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

Rebecca Adriana Waters

This thesis is presented for the Degree of 
Doctor of Philosophy 
of 
Curtin University

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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

Date 9 May 2019
Statement of Contributors

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

**Citation**


**Author contributions**

**Eighty percent** contribution by the candidate and primary author. This included: the design and conceptualisation of the review, all searching, acquisition, retrieval and appraisal of the literature, the all data extraction, analysis of findings and drafting the manuscript.

**Twenty percent** contribution by the co-author including: input on the design of the review, data checking, triangulation of the research data, review of the manuscript and revisions.

The author was provided with support to complete this research via the Australian Government Research Training Scheme. The nature and extent of the intellectual input by the candidate and co-authors have been validated by all authors:

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Professor Donna CHUNG
(Co-supervisor)
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

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\(^1\) 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

Chapter 1: BACKGROUND & CONTEXT

Chapter 2: STUDY OVERVIEW & METHODOLOGY

Stage 1: LITERATURE REVIEW & ANALYSIS
504 Sources
1840 Data Points
7 Themes

Stage 2: KEY INFORMANTS
16 Participants
Survey

Stage 3: CONTENT ANALYSIS
Framework Construction

Stage 4: FRAMEWORK EXTENSION
Focus Group
Service Expression Examples

FRAMEWORK OF PERSON-CENTREDNESS FOR HUMAN SERVICES

Honouring the Person
Being in Relationship
Participation / Engagement
Social Inclusion / Citizenship
Strength / Capacity Focussed
Compassionate Love
Organisational Characteristics

Chapter 3 - 6

Chapter 7

Chapter 8: DISCUSSION

Chapter 9: CONCLUSION
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”.

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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 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 interchangeably 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

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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
CHAPTER 1: BACKGROUND AND CONTEXT

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 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

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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

Chapter 1: BACKGROUND & CONTEXT

Chapter 2: STUDY OVERVIEW & METHODOLOGY

Stage 1: LITERATURE REVIEW & ANALYSIS
504 Sources
1840 Data Points
7 Themes

Stage 2: KEY INFORMANTS
16 Participants
Survey

Stage 3: CONTENT ANALYSIS
Framework Construction

Stage 4: FRAMEWORK EXTENSION
Focus Group
Service Expression Examples

FRAMEWORK OF PERSON-CENTREDNESS FOR HUMAN SERVICES
Honouring the Person
Being in Relationship
Participation / Engagement
Social Inclusion / Citizenship
Strength / Capacity Focussed
Compassionate Love
Organisational Characteristics

Chapter 3 - 6

Chapter 7

Chapter 8: DISCUSSION

Chapter 9: CONCLUSION
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

Chapter 1: BACKGROUND & CONTEXT

Chapter 2: STUDY OVERVIEW & METHODOLOGY

Stage 2: KEY INFORMANTS
16 Participants
Survey

Stage 1: LITERATURE REVIEW & ANALYSIS
504 Sources
1840 Data Points
7 Themes

Stage 3: CONTENT ANALYSIS
Framework Construction

Stage 4: FRAMEWORK EXTENSION
Focus Group
Service Expression Examples

FRAMEWORK OF PERSON-CENTREDNESS FOR HUMAN SERVICES

Honouring the Person
Being in Relationship
Participation / Engagement
Social Inclusion / Citizenship
Strength / Capacity Focussed
Compassionate Love
Organisational Characteristics

Chapter 8: DISCUSSION

Chapter 9: CONCLUSION
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 presuppositions 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

CHAPTER 3: STAGE 1: PERSON-CENTREDNESS ACCORDING TO THE LITERATURE

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 care, being strength and goal focused, 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.

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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 [6] has person-centred approaches as a fundamental priority. 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 [10]. The authors’ own experiences were in the area of intellectual disability in the late 1950s 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 [11–14]. 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-
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 [16,7,10], 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 identifying the persons-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, PsycINFO and PsychInfo, for peer-reviewed publications: ‘person centred’ (title) AND disability (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 the 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 is 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., qualitative 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 adjacent or 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 extractions 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 (KW) 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 rapidly 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
systematic and analytic, the above steps were applied with flexibility to allow the researchers to be iterative and reflective 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 these 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 Knowles' 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 clear.

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 focused. The seventh theme identified organisational characteristics and values that underpinned the service expression of person-centredness. The themes are presented with their component elements and references, 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. Honoursing 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 focused upon individuality and recognizing 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's needs 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]. Lowe and Kelly [33] go so far as to say that being "person-centred" provides for individuals to make their own choices, even if those choices are not recommended... " (p125). 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 focused 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 know 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 [38-41]. 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
CHAPTER 3: STAGE 1: PERSON-CENTREDNESS ACCORDING TO THE LITERATURE

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

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 lifegard especially for people with IDDs 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 relationships [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]. Wu-Parbury 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].
CHAPTER 3: STAGE 1: PERSON-CENTREDNESS ACCORDING TO THE LITERATURE

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<tr>
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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 [15].

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 [27,58]. 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 maximizing the potential of a person's potential [54], and providing supports that are focused on community presence, community participation, positive relationships, respect, and competence [49]. Eke [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 Beath [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-
CHAPTER 3: STAGE 1: PERSON-CENTREDNESS ACCORDING TO THE LITERATURE

3.3.5. Being strengths/capacity focused

This theme focuses 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 [56,63,69], focusing on capacities as a part of the whole life experience [51,43], and assuming that people have competencies [49,64]. These elements underpin the characteristics of having high expectations of people [39] 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 care

This theme captures significant but largely intangible elements of care that reflect the needs of being human and support 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 reflects some fundamental characteristics of respecting humanity.

