011). While the most commonly understood aspects of the concept are easily translated into service expressions and examples, the more elusive aspects relate to contested ideas around the conditions for human flourishing that might be considered 'nice to have' but not essential for human services (eg. Being capacity-focussed, or concerned with social inclusion). These more elusive aspects could be considered as equally necessary for human flourishing as the more recognisable aspects of being person-centred. They are also the aspects that are more susceptible to the discretion of the front-line worker and are concerned with the quality of the interaction between two people. It is here that person-centredness is variously obscured, contested, and difficult to direct through rules and procedures.

9.2 Unique contributions of this research to new knowledge

This research makes unique contributions to new knowledge in four ways. Firstly, the methodology used in this thesis is an important contribution to new knowledge because of the iterations between policy, literature and practitioner perspectives about person-centredness. The findings from this methodology highlight areas of consensus but also demonstrate the contentions in the concept. The consensus in the findings lies mostly in the areas of respecting people as human beings and of being in relationship with others. The iterative research approach used a comprehensive content analysis which showed that the understanding of the content varied according to the author's background and the sector's

historical context. This was affirmed with the focus groups and the key informants who represented the three areas of concern.

Secondly, this thesis offers a multi-level deconstruction of the concept of person-centredness by using a post-structuralist approach. Data collected through the research stages were analysed and compared to deeply explore and understand the concept. In comparing both policy and the academic literature about person-centredness, it was commonly not defined to a degree that would easily be operationalised at the level of either the organisation or front-line practice. In contrast, evidence from practitioners suggested that their understanding of person-centredness was largely concerned with how individual practitioners/ front-line workers treat and respond to people using a service. Across all four sets of data analysis, it was evident that person-centredness was assumed to be an inherently positive way of working. This is consistent with the normative attractiveness and global marketability of Pollitt and Hupe's (2011) magic concepts.

Thirdly, an outcome of the process was the construction of the Framework of Person-Centredness for Human Services (FPCHS) which identified seven themes, multiple sub-themes, characteristics and service expressions. The framework accounts for the available evidence about person-centredness in policy and academic literature and reflects practitioners' viewpoints on service expression. The FPCHS offers a starting point for the development of evidence about person-centredness as a practice.

Lastly, the research process allowed for a reconstruction of person-centredness to explain the aspects of commonality and contestation of the concept. The resultant conceptual model draws attention to the philosophical foundations and underpinnings of the concept and the contrasting ways in which it has developed and been implemented across human service sectors. It explains the importance of the siloed histories confounding the common usage of the term.

9.3 Recommendations for future research

This thesis provides a foundation for future research investigating the ethnography of being the person in person-centred services and approaches. Research which investigates the largely hidden interaction between the person and the front-line worker would add an interesting dimension to future narratives informing policy constructions. In order to use the FPCHS to develop, assess and evaluate person-centred practice in human services, it would be valuable to test the framework in organisations at the policy, organisational culture and service delivery levels with a strong focus on engaging with the person's lived experience of

using services. The FPCHS may also have utility in being developed into a guidance and training tool for organisations to address person-centred practice.

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Appendices

Appendix A: Ethics approvals

A1 Curtin University HREC Approval (PhD)

MEMORANDUM

Curtin University

To:	A/Prof Angus Buchanan School of Occupational Therapy and Social Work
CC:	Ms Rebecca Waters
From	Professor Peter O'Leary, Chair HREC
Subject	Ethics approval Approval number: HR147/2015
Date	05-Aug-15

Office of Research and Development
Human Research Ethics Office

TELEPHONE 9266 2784
FACSIMILE 9266 3793
EMAIL hrec@curtin.edu.au

Thank you for your application submitted to the Human Research Ethics Office for the project: 5230
Evidence-based evaluation of person-centredness across the disability, ageing and mental health sectors

Your application has been approved by the Human Research Ethics Committee at Curtin University at their meeting on 4/08/2015

The Committee commends the research team on the quality of this application.
Please note the following conditions of approval:

1. Approval is granted for a period of four years from **06-Aug-15** to **06-Aug-19**
2. Research must be conducted as stated in the approved protocol.
3. Any amendments to the approved protocol must be approved by the Ethics Office.
4. An annual progress report must be submitted to the Ethics Office annually, on the anniversary of approval.
5. All adverse events must be reported to the Ethics Office.
6. A completion report must be submitted to the Ethics Office on completion of the project.
7. Data must be stored in accordance with WAUSDA and Curtin University policy.
8. The Ethics Office may conduct a randomly identified audit of a proportion of research projects approved by the HREC.

Should you have any queries about the consideration of your project please contact the Ethics Support Officer for your faculty, or the Ethics Office at hrec@curtin.edu.au or on 9266 2784. All human research ethics forms and guidelines are available on the ethics website.

Yours sincerely

Professor Peter O'Leary
Chair, Human Research Ethics Committee

A2 Curtin University HREC Ethics Amendment (PhD)

Curtin University

Office of Research and Development

GPO Box U1987
Perth Western Australia 6845

Telephone +61 8 9266 7863
Facsimile +61 8 9266 3793
Web research.curtin.edu.au

11-Nov-2016

Name: Angus Buchanan
Department/School: School of Occupational Therapy and Social Work
Email: A.Buchanan@curtin.edu.au

Dear Angus Buchanan

RE: Amendment approval
Approval number: HR147/2015

Thank you for submitting an amendment request to the Human Research Ethics Office for the project **Evidence-based evaluation of person-centredness across the disability, ageing and mental health sectors.**

Your amendment request has been reviewed and the review outcome is: **Approved**

The amendment approval number is HR147/2015-08 approved on 11-Nov-2016.

The following amendments were approved:

We will be conducting a three-hour focus group on person-centredness.

The focus group participants (up to 15 people) will include key informants in the are of person centredness form the Perth area. Their data will help shape and confirm the final framework on person centredness. The key informants are all people who work in disability services or family members. All have the capacity to individually consent to participating in the focus group They will be asked questions about what being person-centred looks like in the practice setting.

Any special conditions noted in the original approval letter still apply.

Standard conditions of approval

1. Research must be conducted according to the approved proposal
2. Report in a timely manner anything that might warrant review of ethical approval of the project including:
   - proposed changes to the approved proposal or conduct of the study
   - unanticipated problems that might affect continued ethical acceptability of the project
   - major deviations from the approved proposal and/or regulatory guidelines
   - serious adverse events
3. Amendments to the proposal must be approved by the Human Research Ethics Office before they are implemented (except where an amendment is undertaken to eliminate an immediate risk to participants)
4. An annual progress report must be submitted to the Human Research Ethics Office on or before the anniversary of approval and a completion

report submitted on completion of the project
5. Personnel working on this project must be adequately qualified by education, training and experience for their role, or supervised
6. Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, that bears on this project
7. Changes to personnel working on this project must be reported to the Human Research Ethics Office
8. Data and primary materials must be retained and stored in accordance with the Western Australian University Sector Disposal Authority (WAUSDA) and the Curtin University Research Data and Primary Materials policy
9. Where practicable, results of the research should be made available to the research participants in a timely and clear manner
10. Unless prohibited by contractual obligations, results of the research should be disseminated in a manner that will allow public scrutiny; the Human Research Ethics Office must be informed of any constraints on publication
11. Ethics approval is dependent upon ongoing compliance of the research with the Australian Code for the Responsible Conduct of Research, the National Statement on Ethical Conduct in Human Research, applicable legal requirements, and with Curtin University policies, procedures and governance requirements
12. The Human Research Ethics Office may conduct audits on a portion of approved projects.

Should you have any queries regarding consideration of your project, please contact the Ethics Support Officer for your faculty or the Ethics Office at hrec@curtin.edu.au or on 9266 2784.

Yours sincerely

Professor Peter O'Leary
Chair, Human Research Ethics Committee

A3 Curtin University Initial HREC Approval (MPhil)

This ethics approval document is included because the original survey data was collected under this approval number prior to the candidacy being converted from Master of Philosophy to Doctor of Philosophy in 2014.

Curtin University

Memorandum

To	Professor Errol Cocks Ms Rebecca Waters
From	Teena Bowman
Subject	Protocol Approval **OTSW-12-2011**
Date	12 September 2011

Office of Research and Development

Human Research Ethics Committee

Telephone 9266 2784
Facsimile 9266 3793
Email hrec@curtin.edu.au

Thank you for your "Application for Approval of Research with Low Risk (Ethical Requirements)" for the project titled **'A DESCRIPTIVE FRAMEWORK OF PERSON-CENTREDNESS PRINCIPLES AND ATTRIBUTES IN HUMAN SERVICES FOR THREE VULNERABLE GROUPS'** On behalf of the Human Research Ethics Committee, I am authorised to inform you that the project is approved.

Approval of this project is for a period of twelve months **9 September 2011** to **9 September 2012**.

The approval number for your project is **OTSW-12-2011**. *Please quote this number in any future correspondence*. If at any time during the twelve months changes/amendments occur, or if a serious or unexpected adverse event occurs, please advise me immediately.

