Reclaiming personhood in later life

Towards a new model of decision-making

Suzanne Jarrad

A thesis submitted for the degree of
Doctor of Philosophy

School of Law
Faculty of Education, Humanities and Law
Flinders University
Adelaide, South Australia

May 2015

Contents

List of Tables 7

Summary **8**

Declaration **9**

Acknowledgements **10**

Introduction **11**
- Faith's story 11

1 Beyond the liberal boundary of autonomy **25**
- I The liberal basis of autonomy 27
- II Affronts and injuries to autonomy 29
  - Damage to selfhood 30
  - Prejudice and discrimination 32
  - Coercion and manipulation 35
  - Paternalism 37
  - Structural constraints to choice 40
- III Personhood and autonomy 42
  - Social persons 42
  - Approaches to dis-enfranchised persons 44
- IV Towards a relational approach 46
- V Conclusion 48

2 Decision-making capacity and the legal domain **50**
- I Decision-making capacity in law 51
  - Consent and capacity in common law 51
  - Decision-making capacity in legislation 54
  - A legislative comparison of the notion of autonomy 56
  - In the shadow of the law 61
- II Contentions and controversies arising from the legal approach 64
  - Cognition, rationality and emotion in decision-making 65
  - Procedural and contextual approaches to assessing capacity 67
  - The assessment of capacity 68
    - Tests and tools 69
    - Issues of objectivity in assessments 70
    - Australian approaches to capacity assessments 72
  - Limitations to the use of capacity assessments 76
- III Law in the everyday 79
- IV Conclusion 84

3 Personhood, dementia, and decision-making **86**
- I Notions of personhood 88
  - Legal and philosophical notions of the person 88
  - Personhood in medicine 91
- II Personhood and Dementia 95
  - Dementia in society 95
  - The concept of personhood in dementia 98
- III Approaches to person-centred decision-making 102
  - The combined contextual/procedural approach 102
  - The partnership/ supported decision-making approach 104

The presumption of capacity approach 107
The hermeneutic/narrative approach 108
IV The ethical and legal interface of personhood 111
A review of ethical principles 111
Perceptions of risk and the legal interface 113
V Conclusion 117

4 Methodology 120
I The research methodology 120
II Study methods 124
Focus Groups 124
Preliminary Scoping 125
Ethics approval- focus groups 125
Sampling and recruitment 125
Data collection 126
Study settings and participants 127
Data analysis 128
Case Studies 129
Preliminary scoping 130
Ethics approval - Hospital 1 and 2 131
Sampling and recruitment 131
Data collection 134
General observations 134
Direct observation of assessment 134
Interviews with assessors 135
Interviews with family members 135
Case file data 136
Additional Case Information 137
Data collection matrix 137
Study setting and participants 138
The patients 139
The assessors 139
The family members 140
Key informants 141
Data Analysis 142
III Methodological Considerations 144
The role of the researcher 148
The focus groups 148
The case studies 148
The hermeneutic journey 150
The past horizon 150
The new horizon 152
IV Conclusion 153

5 Ageing and society 154
I The advocates 154
Role and clientele 154
Notions of personhood and autonomy 156
Prevailing values, attitudes and structures 157
The service structure 157
Prevailing attitudes and values 158
Risk and duty of care 160
Perceptions of decision-making capacity 162

Interactions in the socio-legal domain 165
II The guardians 168
Role and clientele 169
Notions of personhood and autonomy 170
Prevailing values, attitudes and structures 172
The service structure 172
Prevailing attitudes and values 173
Risk and duty of care 176
Perceptions of decision-making and capacity 177
Interactions in the socio-legal domain 179
III Advocates and guardians: commonalities and divergence 182
Role and clients 182
Principles and values 182
Prevailing culture and service structure 183
Perceptions of capacity 183
Interactions in the socio-legal domain 184
IV Conclusion 185

6 Case Studies: the person, context and intervention process 187
I The cases 188
The background 188
Andrei 189
Lewis 189
Kathleen 190
Tom 190
Reg 191
Daisy 192
Precipitating aspects of admission 192
Physical decline/dependency 193
Changes in cognition/behaviour/mood 193
Family dynamics and care limitations 194
Community and residential services 194
II The hospital intervention 196
The stages of the hospital intervention 196
Admission 196
Medical and allied assessment 197
Case plan formulation 197
Communication with patient 197
Execution of case plan 198
Discharge 198
The hospital communication processes 199
The case file 199
Clinical team meetings 200
Ad hoc meetings and discussion 200
Individual perceptions and team dynamics 201
The clinical decision-making process 202
Case example: Andrei 204
Case example: Reg 205
Case comparison 206
III Personhood and the patient 207
Language and personhood 207
Knowledge and respect for patient preferences 209

Personhood in relation to cognitive changes and dementia 211
Practices and attitudes that enhance or diminish personhood 213
Andrei 213
Lewis 214
Kathleen 214
Tom 215
Reg 216
Daisy 216
IV Conclusion 217

Chapter 7 Case Studies: The socio-legal domain 220
I Capacity determinations: a legal analysis 221
The common law standard for capacity determinations 221
Presumption of capacity 222
Evidence of brain impairment 223
Understanding of the specific decision 224
Degree and evidence of incapacity commensurate with the decision 226
Consideration of the merit of the choice 226
The language and reasons of the determination 227
Procedural considerations 229
Procedural fairness 230
Evaluation of the reason for the assessment 233
Accuracy of information 236
II Law in the everyday: a socio-legal analysis 240
The context for law in the everyday 241
Roles and identity 241
The organisational sphere 242
The legal interface and the everyday 243
The knowledge of law 244
Medicine as the dominant authority 247
Attitudes and values about the person 250
The law in action 256
Invoking the law 256
Avoiding the law 256
Adapting the law 257
Resisting the law 258
III Conclusion 259

Chapter 8 Reclaiming personhood and autonomy in decision-making 262
I Autonomy in theory and practice 265
The impact of ageism 265
Cognitive status and autonomy 266
Autonomy and personhood 267
II Decision-making law in theory and practice 269
Capacity determinations in practice 270
Medicine as an alternative source of authority 272
III Toward an alternative model of decision-making 275
Autonomy revisited 275
Faith's story re-imagined 277
A person-centred decision-making schema 280

        Assuming capacity 281
        Knowing the person 282
        Creating choices 283
        Supporting decision-making 283
        The default capacity approach 284
    The interface with law 285
    Future directions 289
        Social awareness 290
        Knowledge transfer 290
        Social Policy 291
        Services 292
        Law 292
        Ongoing research 293
  IV Conclusion 294

Conclusion 296

Appendices 301
  Appendix 1 The common law basis of decision-making incapacity 302
  Appendix 2 Common tests and tools used in capacity assessment 309
  Appendix 3 Ethics Approval letter 1 310
  Appendix 4 Ethics Approval letter 2 312
  Appendix 5 Participant Information and Consent Sheets 314
  Appendix 6 Questions for focus group participants 332
  Appendix 7 Interview questions for family member 333
  Appendix 8 A person centred decision-making schema 334

Bibliography 340

List of Tables

Table 1 Focus group 1 participants………………………………………… 127

Table 2 Focus group 2 participants………………………………………… 128

Table 3 Case study data collection matrix………………………………... 137

Table 4 Age, gender and diversity of subjects……………………………… 139

Table 5 Assessors conducting capacity assessments………………………... 140

Table 6 Family member relationship and place of interview……………….. 140

Table 7 Key informants and professional role……………………………… 142

Table 8 Home circumstances and precipitating event to admission………... 193

Table 9 Comparison of aspects preceding admission………………………. 195

Table 10 Case notes pertaining to patient admission………………………… 197

Table 11 Analysis of the stages during the hospital admission………………. 198

Table 12 Matrix of key decision-making in the hospital stages……………… 203

Table 13 Record of patient preferences by profession……………………….. 210

Table 14 Evidence of brain impairment for legislative threshold……………. 224

Table 15 Analysis of content of observed capacity assessments……………… 225

Table 16 Aspects of procedural fairness………………………………………. 232

Table 17 The trigger for the assessment and professional involved…………... 236

Table 18 Information gathering about case by assessor………………………. 237

Table 19 The stages of the person centred decision-making schema…………. 285

Summary

The freedom to be autonomous is highly valued in society, and is a key principle underpinning law. Literature indicates that the freedom to make our own decisions is affirming of identity and selfhood, and persons can experience powerlessness when autonomy is not recognised. Ageism, paternalism, medicalised practices, and a variable understanding of the use of law undermines some of the protections of law in enhancing the autonomy of vulnerable older persons who may not meet the capacity threshold. At the same time, new understandings about decision-making, autonomy and personhood challenge this traditional approach towards persons and its exclusionary nature, with new concepts of autonomy emerging.

Based on empirical research including focus groups and in-depth case studies, this thesis explores the moral and legal personhood of older persons experiencing cognitive changes. This thesis engages a unique approach that recognises and integrates cross-disciplinary knowledge and perspectives towards the phenomenon of decision-making. The socio-legal findings give substance to the idea that autonomy is contextual and relational, and assist us to identify structures and relationships that diminish autonomy and reduce well-being. The findings illustrate the way law is interpreted in the everyday world, and how law is invoked, avoided or adapted in relation to decision-making.

The thesis argues that greater attention to person-centred practices is required, which recognise the value of the person beyond cognitive definitions, and which maximise autonomy and personhood through inclusive decision-making. Capacity assessments, though legally necessary in a minority of situations, should be regarded as a last resort. This approach requires community and health professionals to have a greater knowledge of law. It also demands a better understanding of the interface between law and society, respect for personhood, and a focus on justice. The thesis concludes by proposing legal and cultural strategies that would enable person-centred decision-making.

Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed Suzanne Jarrad

Date 28/5/15

Acknowledgements

This thesis has been possible due to the reality of relational autonomy –from the relationships and events that have shaped my life to the point of choosing this project, and through the support of others to bring it to fruition.

I would like to thank Chris Reynolds, who facilitated my candidacy and provided initial supervision, along with Alan Leaver, and David Worswick. I would also like to acknowledge and thank my current supervisors, Margaret Davies, Carol Grbich and Susannah Sage-Jacobson, who have supported me throughout the remaining journey of learning and synthesis. Their respective areas of critical legal theory, elder law and social science research have provided a scintillating and supportive foundation to my endeavours. In particular, a special thank you to Margaret for her work in ‘unpacking my brain’ with the whiteboard and providing the resources that were intellectual stretching: all aiding me to reach a significant ‘new horizon’ of understanding, particularly of law in the everyday.