Elements included comfort [77,24], safety [78,42], reassurance [55], compassion [65,79], hope [39,40], love [80], Pennock et al. [2007], freedom [52,81], belonging [56,82], and empathy [83,69]. 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 being a commonly shared humanity which people should be supported to maintain [52,86], 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-focused [68], and providing a continuity of care [28].

A significant element relates 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 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 concepts such as education and ethics. There is much confusion between authors about the fundamental roots of person-centred 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 disinstitutionalisation and the operationalisation of the normalization movement [74], yet person-centred approaches to remission in work with people with intellectual disability is credited by other authors to Carl Rogers, with its roots in person-centred psychological theory 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 proliferation 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 of quality, although what that exactly is, is not clear. Again, this contributes to significant misunderstandings 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,
CHAPTER 3: STAGE 1: PERSON-CENTREDNESS ACCORDING TO THE LITERATURE

3.1. Limitations

There were two perceived limitations to this study. Firstly, the literature was gathered from three large databases: ZINAH, 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.

Funding

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Acknowledgement

There are no acknowledgements in relation to this work.

References

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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

Research Stages

Chapter 1: BACKGROUND & CONTEXT

Chapter 2: STUDY OVERVIEW & METHODOLOGY

Stage 1: LITERATURE REVIEW & ANALYSIS
504 Sources
1840 Data Points
7 Themes

Stage 2: KEY INFORMANTS
16 Participants
Survey

Stage 3: CONTENT ANALYSIS
Framework Construction

Stage 4: FRAMEWORK EXTENSION
Focus Group
Service Expression Examples

FRAMEWORK OF PERSON-CENTREDNESS FOR HUMAN SERVICES

Honouring the Person
Being in Relationship
Participation / Engagement
Social Inclusion / Citizenship
Strength / Capacity Focused
Compassionate Love
Organisational Characteristics

Chapter 8: DISCUSSION

Chapter 9: CONCLUSION
The content of this chapter are under embargo until 25/9/2021.

Pages 39 to 48 have been intentionally removed.
Chapter 5: Stage 3: Creating the descriptive framework of person-centredness using content analysis
The content of this chapter are under embargo until 25/9/2021.

Pages 50 to 69 have been intentionally removed.
Chapter 6: Stage 4: Exploration and identification of service expression examples of person-centredness

FRAMEWORK OF PERSON-CENTREDNESS FOR HUMAN SERVICES
- Honouring the Person
- Being in Relationship
- Participation / Engagement
- Social Inclusion / Citizenship
- Strength / Capacity Focussed
- Compassionate Love
- Organisational Characteristics

Chapter 1: BACKGROUND & CONTEXT
Chapter 2: STUDY OVERVIEW & METHODOLOGY
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Service Expression Examples

Chapter 3 - 6
Chapter 7
Chapter 8: DISCUSSION
Chapter 9: CONCLUSION
The content of this chapter are under embargo until 25/9/2021.

Pages 71 to 83 have been intentionally removed.
Chapter 7: The Framework of Person-Centredness for Human Services (FPCHS)
The content of this chapter are under embargo until 25/9/2021.

Pages 85 to 121 have been intentionally removed.
Chapter 8: Discussion

Chapter 1: BACKGROUND & CONTEXT

Chapter 2: STUDY OVERVIEW & METHODOLOGY

Stage 1: LITERATURE REVIEW & ANALYSIS
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Compassionate Love
Organisational Characteristics

Chapter 8: DISCUSSION

Chapter 9: CONCLUSION
The content of this chapter are under embargo until 25/9/2021.

Pages 123 to 146 have been intentionally removed.
Chapter 9: Conclusion

Chapter 1: BACKGROUND & CONTEXT

Chapter 2: STUDY OVERVIEW & METHODOLOGY

Stage 1: LITERATURE REVIEW & ANALYSIS
- 504 Sources
- 1840 Data Points
- 7 Themes

Stage 2: KEY INFORMANTS
- 16 Participants
- Survey

Stage 3: CONTENT ANALYSIS
- Framework Construction

Stage 4: FRAMEWORK EXTENSION
- Focus Group
- Service Expression Examples

FRAMEWORK OF PERSON-CENTREDNESS FOR HUMAN SERVICES
- Honouring the Person
- Being in Relationship
- Participation / Engagement
- Social Inclusion / Citizenship
- Strength / Capacity Focussed
- Compassionate Love
- Organisational Characteristics

Chapter 3 - 6

Chapter 7

Chapter 8: DISCUSSION

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-focused, 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
CHAPTER 9: CONCLUSION

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.
**References**


REFERENCES


REFERENCES


Patient Protection and Affordable Care Act (PPACA), USA Public Law 111-148, (2010).


*Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.*
Appendices

Appendix A: Ethics approvals

A1 Curtin University HREC Approval (PhD)

MEMORANDUM

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

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 commend 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,

[Signature]

Professor Peter O’Leary
Chair, Human Research Ethics Committee
A2 Curtin University HREC Ethics Amendment (PhD)

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: HRI147/2015

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 HRI147/2015-08 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 area of person-centredness from 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
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 Authorities (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 access; 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 Office for your faculty or the Ethics Office at ethics@curtin.edu.au or on 9356 3784.

Yours sincerely,

[Signature]

Professor Peter O'Leary
Chair, Human Research Ethics Committee
APPENDICES

**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.

---

<table>
<thead>
<tr>
<th>Memorandum</th>
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</table>
| **To** | Professor Errol Cocks  
| | Ms Rebecca Waters |
| **From** | Teena Bowman |
| **Subject** | Protocol Approval OTSW-12-2011 |
| **Date** | 12 September 2011 |

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.