TBowman

Teena Bowman
Research Centre Administrator
School of Occupational Therapy and Social Work
Telephone: 9266 4651
Email: t.bowman@curtin.edu.au

Please Note: The following standard statement must be included in the information sheet to participants:
This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number OTSW-12-2011). If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or hrec@curtin.edu.au

CRICOS Provider Code 00301J

Appendix B: Literature search & thematic analysis appendices

B1 Sample search strategy

1. person cent*/
2. person-cent*/
3. ageing/
4. aging/
5. dementia/
6. disability/
7. mental retardation/
8. mental health/
9. mental illness/
10. 1 and 3 or 4 or 5 or 6 or 7 or 8 or 9
11. 2 and 3 or 4 or 5 or 6 or 7 or 8 or 9
12. “person cent*” (title only) AND “ageing” OR “aging” OR “dementia” OR “disability” OR “mental retardation” OR “mental health” OR “mental illness” OR “psychiatry” (title, abstract, full text, all fields)
13. limit 12 to (English language and yr=”1995-current”)

B2 Search results for included literature in Stage 1

Database	Search Terms (post 1995 and English only)	Results
CINAHL	person cen* (title) AND disability (all fields)	27
ProQuest	person cen* (title) AND disability (all fields)	257
PsychInfo	person cen* (title) AND disability (all fields) AND journal	76
CINAHL	person cen*(title) AND mental health (all fields)	38
ProQuest	person cen* (title) AND mental health (all fields)	212
PsychInfo	person cen* (title) AND mental health (all fields) AND journal	192
CINAHL	person cen* (title) AND dementia (all fields)	133
ProQuest	person cen* (title) AND dementia (all fields)	85
PsychInfo	person cen* (title) AND dementia (all fields) AND journal	210
CINAHL	person cen* (title) AND mental retardation (all fields)	45
ProQuest	person cen* (title) AND mental retardation (all fields)	63
PsychInfo	person cen* (title) AND mental retardation (all fields) AND journal	87
CINAHL	person cen* (title) AND ageing (all fields)	3
ProQuest	person cen* (title) AND ageing (all fields)	118
PsychInfo	Person cen* (title) AND ageing (all fields) AND journal	48
	TOTAL NUMBER OF SOURCED ARTICLES	1594

B3 Sample data extraction sheet

Source number	#63
Data set 1 (Author & date)	Dilley, L., & Geboy, L. (2010).
Article title	Staff perspectives of person-centred care in practice
Journal	Alzheimer's Care Today
Data Set 2 (Context)	dementia care
Data Set 3 (Definition)	"person-centered care is defined at LMADC as ""an approach to care that respects and values the uniqueness of the individual, and seeks to maintain, even restore, the personhood of individuals through the creation of a psychological, social and physical care environment that promotes personal worth, agency, social confidence and hope:·"
Data Set 4 (Characteristics)	"a person centred model of care will be founded on the concepts of personhood and person centered care. Personhood is defined by Kitwood as a 'standing or status bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. The concept of personhood is holistic, meaning that the sum total of uniqueness of each person is valued, and the individual's subjective viewpoint is valued."; "From this philosophical point of view, human beings are fundamentally social creatures whose psychological existence relies on the presence of some common interpersonal bonds with others. 3 It follows then, that person-centered care is the kind of care that values personhood."; "However, personhood can be maintained, even potentially restored, through care that supports 4 "global states" of well-being: (1) personal worth: a feeling of self-esteem and personal value; (2) agency: a sense of having some control over one's personal life; (3) social confidence: a feeling of being at ease in the company of others; and (4) hope: a general sense that the future will be good."; ""Person-centered care offers the much needed dimension of social engagement ... he became part of a social community where the various staff personalities helped fulfill his needs"; "participants are the focus. Participants' interests, needs, and choices are what direct the programming"; "However, the central premise is a call to get to know each and every participant from a holistic perspective. The individual's needs-whether medical, social, or personal-are to be considered paramount when providing care in this system. Their social histories are just as important as whether they prefer coffee with their lunch."; "the notion of spending time with participants is a deeply embedded facet of the PCC philosophy."; "the translation of PCC concepts into work routines promoted a culture of a social community of staff and participants exchanging conversations and working together to accomplish mutually agreed-upon tasks and activities. There was a common goal of sharing the days with a sense of happiness and fulfillment."
Data Set 5 (Use)	care
Other notes / comments	Critical review of tools to measure person-centeredness - indicates that there are different outcomes as each tool has a different focus.

Appendix C: Key informant survey materials

C1 Survey questions used in electronic survey format

1. Welcome

Thank you for agreeing to consider participating in a research project looking at person-centredness in human services. You have been identified by the research team at Curtin University's Centre for Research into Disability and Society as someone who has significant knowledge and / or personal experience of person-centredness and we are very interested to hear your thoughts and opinions.

2. Who do I call if I have any questions regarding this research?

If you have any questions regarding this research, you can contact the researchers by phone or email.

Ms Rebecca Waters
Co-Investigator
School of Occupational Therapy and Social Work
Curtin University
GPO Box U1987, Perth, Western Australia
Phone (M): 0422 123 418
Email: r.waters2@curtin.edu.au

Dr Angus Buchanan
Co-Investigator
School of Occupational Therapy and Social Work
Curtin University
GPO Box U1987, Perth, Western Australia
Phone (W): (08) 9266 3632
Email: a.buchanan@curtin.edu.au

Professor Errol Cocks
Chief Investigator
School of Occupational Therapy and Social Work
Curtin University
GPO Box U1987, Perth, Western Australia
Phone (W): (08) 9266 3621
Email: e.cocks@curtin.edu.au

3. What is the purpose of the research?

The aim of this research is to develop a framework of person-centred principles and practices in human services. These principles and practices help shape services to promote the best outcomes for clients or service users. The principles and practices will be later used for evaluation of services and service development. The research is being completed in partnership between Baptistcare and the Centre for Research into Disability and Society, in Curtin University's School of Occupational Therapy and Social Work.

4. What are you being asked to do?

You will be a member of a research group on person-centredness. We are going to ask you questions about being person-centred via an electronic survey. We will review your opinions and may ask for your feedback a number of times, to make sure we understand what you mean.

Participation in the survey and the feedback rounds is entirely voluntary and you are under no obligation to take part. You are free to withdraw at any time and you do not have to give any reasons for doing so. If you decide to withdraw from the research, this will not affect you in any way.

**1. Are you happy to continue?*

□ Yes – I am happy to continue

□ No – Thanks for the opportunity, I'd rather not participate

5. What are the possible benefits or risks of taking part in the research project?

There are no anticipated risks associated with taking part in the research. We are hoping that the results of this research will help make services for people with disabilities, elders and people with mental health issues more person-centred, and ultimately improve services for people.

6. Does this research have ethics approval?

Yes! This study has been approved by the Curtin University of Technology Human Research Ethics Committee (reference OTSW-12-2011).

7. Will my participation be kept confidential?

There are two answers to this question – yes and no.

Research tells us that this type of survey process works better when people have an idea about who else might be participating, so we'd like to do two things.

Firstly, we'd like your permission to identify you by a code (eg. Participant A). Your 'identity' will only be known to the other participants as a code, and this is for the purposes of facilitating an online 'conversation' between group members. Your responses will not be identifiable in any other way, and will not be used in any presentations or publications. Records of your real name, address, email or telephone number will be kept only for the purposes of keeping in contact with you during the research project. If you wish, we can send you information about the results of this research once it is completed.

Secondly, we'd like you to give us a short biographic description of yourself (eg. 'A policy maker in a government agency' or 'a person who has a disability and uses a human service'). We'd like to use these statements to tell group members about the other people joining in this research.

There will be no way of linking these two pieces of information together during the group process. We will use this information in the analysis of the data responses only.

**2. Do you give consent to participate in this research?*

□ Yes please

□ No thanks

**3. I am happy to be identified by a code during this research process to preserve my anonymity*

□ Yes – I am happy to be identified by code during this research

□ No thanks, I'd rather not participate

8. Please create your individual code and biographic statement

We need for you to create an individual 6 digit code so we can track your responses behind the scenes in the research. You will be asked to provide this code each time you respond to the survey. This code will be converted to a simple alphabetic code for your identity in the research.

Please create a 6 digit code using the following logic: Please use the last two letters of your middle name; then two digits from your house number and the last two digits of the year you were born. For example, if your middle name was 'John', you lived at number '7 Happy Street' and were born in 1983; your code would be: HN0783.

**4. Please tell us your identification code*

9. Biographical statement (opt in or out)

We'd find it valuable if you could provide a short biographical statement to share with other participants. If you don't want to do this, that's OK – we can just progress to the next question.

**5. Are you happy to provide a short biographical statement?*

□ Yes – I'm happy to provide a short biographical statement

□ No – I'd rather not

10. Biographical Statement

**6. Please provide a short statement which briefly describes you. For example, "A person with a disability who uses services' or 'a person who works in management in a non-government agency'.*

11. Let's get started!!

First of all, we need to know a little bit about you. It's important that we are able to demonstrate that the people who are providing information in this research have experiences of working in or receiving services.

We use the term 'human service'. A 'human service' is any service which provides supports to a person. In this case, we mean people with disabilities or people who are ageing or people with mental health issues.

**7. What is your age?*

□ 18 to 24

□ 25 to 34

□ 35 to 44

□ 45 to 54

□ 55 to 64

□ 65 to 74

□ 75 or older

**8. Please choose which title best describes you (please choose only one)*

□ I am a person who uses or who has used a human service for support

□ I am a person who works for a human service which provides support

□ I am a person who researches or teaches about human services

□ I am a person who is involved in policy making and influences the design and / or funding of human services

12. Demographics

**9. How long have you been using or have previously used human services for support?*

□ Less than 1 year

□ 1-2 years

□ 2-5 years

□ 5-10 years

□ 10-15 years

□ More than 15 years

□ I don't use human services for support

**10. How long have you worked for human services?*

□ Less than 1 year

□ 1-2 years

□ 2-5 years

□ 5-10 years

□ 10-15 years

□ More than 15 years

□ I do not work for human services

**11. How long have you either researched or taught about human services?*

□ Less than 1 year

□ 1-2 years

□ 2-5 years

□ 5-10 years

□ 10-15 years

□ More than 15 years

□ I don't research or teach about human services

13. What is 'person-centredness'?

In this research, we are interested to find out what you think about 'person-centredness'. We will be aiming to gain clarity around what this means, so that we may develop a framework of person-centred principles and practices in human services across disability, mental health and ageing. We encourage you to be as detailed and descriptive as possible.

Remember, in this research the term 'human service' is any service which provides supports to a person. In this case, we mean people with disability or people who are ageing or people with mental health issues.