I would also like to thank my postgraduate colleagues and the staff in the Flinders School of Law – both for their collegial support and interest, and their practical help. I have benefitted from the immersion in things ’legal’ and of being part of this community of learning.

I also thank Ellie Nitschke, Marilyn Crabtree, Kathryn Flynn, Margaret Bulling, and Pam Bottrill, who facilitated the research project and recruitment, and to all those who contributed as research participants. Thank you to Mavis Sansom for her work in transcribing the interviews.

I also thank family and friends for their interest and support over a sustained length of time, and especially to my husband Alan for his constant encouragement. Finally, I dedicate this work to Joy and Miriam, whose experiences in later life confirmed for me that there must be a better way to support and respect unique older lives.

Introduction

This thesis explores the legal and moral personhood of persons who experience changes to their cognition in later age, through a focus on decision-making, as the exercise of autonomy. I examine the constructs, principles and practices of decision-making capacity, and the related domain of law. I explore the interactions between the social and legal domain in relation to changing perceptions of autonomy and personhood, and give attention to the relationship between respect for persons and self-determination.

I begin this exploration with the story of Faith. This fictional narrative describes a journey over time from an independent, self-contained and private existence to one ultimately of dependency and restriction in an environment shared by others unknown to her. It is characterised by changes in health, cognition, social relationships and personal autonomy. It is a commonplace story enacted daily in an ageing Australia, but of profound consequence to persons like Faith and those in relationship with her.

Faith's story

Faith is a 79 year old optimistic and vivacious person who has lived alone since the sudden death of her husband fifteen years earlier. She has no children. Faith has limited close family, with an ill brother and a deceased sister, and some nieces and nephews and several cousins whom she sees occasionally. Faith's life consists of her church, garden and neighbourhood. She attends church each Sunday and spends most of her day in her rambling garden. She finds company from talkback radio and evening television.

Faith's neighbours include Mary across the road, and a couple next door, Andrew and Sarah, who have three children, and invite Faith regularly for meals. Faith relies on Andrew for household maintenance problems, apologising for 'being a bother'.

While fit from walking, Faith has heart disease and thyroid problems, and takes a number of medications. After persistent headaches and subsequent X-ray, Faith is *told by her GP, Dr Martin, that bone spurs on her neck vertebra are causing reduced blood flow to her brain and that she would require surgery. Faith is informed that she could expect to have memory loss in the future.*

Following her surgery Mary visits Faith in hospital and reports that Faith emerged from the operation 'talking to the fairies'. Sarah visits Faith who describes her hallucinations and how she can't tell at times as to what is real and what isn't. After the hallucinations cease a discharge date is planned but Mary has concerns and informs the hospital staff that Faith should not return home as it is 'too risky'. With discharge delayed, Sarah visits and finds Faith very subdued, telling Sarah that 'she isn't allowed to go home'. Sarah rings the social worker of the ward who relates Mary's concerns about Faith returning home alone, and Faith's resistance to alternative care.

Sarah suggests to Faith that she stay in Sarah's home for a few days upon discharge but Faith does not see the need, so Sarah offers to stay in Faith's house for a few nights after her discharge. Faith, while declaring it was unnecessary, agrees to the option. Sarah informs the social worker and Faith's discharge is organised for the next day. Mary is perturbed but offers to bring Faith home. On arriving home Mary sees that Faith 'is fine' and tells Sarah there is no need to stay overnight after all. Sarah visits and finds Faith pottering happily in her house, with a big smile on her face. She offers to stay overnight but Faith declares it is not necessary, so Sarah checks on her morning and evening for the next few days.

At the follow up visit, Dr Martin tells Faith that she needs to get her affairs in order by giving Enduring Powers to family members. As Faith's brother is ill her only option is her nephew, Graham, and the paperwork to appoint him as her Enduring Power of Guardian and attorney is completed.

Shortly after this event, Faith tells Sarah that Graham has taken her to see the church's retirement village and that her name has been put on a waiting list. She says she isn't at all ready for this but that Graham is insistent. A few weeks later Faith visits Sarah in a highly agitated state, saying that a unit in the retirement homes has been offered but that it was much 'too soon'. Faith says that she would *'have to' sign the form but after some days of distress Faith refuses the offer, telling Graham that she 'is not ready for that yet!'*

Over the next two years, Sarah notices increasing signs of forgetfulness in Faith that had not been apparent before. Faith misses some medical appointments and has overdue bills. Her hair, usually immaculately set and dyed, is unkempt. Sarah assists Faith with medical and hair appointments, and Graham organises for bills to be paid directly. The doctor organises a home assessment with the clinic nurse, with a subsequent referral to Meals on Wheels and the District Nurse, but Faith refuses other home care services offered, saying that they are unnecessary.

Sarah finds increasing disorganisation in Faith's house. Papers are hoarded and fresh food is on top of the fridge, which is full of out of date food. Faith allows Sarah to clean out the fridge but refuses her offer to wash Faith's clothes.

As Faith's memory continues to deteriorate she remains cheerfully pottering in the house and garden, though with increasing disorder. She receives two visits a day by the District Nurse for medication as well as Meals on Wheels every weekday. Graham visits Faith on some weekends with groceries but Faith speaks negatively of Graham, saying she 'doesn't trust him'. After accusing Graham of coming into her house at night and taking her papers, Graham contacts Dr Martin and medication is prescribed for Faith's paranoid delusions. A few weeks later Sarah begins to notice changes in Faith's behaviour. She is extremely confused and walks with stiff mincing steps and has a mask-like expression. Sarah contacts the doctor's surgery and Dr Martin visits and ceases the medication. Some of the extreme symptoms abate, but Faith's confusion remains. Sarah suggests dementia home care services but Graham says he has 'things in hand'.

An Aged Care Assessment occurs and Graham lists Faith's name for residential care, though she becomes very agitated at any suggestion of leaving her home. A bed in a dementia unit becomes available but Faith refuses emphatically. Graham contacts Dr Martin and she makes a referral to a geriatrician, who visits Faith. He assesses her as having advanced dementia, 'lacking insight' into her situation, and not capable of caring for herself. They convince her that a short-term respite stay is needed.

Faith reluctantly assents to this course of action. In the residential care facility Faith is agitated, confused and keeps asking to go home. She is prescribed sedatives by the facility doctor and develops delirium, sleeping during the day and wandering restlessly at night. Her appetite is reduced. The Director of Care confirms to Graham that Faith is incapable of living independently, and Graham utilises his Power of Guardianship to change Faith's respite stay into permanent admission.

Graham informs Sarah and Mary that Faith will not be returning home, that the state of the home was 'disgusting' and that Faith should have gone into the home years ago. At the facility, Sarah finds Faith to be neat and immaculate, but confused and vague. Faith recognises Sarah, but doesn't know where she is and is disinterested in her room and belongings. On subsequent visits Faith is vague and does not appear to recognise Sarah or respond to conversation with her or others.

Faith's story can be analysed through many different perspectives – the organic progression of disease, population demographics, social policy, the human lifecycle, human rights, and the role of the state in protecting its citizens, amongst others. Each of these approaches provides a different frame on Faith's later life and each reflects a truth about her situation with differing emphases. While these are valid perspectives, the interactions within the broad domain of law are my primary interest in this thesis.

A first glance at Faith's story does not suggest an active role of law in a popular sense – there is the visit to the lawyer, but otherwise little to suggest that law has a place in Faith's life, such as the courts or use of law enforcement. However, law's role, while appearing subtle or indifferent in this example, has a profound influence on the elements typified in this story, 'casting a shadow' over the arena in which this story unfolds (Galanter 1981). In this shadow, law shapes 'the values, beliefs, experiences and behaviour patterns' in everyday life through an underlying authority that is usually not discernible to the ordinary person, but which can be illustrated with examples from Faith's story (Engel, 1998 124).

In the early part of the story, there is the depiction of Faith in her everyday life as living freely and independently within the practical circumstances of her situation – tending to her home and garden, pursuing activities of pleasure and necessity, building new relationships, and living within the norms of civil society. She has created a life of meaning based on her personal motivations and values, and is self-contained but also connected to others, while living simply with purpose and meaning.

Law has provided Faith with the protected space in which she can live her unique life. Based on the principle of liberty, law asserts the right of citizens to live as they wish, by limiting the interference of others. Law achieves this by maintaining rules developed through a process of political consensus in liberal western democracies, usually based on respect for autonomy. Faith demonstrates the benefits of this liberty in determining the direction and shape of her life through free choices within this broad mantle of protection, though she may take such freedoms for granted.

In limiting the interference of others, law also imposes a reciprocal requirement on Faith to respect the autonomy of others, demonstrating the principle of equality of persons before the law. Apart from these constraints, Faith is free to live the life that she determines, within her personal and material resource limitations.

Law in western societies also goes beyond creating this space by ensuring the provision of fundamental resources of life to enable Faith to live freely and well. Various statutes, associated policies, and regulations have created the infrastructure of a ‘civil society’. Faith can access affordable medical treatment, public transport, safe food and information, among many other resources offered by the State. She is also provided with a secure financial pension to pay for the needs of life, and if fiscally careful, the freedom to purchase some of her ‘wants’. In return, Faith makes her own contributions to civil life through social participation and through the paying of taxes in her early life.

When requiring surgery, Faith exercises her autonomy and agency within the shadow of the law and gives consent to medical professionals to undertake medical treatment. Made voluntarily and without coercion, her underlying right to body inviolability comes within the shade of the law.

Faith’s familiar world tilts after the surgery with the experience of hallucinations. She finds reassurance that the voices invading her consciousness are a result of anaesthesia and will fade. When Mary alerts hospital professionals about the potential risks in Faith returning home, the laws of negligence trigger a duty of care response, and the clinician tells Faith that she is unable to go home alone. Within law’s shadow, there are competing claims, and a resulting impasse.

Faith’s lack of knowledge of her rights to leave her hospital, combined with her vulnerability and submissiveness to authority, impacts on her situation. Physically, Faith is still recovering from her surgery, with some pain and restricted movement in her neck, and she wishes to return home to convalesce. Despite her claims that she will be ‘fine’ back in her own home, the healthcare team remained concerned and do not give priority to her choice, despite lack of evidence of incapacity. She does not involve any of her extended family, who might advocate for her, in her predicament. Overall, there is a reduction in Faith’s ability to assert her autonomy, and she becomes passive and increasingly depressed.