---

**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

---

ORCIO Provider Code 03987J

165
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

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**TOTAL NUMBER OF SOURCED ARTICLES** 1594
**Sample data extraction sheet**

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<td><strong>Article title</strong></td>
<td>Staff perspectives of person-centred care in practice</td>
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<td><strong>Journal</strong></td>
<td>Alzheimer’s Care Today</td>
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<tr>
<td><strong>Data Set 3</strong> (Definition)</td>
<td>&quot;person-centered care is defined at LMADC as &quot;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&quot;:&quot;</td>
</tr>
<tr>
<td><strong>Data Set 4</strong> (Characteristics)</td>
<td>&quot;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.&quot;; &quot;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.&quot;; &quot;However, personhood can be maintained, even potentially restored, through care that supports 4 &quot;global states&quot; 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.&quot;; &quot;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&quot;; &quot;participants are the focus. Participants' interests, needs, and choices are what direct the programming&quot;; &quot;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.&quot;; &quot;the notion of spending time with participants is a deeply embedded facet of the PCC philosophy.&quot;; &quot;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.&quot;</td>
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<td><strong>Data Set 5</strong> (Use)</td>
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<td><strong>Other notes / comments</strong></td>
<td>Critical review of tools to measure person-centeredness - indicates that there are different outcomes as each tool has a different focus.</td>
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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!
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?**

**A/Professor Angus Buchanan**

Chief Investigator

School of Occupational Therapy and Social Work

Curtin University

GPO Box U1987, Perth, WA 6845

Phone: (W) (08) 9266 3632

Email: a.buchanan@curtin.edu.au

**Professor Errol Cocks**

Co-investigator

School of Occupational Therapy and Social Work

Curtin University of Technology

GPO Box U1987, Perth, Western Australia

Phone (W): (08) 9266 3621

Email: e.cocks@curtin.edu.au

**Ms Rebecca Waters**

Co-investigator

School of Occupational Therapy and Social Work

Curtin University of Technology

GPO Box U1987, Perth, Western Australia

Phone (M): 0422 123 418

Email: r.waters2j@curtin.edu.au
PARTICIPANT INFORMATION SHEET

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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.

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

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Email: r.waters2@curtin.edu.au
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

<table>
<thead>
<tr>
<th>Theme 1: Honouring the person</th>
<th>Frequency of code</th>
<th>First iteration</th>
<th>Second iteration</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme 1.1 Individuality/person as expert</strong></td>
<td><strong>234</strong></td>
<td><strong>1.1.1 the person is treated as an individual</strong></td>
<td><strong>1.1.1 the person is treated as an individual</strong></td>
</tr>
<tr>
<td><strong>Attribute 1.1.1 individualised approach</strong></td>
<td><strong>80</strong></td>
<td><strong>1.1.2 the service caters for the person’s varying needs and requirements</strong></td>
<td><strong>1.1.2 the person’s varying needs and requirements are catered for</strong></td>
</tr>
</tbody>
</table>

| Attribute 1.1.1 individualised approach | **80** | **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** |

- 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.

| Attribute 1.1.2 personalised | **10** | **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** |

- 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.

| Attribute 1.1.3 personal preferences | **64** | **1.1.5 the service honours the person’s preferences for daily living** | **1.1.5 the person’s preferences for daily living are honoured** |

- 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.

- 1.1.6 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
- 1.1.10 the person’s preferences for daily routines are honoured
- 1.1.11 the person’s history, needs and preferences are acknowledged and included
- 1.1.12 the person’s life history and preferences are respected in the establishment of a positive relationship with the service
- 1.1.13 the person’s gifts, strengths and dreams are included in implementing the appropriate supports
<table>
<thead>
<tr>
<th>Attribute 1.1.4 person's perspective</th>
<th>30</th>
</tr>
</thead>
<tbody>
<tr>
<td>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</td>
<td></td>
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<tr>
<td>1.1.10 the service strives to understand the person’s perspective and experiences</td>
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<tr>
<td>1.1.11 the service includes the person’s perspective and experiences in implementing the appropriate supports</td>
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<tr>
<td>1.1.10 the person’s perspective and experience are understood by the service</td>
<td></td>
</tr>
<tr>
<td>1.1.11 the person’s perspective and experiences are included in implementing the appropriate supports</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Attribute 1.1.5 person is central</th>
<th>46</th>
</tr>
</thead>
<tbody>
<tr>
<td>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</td>
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<tr>
<td>1.1.12 the person is firmly located at the centre of any process involving them</td>
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<tr>
<td>1.1.13 the person is at the centre of all planning, action and decision-making</td>
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<tr>
<td>1.1.14 the person co-owns the support plan</td>
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<tr>
<td>1.1.15 the person is at the centre of their own story, not their diagnosis or illness</td>
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<tr>
<td>1.1.16 the service encourages the building of an alliance of supporters around the person</td>
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<tr>
<td>1.1.17 the person is the focal point in a service partnership that is both respectful and reciprocal</td>
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<tr>
<td>1.1.18 the service focusses entirely on the interests of the person and keeps them first</td>
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</tr>
<tr>
<td>1.1.12 the person is firmly located at the centre of any process involving them</td>
<td></td>
</tr>
<tr>
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<td></td>
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<tr>
<td>1.1.14 the person co-owns the support plan</td>
<td></td>
</tr>
<tr>
<td>1.1.15 the person is at the centre of their own story, not their diagnosis or illness</td>
<td></td>
</tr>
<tr>
<td>1.1.16 the person is supported to build an alliance of supporters by the service</td>
<td></td>
</tr>
<tr>
<td>1.1.17 the person is the focal point of a respectful and reciprocal service partnership</td>
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<tr>
<td>Attribute 1.1.6 expert</td>
<td>4</td>
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<tr>
<td>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</td>
<td></td>
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<table>
<thead>
<tr>
<th>Subtheme 1.2 Choice / decision making</th>
<th>118</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attribute 1.2.1 individualised decision making</td>
<td>33</td>
</tr>
<tr>
<td>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</td>
<td>1.2.1 the staff assume people have competence in decision-making</td>
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<tr>
<td></td>
<td>1.2.2 the staff use approaches that are open and inquisitive in determining appropriate supports</td>
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<tr>
<td></td>
<td>1.2.3 the person is regularly involved in decision-making</td>
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<tr>
<td></td>
<td>1.2.4 the person directs their own decision-making</td>
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<tr>
<td></td>
<td>1.2.5 the staff support the person’s decision-making autonomy</td>
</tr>
</tbody>
</table>