**12. How would you describe person-centredness in services and supports for people who use human services? Please provide as much detail as possible.*

14. Application of person-centredness

**13. What do you think are the issues in relation to the application of person-centredness in human services? Again, please provide as much detail as possible.*

15. Additional information

14. Are there any other comments or information you would like to make available to the researchers?

16. Thank you!

Thank you for your time. Your participation in this survey is greatly appreciated! We will be taking the time to review your responses carefully and we will be in touch. We hope to provide you with some initial information about the next stage of this process once this review and analysis has occurred.

This is the end of the survey!

C2 Participant Information Sheets and Consent Form

PARTICIPANT INFORMATION SHEET – SERVICE USER

What is the purpose of the research?

The aim of the research is to develop a framework of person-centred principles and practices in human services. These principles and practices help shape services to promote the best outcomes for clients or service users. The principles and practices will be later used for evaluation of services and service development. This research is being completed in partnership between Baptistcare and the Centre for Research into Disability and Society, in Curtin University's School of Occupational Therapy and Social Work.

What am I being asked to do?

We would like to ask you about person-centredness. We are going to ask you questions about what being person-centred means to you, and where and how you may have experienced this while receiving services from Baptistcare. We will review your opinions and may ask for your feedback a number of times, to make sure we understand what you mean. Participation in the interviews are entirely voluntary and you are under no obligation to take part. You are free to withdraw at any time and you do not have to give any reasons for doing so. If you decide to withdraw from the research, this will not affect you in any way.

What are the possible benefits or risks of taking part in the research project?

We are hoping that the results of this research will help make services for people with disabilities, elders and people with mental health issues more person-centred, and improve services for people. There are no anticipated risks associated with taking part in the research.

Will my participation be kept confidential?

Yes. We will not use your real name or other information that might identify you in the research report and in any publications or presentations. People who use Baptistcare services, staff members and managers at Baptistcare will not be provided with any individual information that you provide during any of the research processes.

Records of your real name, address and telephone number will be kept only for the purposes of keeping in contact with you during the research project. If you wish, we can send you information about the results of this research once it is completed.

All records associated with this research will be securely stored at Curtin University. When the research finishes, all electronic and hard copy data will be stored in a locked archive for five years and after this time all records will be destroyed in a secure manner.

Does this research have ethics approval?

This study has been approved by the Curtin University of Technology Human Research Ethics Committee (reference OTSW-12-2011). If needed, verification can be obtained either by writing to the Curtin University Human Research Ethics Committee, C/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth 6845 or by telephoning (08) 9266 2784.

Who do I contact if I have any questions about the research project?

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PARTICIPANT INFORMATION SHEET

What is the purpose of the research?

The aim of the research is to develop a framework of person-centred principles and practices in human services. These principles and practices help shape services to promote the best outcomes for clients or service users. The principles and practices will be later used for evaluation of services and service development.

What are you being asked to do?

We would like you to be a member of a reference group on person-centredness. We are going to ask you questions about being person-centred. We will review your opinions and may ask for your feedback a number of times, to make sure we understand what you mean. Later in the research, we may ask you to participate in some half-day workshops. Participation in the surveys and feedback rounds is entirely voluntary and you are under no obligation to take part. You are free to withdraw at any time and you do not have to give any reasons for doing so. If you decide to withdraw from the research, this will not affect you in any way.

What are the possible benefits or risks of taking part in the research project?

We are hoping that the results of this research will help make services for people with disabilities, elders and people with mental health issues more person-centred, and improve services for people. There are no anticipated risks associated with taking part in the research.

Will my participation be kept confidential?

Yes. We will not use your real name or other information that might identify you in the research report and in any publications or presentations.

Records of your real name, address and telephone number will be kept only for the purposes of keeping in contact with you during the research project. If you wish, we can send you information about the results of this research once it is completed.

All records associated with this research will be securely stored at Curtin University. When the research finishes, all electronic and hard copy data will be stored in a locked archive for seven years and after this time all records will be destroyed in a secure manner.

Does this research have ethics approval?

This study has been approved by the Curtin University of Technology Human Research Ethics Committee (reference OTSW-12-2011). If needed, verification can be obtained either by writing to the Curtin University Human Research Ethics Committee, C/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth 6845 or by telephoning (08) 9266 2784.

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CONSENT FORM

I have been informed of and understand the purpose of the study.

I have been given an opportunity to ask questions.

I understand I can withdraw at any time without prejudice.

I have freedom to ask for any help.

Any information which might potentially identify me will not be used in published material.

I agree to participate in the study as outlined to me.

_____ ____/ ____/ ____

Signature of Participant Date

_____

Name of Participant (Printed)

_____ ____/____/____

Signature of Investigator Date

_____

Name of Investigator (Printed)

Appendix D: Content analysis (results from second iteration)

Matrix: Characteristics	*Frequency of code*	First iteration	Second iteration
Theme 1: Honouring the person			
Subtheme 1.1 Individuality /person as expert	*234*		
Attribute 1.1.1 individualised approach	80		
services are individualised; services must cater for each individual's varying needs and desires; about listening to what is important to the individual; services should be individually designed; an individualised rather than institutionalised philosophy of care; high quality individualised care; individualised interventions; incorporates the use of individually tailored psychosocial and complementary interventions; highly individual comprehensive approach to assessment and intervention; treating people as individuals; individualistic approach to social care; individualised programs; individualised activities; Individual self-directs care; recognising the individuality of people with dementia; individualised care planning; meets individual needs; requires staff to individualise the way they select, combine and implement the various elements of care; defined by the individual		1.1.1 the person is treated as an individual 1.1.2 the service caters for the person's varying needs and requirements 1.1.3 the person has an individualised selection, combination and implementation of supports and/or care	1.1.1 the person is treated as an individual 1.1.2 the person's varying needs and requirements are catered for 1.1.3 the person has an individualised selection, combination and implementation of supports and/or care
Attribute 1.1.2 personalised	10		
Would mostly involve one-to-one support personalised to suit the needs of that person; intended to personalise care; care that is personalised and tailored to meet each care recipient's needs; aimed at providing and improving personalised care; involving personalising care and the environment; supports the notion of holistic personalised care; personalised services; personalisation of the person's care		1.1.4 the person receives a personalised holistic approach to their needs	1.1.4 the person receives a personalised holistic approach to their needs
Attribute 1.1.3 personal preferences	64		
Respond to personal preferences; should take into account personal preferences; honouring resident's preferences for daily living; to have values and preferences supported; daily routines tailored to residents' preferences; care planning informed by the person's history, needs and preferences; increasing self-determination by expressing preferences and choices; social model of care that reflects the patient's values, needs and preferences; building a positive relationship which respects the person's life history and preferences; individualised and driven by patient's needs and preferences; meets each care recipient's needs and preferences; to identify a person's gifts, preferences and needs; takes into account each individual's unique values and preferences; are more respectful of individuals' needs, particularities and preferences; focussing on strengths, preferences and dreams; provides a context where people can identify their preferences, needs and values to develop a positive story		1.1.5 the service honours the person's preferences for daily living 1.1.6 the service honours the person's preferences for daily routines 1.1.7 the service acknowledges and includes the person's history, needs and preferences 1.1.8 the service builds a positive relationship with the person which respects the person's life history and preferences 1.1.9 the service includes the person's gifts, strengths and dreams in implementing the appropriate supports	1.1.5 the person's preferences for daily living are honoured 1.1.6 the person's preferences for daily routines are honoured 1.1.7 the person's history, needs and preferences are acknowledged and included 1.1.8 the person's life history and preferences are respected in the establishment of a positive relationship with the service 1.1.9 the person's gifts, strengths and dreams are included in implementing the appropriate supports

Attribute 1.1.4 person's perspective	30		
Involves stepping into the shoes and worldview of the person to understand how they see the world, make sense of the world and make meaning of their experiences; consciously adopts the patient's perspective; personal perspectives; acknowledging the perspective of the person with dementia; includes people's subjective experience of illness; striving to take the standpoint of the patient; that it is the client's view of themselves, their problems and the world that form the starting point in the search for meaning; feeling the experience from the perspective of the person they are supporting; involves 'wearing someone else's shoes'; recognising the perspective of the person; identify what is important to a person from his or her own perspective; understand and reflect on the experience from the perspective of the person with ID; involves getting into someone else's shoes; looking at what is important to the person from their own perspective		1.1.10 the service strives to understand the person's perspective and experiences 1.1.11 the service includes the person's perspective and experiences in implementing the appropriate supports	1.1.10 the person's perspective and experience are understood by the service 1.1.11 the person's perspective and experiences are included in implementing the appropriate supports
Attribute 1.1.5 person is central	**46**		
fundamentally it is about putting the person with their unique set of needs and values, strengths and capacities in the centre of their own lives; working with someone who is at the centre of the process; keeping the person at the centre; putting the person at the centre of all the planning, action and decision making of how they would like to see their lives unfold; co-owned by the person at the centre of care; people are at the centre of their own story; of the person, for the person, by the person and with the person; that the person should be the focus of care delivery and not the disease or illness; aim to put the person rather than the disease at the centre of health care; emphasise the introspectiveness and centrality of the individual; puts the person at the centre of treatment planning; focus on the person and a strategy of building an alliance of supporters around the person; notion of the person being the focal point in a partnership that is both respectful and reciprocal; at the centre of decision making processes; focussed entirely on the interests of the individual with disabilities and keeps them first		1.1.12 the person is firmly located at the centre of any process involving them 1.1.13 the person is at the centre of all planning, action and decision-making 1.1.14 the person co-owns the support plan 1.1.15 the person is at the centre of their own story, not their diagnosis or illness 1.1.16 the service encourages the building of an alliance of supporters around the person 1.1.17 the person is the focal point in a service partnership that is both respectful and reciprocal 1.1.18 the service focusses entirely on the interests of the person and keeps them first	1.1.12 the person is firmly located at the centre of any process involving them 1.1.13 the person is a the centre of all planning, action and decision-making 1.1.14 the person co-owns the support plan 1.1.15 the person is at the centre of their own story, not their diagnosis or illness 1.1.16 the person is supported to build an alliance of supporters by the service 1.1.17 the person is the focal point of a respectful and reciprocal service partnership