Sarah, one of Faith’s neighbours, resolves the impasse by offering to stay with Faith upon her discharge. Though later proving unnecessary, this solution has minimised possible risks to Faith, and the hospital’s fear of a possible negligence claim is resolved. Discharge occurs and along with it, her status as a patient concludes and hospital concern for Faith’s risks or recovery ends. Her medical care is handed back to her doctor and her general safety to the informal relationships with her neighbour.

Later, Faith’s doctor talks with her about her prognosis and the need for future planning. Law aids Faith to extend her autonomy into the future by selecting someone to make decisions on her behalf within the legal shadow of substitute decision-making provisions. In suggesting family members for the role of future decision-making for Faith, Dr Martin acknowledges the special role of family as supported in law, and also offers an option which gives Faith the greatest personal control, and the least interference by the State. Faith also has the freedom to express her autonomy through not taking the Doctor’s advice, or by selecting someone else to be her future decision maker, though this would require that she understand these implicit freedoms.

With Faith appointing Graham with her Enduring Power of Guardianship, he oversteps his legal obligations by planning the accommodation aspects of Faith’s life, despite her still meeting the autonomy threshold. These plans do not reflect what is important for Faith in the tenor of her life, and she has the confidence to exercise her autonomy and refuse his accommodation plan. This may not have been the case should Faith have been unwell or sufficiently intimidated to submit to Graham’s plan. While law provides some protection regarding undue influence, it requires initiation by parties who know the law.

In the situation where the person’s autonomy is fluctuating, the law requires the substitute decision -maker to consider the wishes and preferences of the person. Law also provides Faith with the opportunity to revoke Graham’s Enduring Power of Guardianship while she is still capable. Both of these aspects require a level of legal consciousness of the parties, and in the absence of this legal knowledge, Faith is vulnerable.

Faith chooses to maintain living in her own home even though her day-to-day functioning slowly deteriorates. The nephew’s concerns about Faith’s paranoid claims, and the subsequent impact of anti-psychotic medication tips this fragile balance of protection and non-interference. The doctor observes Faith as having advanced dementia and as unable to manage at home, with her condition requiring residential care. When Faith refuses this option, the doctor finds that she is ‘lacking insight’ into her situation, which is a legal marker in health law for decision-making incapacity.

The shift from Faith’s autonomy as primary, to others determining her best interests, is immediate. Triggered by her refusal to contemplate respite care, Faith’s view of what she wants conflicts with the view of medical authority of what she requires. Her loss of insight from dementia justifies their intervention. While the cognitive changes and increasing disorganisation have been occurring slowly over time, Faith’s paranoia and the resultant reaction to the medication given in response have brought the situation to a critical point. Faith’s autonomy to live as she wishes is lost virtually overnight, along with the familiarity of her home and her freedom. The doctor, specialist and aged care facility align with the solution of residential care, following the request from the nephew for advice in a situation that he was finding unworkable.

Under pressure, Faith assents with great reluctance to short-term respite, and finds herself in a secure unit, which is commonplace for people with dementia. In reluctantly moving from her home to an unfamiliar environment, she reacts with increasing agitation, especially as her request to return home is disregarded. This reaction, followed by the effects of sedation, confirms for those caring for her that she is not capable of returning home.

Faith has lost any remaining control over her life. Though others have deprived her of her liberty, this does not trigger any scrutiny. For an autonomous person, this loss of liberty would be unlawful, but passes unnoticed in the current situation of Faith’s perceived requirement for physical care and safety. Staff at the facility viewed Faith’s verbal requests to go home as part of her mental inability to understand the care she requires. Consideration by others of Faith’s best interests outweighs respect for her autonomy.

The quality of the relationship between Graham and Faith is not examined in this process. The doctor does not question the decisions that Graham makes on Faith’s behalf, even though there are relevant legislative principles such as the need to seek the person’s preferences, and to maintain a familiar environment and activities where possible. Faith is viewed as not managing due to her dementia, triggering the legal decision-making authority of her nephew as her next of kin, due to the Enduring Power of Attorney. Even without this authority, the doctor would have presumably given primary consideration to Graham’s concerns as her next of kin. There is no attempt to seek alternatives that may have maintained Faith at home for a while longer, such as the use of dementia care services, or an assessment of the risks and benefits to her arising from residential care. There is an assumption that residential care is the only option.

Faith’s loss of home and freedom, and subsequent well-being, was not a consideration in relation to her progressive dementia and her clear failure to manage. There were no other alternative voices in her extended family and no scrutiny of this life-changing decision by any other authority. This basic freedom to make choices and determine her life’s direction ceased suddenly and irrevocably, and Faith’s personhood, as endowed by others, was diminished.

There is a range of significant variables operating in this story. Faith’s relationships, her unique view and experience of life, education, personality, values, and the decisions and choices she makes create the particular context for her life and its expression in the space of freedom that law provides. Such aspects shape the individualised expression of her autonomy and personhood. Similarly, others in Faith’s story also provide contextual influences based on their personality, values, knowledge, obligations, resources and relationship with her. These aspects comprise the private and free life of citizens that has expression in the space created, maintained and influenced by law.

There are broader factors operating contextually in this space and interacting with law, such as social norms about ageing, risk aversion, professional knowledge and values, the provision of public services and varying levels of choice, and law’s instruments to prevent harm. In everyday life these factors are shaped by law and also, in turn, change law, in a dynamic relationship: ‘everyday life constitutes law and is constituted by it’ (Engel, 1998, 126).

Faith’s story is indicative of the complexity and nuances in the lives of older people whose autonomy is impacted by neurocognitive changes. Central to the story is the role of autonomy, and the understanding of the characteristics of autonomy by others. Debates regarding the nature of autonomy are ongoing but critical to issues of justice for those who may not measure up to the traditional views of the autonomous person.

Views held by, and subsequent actions by, significant others who had a relationship with Faith had powerful influences on her story. The extent of their understanding of Faith and her values and life meaning, and their perceived responsibilities, socially or legally mandated, interacted with the normative aspects present in her story and contributed to her changing personhood. The medical subculture, with its own values and interpretation of legal requirements and practices, also had an effect on Faith's autonomy.

While moral personhood is one part of the story, within this narrative Faith also holds attributes of legal personhood, which endow her with some rights and protections available equally to all citizens. Common law and legislation provide methods to resolve common problems in society and knowledge of these, and their applied use and implementation vary. The understanding and application of law by persons in 'everyday' life (Sarat and Kearns 1994) interacts with these other aspects and further shapes the expression of her legal personhood.

The transition from an autonomous person to one of dependency through the related effects of ageing and disease is one enacted daily in developed countries where improvements in living standard, health promotion and advances in medicine have seen increasing longevity (Australian Bureau of Statistics, 2012). Along with older age has come increased prevalence of disability, of which neurocognitive disorders such as dementia are increasing in both prevalence and incidence.[1]

While the changes in ability to live autonomously can affect persons with a range of conditions, those with dementia are a significant group due both to the fluctuations in cognition and memory over a prolonged period of time (Fazel, Hope and Jacoby 1999), and the increasing size of this group as Australia's population ages (Alzheimer's Australia 2006).

---

[1] 'It is estimated there are 266,574 people with dementia in Australia in 2011. This is projected to increase to 553,285 people by 2030, and 942,624 people by 2050' (Deloitte Access Economics, 2011, 5). It is estimated that a thousand new people are diagnosed each week with this due to steadily increase over the next four decades (Access Economics 2005).

Neurocognitive illness associated with ageing is a relatively new phenomenon in western society, challenging traditional approaches to persons and their autonomy. Historically, cognitive disability from intellectual impairments and mental illness took familiar trajectories and led to specific service responses. The extension of life expectancy has led to a rapid rise in cognitive disorders related to ageing, where for an extended period of time autonomy may fluctuate. The progression of dementia creates a continuum along which capacity to make decisions is gradually more impaired, and this raises the issue of who determines when the person can no longer be self-determining and by what standard, while there are those that challenge this legalistic approach as no longer appropriate (Wood and Pratt 2005; O'Connor and Purves 2009).

Societal norms and values about older people affect the views of service providers, health professionals and the community. Older people are seen as 'different' to the rest of the younger population. Negative attitudes towards older persons are prevalent, with one example being that of discriminatory practices towards older persons in employment (COTA 2014). In addition, disability increases with the chronic illnesses affecting older age persons in later age and adds to the reduced status of older people in the eyes of others, especially as cognitive decline in dementia is stigmatized (Alzheimer's Australia 2012a).

The approach of the law to transitions in the status of persons, and their decision-making within law's shadow, has led to increasing debate across disciplines. Central to this debate is the seemingly non-commensurable approaches of moral personhood and legal personhood, and the limitation of the liberal notion of autonomy in relation to persons who do not achieve the capacity threshold. There is increasing interest in the challenging interface between dementia, law and decision-making and the need for further debate and research (O'Connor and Purves, 2009).

At the same time, the everyday practices in this area are in dynamic relationship with law, as while they are shaped by law, they are also acting on law. For example, there has been significant guardianship law reform in the United Kingdom with the *Mental Capacity Act 2005,* and a substantial review of guardianship legislation in the

Australian state of Victoria (Victorian Law Reform Commission, 2011). The Australian Law Reform Commission has recently released their Inquiry into Equality, Capacity and Disability in Commonwealth Laws, investigating the ‘rights for people with disability to recognition before the law, to legal capacity and … freedom to make one’s own choices…’ with regard to the United Nations Convention on the rights of Persons with Disabilities (Australian Law Reform Commission 2014, 9).

Governments have also given attention to policy issues in this regard. For instance, the Attorney General in New South Wales has explored the protection of rights for people with decision-making impairment resulting in the development of a toolkit to guide professionals (NSW Attorney General’s Department, 2008). The Commonwealth Inquiry into Older People and the Law noted that there was little guidance in capacity assessment available for legal and health professions and recommended that a ‘nationally consistent approach to the assessment of capacity’ be developed and implemented (House of Representatives Standing Committee 2007, 91). Overall, this focus in policy and law represents a growing urgency and importance for new approaches towards the area of decision-making capacity.