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<thead>
<tr>
<th>Attribute 1.2.2 choice</th>
<th>59</th>
</tr>
</thead>
<tbody>
<tr>
<td>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</td>
<td>1.2.6 the person is supported to make choices about their own lives</td>
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<td></td>
<td>1.2.7 the person is supported in ways to enhance their own autonomy</td>
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<td></td>
<td>1.2.8 the person is supported to make choices even in the presence of dignity of risk taking and the right to failure</td>
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<td></td>
<td>1.2.9 the person is supported to make informed choices about their own lives</td>
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<tr>
<td></td>
<td>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</td>
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<tr>
<td></td>
<td>1.2.11 the person’s choices are respected</td>
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<tr>
<td>Attribute 1.3.3 shared decision making</td>
<td>26</td>
</tr>
<tr>
<td>---------------------------------------</td>
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</tr>
<tr>
<td>sharing decision making; partnership and negotiations in decision making; facilitating or offering shared decision making; shared action through creative problem solving</td>
<td>1.2.12 the person is an equal participant in shared decision-making</td>
</tr>
<tr>
<td></td>
<td>1.2.13 the service supports shared action through creative problem solving</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Subtheme 1.3 Knowing the person well</th>
<th>92</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attribute 1.3.1 knowing the person well</td>
<td>28</td>
</tr>
<tr>
<td>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</td>
<td>1.3.1 the service seeks to know the person well</td>
</tr>
<tr>
<td></td>
<td>1.3.2 the service seeks to know the person’s significant others, including family and friends</td>
</tr>
<tr>
<td></td>
<td>1.3.3 the service seeks to understand the person’s particularities</td>
</tr>
<tr>
<td></td>
<td>1.3.4 the service has procedures in place that support staff getting to know the person well through spending time with them</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Attribute 1.3.2 narrative / personal history</th>
<th>62</th>
</tr>
</thead>
<tbody>
<tr>
<td>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</td>
<td>1.3.5 the service seeks to find out and understand the person’s narrative and history</td>
</tr>
<tr>
<td></td>
<td>1.3.6 the service uses the person’s life history and narrative to tailor appropriate supports</td>
</tr>
<tr>
<td></td>
<td>1.3.7 the service tailors supports to the person’s life experiences</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Attribute 1.3.3 personal profile</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>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</td>
<td>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</td>
</tr>
</tbody>
</table>

<p>| 1.3.7 the person is an equal participant in shared decision-making |
| 1.2.13 the service supports shared action through creative problem solving |</p>
<table>
<thead>
<tr>
<th>Subtheme 1.4 Self-determination / control</th>
<th>55</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attribute 1.4.1 self determination</strong></td>
<td>25</td>
</tr>
<tr>
<td>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</td>
<td>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</td>
</tr>
<tr>
<td><strong>Attribute 1.4.2 Control</strong></td>
<td>30</td>
</tr>
<tr>
<td>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</td>
<td>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</td>
</tr>
<tr>
<td>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</td>
<td>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</td>
</tr>
<tr>
<td>Subtheme 1.5 Being respected</td>
<td>34</td>
</tr>
<tr>
<td>--------------------------------</td>
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</tr>
<tr>
<td>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</td>
<td></td>
</tr>
<tr>
<td>1.5.1 the person is respected</td>
<td></td>
</tr>
<tr>
<td>1.5.2 the rights and respect for the person are paramount</td>
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<tr>
<td>1.5.3 the service has a nurturing, empowering and respectful culture</td>
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<tr>
<td>1.5.4 the service promotes an approach to care that respects and values the uniqueness of people</td>
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<tr>
<td>1.5.5. the service promotes the dignity and responsibility of each individual person</td>
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<tr>
<td>1.5.6 the service is founded on mutual respect between all people</td>
<td></td>
</tr>
<tr>
<td>1.5.7 the service facilitates partnerships with people that are both respectful and reciprocal</td>
<td></td>
</tr>
<tr>
<td>1.5.1 the person is respected</td>
<td></td>
</tr>
<tr>
<td>1.5.2 respect for the person and their rights are paramount</td>
<td></td>
</tr>
<tr>
<td>1.5.3 the service has a nurturing, empowering and respectful culture</td>
<td></td>
</tr>
<tr>
<td>1.5.4 the person is respected and valued as being unique</td>
<td></td>
</tr>
<tr>
<td>1.5.5 the person’s dignity and responsibility is promoted</td>
<td></td>
</tr>
<tr>
<td>1.5.6 the service is founded on mutual respect between all people</td>
<td></td>
</tr>
<tr>
<td>1.5.7 the service facilitates partnerships with people that are both respectful and reciprocal</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Subtheme 1.6 Being reflective /exploring thoughts &amp; feelings</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.6.1 being reflective</td>
<td></td>
</tr>
<tr>
<td>the doctor and the patient need to be empathic and reflective</td>
<td></td>
</tr>
<tr>
<td>1.6.2 exploring thoughts and feelings</td>
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<tr>
<td>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</td>
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</tr>
<tr>
<td>1.6.2 the person is supported to explore their thoughts and feelings</td>
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</tr>
<tr>
<td>1.6.3 the person is supported to explore their dreams</td>
<td></td>
</tr>
<tr>
<td>1.6.2 the person is supported to explore their thoughts and feelings</td>
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</tr>
<tr>
<td>1.6.3 the person is supported to explore their dreams</td>
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</tr>
</tbody>
</table>

| All appearances of codes for 'honouring the person' | 542 |
**Theme 2: Being in relationship**