Attribute 1.1.6 expert	**4**		
emphasises the person as the expert and promotes participation; patient as expert and an active participant in the rehabilitation process; means the person is expert		1.1.19 the person is treated as an equal expert	1.1.19 the person is treated as an equal expert
Subtheme 1.2 Choice / decision making	***118***		
Attribute 1.2.1 individualised decision making	33		
Practitioners who convey their belief and faith in a person's decision making ability exhibit a non-judgemental stance which is open and inquisitive; clients are regularly involved in decision making; need to understand the complexities of authoritative decision making; support someone else's autonomy and decision making; promotes person directed decision making; decision making on how they would like to see their life unfold		1.2.1 the staff assume people have competence in decision-making 1.2.2 the staff use approaches that are open and inquisitive in determining appropriate supports 1.2.3.the person is regularly involved in decision-making 1.2.4 the person directs their own decision-making 1.2.5 the staff support the person's decision-making autonomy	1.2.1 the person is treated as having competence in decision-making 1.2.2 the staff use approaches that are open and inquisitive in determining appropriate supports 1.2.3 the person is regularly involved in decision making 1.2.4 the person directs their own decision-making 1.2.5 the person's autonomy in decision making is supported
Attribute 1.2.2 choice	59		
enable people to make choices about their own lives; respond to choice effortlessly; expand potential for choice; express choice and control; promotes person directed choice; adopt and implement personalised care intended to enhance resident's autonomy, choice, etc.; emphasises choice (even in the presence of dignity of risk taking and the right to failure); honouring choices; providing choice; create choice for users; some participants equated person-centred care with a choice of activities; provides for individuals to make their own choices; make decisions based on informed choices; supporting a person to assert their choices; based on the fundamental principle of choice with the aim of empowering and supporting individuals to achieve their aspirations and to become more included in their communities; having choices; respecting choices; freedom of choice		1.2.6 the person is supported to make choices about their own lives 1.2.7 the person is supported in ways to enhance their own autonomy 1.2.8 the person is supported to make choices even in the presence of dignity of risk taking and the right to failure 1.2.9 the person is supported to make informed choices about their own lives 1.2.10 the person is supported to make their own choices with the purpose of empowering people to achieve their aspirations and become more included 1.2.11 the person's choices are respected	1.2.6 the person is supported to make choices about their own lives 1.2.7 the person is supported in ways to enhance their own autonomy 1.2.8 the person is supported to make choices with the dignity of risk taking and the right to failure 1.2.9 the person is supported to make informed choices about their own lives 1.2.10 the person is supported to make their own choices with the purpose of being empowered to achieve their aspirations and become more included 1.2.11 the person's choices are respected

Attribute 1.2.3 shared decision making	26		
sharing decision making; partnership and negotiations in decision making; facilitating or offering shared decision making; shared action through creative problem solving		1.2.12 the person is an equal participant in shared decision-making 1.2.13 the service supports shared action through creative problem solving	1.2.12 the person is an equal participant in shared decision-making 1.2.13 the service supports shared action through creative problem solving
Subtheme 1.3 Knowing the person well	*92*		
Attribute 1.3.1 knowing the person well	28		
knowing the person; 'knowing' the person and recognising the whole person and the life they and their family previously experienced as normal; finding out exactly who they are; stresses the importance of knowing a person well; need to know who the person he or she is encountering really is; points to specific elements of knowing the person; personal knowledge of service users; using knowledge of the particularities of the resident; importance of knowing about a person; getting to know the person is fundamental; knowing the resident in detail; process of listening carefully to the hearts of people with disabilities; knowing residents as individuals; getting to know each individual is emphasised through spending time with them		1.3.1 the service seeks to know the person well 1.3.2 the service seeks to know the person's significant others, including family and friends 1.3.3 the service seeks to understand the person's particularities 1.3.4 the service has procedures in place that support staff getting to know the person well through spending time with them	1.3.1 the person is well-known by the staff at the service 1.3.2 the person's family, friends and significant others are well known by the staff at the service 1.3.3 the person's particularities are understood by the staff at the service 1.3.4 the person is well known by staff who are permitted to spend time getting to know them
Attribute 1.3.2 narrative / personal history	62		
patient narrative; people need to be seen in their bio-psychosocial entity and draws medical attention to patients' personal identities; tailored to life experiences; allows a person to move from an object of attention to a communicating person who can construct categories of self in the development of his or her story for everyone to learn; people are at the centre of their own story; the interpretive act of listening to narrative is central; life history of residents is used in care plans; exploration of the person's life history and lived experiences; informed by the person's history; respects the person's life history		1.3.5 the service seeks to find out and understand the person's narrative and history 1.3.6 the service uses the person's life history and narrative to tailor appropriate supports 1.3.6 the service tailors supports to the person's life experiences	1.3.5 the person's narrative and history is understood by the staff at the service 1.3.6 the person's narrative and life history are used by the staff at the service to tailor appropriate supports 1.3.7 the person's life experiences are used by the staff at the service to inform and tailor supports
Attribute 1.3.3 personal profile	2		
allows the person with a disability, family members and friends an opportunity to share information regarding the individual to develop a personal profile and future vision for the person; the profile and the vision provide a foundation for the group to plan ways to improve the person's life; incorporating biographical knowledge in care		1.3.7 the person, their family and friends are able to share information regarding the person to develop a personal profile and vision for the future	1.3.7 the person, their family and friends are able to share information regarding the person to develop a personal profile and vision for the future

Subtheme 1.4 Self-determination / control	*55*		
Attribute 1.4.1 self determination	25		
deeply understand the complexities of self-determination; focus on self-determination; individual right to self-determination; principles of person centred care have been defined in terms of the rights of clients to self-determination; effects that have been measured in the older person include…. Improved self-determination; increasing self-determination by expressing preferences and choices; includes self-directed support; directly linked to the domain of self-determination; aligned with consumer direction; recognise freedom of self-determination as a fundamental human right; importance methods for enabling self-determination		1.4.1 the service deeply understands the complexities of self-determination 1.4.2 the person is supported to self-determine as a fundamental human right 1.4.3 the service places importance on processes to support self-determination	1.4.1 staff at the service deeply understand the complexities of self-determination 1.4.2 the person is supported to self-determine as a fundamental human right 1.4.3 the person is supported to self-determine by service approaches and procedures
Attribute 1.4.2 Control	30		
active role; giving service users a sense of control over their lives; promoting a sense of power and control in the resident; address the issue of empowerment; linked to personal control; maximising choice and control; means we have a way to negotiate and determine how our lives will be; where the person is driving the process; capacity to clearly express choice and control; active role; as a self-interpreting agent engaged in a world shared with other persons; help the service user to achieve control over the his/her life; promoting a sense of power and control; has been shown though evidenced-based practice to increase the degree of choice and control in people's lives; maximising control over one's environment; making sure people are in control of their own lives; opportunity to exercise control; explicit emphasis on personal empowerment that allows service users to take more control over their own lives		1.4.4 the person has power and control in their life 1.4.5 the service supports maximising people's power and control over their environment 1.4.6 the person is supported to exercise their power and control in determining how their life will be	1.4.4 the person has power and control in their life 1.4.5 the person's power and control over their environment is maximised by staff at the service 1.4.6 the person's power and control over their life is maximised by staff at the service

Subtheme 1.5 Being respected	*34*		
respect; respect for the person; where the rights and respect for the person are paramount; defined by respect for the person; mutual respect; rights and respect for the individual are paramount; to be treated with respect; calm reassurance, hope and respect need to be communicated; relationship of mutual trust; culture that is nurturing, empowering and respectful; within each human being is the desire to be respected; respects the patient as a person; an approach to care that respects and values the uniqueness of the individual; ethic of respect; founded on mutual respect for the dignity and responsibility of each individual person; partnership that is both respectful and reciprocal; promoting respect; treated as any other person with respect and dignity		1.5.1 the person is respected 1.5.2 the rights and respect for the person are paramount 1.5.3 the service has a nurturing, empowering and respectful culture 1.5.4 the service promotes an approach to care that respects and values the uniqueness of people 1.5.5. the service promotes the dignity and responsibility of each individual person 1.5.6 the service is founded on mutual respect between all people 1.5.7 the service facilitates partnerships with people that are both respectful and reciprocal	1.5.1 the person is respected 1.5.2 respect for the person and their rights are paramount 1.5.3 the service has a nurturing, empowering and respectful culture 1.5.4 the person is respected and valued as being unique 1.5.5 the person's dignity and responsibility is promoted 1.5.6 the service is founded on mutual respect between all people 1.5.7 the service facilitates partnerships with people that are both respectful and reciprocal
Subtheme 1.6 Being reflective /exploring thoughts & feelings	*9*		
1.6.1 being reflective	1		
the doctor and the patient need to be empathic and reflective		1.6.1 the service supports staff to be empathic and reflective	1.6.1 staff at the service are empathic and reflective
1.6.2 exploring thoughts and feelings	8		
so that clients can explore thoughts and feelings; accepted as a foundation for making sense of their thoughts, feelings and purpose in life; being supportive of their current feelings; working together to develop a feeling-based service; a belief in person-centredness being an approach to life and something we feel and are; help people explore their dreams		1.6.2 the person is supported to explore their thoughts and feelings 1.6.3 the person is supported to explore their dreams	1.6.2 the person is supported to explore their thoughts and feelings 1.6.3 the person is supported to explore their dreams
All appearances of codes for 'honouring the person'	*542*		