In this thesis, as an outsider to law rather than a legal practitioner, my focus is on the impact and interactions of law in everyday life, and by extension, the law’s role in facilitating or constraining human flourishing and well-being, within which decision-making is central. This approach necessitates the exploration of autonomy, personhood, and the legal domain, with the understanding that these aspects together create an intrinsic framework: ‘self, autonomy, and rights and law are each tied to each other – a set of ideas, beliefs, practices and institutions’ (Nedelsky 2011, 5). As such, my approach will take into account the nature of social construction on persons and society. I will use law to frame this analysis with particular attention to the relationships and structures in society that emanate from law’s pervasive influence. These in turn shape law, and support or inhibit the autonomy and well-being of the person. Within this approach, autonomy and personhood is redefined to fit contemporary understanding.

Commencing with the liberal ideal of the individual person as underpinning law, in the first chapter I summarise the key elements and benefits of this model and outline the major critiques and limitations of the liberal approach. This leads to a consideration in Chapter 2 of the effects of the prevailing liberal ideology on approaches to decision-making in law, and the gradual evolution of a broader notion of autonomy. This chapter also explores the way law can be interpreted and adapted in the everyday world. With the intrinsic relationship between autonomy, law and self, the third chapter gives a focus on models of personhood, and gives an example of medicine's approach to the person. The idea that the context within which each person lives shapes and contributes to their personhood reflects a social constructionist perspective, and the implications of this phenomenon for persons with diminishing cognition is explored. This leads to alternative approaches to decision-making than currently defined through the rational cognitive approach of law.

From this basis, a methodology of focus groups and in-depth case studies was constructed to gather data in the everyday world, and is described in Chapter 4. Chapter 5 provides an analysis of the perspective of guardians and advocates in their championing of persons with intact and challenged cognition, highlighting some impediments to full personhood. Chapter 6 introduces six case study participants in a hospital setting, with analysis of the interactions and informal decision-making processes in this setting providing evidence of depersonalisation and exclusion from decision-making. In Chapter 7, there is an analysis of the formal capacity assessments of these participants, illustrating a disparity between theory and practice. With the interpretations of law shaped by limited legal knowledge, the variable values of the actors in this domain, and the prevailing norms of the medical culture, come into focus.

In the final chapter, I discuss these findings, emphasising in particular the assumptions, myths and prejudices about cognitive changes and legal capacity, which adversely affect the personhood of those vulnerable from physical, cognitive and social ageing. I argue that the relational construct of autonomy is valuable in providing a fuller understanding of this concept, providing insight into how relationships and structures in society enhance or diminish autonomy, including ways in which it is understood by law.

Within the socio-legal domain, the implementation of the legal capacity approach is adapted to fit the prevailing norms and serve medicine's purposes, leading to reduced personhood and controlled outcomes for vulnerable persons. This leads to the conclusion that capacity determinations in the informal domain should be a last resort. Independent assessment is desirable where the decision is of a personal or social nature, rather than related to a medical treatment. If this is not available, independent scrutiny is required as a safeguard where the outcome of a determination leads to lifestyle restrictions for the person.

From the perspective of law's role in society, there is often freedom to resolve issues informally without invoking the use of formal law. I extend this to include the avoidance of invoking the legal construct of capacity unless absolutely necessary, to require a high and scrutinised threshold before any assessment occurs. While the capacity construct has a role to serve law and therefore society's interests, care must be taken that it is not misused as a tool of social control in order to serve specific interests.

From the research findings, I conclude that there is a need for greater focus on enhancing decision-making capability and maximising options within the space provided by law. Both the ends and the means of the decision-making process can enhance autonomy. Using decision-making approaches advanced by recent literature, and combined with learning from this research, I propose an idealised person-centred model of decision-making that is respectful to each unique person. This model aims to increase the transparency of socially constituted constraints to autonomy, seeking outcomes as congruent as possible to the person's personal priorities and values, as is practicable. It recognises the interconnectedness of the person as situated within a fuller network of relationships and societal structures, with its constraining power differentials, resource constraints and human limitations. Finally, I indicate the different mechanisms that can be utilised to further advance person-centred decision-making across the socio-legal domain.

1 Beyond the liberal boundary of autonomy

The thesis commenced with a story about Faith and her transition from a state of privacy and independence to one of vulnerability and dependence on others, and constrained self-determination. As the basis for freedom in decision-making and acting on one's own choices, autonomy is central to this story. Faith's story illustrates several aspects of her autonomy. In the earlier part of her life, Faith's freedom to shape her life was evident in the individualised interests she pursued and the friends she made. The minutia of each choice was an expression of her autonomy, which created the uniqueness of her life. While she was subject to citizenship requirements such as paying taxes, and limitations imposed by her financial circumstances, health, widowhood and socialisation, Faith was free to pursue those things in life that had meaning and benefit to her, without unwanted intervention.

The liberal notion of autonomy is a dominant ideal that pervades society. The idea of personal liberty as a right is so imbedded in the social fabric of western democracies that those who enjoy autonomous action are rarely aware of the everyday privileges of this political and social freedom. Agich (1990, 15) comments:

> *...actual autonomy is always present, though sometimes submerged from view as individuals go about their daily lives. It is because autonomy is always present that it is so difficult to bring into view. Actual autonomy is utterly ordinary and unremarkable most of the time.*

In this description, autonomy takes form as the freedom of individuals to make everyday choices, without interference by others, as described in Faith's story. However, as an abstract concept, autonomy has variable meanings and is given different attributes in different contexts. For instance, autonomy is described to have benefits for persons such as facilitating individual self-awareness, self-development and authenticity (Kerridge, Lowe and McPhee 1998), and in satisfying a person's intrinsic needs for self-determination (Mill 1906; Deci 1980). It is understood as 'a kind of achievement' and necessary for well-being (Raz 1986, 204). The range of 'diffuse meanings' given to the concept of autonomy is further described by Agich (2003, 6):

> *Autonomy is taken to be equivalent to liberty…self-rule, self-determination, freedom of will, dignity, integrity, individuality, independence, responsibility, and self-knowledge; it is also identified with the qualities of self-assertion, critical reflection, freedom from obligation, absence of external causation, and knowledge of one's own interest, and is related to actions, beliefs, reasons for acting, rules, the will of others, thoughts, as well as principles.*

Debates about the primacy given to autonomy and its nature and context come from within a range of disciplines and schools of thought. This chapter commences with attention to the liberal notion of autonomy emanating from political philosophy, an ideal which has been powerful in shaping law in western societies. It commences with a description of the liberal tradition of autonomy as the requirement of non-interference towards autonomous persons, who are individualistically self-determining (Berlin 1958). The chapter continues with the explanation of the inherent limitations of this model to fully protect the liberty of persons in practice, exposing weaknesses of the construct (Agich 1990).

The political ideal assumes the equal ability of citizens to claim autonomy, whereas various personal, interpersonal and societal dynamics affect the ability of the person to exercise autonomy, as considered in the second section of the chapter. These critiques come from a relational viewpoint, recognising that the construct of an autonomy threshold in the liberal model disenfranchises some groups of persons from exercising the freedom of self-determination, which I describe in the third section of the chapter. I conclude that these limitations, dependent on the contested attribute of reasoning ability, and which ignore the constitutive influence of social relations on autonomy, highlight the narrow liberal boundary and its restriction on fuller notions of social personhood. I conclude this chapter with the view that a broader view of autonomy, which recognises both the myriad influences that can enhance or diminish the ability of a person to be autonomous, and the importance of self-determination to selfhood, is required. I describe further in Chapter 3 an expanded notion of autonomy that respects the need and value of self-determination in individuals to whom this freedom is often denied.

I The liberal basis of autonomy

The philosophical construct of liberal autonomy in western liberal democracies is characterised by the political ideal that citizens are free to self-govern and to take responsibility for their actions (JS Mill 1906; Rawls 1971; Kymlicka 1989; Kukathas 1993). This ideology defines citizen and state relations, and autonomy becomes the basis for the ‘legitimacy of our personal decisions in a social, political and legislative context’ (Dryden 2010, 5).

Faith’s story indicates an essential element of liberty, that of being free from interference, as a basis of autonomy. In defining relations between the state and citizens, liberty has a requirement for the state and other institutions not to interfere in the choices and activities of its citizens, and to accommodate individual conceptions of good. This related notion of neutrality also extends to the state refraining from moral judgments about the choices and activities of citizens, as otherwise, any judgments by the state would rank some lives as ‘intrinsically better than others’ (Dworkin 1993, 361). In this way, autonomy becomes ‘neutral with respect to egoistic and altruistic concerns’ (Mappes and Zembarty 1994, 30). This socio-political tolerance naturally leads to a diversity of thought, behaviour, and values in society, implying mutuality in societal relationships by requiring persons to accept or tolerate the life lived by others (Agich 2003).

Despite this stance of moral neutrality by the state towards its citizens and their activities, it is not always reflected in practice. For instance, the state may decide that promoting the capacity of its citizens through compulsory education is more important than non-interference. By placing a preferred value on education, the state departs from the value of liberal neutrality and therefore reduces the negative freedom of its citizens. Such intrusions on personal liberty require a minimum consensus about social morality, which is becomes part of the democratic process (Christman 2003; Rawls 1971), with law instrumental in implementing the outcome.

A second important element of liberty is ‘positive’ liberty (Berlin 1958), which has its basis in the assumption of each citizen’s ability for self-government. Each citizen is understood to be able to engage reason in pursuit of her or his good, and to be accountable for her or his actions. There is a belief that only each person can know what is right for her or him, and that freedom for self-determination enables persons to make authentic choices in their pursuit of personal good (Mills 1906). Positive liberty, the exercise of one's freedom in determining one's choices, as described by Berlin, requires one to be 'a thinking, willing, active being, bearing responsibility for my choices, and able to explain them by reference to my own ideas and purposes' (Berlin 1958, 8).

In the earlier example regarding compulsory education, the provision of knowledge, skills and socialisation by the state, while limiting individual freedom, can also be viewed as assisting persons to exercise their autonomy more fully, by expanding their choices that result from these developed attributes.

In the liberal approach, the process of reasoning, though important, is not dependent on any values of benefit or harm that might result from the decision (Dryden 2010; Stoljar 2013), and is therefore morally neutral, with 'no value or set of preferences that an autonomous person must endorse' (Stoljar 2013, 10; Christman 2003). This is an attractive approach to many in that it enables and enhances autonomy without moral judgment (Stoljar 2013).