<table>
<thead>
<tr>
<th>Subtheme 2.1 Focus on developing relationships</th>
<th>92</th>
</tr>
</thead>
<tbody>
<tr>
<td>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</td>
<td></td>
</tr>
<tr>
<td>2.1.1 the service has a focus on developing meaningful relationships with the person</td>
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<tr>
<td>2.1.2 the service promotes a shared responsibility among staff to develop meaningful relationships with the person</td>
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<tr>
<td>2.1.3 the service involves the person and their family in promoting beneficial relationships</td>
<td></td>
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<tr>
<td>2.1.4 the service supports and develops existing and new relationships</td>
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</tr>
<tr>
<td>2.1.5 the service supports the development of relationships that transcend professional boundaries</td>
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<tr>
<td>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</td>
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</tr>
<tr>
<td>2.1.1 staff at the service focus on developing meaningful relationships with the person</td>
<td></td>
</tr>
<tr>
<td>2.1.2 staff at the service share a responsibility to develop meaningful relationships with the person</td>
<td></td>
</tr>
<tr>
<td>2.1.3 staff at the service involve the person and their family in promoting beneficial relationships</td>
<td></td>
</tr>
<tr>
<td>2.1.4 staff at the service support and develop new and existing relationships</td>
<td></td>
</tr>
<tr>
<td>2.1.5 staff at the service support the development of relationships that transcend professional boundaries</td>
<td></td>
</tr>
<tr>
<td>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</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subtheme 2.2 Family relationships</th>
<th>38</th>
</tr>
</thead>
<tbody>
<tr>
<td>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</td>
<td></td>
</tr>
<tr>
<td>2.2.1 the service actively engages with and welcomes the family’s participation and involvement</td>
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<tr>
<td>2.2.2 the service aims to achieve the most positive outcome for the person and their carer and family</td>
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</tr>
<tr>
<td>2.2.3 the service considers family members and friends as full partners</td>
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</tr>
<tr>
<td>2.2.1 the person’s family are welcome, involved and engaged in the service</td>
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<tr>
<td>2.2.2 the person, their carer and family can expect the staff at the service to work towards the most positive outcome</td>
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<tr>
<td>2.2.3 the person’s family and friends are treated as full partners by the staff at the service</td>
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</tr>
<tr>
<td>Subtheme 2.3 Person - staff partnership</td>
<td>13</td>
</tr>
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<td>----------------------------------------</td>
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<tr>
<td>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</td>
<td>2.3.1 the service supports building support partnerships between the person and staff as a commitment to a strong therapeutic alliance</td>
</tr>
<tr>
<td></td>
<td>2.3.2 the service encourages collaboration and partnerships between people and practitioners</td>
</tr>
<tr>
<td></td>
<td>2.2.4 staff at the service prioritise building support relationships as a commitment to a strong therapeutic alliance</td>
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<tr>
<td></td>
<td>2.2.5 staff at the service encourage collaboration and partnerships between the person and others</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Subtheme 2.4 Being in relation with others</th>
<th>11</th>
</tr>
</thead>
<tbody>
<tr>
<td>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</td>
<td>2.4.1 the service supports the person to be in relationship with others</td>
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<tr>
<td></td>
<td>2.4.2 the service supports the person to be in relationship with caregivers</td>
</tr>
<tr>
<td></td>
<td>2.4.3 the service supports the person to maintain or establish social relationships</td>
</tr>
<tr>
<td></td>
<td>2.4.4 the service supports people to share in everyday life with a sense of nearness</td>
</tr>
<tr>
<td></td>
<td>2.4.1 the person is supported to be in relationship with others</td>
</tr>
<tr>
<td></td>
<td>2.4.2 the person is supported to be in relationship with caregivers</td>
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<tr>
<td></td>
<td>2.4.3 the person is supported to establish or maintain social relationships</td>
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<tr>
<td></td>
<td>2.4.4 the person is supported to share in everyday life with a sense of nearness</td>
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<table>
<thead>
<tr>
<th>Subtheme 2.5 Positive &amp; therapeutic relationship</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attribute 2.5.1 therapeutic relationship</strong></td>
<td>4</td>
</tr>
<tr>
<td>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</td>
<td>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</td>
</tr>
<tr>
<td></td>
<td>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</td>
</tr>
<tr>
<td><strong>Attribute 2.5.2 positive relationship</strong></td>
<td>3</td>
</tr>
<tr>
<td>building a positive relationship; positive interaction in relationships</td>
<td>2.5.2 the service supports positive interactions in relationships between the person and staff</td>
</tr>
<tr>
<td></td>
<td>2.5.2 the person and staff at the service are supported to have positive interactions in relationships</td>
</tr>
</tbody>
</table>
### Subtheme 2.6 Natural or informal support

| 6 | 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 |

<p>| All appearances of codes for 'being in relationship' | 167 |</p>
<table>
<thead>
<tr>
<th>Theme 3: Facilitating participation / engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme 3.1 Meaningful activity / occupation</strong></td>
</tr>
<tr>
<td>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</td>
</tr>
<tr>
<td>3.1.1 the person is supported to be engaged in meaningful activity</td>
</tr>
<tr>
<td>3.1.2 the person is assisted to seek opportunities to engage in meaningful activity</td>
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<tr>
<td>3.1.3 the service acts to assist people to have something interesting to do during the day</td>
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<tr>
<td>3.1.4 the person is supported to do activities they enjoy</td>
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<tr>
<td>3.1.5 the person’s activities and occupations are individualised</td>
</tr>
<tr>
<td>3.1.1 the person is supported to be engaged in meaningful activity</td>
</tr>
<tr>
<td>3.1.2 the person is assisted to seek opportunities to engage in meaningful activity</td>
</tr>
<tr>
<td>3.1.3 the service acts to assist people to have something interesting to do during the day</td>
</tr>
<tr>
<td>3.1.4 the person is supported to do activities they enjoy</td>
</tr>
<tr>
<td>3.1.5 the person’s activities and occupations are individualised</td>
</tr>
</tbody>
</table>