Theme 2: Being in relationship			
Subtheme 2.1 Focus on developing relationships	*92*		
means building relationship with the person and their family and friends; focussed on the development of a relationship; promote a shared responsibility among staff to develop meaningful relationships with residents so they can understand their physical and psychosocial needs; establish and maintain relationships; involves the person and their significant others promoting beneficial relationships; collecting and using personal experiences of life and relationships to individualise care and the environment; prioritising relationships as much as care tasks; relationship-based care; this concept entails a set of practices aimed at helping the person with dementia enter into a relationship (with formal and informal caregivers, and with other residents) – what we call "Being in a relationship"; positive relationships; The development of a meaningful relationship is vital in the process of defining life goals especially for people with IDs who have limited verbal communication; By decreasing clinical terms, direct service providers have higher expectations and develop relationships that transcend professional boundaries; maintaining important relationships and developing new relationships; It is established through the formation and fostering of relationships among all care providers, older people and people who are significant to them; Caring, empathic relationships are as crucial to a resident's quality of life as providing quality of care and quality of management; supporting positive relationships; developing and maintaining relationships with peers		2.1.1 the service has a focus on developing meaningful relationships with the person 2.1.2 the service promotes a shared responsibility among staff to develop meaningful relationships with the person 2.1.3 the service involves the person and their family in promoting beneficial relationships 2.1.4 the service supports and develops existing and new relationships 2.1.5 the service supports the development of relationships that transcend professional boundaries 2.1.6 the service is aware and understands the importance of caring empathic relationships to quality of life, quality of care and quality of management	2.1.1 staff at the service focus on developing meaningful relationships with the person 2.1.2 staff at the service share a responsibility to develop meaningful relationships with the person 2.1.3 staff at the service involve the person and their family in promoting beneficial relationships 2.1.4 staff at the service support and develop new and existing relationships 2.1.5 staff at the service support the development of relationships that transcend professional boundaries 2.1.6 staff at the service are aware and understand the importance of caring empathic relationships to quality of life, quality of care and quality of management
Subtheme 2.2 Family relationships	*38*		
a service that actively engages with and welcomes the family's participation and involvement; building relationship with the person and their family; involves the person and their significant others promoting beneficial relationships; involving family members; aims to achieve the most positive outcome for the patient as well as their carers and family; welcoming family; spending time with family; The family participants also described that welcoming them into the life and care of the person was another element central to person-centred care; acting in alliance with family; family members and friends are full partners; involvement of families		2.2.1 the service actively engages with and welcomes the family's participation and involvement 2.2.2 the service aims to achieve the most positive outcome for the person and their carer and family 2.2.3 the service considers family members and friends as full partners	2.2.1 the person's family are welcome, involved and engaged in the service 2.2.2 the person, their carer and family can expect the staff at the service to work towards the most positive outcome 2.2.3 the person's family and friends are treated as full partners by the staff at the service

Subtheme 2.3 Person - staff partnership	*13*		
partnership; starts with partnership building; commitment to build a strong therapeutic alliance; encouragement of partnership and collaboration; multidirectional relationships are a part of meaningful engagement; partnerships between people and practitioners; partnership and negotiations in decision-making; an equal partnership between the health professional and the service user		2.3.1 the service supports building support partnerships between the person and staff as a commitment to a strong therapeutic alliance 2.3.2 the service encourages collaboration and partnerships between people and practitioners	2.2.4 staff at the service prioritise building support relationships as a commitment to a strong therapeutic alliance 2.2.5 staff at the service encourage collaboration and partnerships between the person and others
Subtheme 2.4 Being in relation with others	*11*		
being in relation, which refers to the importance of promoting the resident's relationships, especially with caregivers; human beings are fundamentally social creatures whose psychological existence relies on the presence of some common interpersonal bonds with others; being in relation (social relationships); sharing everyday life with a sense of nearness		2.4.1 the service supports the person to be in relationship with others 2.4.2 the service supports the person to be in relationship with caregivers 2.4.3 the service supports the person to maintain or establish social relationships 2.4.4 the service supports people to share in everyday life with a sense of nearness	2.4.1 the person is supported to be in relationship with others 2.4.2 the person is supported to be in relationship with caregivers 2.4.3 the person is supported to establish or maintain social relationships 2.4.4 the person is supported to share in everyday life with a sense of nearness
Subtheme 2.5 Positive & therapeutic relationship	*7*		
Attribute 2.5.1 therapeutic relationship	4		
the centrality of the professional relationship which is the conduit for processes of practice such as engagement, advocacy, assessment, collaborative planning, and intervention; the development of therapeutic relationships; creating a therapeutic culture		2.5.1 the service acknowledges the centrality of the professional relationship between the person and staff as a means of supporting engagement, advocacy, collaborative planning, and intervention	2.5.1 the person and the staff at the service acknowledge the centrality of the professional relationship as a means of supporting engagement, advocacy, collaborative planning, and intervention
Attribute 2.5.2 positive relationship	3		
building a positive relationship; positive interaction in relationships		2.5.2 the service supports positive interactions in relationships between the person and staff	2.5.2 the person and staff at the service are supported to have positive interactions in relationships

Subtheme 2.6 Natural or informal support	*6*		
seeking help from informal or 'natural' supports in his or her community (e.g.,family, clergy, etc.) rather than relying on formal systems of support inside the mental health system; network of informal support is regarded as central to PCP; attempts to include and mobilise the individuals family and wider social network; natural or community supports; circle of support		*2.6.1 the service encourages informal and natural relationships as a valuable component of being person-centred* *2.6.2 The service supports the inclusion and mobilisation of the person's family and wider social network*	*2.6.1 staff at the service acknowledge and encourage informal and natural relationships as a valuable component of the person's social network* *2.6.2 the person's wider social network are included and mobilised*
All appearances of codes for 'being in relationship'	*167*		

Theme 3: Facilitating participation / engagement			
Subtheme 3.1 Meaningful activity / occupation	*35*		
support people to be engaged in meaningful activity and relationships; engage and interact in meaningful activities; assist you to make your life as meaningful and interesting as possible; provision of meaningful activity and occupation; seeking opportunities for clients to engage in activities, while recognising that different levels of engagement are appropriate for different people; individualised activities; having something interesting to do during the day; meaningful engagement for residents; meaningful engagement refers to activities and pastimes that residents choose and find satisfying; occupation; continuing to acquire skills; engagement in meaningful activities is ensured; fulfilment; Individually targeted activities were described not only as providing a meaningful content to the day, but also as a means in reaffirming the residents as individual persons who were able to do the things they enjoyed; providing opportunities for occupation; promote engagement through recreation and socialization; engage in preferred activities		3.1.1 the person is supported to be engaged in meaningful activity 3.1.2 the person is assisted to seek opportunities to engage in meaningful activity 3.1.3 the service acts to assist people to have something interesting to do during the day 3.1.4 the person is supported to do activities they enjoy 3.1.5 the person's activities and occupations are individualised	3.1.1 the person is supported to be engaged in meaningful activity 3.1.2 the person is assisted to seek opportunities to engage in meaningful activity 3.1.3 the service acts to assist people to have something interesting to do during the day 3.1.4 the person is supported to do activities they enjoy 3.1.5 the person's activities and occupations are individualised
Subtheme 3.2 Participation	*15*		
participation; should create the conditions for older people to participate in meaningful lives; increase participation in community activities, social activities and daily life activities; should provide opportunities for patient participation; evidence of patient participation; facilitating patient participation; promoting participation; improving participation in social relationships, home life, education, work and economic life; community participation		3.2.1 the person's participation in meaningful life is encouraged 3.2.2. the person is supported to participate in their community 3.2.3 the person is supported to participate in daily life activities and routines 3.2.4 the person is supported to participate in social activities and relationships 3.2.5 the person is supported to participate in education 3.2.6 the person is supported to participate in work and economic life	3.2.1 the person's participation in meaningful life is encouraged 3.2.2. the person is supported to participate in their community 3.2.3 the person is supported to participate in daily life activities and routines 3.2.4 the person is supported to participate in social activities and relationships 3.2.5 the person is supported to participate in education 3.2.6 the person is supported to participate in work and economic life
Subtheme 3.3 Facilitating independence	*10*		
independence; language is intrinsically linked to autonomy and independence; should be underpinned by the key principles of rights, independence, choice and inclusion; to live full and independent lives; supports independence and inclusion		3.3.1 the person is supported to live a full and independent life	3.3.1 the person is supported to live a full and independent life

Subtheme 3.4 Engagement / involvement	*13*		
Attribute 3.4.1 engagement	10		
the person- centered approach assumes a sustained commitment and high degree of engagement and follow-up case management of individual cases; promote engagement through activity; engagement; true person-centred care is a product of genuine engagement with the person whose fears and aspirations are being disclosed; Use of core mental health nursing therapeutic engagement skills		3.4.1 staff at the service assume a sustained commitment to the person with a high degree of engagement and follow-up case management 3.4.2 staff at the service foster a genuine engagement with the person	3.4.1 staff at the service have a sustained commitment to the person with a high degree of engagement and follow-up case management 3.4.2 staff at the service foster a genuine engagement with the person
Attribute 3.4.2 level of involvement	3		
An important distinction is the level of involvement of the individual required in order for care to be person centred; being involved		3.4.3 staff at the service have a commitment to a high level of involvement with the person	3.4.3 staff at the service have a high level of involvement with the person
Subtheme 3.5 Interests / Likes	*5*		
a service based upon knowledge of the person's history, health, preferences, needs, interests, routines and habits; each person (including those with dementia) have unique interests and life stories, it is crucial to consider the person's abilities, preferences, interests, values and spirituality; work together to assist students in exploring and pursuing their interests, desires, and goals		*3.5.1 the person's history, health, needs, preferences, interests, routines and habits inform the type and level of support* *3.5.2 the person's abilities, values and spirituality inform he type and level of support* *3.5.3 the person is assisted to explore and pursue their interests, desires and goals*	*3.5.1 the person's history, health, needs, preferences, interests, routines and habits inform the type and level of support* *3.5.2 the person's abilities, values and spirituality inform he type and level of support* *3.5.3 the person is assisted to explore and pursue their interests, desires and goals*
All appearances of codes for 'facilitating participation / engagement'	*78*		