There have been a range of debates about the attribute of reason, understood as the internal process of critical reflection and evaluation (Agich 1990) as being an ideal underpinning the notion of liberal autonomy. One critique is in relation to reason as rarely achievable and as developing variably in persons (Christman 2003). As there is a continuum of ability in reality, establishing an autonomy threshold is problematic (Agich 1990; Christman 2003), with debates as to what constitutes a minimum threshold (Gillon 1985; Narayan 2002; Stoljar 2013). Different social, political and legal views have resulted in the exclusion of some persons from the benefits enjoyed by those who achieve this contentious threshold.

A second major concern resulting from the liberal emphasis on the attribute of reason is that it ignores the important influence and role of values, emotions and intuition on choice (Devereaux and Parker 2006; Kerridge, Lowe and McPhee 1998; Charland 1998). As a result, society has been criticised as hyper-cognitive (Post 1995), with Christman also concerned at the narrow focus on intellectualism, suggesting that a more accurate concept of persons is that of ‘passionate reasoners’ (2003, 7).

For some, the reliance on reason in autonomy does not give sufficient attention to outcome, with ‘the status of autonomy… challenged as long as the principle has been revered’ (Donnelly 2010, 1). In ethical debates, the tension between the principles of autonomy and beneficence (Gillon 1985; Beauchamp and Childress 2001; Foster 2009) remains in an ongoing dance. This aspect has led to significant philosophical debates about the attributes required for the exercise of autonomy. While reason is the basic agreed attribute, there is significant philosophical debate as to others, such as the capability for will and action (Gillon 1985), authenticity in one’s desires (Christman 2003), and the ability for accountability to others (Mackenzie and Rogers 2013, 43).

The contentious nature of autonomy, and its application in everyday life, is a theme of this thesis. Further critiques relate to the narrow conceptions of persons based on the construct of reason, and the resulting exclusivity, and I return to these concerns in a later section of this chapter. For now, attention is given to some affronts to autonomy within liberal society, using the concepts of internal and external threats (Mackenzie and Rogers 2013).

II Affronts and injuries to autonomy

To be autonomous is to be ‘one’s own person’…directed by considerations, desires, conditions …that are part of …one’s authentic self’, with freedom from external impositions (Christman 2003, 2). This includes interpersonal controlling behaviours such as manipulation, coercion and paternalism (Faden, Beauchamp and King 1986), or societal constraints arising from resource inadequacies (Oshana 2005), which restrict choice. Such events arise from outside of the person, such as in relationships with others, or from environmental constraints. Both provide examples of the fundamental inability of liberal society to prevent restrictions on freedom in practice.

There is also a parallel internal process. These events, along with oppressive social norms, can be internalised thus damaging the person’s sense of self and personal worth, resulting in a reduced ability of the person to self-govern (Mackenzie and Rogers 2013; Stoljar 2013; Raz 1986). In this section, I will give attention to these internal processes of the self, and then to contributing aspects such as societal attitudes of ageism and prejudice, and interpersonal dynamics of power and control. Finally, I discuss the effects on autonomy from structural constraints limiting real choice. These different influences give weight to the idea of a constitutively relational view of autonomy.

Damage to selfhood

A range of different dynamics can harm selfhood. The first is a denial of the right for self-determination. Psychological theory proposes that persons have an ‘intrinsic need for competence and self-determination’ in satisfying their needs, and this is a source of motivation for living (Deci 1980, 26). Frustration of this most basic psychological human function has adverse psychological effects. It damages selfhood and leads to psychological disempowerment (Winick 1996).

> *Excluding persons from taking part in decisions can result in depression, frustration and anger (Smebye, Kirkevold and Engedal 2012, 2).*

Oppression of persons is another dynamic that shapes the ability to be autonomous. Oppressive norms, environment and relationships can lead to a loss of self-image, self-confidence (Faden, Beauchamp and King, 1986), perceived self-worth (Stoljar, 2013) and can erode self-trust, an important ‘optimism about our own competence and moral integrity’ (McLeod 2002, 6). All of these attributes are necessary for autonomy to be fully exercised.

Sherwin argues that oppression creates a barrier in the development of skills necessary to express one’s convictions (1992). When internalised, ‘autonomy-devaluing’ oppressive norms can cause psychological changes to how the person thinks about himself or herself (Friedman, 2003, 24). These thoughts affect the person’s sense of worth and can consequently affect his or her ability to make or express true rational choices (Stoljar 2013). Likewise, dominant norms can limit perceptions of opportunities and create internalised constraints on choice, with the person turning away from choices that they would choose otherwise (Cudd 2006). These psychological harms to self-worth can affect the essential task of autonomous self-reflection:

> *Restrictive or oppressive social relationships may hamper an agent's ability to develop the capacity for critical self-reflection that is required for autonomy (Friedman 2003, 97).*

Oppressive conditions can also limit a person's choices, as he or she adapts his or her preferences to what he or she 'perceives to be the options available' (Stoljar 2013, 5). Such preference adaption may result from an unconscious social conditioning to oppressive constraints, where the person accepts the limited options arising from that environment without question (Nussbaum 2001), unavoidably influencing a person's choices and preferences (Benson, 2005).

These elements support the idea that the sense of self, and therefore autonomy, is socially constituted. Downie and Llewellyn describe the person as situated within relationships at the 'individual, collective and even institutional levels' with the influence of these relationships shaping the life of the person (2012, 4). Social norms shape the lifelong activity of autonomy development, with '… the various socially salient features of a person's identity such as gender, race, age, disability, sexuality or class…likely to affect their social position and range of opportunities in making choices'(Sherwin 1992, 160). Sherwin considers that these influences are 'situated in a particular social, economic, and historical time and place' and are contextual to each person (1992, 160). These socially constituted influences can be enhancing of selfhood and subsequently of autonomy, or may be diminishing, subject to the quality of relationships and social structures (Nedelsky 2011).

A constitutively relational view of Faith's autonomy takes into account Faith's socialisation of subservience to authority, and her lack of education and life experience, which limit her receptivity and reflection to other choices. These influences on the internal development of self lead to unconscious self-constructed constraints and limitations to autonomy.

This section has given general consideration of the relationship between selfhood and autonomy, and the damage that can occur to persons when there is oppression of the right to autonomy, or where oppressive norms become internalised, demonstrating the socially constitutive nature of autonomy. This next section explores the specific characteristics of stereotyping, prejudice and discrimination. Through disempowerment and discrimination, these activities can deprive persons of real or perceived choice, and by the internalising of the accompanying negative stereotypes, modify expectations and autonomous behaviour.

Prejudice and discrimination

Prejudice and discrimination are affronts to liberal autonomy as they devalue groups of autonomous persons. Prejudice results from stereotypes, an autonomic categorisation of persons into socially determined stereotypes such as those related to race, gender and age (Butler 1969; Nelson 2005). Age related stereotypes result from ‘messages so well learnt that people respond to them below the conscious level’ (Kite and Wagner 2004, 130). Attitudinal surveys about stereotypes towards older people identified subtypes as either positive, such as the ‘perfect grandparent’, or negative images such as the ‘despondent’ or ‘severely impaired’ older person (Hummert et al 1994 cited by Cuddy and Fiske, 2004, 7). While positive stereotypes of older persons can cause envy, admiration, and contempt, negative stereotypes result in pity becoming the main emotion directed towards elderly persons (Kite and Wagner 2004). The resulting ageism involves judgments on the basis of age, resulting in prejudice and discrimination (Iverson, Larsen and Solem 2009).

Elders in western society generally have a low social status. Contributing factors include cultural shifts over time, such as changing family structures with less reliance on elders’ knowledge and wisdom, and increased longevity and institutionalised retirement, associated with a reduced economic value of older persons (Nelson 2005; Cuddy and Fiske 2004). These views of elders as ‘non-contributing burdens on society’ with ‘nothing to offer society’ (Nelson 2005, 209) elicit perceptions of older persons as incompetent and impassive (Cuddy and Fiske 2004). Kite and Wagner identify that these beliefs about persons are socially constructed and ‘linked to the roles they are perceived to occupy’ (2004, 138).

Stereotyping in itself is a natural psychological process that aids people to function in modern society. Cuddy and Fiske suggest that categorising people into stereotypes aids human functioning, by simplifying the intake of information in a complex social environment (2004, 18):

> *Distinguishing each person as unique…requires ample time and effort, draining us of our mental assets. When we do individuate, we must attend to and process complex information. Categorization, on the other hand, is simple and reasonably effortless….*

However, assisting in processing information in complex cognitive situations, Cuddy and Fiske believe these categorisations to shape behaviour in a process of 'behavioural confirmation', which at an unconscious level 'lead us to behave in ways that confirm the stereotypes' (2004, 18).

As well as being based in beliefs, the motivation for stereotyping can also arise from a person's need for belonging, achieved through excluding other social groups, or maintaining a sense of control by placing stereotyped groups lower in the hierarchy of social power to gain a 'self-beneficial contrast' (Cuddy and Fiske 2004,17). The stereotyping of older persons may also play a role in the denial of mortality and the 'self-threatening aspects of old age' for persons at different stages of the life cycle (Nelson 2005, 214). There remains significant ambivalence towards ageing, even though most people will achieve later age (Kite and Wagner 2004).

A second major consequence of such norms, prescribed social roles, and labels is the human tendency to internalise them, with resultant effects on self-image, as described earlier. These ageist behaviours and practices can socially condition the older person into accepting and responding to labels, reducing their internal self-respect and self-worth, necessary for autonomous thought and action (McLeod 2002; Benson 1994). Scholl and Sabat found that 'the mere threat of being stereotyped negatively' affected the person adversely (2008, 103). Responses of helplessness and dependency to these stereotypes (Cohen 1990; Darley and Fazio 1980) can lead to the phenomenon of the 'self-fulfilling prophecy' (Merton 1968). Cuddy and Fiske explain that 'believing older people are incompetent leads others to treat them as incompetent' (2004, 18) and Kite and Wagner express the view that (2004, 272):

> *Pity may look benign on its surface, but it can create a dangerous self-fulfilling prophecy…*

As well as the effects on self-image and resultant constrained behaviour, ingrained stereotypical attitudes can also lead to prejudice and subsequent discriminatory behaviour to persons (Kite and Wagner 2004). Ageism resulting from prejudice and discrimination offends against liberal autonomy. Negative attitudes shape behaviour, such as limiting the information and choices provided to the older person (Resnick, Cowan and Kubrin 1998). The older person is disempowered from this lack of information and therefore unable to maximise choices, diminishing their autonomy. Stereotypes about older persons can be particularly damaging when they occur in a situation of unequal power relations and role constraints. For instance, health professionals are ‘as likely to be prejudiced against older people as other individuals’ (Nelson 2005, 211; Lothian and Philp 2001) and are ‘a major source of ageist treatment’ (Minichello, Browne and Kendig 2000, 253) with attitudes ‘imbedded in care systems’ (Surtees 2014, 453). The social exclusionary practice of segregating older people in aged care and accommodation services further shapes the social identity and status of the older person.