| **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 |

<p>| <strong>Subtheme 3.3 Facilitating independence</strong> | 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 |</p>
<table>
<thead>
<tr>
<th>Subtheme 3.4 Engagement / involvement</th>
<th>13</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attribute 3.4.1 engagement</strong></td>
<td>10</td>
</tr>
<tr>
<td>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</td>
<td>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</td>
</tr>
<tr>
<td>3.4.2 staff at the service foster a genuine engagement with the person</td>
<td>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</td>
</tr>
<tr>
<td><strong>Attribute 3.4.2 level of involvement</strong></td>
<td>3</td>
</tr>
<tr>
<td>An important distinction is the level of involvement of the individual required in order for care to be person centred; being involved</td>
<td>3.4.3 staff at the service have a commitment to a high level of involvement with the person</td>
</tr>
<tr>
<td>3.4.3 staff at the service have a high level of involvement with the person</td>
<td>3.4.3 staff at the service have a high level of involvement with the person</td>
</tr>
<tr>
<td><strong>Subtheme 3.5 Interests / Likes</strong></td>
<td>5</td>
</tr>
<tr>
<td>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</td>
<td>3.5.1 the person’s history, health, needs, preferences, interests, routines and habits inform the type and level of support</td>
</tr>
<tr>
<td>3.5.2 the person’s abilities, values and spirituality inform the type and level of support</td>
<td>3.5.1 the person’s history, health, needs, preferences, interests, routines and habits inform the type and level of support</td>
</tr>
<tr>
<td>3.5.3 the person is assisted to explore and pursue their interests, desires and goals</td>
<td>3.5.2 the person’s abilities, values and spirituality inform the type and level of support</td>
</tr>
<tr>
<td><strong>All appearances of codes for 'facilitating participation / engagement'</strong></td>
<td>78</td>
</tr>
<tr>
<td>3.5.3 the person is assisted to explore and pursue their interests, desires and goals</td>
<td>3.5.3 the person is assisted to explore and pursue their interests, desires and goals</td>
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<tr>
<td><strong>Theme 4: Social inclusion / citizenship</strong></td>
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</tr>
<tr>
<td><strong>Subtheme 4.1 Social / community inclusion</strong></td>
<td>78</td>
</tr>
<tr>
<td><strong>Attribute 4.1.1 community inclusion</strong></td>
<td>29</td>
</tr>
</tbody>
</table>
| 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 |
<p>| <strong>Attribute 4.1.2 community presence</strong> | 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 |</p>
<table>
<thead>
<tr>
<th>Attribute 4.1.3 social inclusion</th>
<th>27</th>
</tr>
</thead>
</table>
| 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 |

<table>
<thead>
<tr>
<th>Subtheme 4.2 Being part of the social world</th>
<th>13</th>
</tr>
</thead>
</table>
| 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 |

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<thead>
<tr>
<th>Subtheme 4.3 Citizenship</th>
<th>6</th>
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</thead>
</table>
| 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 |

<table>
<thead>
<tr>
<th>Subtheme 4.4 Making a positive contribution</th>
<th>5</th>
</tr>
</thead>
</table>
| 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 Focused

**Subtheme 5.1 Strengths/Capacity Focused**  

<table>
<thead>
<tr>
<th>Attribute 5.1.1 Strengths</th>
<th>41</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attribute 5.1.2 Capacities</strong></td>
<td>20</td>
</tr>
</tbody>
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<thead>
<tr>
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<tbody>
<tr>
<td>5.1.1 Staff at the service use strengths-based assessment strategies</td>
<td>5.1.1 The person is assessed using strengths-based assessment strategies</td>
<td>5.1.1 The person is supported to retain their capacities by enhancing their remaining strengths</td>
</tr>
<tr>
<td>5.1.2 The person is supported to retain their capacities by enhancing their remaining strengths</td>
<td>5.1.2 The person is supported to retain their capacities by enhancing their remaining strengths</td>
<td>5.1.2 The person is supported to retain their capacities by enhancing their remaining strengths</td>
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<tr>
<td>5.1.3 The person’s unique strengths are recognised</td>
<td>5.1.3 The person’s unique strengths are recognised</td>
<td>5.1.3 The person’s unique strengths are recognised</td>
</tr>
<tr>
<td>5.1.4 The person is perceived in a positive and proactive manner focusing on strengths and abilities</td>
<td>5.1.4 The person is perceived in a positive and proactive manner focusing on strengths and abilities</td>
<td>5.1.4 The person is perceived in a positive and proactive manner focusing on strengths and abilities</td>
</tr>
<tr>
<td>5.1.5 The person is supported to utilise their capacities and assets rather than limitations or deficiencies</td>
<td>5.1.5 The person is supported to utilise their capacities and assets rather than limitations or deficiencies</td>
<td>5.1.5 The person is supported to utilise their capacities and assets rather than limitations or deficiencies</td>
</tr>
<tr>
<td>5.1.6 Staff at the service search for capacity in the person rather than limitation</td>
<td>5.1.6 Staff at the service search for capacity in the person rather than limitation</td>
<td>5.1.6 Staff at the service search for capacity in the person rather than limitation</td>
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<tr>
<td>5.1.7 Staff at the service act to build capacity to support the person in their community</td>
<td>5.1.7 Staff at the service act to build capacity to support the person in their community</td>
<td>5.1.7 Staff at the service act to build capacity to support the person in their community</td>
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</table>