Theme 4: Social inclusion / citizenship			
Subtheme 4.1 Social / community inclusion	*78*		
Attribute 4.1.1 community inclusion	29		
embracing a life of inclusion and contribution; valuing community inclusion as a commonly identified and desired outcome; will be engaged and integrated in the community; Offering choice and promoting inclusion into the mainstream and community at large; should be underpinned by the key principles of rights, independence, choice and inclusion; a service culture that embraces the ideas of empowerment and inclusion; promotes inclusiveness; Based on the premise that people with disabilities should enjoy life in the community, person-centered planning seeks to reduce social isolation; be supported as a valued community member; inclusion; emphasis on the settings, services, supports, and routines available in the community at large rather than those designed for people with disabilities; participating in community life		4.1.1 the person is supported as a valued community member 4.1.2 the person is supported in way that is underpinned by the principles of rights, independence, choice and inclusion 4.1.3 staff at the service provide support to person that promotes inclusion and inclusiveness 4.1.4 the person is supported to access settings, services, supports and routines available in the community at large 4.1.5 the person is supported to participate in community life	4.1.1 the person is supported as a valued community member 4.1.2 the person is supported in way that is underpinned by the principles of rights, independence, choice and inclusion 4.1.3 staff at the service provide support to person that promotes inclusion and inclusiveness 4.1.4 the person is supported to access settings, services, supports and routines available in the community at large 4.1.5 the person is supported to participate in community life
Attribute 4.1.2 community presence	22		
increase their community presence to include current and new sites; focussed on community presence; community presence		4.1.6 the person is supported to establish and maintain a community presence	4.1.6 the person is supported to establish and maintain a community presence

Attribute 4.1.3 social inclusion	*27*		
social inclusion; involvement in the community; person-centred approach to meeting needs that has social inclusion and citizenship at its heart; supporting individuals to be more included in their communities; become part of a social community; social inclusion in groups		*4.1.7 the person is supported to be socially included* *4.1.8 the person's citizenship is supported*	*4.1.7 the person is supported to be socially included* *4.1.8 the person's citizenship is supported*
Subtheme 4.2 Being part of the social world	*13*		
being in a social world; social beings worthy of relationship; being in a social world, which refers to the importance of recognizing and affirming the resident's "goals in life," which are often embodied in her/his life history; become part of a social community; social being; draw people with dementia into a social world; constituted in collective social activity; Recovery is considered a dynamic and social process, incorporating individual as well as environmental perspectives and the dynamic inter-relationships between the two ; people are social beings		*4.2.1 the person is supported to be in a social world* *4.2.2 the environment is set up to support the establishment and maintenance of social relationships*	*4.2.1 the person is supported to be in a social world* *4.2.2 the environment is set up to support the establishment and maintenance of social relationships*
Subtheme 4.3 Citizenship	*6*		
person-centred approach to meeting needs that has social inclusion and citizenship at its heart; But recognizing individuals with serious mental illnesses as fellow human beings with citizenship rights will require an approach in which each person's basic humanity and everyday life are acknowledged as primary and of central importance within a helping relationship; to acknowledge that disabled persons are full-fledged citizens; Support to become equal citizens in our society; person-centred planning has emerged as one of the most promising best practices for creating and sustaining full citizenship for people with disabilities; This quest involves building more compassionate communities, while simultaneously embracing the capacity of typical citizens to directly and indirectly nurture and support students with disabilities to become contributing citizens		*4.3.1 the person is supported in a way that has social inclusion and citizenship at its heart* *4.3.2 the person has equal citizenship rights* *4.3.3 the person is supported to be a contributing citizen*	*4.3.1 the person is supported in a way that has social inclusion and citizenship at its heart* *4.3.2 the person has equal citizenship rights* *4.3.3 the person is supported to be a contributing citizen*
Subtheme 4.4 Making a positive contribution	*5*		
contribute and belong; imagining a better world where people are valued, contribute and belong		*4.4.1 the person is supported to contribute and belong*	*4.4.1 the person is supported to contribute and belong*
All appearances of codes for 'social inclusion / citizenship'	*102*		

Theme 5: Strengths/ capacity focussed			
Subtheme 5.1 Strengths/capacity focussed	*41*		
Attribute 5.1.1 strengths	21		
strengths-based assessment strategies; designed to cultivate the retention of capacities by enhancing remaining strengths; the doctor must understand ….their strengths and weaknesses; emphasising youth's unique strengths and abilities; identifying and working with the strengths of the individual; organised around a person's unique strengths and preferences; Recovery comes as much from identifying and building on strengths as it does from resolving problems; relevant and strengths based; focussing on the strengths, preferences and dreams of the individual; all members take a positive and proactive view of the student by focussing on strengths and abilities rather than the disability; a focus on respective strengths and needs; the time taken to listen to and build from accomplishments, strengths, and vision		5.1.1 staff at the service use strengths-based assessment strategies 5.1.2 the person is supported to retain their capacities by enhancing their remaining strengths 5.1.3 the person's unique strengths are recognised 5.1.4 the person is perceived in a positive and proactive manner focussing on strengths and abilities	5.1.1 the person is assessed using strengths-based assessment strategies 5.1.2 the person is supported to retain their capacities by enhancing their remaining strengths 5.1.3 the person's unique strengths are recognised 5.1.4 the person is perceived in a positive and proactive manner focussing on strengths and abilities
Attribute 5.1.2 capacities	20		
caregivers regard the whole of life experience and capacities of living with dementia; care environment must be designed to cultivate the retention of capacities by enhancing remaining strengths rather than managing deficits; Focuses on the persons gifts, capacities, dreams and desires; person centred planning reflects a person's capacities; to collaboratively develop strategies that build on the capacity of individuals and communities; The Person-Centered Plan is seen as not disability-specific, but a capacity- building process in which the personnel involved are key to linking the individual to the community in order for dreams and personal goals to be realized; outcomes focus on promoting capacities and preferences of individuals; aims to consider aspirations and capacities expressed by the service user or those speaking on the service users behalf; Person-centred planning approaches are often referred to as capacity building approaches to planning; capacity-building evaluation; focus on capacities and assets of the individual rather than on limitations and deficiencies; understand a person's capacities and choices; shifted the emphasis to a search for capacity in the person		5.1.5 the person is supported to utilise their capacities and assets rather than limitations or deficiencies 5.1.6 staff at the service search for capacity in the person rather than limitation 5.1.7 staff at the service act to build capacity to support the person in their community	5.1.5 the person is supported to utilise their capacities and assets rather than limitations or deficiencies 5.1.6 staff at the service search for capacity in the person rather than limitation 5.1.7 staff at the service act to build capacity to support the person in their community

Subtheme 5.2 Assuming people's competence / abilities	*13*		
competence; It facilitated disabled persons voices to be heard, their expertise and competence to be acknowledged; develop competence; emphasizing youths' unique strengths and abilities; built on people's abilities, ambitions and hopes for the future; they possess a certain quantity of abilities; the focus on what the person can do, rather than the abilities that have been lost owing to the disease		5.2.1 the person's competence is acknowledged and assumed in the provision of supports 5.2.2 the person is supported by focussing on what the person can do rather than the abilities that have been lost due to disease or disability	5.2.1 the person's competence is acknowledged and assumed in the provision of supports 5.2.2 the person is supported by focussing on what the person can do rather than the abilities that have been lost due to disease or disability
Subtheme 5.3 Having high expectations	*6*		
higher expectations; it is about what is possible, not what's available; individualizing supports based on high expectations of the person's development and capabilities		5.3.1 staff at the service have high expectations of the person's development and capabilities	5.3.1 staff at the service have high expectations of the person's development and capabilities
Subtheme 5.4 Without concern for limitations / barriers	*6*		
encouraged to express their desires without concern for limitations or barriers; reflect the individual's preferences, not the availability of resources; focus on the assets of the individual rather than on limitations and deficiencies		5.4.1 the person is encouraged to express their desires without concern for limitations or barriers 5.4.2 staff at the service focus on the assets of the person	5.4.1 the person is encouraged to express their desires without concern for limitations or barriers 5.4.2 the person's assets are a focus of the service
Subtheme 5.5 Commitment to positive outcomes	*5*		
commitment to development of a plan of action that results in real change in the life of the focus person; a shared commitment to actions that will uphold their rights; and continual listening, learning and action, helping the person get what they want out of life; learning and action and helps the person get what they want		5.5.1 staff at the service have a commitment to positive outcomes for the person 5.5.2 the person is supported to get what they want out of life 5.5.3 the person and the staff at the service share a commitment to actions that will uphold the person's rights	5.5.1 staff at the service have a commitment to positive outcomes for the person 5.5.2 the person is supported to get what they want out of life 5.5.3 the person and the staff at the service share a commitment to actions that will uphold the person's rights
All appearances of codes for 'strengths / capacity focussed'	*71*		

Theme 6: Experiencing compassionate love			
Subtheme 6.1 Humanity	*20*		
it's about seeing a person as a human being; a shared humanity, especially in relation to emotional aspects of human existence; focus on residents' holistic well-being and maintenance of their humanity; philosophy to design and deliver clinical care as it shows respectful, humanitarian, and ethical values that should be of benefit to those with dementia; reflects more humanistic care with few reported risks; require an approach in which each person's basic humanity and everyday life are acknowledged as primary and of central importance within a helping relationship; what they need in life to be uniquely fulfilled as a human being; The word 'person' captures those attributes that represent our humanness; he term "person" denotes a holistic humanness and the equal value of individuals; Respect for persons within a culture of life rightly states, 'Our care for people who are sick, aged or disabled is founded on love and respect for the inherent dignity of every human being'; a person enters and leaves this life as a human being not a human doing; None of us is separate from each other in our experience as human beings; for someone receiving support, being person-centred means being treated as a whole human being-as an individual; PCC is founded on the ethic that all human beings are of absolute value and worthy of respect; allows the carer to connect with the person on a human level		6.1.1 the person is related to as a human being 6.1.2 the person is acknowledged in the emotional aspects of human existence 6.1.3 the person's well-being and maintenance is central 6.1.4 the person's humanity and everyday life are of primary and central importance 6.1.5 the person has holistic humanness and is of equal value to any other person 6.1.6 the person is respected within a culture of life 6.1.7 the person has absolute value and is worthy of respect	6.1.1 the person is related to as a human being 6.1.2 the person is acknowledged in the emotional aspects of human existence 6.1.3 the person's well-being and maintenance is central 6.1.4 the person's humanity and everyday life are of primary and central importance 6.1.5 the person has holistic humanness and is of equal value to any other person 6.1.6 the person is respected within a culture of life 6.1.7 the person has absolute value and is worthy of respect
Subtheme 6.2 Comfort	*9*		
care systems that support the person's needs for love, attachment, comfort, identity, occupation and inclusion will enhance the person's global sense of self-worth and feeling valued; comfort care; meet their psychosocial needs for comfort; psychological comfort; things that comfort the person with dementia; comfort and attachment; promoting emotional and physical comfort		6.2.1 the person's needs for comfort are addressed 6.2.2 the person's psychological needs for comfort are addressed 6.2.3 the person has access to objects, items and activities that provide comfort 6.2.4 the person experiences both physical and emotional comfort	6.2.1 the person's needs for comfort are addressed 6.2.2 the person's psychological needs for physical and emotional comfort are addressed 6.2.3 the person has access to objects, items and activities that provide comfort