Stereotypes can also lead to the common assumption of older persons being incapable of decision-making (Batsch and Mittleman 2012). This form of prejudice is further disempowering and diminishes opportunities for self-determination. While social structures have been developed to monitor and control discriminatory behaviour, such as anti-discrimination commissions and advocacy agencies, the insidious and unconscious stereotypes of ageing and associated cognitive changes flourish in society, often so ingrained they are not recognised.

In this section, I have described negative age stereotyping and resulting ageism as a prevailing societal norm that both restrains choice and affects an individual’s sense of self and subsequently their autonomy. In the next section, I describe effects on autonomy from behaviours of control such as coercion and manipulation, where persons are ‘entirely dominated by the will of the other’ (Faden, Beauchamp and King 1986, 258), influencing tangible outcomes and internal psychological processes.

Coercion and manipulation

Manipulation is a category of control understood as the 'intentional and successful influence of a person by … altering the actual choices available to a person or … the person's perceptions of these choices' (Faden, Beauchamp and King 1986, 261). Manipulation can come from threats or offers and varies in the degree of control, with deception at the controlling end of a continuum, and actions that keep a person 'in partial ignorance or in confusion' at the other end (Faden, Beauchamp and King, 1986, 362).

One significant aspect of manipulation is that of 'role constraints' (Faden, Beauchamp and King 1986, 368). This psychological concept refers to the person's role as defined by social and cultural mores, which carry 'expectations for behaviour…that limit or constrain the person's autonomous expression', such as the 'good' patient being passive and dependent (Faden, Beauchamp and King 1986, 368). Role constraints involve the 'relative powerlessness' of the person, 'with authority figures in complementary roles of power and control' (Faden, Beauchamp and King 1986, 368-369). There is a necessity to identify those at 'high risk' of role constraints due to potential oppression (Faden, Beauchamp and King 1986, 372), with the 'frail, elderly, poorly educated … and the hospitalized [as having] less opportunity …to act autonomously than people not in these roles' (Faden, Beauchamp and King 1986, 371).

Manipulation from role constraints seemed at play when Faith stayed unwillingly in the hospital after surgery, resulting in depressed thoughts and behaviour. Her passive acceptance of her role as a patient in this instance increased her vulnerability and her ability to protect her own interests (cf Mackenzie and Rogers 2013). In this way, social norms and role expectations, which form 'the entire fabric of social experience,' can affect the social construction of personal identity (Faden, Beauchamp and King 1986, 368) and diminish autonomy.

Coercion is another form of controlling behaviour, defined as when 'one party intentionally and successfully influences another by presenting a credible threat of unwanted and unavoidable harm' (Faden, Beauchamp and King 1986, 261).

Coercion can be either forcing an action to occur or preventing an action from occurring, through depriving persons of ‘meaningful choices’ by forcefully imposing upon another's will (Faden, Beauchamp and King 1986, 345).

Coercion relies on the belief of the vulnerable person that the coercer has the power to fulfil the threat and therefore relies on the subjective interpretation of the particular individual towards the power and influence of those being coercive (Faden, Beauchamp and King 1986). As such, ‘relevant abilities, life experiences, and values’ contribute to the effectiveness of perceived or real control (Faden, Beauchamp and King 1986, 342). Power differentials in relationships can also be a factor, where the coercer may be in a position of trust, or the vulnerable person is physically or emotionally dependent on the coercer to meet her or his needs (Aged Rights Advocacy Service 2010). The individual’s vulnerability, the intentions of the coercer, and the relationship between them, are contextual factors in relationships that represent some of the influences on autonomy (Stoljar 2013; Nedelsky 2011). Persuasion is another interpersonal dynamic, in this case taking advantage of a person’s susceptibilities by using ‘interpersonal influence’ to convince them to change their mind (Faden, Beauchamp and King 1986, 347):

> *…the intentional and successful attempt to induce a person, through appeals to reason, to freely accept – as his or her own- the beliefs, attitudes, values, intentions, or actions advocated by the persuader…’.*

Different factors can render the person vulnerable to persuasion as a form of control. These include the belief systems of the individual, which may not be entirely rational (Tedeschi 1970); the psychological perspectives and needs of the individual, such as the credibility of the persuader in the person’s eyes; or the desire to make the influencer happy or secure approval (Faden, Beauchamp and King 1986). A person’s ability to resist persuasive attempts is therefore dependent on the person’s individual belief system and their psychological needs, relating to internal self-image and self-worth.

The story of Faith indicates how some of these different forms of psychological control may take place, in this instance with someone with cognitive vulnerability. Faith acquiesced to entering a residential care facility though it was not her wish.

While having impaired cognition, her intent to stay at home was evident. Persuasion, coercion or manipulation may therefore have featured. For instance, trust by Faith in the doctor's argument for the necessity for respite care would be indicative of persuasion, but Faith's perception of the doctor's authority, and the accompanying role constraint, is an underlying form of manipulation that may have diminished her sense of autonomy. If the doctor or nephew offered limited or false choices to Faith, manipulation would also be evident, while coercion might include threats of compulsory admission.

While these forms of control have varying nuances, they each exert an external form of psychological pressure and intimidation. Faith's inability to resist this pressure, in whatever form, was amplified by 'intrinsic' factors (Mackenzie and Rogers 2013), such as her knowledge, self-confidence, cognitive functioning, beliefs and relationships with the doctor and her nephew. Faith's vulnerability from the contextual factors and her internal response, leading to diminished autonomy, fit within a broader mantle of cultural, social and legal structures that exert influences on autonomy (Nedelsky 2011).

Another form of inter-relational power is in the form of paternalism, which is a significant concept in later discussions on decision-making and personhood.

Paternalism

Paternalism, where one exerts power over another with the perception or belief of providing a benefit to the person, is evident in Faith's story. Health professionals, following concerns expressed by one of her neighbours, withheld Faith's discharge from hospital, despite Faith's desire to return home. Paternalistic interventions are an expression of power relations, in this case represented by a doctor using his medical authority to ignore the autonomy of the patient, due to his concern for the outcome.

Undue paternalism offends against the freedom necessary for the person to self-govern, as it interferes against a person's will (Christman 2003). Kleinig identifies control as a feature of paternalism where one party imposes on another either physically or morally:

> *…the paternalist exercises some measure of control over some aspect of the life of another- be it the thwarting of the other's desires, a manipulation of the other's beliefs, or a channelling of the other's behaviour' (Kleinig 1983, 7).*

While there are many terms to describe the characteristics of paternalism (Dworkin 2005), I use the terminology from health law and ethics, which is relevant in later debates on autonomy and decision-making. In health law literature, 'strong' paternalism describes actions that override the will of competent persons, while 'weak' paternalism justifies beneficent intervention for those not competent and at risk of harm (Kerridge, Lowe and McPhee, 1998; Beauchamp and Childress 1994).

Strong paternalism, which is the domination of persons who meet the liberal notion of autonomy, is clearly an affront to the liberal entitlement of freedom. Weak paternalism, which occurs when a person is not competent to give informed consent or make her or his own decisions, is less controversial in liberal ideology, as it meets the threshold to justify intervention (Faden, Beauchamp and King 1986; Devereaux and Parker 1999), and protect the person from harm (Carney 1991).

Both strong and weak forms of paternalistic intervention rely on moral justification of benefits to the person:

> *…the interference with a person's liberty of action justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person being coerced (Dworkin 1971, 108).*

This justification includes an implicit moral judgment about the person's inability to 'pursue their own good' (Christman 2003, 9), with philosophical debates as to the subjective or objective nature of good, whether short term or long-term benefit has priority, and the effect of one person's good on another, or on society. Paternalists view persons as having a poor ability to know what is best for them, with concerns that poor choices will result in poor outcomes for the person:

> *…despite the interest that people have in their [own] well-being, there is ample evidence that they are poor judges of it' (Kleinig 1983, 48).*

The presumed knowledge by persons of what is in the best interests of another is a value judgement and may be used as a justification to impose their view onto the person. This focus on the outcome is a form of consequentialism, an ethic designed to secure an end that has the person's well-being in mind (Kleinig 1983). In this way, it focuses on the general impersonal outcomes or 'ends', with the person's good as the 'means' (Kleinig 1983, 55). In contrast, liberal ideology considers autonomy as a 'means' as well as an end, with autonomy an intrinsic 'source of satisfaction' in itself (Kleinig 1983, 50; Gillon 1985). Paternalism has a 'demeaning, or degrading' character, says Kleinig, as it denies an autonomous individual the 'opportunity to make his or her own choices, thus violating the claims of individuality' (1983, 55).

The role of personal values shapes a person's understanding of their own good in a process of reconciliation between their present 'good' with future 'good', and these values may not be known or understood by others (Veatch 2009). However, paternalists are at risk of filtering information about the other through their own values and preferences and subsequently interpreting 'the other's good in ways that reflect his or her own conception of good' (Kleinig 1983, 29). In addition, paternalists are often at a distance from the person, with less knowledge or interest in the person compared to the individual's own knowledge of themselves (Kleinig 1983).

Paternalism can have material effects, in that the person may lose tangible options that they consider of benefit to them. However, there are also internal consequences, with the intrinsic psychological need for self-determination not met (Kerridge, Lowe and McPhee 1998; Deci 1980). The overriding of the will of another can also affect self-esteem and self-identity, and lead to increasing powerlessness and hopelessness, increasing vulnerability. A study of the views of older persons found that 'a loss of self-esteem arose from being patronised, excluded from decision-making, and treated as an object' (Woolhead et al 2004, 165).

This section has explored the ways that the paternalistic imposition of outcomes by those with real or perceived power can constrain and damage the autonomy of persons. The next section discusses how the societal organisation of resources can also constrain choice, with societal resource allocation influential in shaping the autonomy of persons (Nedelsky 2011). While resource allocation can support positive liberty, competing priorities of society for its limited resources can lead to constraints to autonomy.