- 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
- 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 person’s 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.
<table>
<thead>
<tr>
<th>Subtheme 5.2 Assuming people's competence / abilities</th>
<th>13</th>
<th>5.2.1 the person’s competence is acknowledged and assumed in the provision of supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>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</td>
<td></td>
<td>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</td>
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<tr>
<td></td>
<td></td>
<td>5.2.1 the person’s competence is acknowledged and assumed in the provision of supports</td>
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<td></td>
<td>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</td>
</tr>
<tr>
<td>Subtheme 5.3 Having high expectations</td>
<td>6</td>
<td>5.3.1 staff at the service have high expectations of the person’s development and capabilities</td>
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<tr>
<td></td>
<td></td>
<td>5.3.1 staff at the service have high expectations of the person’s development and capabilities</td>
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<tr>
<td>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</td>
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<tr>
<td>Subtheme 5.4 Without concern for limitations / barriers</td>
<td>6</td>
<td>5.4.1 the person is encouraged to express their desires without concern for limitations or barriers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5.4.1 the person is encouraged to express their desires without concern for limitations or barriers</td>
</tr>
<tr>
<td>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</td>
<td></td>
<td>5.4.2 staff at the service focus on the assets of the person</td>
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<td></td>
<td>5.4.2 staff at the service focus on the assets of the person</td>
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<td></td>
<td>5.4.2 the person’s assets are a focus of the service</td>
</tr>
<tr>
<td>Subtheme 5.5 Commitment to positive outcomes</td>
<td>5</td>
<td>5.5.1 staff at the service have a commitment to positive outcomes for the person</td>
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<td></td>
<td>5.5.1 staff at the service have a commitment to positive outcomes for the person</td>
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<tr>
<td>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</td>
<td></td>
<td>5.5.2 the person is supported to get what they want out of life</td>
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<td></td>
<td></td>
<td>5.5.3 the person and the staff at the service share a commitment to actions that will uphold the person’s rights</td>
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<td>5.5.2 the person is supported to get what they want out of life</td>
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<td></td>
<td>5.5.3 the person and the staff at the service share a commitment to actions that will uphold the person’s rights</td>
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<tr>
<td>All appearances of codes for 'strengths / capacity focussed'</td>
<td>71</td>
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### Theme 6: Experiencing compassionate love

#### Subtheme 6.1 Humanity

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<tbody>
<tr>
<td>20</td>
<td>6.1.1 the person is related to as a human being</td>
<td>6.1.1 the person is related to as a human being</td>
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<tr>
<td></td>
<td>6.1.2 the person is acknowledged in the emotional aspects of human existence</td>
<td>6.1.2 the person is acknowledged in the emotional aspects of human existence</td>
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<tr>
<td></td>
<td>6.1.3 the person’s well-being and maintenance is central</td>
<td>6.1.3 the person’s well-being and maintenance is central</td>
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<td></td>
<td>6.1.4 the person’s humanity and everyday life are of primary and central importance</td>
<td>6.1.4 the person’s humanity and everyday life are of primary and central importance</td>
</tr>
<tr>
<td></td>
<td>6.1.5 the person has holistic humanness and is of equal value to any other person</td>
<td>6.1.5 the person has holistic humanness and is of equal value to any other person</td>
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<tr>
<td></td>
<td>6.1.6 the person is respected within a culture of life</td>
<td>6.1.6 the person is respected within a culture of life</td>
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<tr>
<td></td>
<td>6.1.7 the person has absolute value and is worthy of respect</td>
<td>6.1.7 the person has absolute value and is worthy of respect</td>
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</tbody>
</table>

- 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

#### Subtheme 6.2 Comfort

<p>| | | |</p>
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<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>9</td>
<td>6.2.1 the person’s needs for comfort are addressed</td>
<td>6.2.1 the person’s needs for comfort are addressed</td>
</tr>
<tr>
<td></td>
<td>6.2.2 the person’s psychological needs for comfort are addressed</td>
<td>6.2.2 the person’s psychological needs for comfort are addressed</td>
</tr>
<tr>
<td></td>
<td>6.2.3 the person has access to objects, items and activities that provide comfort</td>
<td>6.2.3 the person has access to objects, items and activities that provide comfort</td>
</tr>
<tr>
<td></td>
<td>6.2.4 the person experiences both physical and emotional comfort</td>
<td>6.2.4 the person experiences both physical and emotional comfort</td>
</tr>
</tbody>
</table>

- 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
### Subtheme 6.3 Empathy

Empathy is central to understanding and relating to others. 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. |

### Subtheme 6.4 Hope

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. |

### Subtheme 6.5 Compassion

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

<p>| 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. |</p>
<table>
<thead>
<tr>
<th>Subtheme 6.6 Love</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>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</td>
<td>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</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subtheme 6.7 Belonging</th>
<th>4</th>
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</thead>
<tbody>
<tr>
<td>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</td>
<td>6.7.1 the person experiences a sense of belonging and togetherness</td>
</tr>
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<thead>
<tr>
<th>Subtheme 6.8 Safety</th>
<th>2</th>
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<tbody>
<tr>
<td>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</td>
<td>6.8.1 the person’s safety is protected while maintaining the essence of the person</td>
</tr>
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<tr>
<th>Subtheme 6.9 Reassurance</th>
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<tbody>
<tr>
<td>providing reassurance</td>
<td>6.9.1 the person is reassured when required</td>
</tr>
</tbody>
</table>

| All appearances of codes for 'experiencing compassionate love' | 63 |

197
<table>
<thead>
<tr>
<th>Subtheme 7.1 Staff attributes</th>
<th>40</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attribute 7.1.1 staff attitudes</td>
<td>12</td>
</tr>
</tbody>
</table>