Subtheme 6.3 Empathy	*9*		
Compassion and understanding are central, particularly as the greatest challenge to empathy is to step into the shoes of individuals we least relate to and categorise as most different to ourselves; the values of acceptance, genuineness and empathy become central to who we are and how we relate to others"; understanding the resident through empathy; the focus on identity building, unconditional acceptance, caring, and empathic understanding reminds us of the core principles of the humanistic, person-centred approach; Rogers' relationship qualities of congruence, empathy, and unconditional positive regard must be maintained; What is required is the structure in which a relationship can develop with a clinician trained in the interpersonal skills required to establish those language and empathetic communications by which one human conveys the nature of his inner world to another; accurate empathy; empathic listening		6.3.1 the person experiences empathy as a part of the process of being understood 6.3.2 the person is considered with unconditional positive regard 6.3.3 the person understood through empathy	6.3.1 the person experiences empathy as a part of the process of being understood 6.3.2 the person is considered with unconditional positive regard 6.3.3 the person understood through empathy
Subtheme 6.4 Hope	*6*		
a social model which emphasises wellbeing, social inclusion, self-management and hope; calm reassurance, hope, and respect need to be communicated; promotes personal worth, agency, social confidence and hope; hope: a general sense that the future will be good; person centred care offered hope to the person with dementia; having hope and a purpose in life is critically important		6.4.1 the person experiences a sense of hope and purpose in life 6.4.2 the person is supported in a way that emphasises well-being and hope 6.4.3 the person has a sense that their future is positive	6.4.1 the person experiences a sense of hope and purpose in life 6.4.2 the person is supported in a way that emphasises well-being and hope 6.4.3 the person has a sense that their future is positive
Subtheme 6.5 Compassion	*7*		
A universal need for every person who requires assistance is to be valued, deeply listened to, and to have compassionate understanding communicated to them; Compassion and understanding are central; focusing more on 'being' with people in creative, flexible, compassionate and responsive ways; Compassion in this manuscript refers to an overarching concept of caring, empathy, personal engagement, responsiveness and sensitivity to a person's needs and values; When we fail to respond to them with compassion we not only diminish their humanity but also our own; When there is a mutually respectful relationship between a member of staff and a resident, the staff member also receives a unique opportunity to deepen and develop his / her humanity, compassion, humour and creativity; This quest involves building more compassionate communities		6.5.1 the person is valued 6.5.2 the person is deeply listened to 6.5.3 the person has compassionate understanding communicated to them 6.5.4 the person experiences compassion as a part of caring, empathy, and sensitivity to needs and values 6.5.5 the person is responded to with compassion 6.5.6 staff at the service experience compassion through developing mutually respectful relationships with people	6.5.1 the person is valued 6.5.2 the person is deeply listened to 6.5.3 the person has compassionate understanding communicated to them 6.5.4 the person experiences compassion as a part of caring, empathy, and sensitivity to needs and values 6.5.5 the person is responded to with compassion 6.5.6 staff at the service experience compassion through developing mutually respectful relationships with people

Subtheme 6.6 Love	*5*		
care systems that support the person's needs for love will enhance the person's global sense of self-worth and feeling valued, and reduce the incidence of disruptive behaviours; loving relationships maintain our well-being; highlights supportive care and basic needs for attachment, comfort, identity, occupation and inclusion, which builds towards a central care need of being loved; a culture that celebrates working with people with dementia and loves each individual for who they are; The person with a disability is at the centre of the planning, and those who love the person are the primary authorities on the direction of the person's life		6.6.1 the person's need of being loved is met 6.6.2 the person is supported to establish and maintain loving relationships 6.6.3 the person is loved for who they are 6.6.4 aside from the person, people who love the person are the primary authorities on the direction of the person's life	6.6.1 the person's need of being loved is met 6.6.2 the person is supported to establish and maintain loving relationships 6.6.3 the person is loved for who they are 6.6.4 aside from the person, people who love the person are the primary authorities on the direction of the person's life
Subtheme 6.7 Belonging	*4*		
PCP aims to "listen closely to the hearts of people with disabilities and to imagine with them a better world in which they can be valued members, contribute, and belong; encouraging a sense of belonging; everyone needs to feel a sense of togetherness and community with one another; with them imagining a better world where they are valued, contribute and belong		6.7.1 the person experiences a sense of belonging and togetherness	6.7.1 the person experiences a sense of belonging and togetherness
Subtheme 6.8 Safety	*2*		
ensuring that communication systems respect the essence of the person and protect his or her safety in a way that maintains person-centred values and continuity of care; ensure security and success through a positive environment		6.8.1 the person's safety is protected while maintaining the essence of the person	6.8.1 the person's safety is protected while maintaining the essence of the person
Subtheme 6.9 Reassurance	*1*		
providing reassurance		*6.9.1 the person is reassured when required*	*6.9.1 the person is reassured when required*
All appearances of codes for 'experiencing compassionate love'	*63*		

Theme 7: Organisational factors			
Subtheme 7.1 Staff attributes	*40*		
Attribute 7.1.1 staff attitudes	12		
must work through others on their team to ensure that staff truly relate to their residents, posits that DCM is based on Kitwood's social-psychological theory of personhood in dementia and that much ill-being that people with dementia experience is due to negative environmental influences, including staff attitudes and care practices, increasing the number of effective staff– resident interactions and relationship; that staff will benefit from person-centered care which involves satisfying the wishes and needs of residents, by providing meaningful activities and interactions to promote a normal daily life of the residents, rather than concentrating on tasks that need to be performed; staff had to be available and present; staff are sufficiently flexible to accommodate these individual conditions; manager that models person-centred care with staff and provides leadership rather than management, a team that has a sense of pride, passion and togetherness, which fosters and grows feeling-based and instinctive care; staff need to be competent and committed to be person-centered, that they need to have interpersonal skills and know themselves; the nurse's values and the context of the care environment		7.1.1 staff at the service truly relate to the person 7.1.2 staff at the service have positive attitudes and care practices 7.1.3 staff at the service work to satisfy the wishes and needs of people 7.1.4 staff at the service are available and present for people rather than just focussing on tasks that need to be performed 7.1.5 staff at the service are sufficiently flexible to accommodate individual conditions 7.1.6 management staff at the service models being person-centred with staff and provides leadership 7.1.7 staff at the service feel part of team that has a sense of pride, passion and togetherness 7.1.8 staff at the service foster and grow feeling-based and instinctive care and support 7.1.9 staff at the service have excellent interpersonal skills and know themselves well	7.1.1 staff at the service truly relate to the person 7.1.2 staff at the service have positive attitudes and care practices 7.1.3 staff at the service work to satisfy the wishes and needs of people 7.1.4 staff at the service are available and present for people rather than just focussing on tasks that need to be performed 7.1.5 staff at the service are sufficiently flexible to accommodate individual conditions 7.1.6 management staff at the service models being person-centred with staff and provides leadership 7.1.7 staff at the service feel part of team that has a sense of pride, passion and togetherness 7.1.8 staff at the service foster and grow feeling-based and instinctive care and support 7.1.9 staff at the service have excellent interpersonal skills and know themselves well

Attribute 7.1.2 staff empowerment	10		
staffing models focussed on staff empowerment; using staff continuity as a way to promote therapeutic relationships; It also requires energy, motivation, sufficient resources, staff support and, for those who are not yet aware of its principles, training and reinforcement; for an organization, being person-centred is about creating a culture where the (care) service brings out the best in individual staff and tho.se receiving the service; Person-centred care encourages all staff to initiate, become involved in, and take ownership of changes in practice; staff should have autonomy		7.1.10 staff at the service are empowered by staffing models 7.1.11 staff at the service have continuity with people as a way to promote therapeutic relationships 7.1.12 staff at the service have energy, motivation, sufficient resources, training and reinforcement to be person-centred 7.1.13 staff at the service experience a culture that brings out the best in them and those receiving the service 7.1.14 staff at the service are able to initiate, become involved in, and take ownership of changes in practice to support being person-centred 7.1.15 staff at the service have autonomy in their work	7.1.10 staff at the service are empowered by staffing models 7.1.11 staff at the service have continuity with people as a way to promote therapeutic relationships 7.1.12 staff at the service have energy, motivation, sufficient resources, training and reinforcement to be person-centred 7.1.13 staff at the service experience a culture that brings out the best in them and those receiving the service 7.1.14 staff at the service are able to initiate, become involved in, and take ownership of changes in practice to support being person-centred 7.1.15 staff at the service have autonomy in their work
Attribute 7.1.3 staff satisfaction	18		
staff indicating satisfaction with their work environments; has been shown to have positive effects on general job satisfaction, job demands on psychogeriatric wards, emotional exhaustion and personal accomplishment; staff are free to alter work routines based on residents preferences; evidence of positive outcomes on staff job satisfaction; job quality of providers; person-centered care was quite strongly associated with higher job satisfaction; When there is a mutually respectful relationship between a member of staff and a resident, the staff member also receives a unique opportunity to deepen and develop his / her humanity, compassion, humour and creativity		7.1.16 staff at the service are satisfied with their work environments 7.1.17 staff at the service have job satisfaction 7.1.18 staff at the service are able to alter work routines based on people's preferences	7.1.16 staff at the service are satisfied with their work environments 7.1.17 staff at the service have job satisfaction 7.1.18 staff at the service are able to alter work routines based on people's preferences