Structural constraints to choice

Structured and limited choices impede the ability of the person to exercise agency and autonomous will (Tetley, Grant and Davies 2009). One example in Australia is the limited choice of care for dependent older persons. Traditionally, the care of older persons has been the province of the family, with the alternative being that of care in nursing home institutions. Factors such as increased demand, cost of residential care, and the desire of older persons to stay in the familiar environment of their own home, has led to the introduction of home based care ‘packages’ over the past few decades. However, these resources have been limited for the population of eligible clients (Productivity Commission 2011, xxi), and their distribution often inequitable. This often leads to residential care being the only remaining ‘option’ for those in need. While expanded care options are proposed, the government is yet to allocate funding for their implementation, representing political priorities and agendas, and competition with other groups for limited resources. Situations such as these, where options do not reflect the person’s real preferences, can be oppressive to autonomy:

> *When in a double bind, a person can display agency- she can make an informed and rational choice – but it does not seem right to call her choice autonomous when the structure does not offer her any option that fully reflects her deepest values and interests (Sherwin 2012, 17).*

Further, limits to true choice can result in persons choosing the option that continues to oppress their social group (Sherwin 2012; Young 2006). Reduced home care options leads to greater numbers of people waiting for residential care. This demand is in turn used by policy makers as confirmation of this service model, even though it is more expensive and not the first preference of many older persons. Ironically, acceptance by older persons of an unwanted service, as a result of limited choice, maintains the status quo of service provision and reinforces the conditions that oppress them (Sherwin 2012).

In Faith’s story, resource constraints were evident. Health care staff did not support Faith’s wish to return home from hospital due to their concern about potential risks to her in living alone. There was no offer of alternative options to staying in hospital, such as convalescence services, or support to transition to independence at home, such as day leave or home services, as these are in scarce supply. In this instance, Faith experienced diminished autonomy because of limited real choices.

An inadequate supply of services in relation to need is an external constraint to the person's exercise of autonomy. Such limitations can severely curtail options and choice, and 'practical control is removed' regardless of the person's personal competence and will (Oshana 2005, 411). Allocation of resources in society reflects prevailing social and cultural norms that shape political priority setting (Lovitt and Wilkinson 2010), and the example in Faith's story is indicative of the restricted range of choices for older persons. Attempts at redress through affirmative advocacy remain constrained by the underlying societal norms that affect political priority setting.

In summary, affronts and injuries to autonomy occur in liberal societies despite the fundamental requirement of non-intervention. Psychological harms to persons can result from internalised norms and attitudes, and lead to reduced self-worth and a limited capacity to act autonomously. Negative stereotypes and attitudes, such as in ageism, are also excluding and disempowering of persons, affecting self-identity. Forms of domination and control over another can occur interpersonally through coercion, manipulation and paternalism, and can be oppressive to the person and their autonomy. Structural inequalities, reflecting prevailing norms affect tangible choices and limit autonomy.

This overview demonstrates the weakness of the liberal ideal in ensuring the capable expression of autonomy by its citizens, and confirms the relational aspects of autonomy. The influences of social norms, social power, relationships and resources on autonomy, demonstrate autonomy's socially constituted and relational character.

In the next section, I focus on other critiques that further magnify the limitations of the liberal model of autonomy, leading to a requirement to broaden the concept of autonomy to encompass social and constitutional aspects of autonomy.

III Personhood and autonomy

This section considers critiques of the liberal model, in particular in relation to the nature of social and legal persons. Personhood, which is a socially or legally conferred status, is different from the idea of a natural person, who is simply a human being. A natural person who is regarded legally or socially as autonomous is given personhood status, along with accompanying rights.

The person in the liberal model is conceptualised as individualistic, with little recognition of their social relationships. The traditional liberal approach also excludes those who do not meet the rational cognitive threshold from legal personhood and full citizenship. These aspects are indicative of the overlap between the abstract notion of autonomy (and necessary personal attributes) with the status conferred on a person either in law or by society. This interface of autonomy and personhood is introduced in this section and discussed more fully in Chapter 3. While benefits and attributes of value arise from the liberal framework, I conclude this chapter with the viewpoint that its boundaries are too narrow for the full support of a broader and relational view of autonomy and persons.

Social persons

Many commentators hold concerns for the high value accorded to liberal autonomy, where the individual, through the protection of non-interference, acts separately to others. Preston, for instance, argues that ‘the rhetoric of self-determination and autonomy’ can lead to persons ceasing to care for others (1996, 132), and Callahan (1984) considers that the status given to autonomy justifies selfishness.

Other writers are concerned with how an individualistic approach affects social relations, with the pursuit of individual autonomy leading to insufficient regard for the value of interdependence (Ritchie, Sklar and Steiner 1998), diminishing the importance of human relationships (Kerridge, Lowe and McPhee 1998). Communitarian and feminist writings are also critical of the liberal concept of autonomy, which they consider ignores the reality of humanity's inter-relatedness (Christman 2003; Sherwin 1992; Nedelsky 2011). These criticisms give recognition to the liberal model as deficient in ignoring the social connectedness of persons in the expression of autonomy.

In this social view, rather than being a separate unit (Sherwin 2012), humans are instead conceptualised as social beings interconnected through relationships that create and inform identity. McCall Smith comments that while liberal autonomy promotes the view of individualist pursuits, in reality '…nobody's life is his or her own… Every significant decision we make entails the potential co-operation or involvement of others' (1997-98, 37).

Another view recognising the interconnected nature of the person comes from feminist theory, which gives ethical attention to the inter-dependency of persons:

> *…male dominant western traditions have failed to provide a coherent or universal moral philosophy that incorporates…the relative importance of care (as opposed to rationality), interpersonal relationships (as opposed to autonomy) and communitarianism (as opposed to individual rights)… (Kerridge, Lowe and McPhee et al 1998, 22):*

Feminist critiques have given rise to the development of an 'ethics of care', which offers an alternative to individualistic autonomy with an emphasis on qualities of love, care, trust and responsibility (Kerridge, Lowe and McPhee 1998, 23; Gilligan 1982). This approach makes a valued contribution in challenging oppression, authority and power imbalances, which not only underscore autonomy but also provides needed reminders regarding relationships and emotions in ethical debates (Kerridge, Lowe and McPhee 1998).

A second contribution from feminist theory also rejecting the abstract ideal of liberal individualism, is the concept of 'relational autonomy' (Stoljar 2013; Nedelsky 2011). This term integrates the concept of respect for the autonomous person, but removes the idea of persons as separate from each other. Instead, it incorporates relationships as a feature of autonomy, with a 'positive conception of human agency that recognizes relational experiences as an integral dimension of individuality' (Donchin 2001, 367). This account of autonomy supports the concept of humanity as including the development and expression of self, the validity of emotional responses, and personal identity as enabled through important social relationships (MacKenzie and

Stoljar 2003). Thus, self-determination is grounded in the concept of social interconnectedness with others, contrasting with the liberal value of individual independence.

In addition to the lack of recognition of persons as social beings, the exclusion of some persons from the liberal ideal has also resulted in significant disenfranchisement of persons. The next section discusses the social worth of persons, completing this overview of the limits inherent in the liberal construct of autonomy.

Approaches to dis-enfranchised persons

A major criticism of liberal autonomy is its exclusive nature, which denies full personhood status for those who do not meet the rational cognitive ideal of liberal autonomy. The liberal basis of autonomy and freedom is theoretically dependent on each citizen possessing equal abilities and attributes, such as will, cognitive reasoning, and action. In reality, people are not equal in the personal attributes they can exercise in their autonomy, and this requirement excludes some members of society (Stone 1991).

The cognitive ability for rational thought and reflection, essential for self-government, is the demarcation point for the boundary of autonomy. This has pervasively shaped society's moral and political landscape and remains a key measure in decision-making (Christman 2003). This view of autonomy is binary – either one has autonomy or has not – and is an absolute concept. Those without this substantive ability are not considered self-determining and the person's social status is devalued (Carney 1991). As a result, those without autonomy join a lesser class of persons who reside on the 'margins' of personhood and law (Carney 1991) as the 'other' (Donnelly 2014, 45), and rather than respect, such persons instead receive 'sympathy, pity or invasive paternalism' (Christman 2003, 3). This form of differentiation is seen by Post as a form of 'elitism' based on worth (2006, 224), with the resulting process of devaluation leading to further functional disability and counter dependency (Agich 2003; Gordon and Verdun-Jones 1992; Preston 1996).

While the attribute of reason is a central requirement of liberal autonomy, there is a range of views that dismiss this prerequisite in concepts of autonomy (Kerridge, Lowe and McPhee 1998). Agich suggests that the 17th century political ideology that underpins the liberal model of autonomy is abstract and should be contained within legal and political worlds, as it does not translate well into the real world of dependent and inter-dependent persons (2003; also Sherwin 1992). There is a growing voice of writers and advocates who maintain that the cognitive realm is too limited and that autonomy is not absolute, arguing for a revision of the rationality concept (Devereaux and Parker 2006; Christman 2003; Post 2006), and recognition of the important role of values and emotion (Charland 1998). These concepts relate to the idea of personhood, which receives specific attention in Chapter 3.

Different commentators argue for the development of more respectful responses towards those with diminished autonomy, through enhancing the person’s autonomy to the fullest extent possible, regardless of their cognition, and facilitating their participation in choices, however limited this participation may be (Nuffield Council of Bioethics 2009; South Australian Office of the Public Advocate, 2009). This approach is argued from both an ethical perspective (Nuffield Council of Bioethics 2009), and from a human rights approach. Human rights advocates view that the state should respond further in enhancing the positive rights of vulnerable citizens, based on ‘…the belief that all individuals are of equal worth and are thus entitled to be able to meet their basic human needs, experience equality of opportunity and be protected from unjustifiable inequities’ (Barnes and Brannelly 2008, 385). This discourse has been employed to advocate for affirmative action for those with limited material, personal and social assets; welfare for those whose physical or mental state renders them unable to claim the benefits that other citizens utilise, and in the consideration of rights for those who are vulnerable (Carney, 1991; South Australian Office of the Public Advocate, 2009). The latter has been extended to the ‘exercise of legal capacity’ with the Convention of the Rights of the Person with Disabilities (Gooding 2013, 433), with principles of support for dignity, autonomy, inclusion and equality.[2]

---

[2] ‘The principles of the present Convention shall be: (*a*) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons; (*b*) Non-discrimination; (*c*) Full and effective participation and inclusion in society; (*d*) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

Affirmative 'positive' rights, described by Levin as evolving from the positive aspect of liberty, are based on enhancing opportunities for autonomy available to a person, and their ability to utilise opportunities (Levin in Kukathas 1993, 536). Underpinning this approach is that of respect for persons, based on unconditional worth as a universal value, and not just for those who meet the liberal ideal (Christman, 2003). This aligns with relational theory and support for approaches that seek to maximise the autonomy of all persons (Nedelsky 2011), which is given attention in the next section.