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 | 7.1.1 staff at the service truly relate to the person |
| 7.1.2 staff at the service have positive attitudes and care practices | 7.1.2 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 | 7.1.3 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 | 7.1.4 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 | 7.1.5 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 | 7.1.6 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 | 7.1.7 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 | 7.1.8 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 | 7.1.9 staff at the service have excellent interpersonal skills and know themselves well |
### Attribute 7.1.2 staff empowerment

| 10 | 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 |
|------------------------------------------------|

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 those 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

### Attribute 7.1.3 staff satisfaction

| 18 | 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 |
|------------------------------------------------|

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 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

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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

<table>
<thead>
<tr>
<th>Attribute 7.2.1 values - based</th>
<th>28</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
<td>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.</td>
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<table>
<thead>
<tr>
<th>Attribute 7.2.2 holistic</th>
<th>17</th>
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<tbody>
<tr>
<td>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.</td>
<td>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.</td>
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<table>
<thead>
<tr>
<th>Attribute 7.2.3 holistic</th>
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<tbody>
<tr>
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<td>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.</td>
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</tbody>
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**Subtheme 7.3 Flexibility / responsiveness**

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<tr>
<th>Attribute 7.3.1 flexibility</th>
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<tbody>
<tr>
<td>organisations are timely and flexible in their response to individuals and families/carers; more-flexible care practices, less constraining work organisations, 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</td>
<td></td>
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<tr>
<td>7.3.1 the service is timely and flexible in their response to people and their families</td>
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<tr>
<td>7.3.2 the service is flexible in its practices</td>
<td></td>
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<tr>
<td>7.3.3 the service has less constraining work environments</td>
<td></td>
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<tr>
<td>7.3.4 the service uses flexible routines adopted to suit people’s needs rather than staff needs</td>
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<tr>
<td>7.3.5 the service supports staff to ‘be’ with people and to let go of the drive to ‘do’</td>
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<tr>
<td>7.3.6 the service is able to easily adjust its supports for people if the person’s needs change</td>
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<tr>
<td>7.3.7 the service’s processes are flexible and informal</td>
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<tr>
<td>7.3.1 the service is timely and flexible in their response to people and their families</td>
<td></td>
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<tr>
<td>7.3.2 the service is flexible in its practices</td>
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<tr>
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<tr>
<td>7.3.6 the service is able to easily adjust its supports for people if the person’s needs change</td>
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<tr>
<td>7.3.7 the service’s processes are flexible and informal</td>
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<tr>
<th>Attribute 7.3.2 responsiveness</th>
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<tbody>
<tr>
<td>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</td>
<td></td>
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<tr>
<td>7.3.8 the service is responsive to the people</td>
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<tr>
<td>7.3.9 the service supports staff to remove the professional boundaries of care to be more responsive</td>
<td></td>
</tr>
<tr>
<td>7.3.8 the service is responsive to the people</td>
<td></td>
</tr>
<tr>
<td>7.3.9 the service supports staff to remove the professional boundaries of care to be more responsive</td>
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**Subtheme 7.4 Continuity /consistency of support**

<table>
<thead>
<tr>
<th>Attribute 7.4.1 continuity</th>
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</tr>
</thead>
<tbody>
<tr>
<td>assigning residents to the same care staff; and experiencing flexibility and continuity</td>
<td></td>
</tr>
<tr>
<td>7.4.1 staff at the service are assigned to the same people for continuity</td>
<td></td>
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<tr>
<td>7.4.1 staff at the service are assigned to the same people for continuity</td>
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</table>

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<thead>
<tr>
<th>Attribute 7.4.2 staff consistency</th>
<th>3</th>
</tr>
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<tbody>
<tr>
<td>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</td>
<td></td>
</tr>
<tr>
<td>7.4.2 staff at the service are sensitized to the person’s unique personality</td>
<td></td>
</tr>
<tr>
<td>7.4.2 staff at the service are sensitized to the person’s unique personality</td>
<td></td>
</tr>
<tr>
<td>Subtheme 7.5 Other organisational factors</td>
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<td>All appearances of codes for 'organisational factors'</td>
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</tbody>
</table>
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
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
Chief Investigator
School of Occupational Therapy and Social Work
Curtin University
GPO Box U1987, Perth, WA 6845
Phone: (W) (08) 9266 3632
Email: a.buchanan@curtin.edu.au

Professor Donna Chung
Co-investigator
School of Occupational Therapy and Social Work
Curtin University of Technology
GPO Box U1987, Perth, Western Australia
Phone (W): (08) 9266 3340
Email: d.chung@curtin.edu.au

Ms Rebecca Waters
Co-investigator / PhD Student
School of Occupational Therapy and Social Work
Curtin University of Technology
GPO Box U1987, Perth, Western Australia
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 O'Brien

[HEAP_3789] Copyright query
To: Rebecca Waters

Dear Ms Waters,

Many thanks for getting in touch to query if you can include a reproduction of this work in your PhD thesis. I can confirm that yes this is permitted. Authors can use their articles, in full or in part, for a wide range of scholarly, non-commercial purposes such as: inclusion in a thesis or dissertation (provided that this is not to be published commercially).

For more information about copyright here is a helpful link - https://www.elsevier.com/about/our-business/policies/copyright

Best wishes,

Nicole

Nicole O'Brien
Journal Manager – Health Policy
ELSEVIER | Global Journals Production
rubrien.1@elsevier.com
www.elsevier.com
Stower Court
Banbury Street
Oxford
OX1 2AH

Please do not print this email unless really required.

From: Rebecca Waters [mailto:R.Waters2@curtin.edu.au]
Sent: 07 September 2017 18:45
To: Dash, Minakelian (ELS-CON)
Subject: Re: Production has begun on your article [HEAP_3789] in Health policy

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Dear sir / madam

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Kind regards

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