Subtheme 7.2 Values-based / holistic	*28*		
Attribute 7.2.1 values - based	11		
It has been argued that person-centred care can be perceived as a value base; an approach to care that respects and values the uniqueness of the individual, and seeks to maintain, even restore, the personhood of individuals through the creation of a psychological, social and physical care environment that promotes personal worth, agency, social confidence and hope; The core quality of person-centered care is to value and use people's subjective experience of their illness regardless of cognitive ability; Authors in the field of person centeredness and gerontology identify person-centred care as inclusive of all those in the care environment, where their personal values and the living environment represent a person-centred philosophy; values-based approach for thinking about, communicating with, assessing, and planning for, and supporting people with disabilities		7.2.1 the service has a value-base that respects and values the uniqueness of people and seeks to maintain and/or restore personhood 7.2.2 the service values the person's subjective experience of illness or disability 7.2.3 the service takes a values-based approach to thinking about, communicating with, assessing, and planning for, and supporting people	7.2.1 the service has a value-base that respects and values the uniqueness of people and seeks to maintain and/or restore personhood 7.2.2 the service values the person's subjective experience of illness or disability 7.2.3 the service takes a values-based approach to thinking about, communicating with, assessing, and planning for, and supporting people
Attribute 7.2.2 holistic	17		
person centredness is about 'seeing the wholeness of an individual (not their label or disability or culture); holistic philosophy of care; describe a holistic model care that is based on the patients prioritized needs and wishes, involves the person and their significant others, promoting beneficial relationships, and incorporates the use of individually tailored psychosocial and complementary interventions inasmuch as traditional medical interventions; Holistic (or biopsychosocial) in perspective; supports the notion of holistic personalised care; Treating the client as a "whole person" is the essence of a person-centred approach to care; includes and supports the consideration of each person's needs and preferences from a holistic perspective that includes associated relationships and the impact that other people, practices and/or the physical environment may have on the individual; person- centredness means addressing the person's specific and holistic properties - should understand the uniqueness of people as opposed to similarities		7.2.4 the service values a holistic philosophy of care and support 7.2.5 the person is treated as a 'whole person' and supports the consideration of the person's needs and preferences from a holistic perspective	7.2.4 the service values a holistic philosophy of care and support 7.2.5 the person is treated as a 'whole person' and supports the consideration of the person's needs and preferences from a holistic perspective

Subtheme 7.3 Flexibility / responsiveness	*15*		
Attribute 7.3.1 flexibility	9		
organisations are timely and flexible in their response to individuals and families/carers; more-flexible care practices, less constraining work organizations, and a modified physical environment; experiencing flexibility and continuity; aged care facilities need to have flexible routines adapted to the person with dementia's needs rather than the needs of staff, especially in relation to staffing, care tasks and activities; letting go of the drive ' to do' and focusing more on 'being' with people in creative, flexible, compassionate and responsive ways; requires staff to have a flexible and responsive approach; flexible support; types of supports are flexible, not tied to particular settings, and can be adjusted if the person's needs change; the process is flexible and informal		7.3.1 the service is timely and flexible in their response to people and their families 7.3.2 the service is flexible in its practices 7.3.3 the service has less constraining work environments 7.3.4 the service uses flexible routines adopted to suit people's needs rather than staff needs 7.3.5 the service supports staff to 'be' with people and to let go of the drive to 'do' 7.3.6 the service is able to easily adjust its supports for people if the person's needs change 7.3.7 the service's processes are flexible and informal	7.3.1 the service is timely and flexible in their response to people and their families 7.3.2 the service is flexible in its practices 7.3.3 the service has less constraining work environments 7.3.4 the service uses flexible routines adopted to suit people's needs rather than staff needs 7.3.5 the service supports staff to 'be' with people and to let go of the drive to 'do' 7.3.6 the service is able to easily adjust its supports for people if the person's needs change 7.3.7 the service's processes are flexible and informal
Attribute 7.3.2 responsiveness	7		
Services that are individualised, responsive and enable people to make choices about their own lives; letting go of the drive ' to do' and focusing more on 'being' with people in creative, flexible, compassionate and responsive ways; suggest removing the professional boundaries of care to become more responsive; . requires staff to have a flexible and responsive approach; being responsive to individual and family characteristics		7.3.8 the service is responsive to the people 7.3.9 the service supports staff to remove the professional boundaries of care to be more responsive	7.3.8 the service is responsive to the people 7.3.9 the service supports staff to remove the professional boundaries of care to be more responsive
Subtheme 7.4 Continuity /consistency of support	*5*		
Attribute 7.4.1 continuity	2		
assigning residents to the same care staff; and experiencing flexibility and continuity		7.4.1 staff at the service are assigned to the same people for continuity	7.4.1 staff at the service are assigned to the same people for continuity
Attribute 7.4.2 staff consistency	3		
instituting consistent staff assignment so that care providers work with the same residents over time; care staff who are sensitized to the person's unique personality, and who are able to interpret responses and behaviours and adjust care practices accordingly		7.4.2 staff at the service are sensitized to the person's unique personality	7.4.2 staff at the service are sensitized to the person's unique personality

Subtheme 7.5 Other organisational factors	*55*	
All appearances of codes for 'organisational factors'	*143*	
Subtotal of appearance of codes for all themes	*1166*	
codes related to context / strategies	679	
TOTAL CODES	1839	

Appendix E: Focus group information sheet and consent form

E1 Invitation and Information sheet

Dear

RE: PhD research into Person-Centredness across Human Services

As you may be aware, I have been conducting some research into person-centredness across the disability, ageing and mental health sectors for a couple of years now. I am happy to say that I have almost finished developing a descriptive framework that will eventually be used in constructing an evaluation tool for use in human services.

I have one more phase to complete prior to finalising the framework, and that's where you come in. I am writing to invite you to participate in a brainstorming session looking at how person-centredness is expressed in practice settings. This invitation is being made to you because of your personal experience in either the use, delivery, design or research of services in disability, ageing and / or mental health. This isn't just about the words, this is about what matters in people's lives.

This brainstorming session will be incredibly focussed during an approximately 2.5 hour-session with a target of identifying and collating examples of person-centredness in practice. Of course, food and wine will be provided to get the thinking juices flowing!

Where:	Curtin University Building 401: 245
	School of Occupational Therapy and Social Work
When:	Wednesday 22nd November, 2017 from 5 to 8pm.
RSVP:	Friday 17th November, 2017 on 92661679, mobile 0422123418 or by email at r.waters2@curtin.edu.au

Please do not hesitate contact me if you have any further queries on 92661679 or r.waters2@curtin.edu.au.

Warm regards

Rebecca Waters

PhD Student
School of Occupational Therapy and Social Work

PARTICIPANT INFORMATION SHEET

What is the purpose of the research?

The aim of the research is to develop a framework of person-centred principles and practices in human services. These principles and practices help shape services to promote the best outcomes for clients or service users. The principles and practices will be later used for evaluation of services and service development.

What are you being asked to do?

We would like you to be a member of a three-hour focus group on person-centredness. We are going to ask you questions about what being person-centred looks like in the practice setting. Participation in the focus group is entirely voluntary and you are under no obligation to take part. You are free to withdraw at any time and you do not have to give any reasons for doing so. If you decide to withdraw from the research, this will not affect you in any way.

What are the possible benefits or risks of taking part in the research project?

We are hoping that the results of this research will help make services for people with disabilities, elders and people with mental health issues more person-centred, and improve services for people. There are no anticipated risks associated with taking part in the research.

Will my participation be kept confidential?

Yes. We will not use your real name or other information that might identify you in the research report and in any publications or presentations. Records of your real name, address and telephone number will be kept only for the purposes of keeping in contact with you during the research project. If you wish, we can send you information about the results of this research once it is completed.

All records associated with this research will be securely stored at Curtin University. When the research finishes, all data will be digitised and stored in accordance with Curtin's Research Data Management Plan for seven years. After this time all records will be destroyed in a secure manner.

Does this research have ethics approval?

This study has been approved by the Curtin University of Technology Human Research Ethics Committee (HR147/2015). If needed, verification can be obtained either by writing to the Curtin University Human Research Ethics Committee, C/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth 6845 or by telephoning (08) 9266 2784.

Who do you contact if you have any questions about the research project?

A/Professor Angus Buchanan

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School of Occupational Therapy and Social Work
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Email: a.buchanan@curtin.edu.au

Professor Donna Chung

Co-investigator
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Email: d.chung@curtin.edu.au

Ms Rebecca Waters

Co-investigator / PhD Student
School of Occupational Therapy
and Social Work
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Phone (M): 0422 123 418
Email: 08721859@student.curtin.edu.au or
r.waters2@curtin.edu.au

E2 Focus group consent form

PARTICIPANT CONSENT FORM

I have been informed of and understand the purpose of the study.

I have been given an opportunity to ask questions.

I understand I can withdraw at any time without prejudice or consequence.

I have freedom to ask for any help.

Any information which might potentially identify me will not be used in published material.

I agree to participate in the focus group as a part of the research study as outlined to me.

_____

Participant Name

_____

Participant Signature **Date**

Appendix F: Copyright permission

Nicole Obrien 8/9/17

[HEAP_3789] Copyright query Details

To: Rebecca Waters

Dear Ms Waters,

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Kind regards

Rebecca Waters
Lecturer | School of Occupational Therapy & Social Work
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Curtin University

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