IV Towards a relational approach

Nedelsky addresses these liberal blind spots within her framework of relational autonomy (2011). Her approach integrates individual worth with the variable influences in real life that are constitutive of autonomy at the personal, social, political, institutional and legal levels. Relational theory recognises that, rather than separating and labelling groups of individuals based on diminished autonomy, all individuals experience fluctuations in dependency throughout life, relying on others at these times. Relational theory recognises that persons are 'socially situated, defined and shaped in a relational context' (Tsai, 2009). Relational autonomy recognises the importance of the freedom for individual self-determination and respect for sense of self, which takes place within, and is dynamically shaped by, our social relationships (Nedelsky 2011).

The idea of social relations and interconnectedness as a closer reflection of the nature of autonomy is valuable in tempering the purely liberal ideal of autonomy (Kerridge, Lowe and Stewart 2009). In particular, it offers an approach to analyse relations shaped by political, legal and institutional structures that enhance or diminish the expression of autonomy. In acknowledging the individual's capacity for self-determination in spite of constraints, relational theory 'rehabilitates' or transforms the liberal notion of autonomy to encompass the realities that infringe on personal

---

(*e*) Equality of opportunity; (*f*) Accessibility; (*g*) Equality between men and women; (*h*) Respect for the evolving capacities of children with disabilities; and respect for the right of children with disabilities to preserve their identities': Article 3, *Convention on the Rights to the Person with Disabilities*, viewed 16 May 2015, <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.

autonomy, rather than fully rejecting liberalism (Downie and Llewellyn 2012, 6; Nedelsky 2011).

Such an expanded approach requires a contemporary understanding of persons and society, which opens the concept of autonomy towards one that is broader in merit and applicability. This includes recognition of the dynamic and constitutive nature of autonomy, and a fuller understanding of personhood. Autonomy is relative to each person and his or her context, rather than an absolute state. Therefore, the primary goal becomes that of understanding the importance of autonomy for well-being, and maximising autonomy as a 'kind of achievement' (Raz 1986, 204), as a basis of respect for the worth and dignity of all persons. This gives a contemporary understanding of personhood, which is the focus in Chapter 3.

A framework of relational autonomy allows for the analysis of social relations and the identification of processes and structures that diminish autonomy, as well as indicating ways to enhance autonomy (Nedelsky 2011). The challenge is to integrate relational autonomy in practice, and alter social relations in order to support autonomy (Nedelsky 2011). While positive rights have traditionally been part of the welfare model, the schema of relational autonomy offers opportunities to enhance autonomy of all individuals through changes in structural social relations that influence power, collective values, and resources. Positive liberty can extend beyond a compensatory welfare approach, to one of greater empowerment.

In the relational paradigm, broader concepts of law also exist. For instance, Nedelsky conceptualises a correlation between law and autonomy, but extends this relationship to include notions of the self, as law not only structures the relationship between citizens and the state, but also between citizens (2011). This occurs through law's shaping of societal structures and institutions that impact on notions of the self and the expression of personal autonomy, and gives a role to law to examine and alter the structural relationships that are constitutive to autonomy:

> *There is an opportunity for law, currently constructed on a liberal ideology basis, to integrate relational approaches towards autonomy. As the vehicle for how power is 'exercised, shaped and justified' in society, law can give greater attention to societal structures that organise social relationships and collective values (Nedelesky 2011, 72).*

As an emerging concept, relational theory is gaining traction in philosophical thought (Kerridge, Lowe and Stewart 2009) and contributing to a broader understanding of autonomy and its social interrelationships. It has ‘shifted attention…to the social and interdependent dynamics that shape its enjoyment, connecting ideas about autonomy and broader issues of social justice, recognition, and social practices’ (Christman 2011, 3.3).

V Conclusion

Where does this leave us with the notion of autonomy? Autonomy continues to be of strong moral and political value in our society. The liberal ideal offers a vision for autonomy that respects the autonomous right to make choices free from interference, and respects the moral diversity of its citizens through value neutrality.

Despite these values of respect for autonomy and limits to interference, human activities overrule, discount or diminish the autonomy of others, compromising the liberal ideal. Power relations, often neglected in the individualistic liberal approach, exist naturally within society, but when used to control or dominate persons, are an oppressive force that harms autonomy, choice and agency. Paternalism offends against the fundamental need for self-determination in imposing others’ view of what is good, leading to external and internal restraints on autonomy. These activities and their effects reinforce the view of persons as not separate but socially situated, developing and expressing their autonomy within a framework of relationships and relations, making the limitations of the liberal approach transparent.

There is increasing focus on social relations, with growing recognition of the way relationships and social structures can either limit or enhance autonomy and human well-being. Tension regarding the nature of persons, the psychology of decision-making processes, and the dis-enfranchisement of some citizens adds to this inadequacy of the liberal model. Overall, these factors indicate that the traditional understanding of autonomy has outgrown its boundaries, with emerging interest in an expansive approach.

Broadening the concept of autonomy to give a more accurate reflection of humanity has the potential to shape a society that provides greater support of autonomy, especially those who are particularly vulnerable. Knowledge about cognition and emotion, and recognition of the inter-connectedness of persons, contributes to the view that persons are social and relational as well as cognitive beings. An expanded approach requires the incorporation of a contemporary understanding of persons and society, including the constitutive nature of autonomy, and a fuller understanding of personhood. Autonomy is relative to each person and his or her context, rather than an absolute state, and the framework of relational autonomy allows for the identification of relationships, processes and structures that enhance or diminish autonomy.

Before returning to the ongoing discussion on an expanded view of autonomy in Chapter 3, the next chapter explores the influence of the liberal view of autonomy on the legal concept of decision-making. The use of the liberal concept of autonomy in common law doctrine regarding decision-making capacity, and of relevant legislation, is reviewed. The idea of a broader socio-legal frame is also introduced, along with different responses to law identified in this domain.

2 Decision-making capacity and the legal domain

The freedom of an individual to make self-determining decisions is an everyday activity usually taken for granted, until such time as it is questioned, challenged, overpowered or even removed. While paternalism and other forms of control can cause challenges to this freedom, law sets out boundaries for the protection or loss of decision-making rights. This chapter will commence with a description of the common law and South Australian legislation concerned with decision-making. I trace the influences of the liberal model of autonomy both in common law, and in guardianship and Advance Care Directives legislation, and analyse the different models of autonomy in each. This shows a broadening of the concept of autonomy in recent law reform.

However, the application of the legal concept of decision-making into practice has led to contentions, controversies and debates, with concerns regarding interpretation and implementation. In order to apply the law, medicine and its allied sciences have developed a proliferation of tests for capacity, with a range of approaches. The ongoing empirical search for a single standard test indicates misunderstanding about the complexity of autonomy and associated decision-making, and portrays a simplistic approach to law’s role and application in this arena.

A constructionist approach extends the concept of law from a singular dimension of posited rules and principles to the idea of law as a field of activity in dynamic interaction. Law becomes an iterative domain, with everyday activities part of an ongoing social construction. Rather than fixed rules that persons use at rare times and for circumscribed purposes, there is a shift to understanding law as creating a space where cultural and normative influences, human problems, legal relations, social structures, and institutions, are in dynamic interplay.

This perspective facilitates analysis of the context within which capacity assessments occur, and the way law is ‘created’ in this domain. The idea of ‘law in the everyday’ (Ewick and Silbey 1998) illuminates the interplay of activities that occur in the shadow of the law that reflect, support or alternatively resist legal norms and rules. In the decision-making domain, rules can be changed, ignored or created to fit different contexts. From this perspective, my view is that the law creates a legitimate domain in which to maximise autonomy, based on law’s fundamental respect for personal freedom. This domain allows for the everyday navigation of human relationships and the informal resolution of human problems, avoiding the use of the formal legal system and its limitations. Therefore, given the limitations of the rational-cognitive approach relied on in formal law, I conclude that an alternative approach to decision-making, based on respect for persons, has legitimacy. As the full legal domain allows creative and just approaches towards decision-making, such an approach can be more finely tuned and responsive to human complexity than current prevailing approaches. I conclude that such an approach, though based on empowerment rather than non-interference, needs to be sufficiently complementary that it enables the formal use of law as a last resort.

I Decision-making capacity in law

Law provides rules for society that reflect and maintain the political social order, with a pragmatic function of organising human activities and mediating the problems that arise in human relationships (Kerridge, Lowe and McPhee 1998; Naffine 2009). One area law governs is the point at which someone is deemed to be ‘incompetent’ to make decisions in relation to his or her daily life. This includes entering into contracts, which is important in ensuring certainty and reliability in human transactions. Common law is the primary source of current approaches towards decision-making capacity, and is developed by court judgments and regarded as ‘accumulated social and political custom’ (Davies 2008, 40). More recently, definitions of legal competence are found in legislation, as developed by governments and enacted by parliament.

Consent and capacity in common law

The concept of capacity for decision-making has its basis in the common law doctrines of informed consent, which arises from tort law, designed to protect the civil liberties of persons (Kerridge, Lowe and Stewart 2009; Skene 1998). The doctrine of informed consent is based on the principle of autonomy, with the tort of trespass to the person protecting the person's right to bodily inviolability: 'a competent person has the right to decide what will be done to his or her body' (Skene 1998, 38). The law of informed consent imposes a legal obligation on the treating doctor to provide information about risk and obtain consent from any patient before providing treatment; otherwise, the competent patient can sue the doctor even if the patient has not suffered any injury (Skene 1998). Failure to do this can result in a claim of trespass to the person or negligence against the doctor by the patient.

Tort law may be considered as both a 'moral and coercive' force in setting standards in relation to non-interference 'with the rights and liberties of other members of the community' (Davis 2012, 11). In this way tort law echoes the liberal ideal of personal sovereignty (Brazier and Lobjoit 1991). However, tort law has a focus on the negative and extreme consequences of interference and negligence rather than a positive focus on supporting the everyday autonomy of the patient:

> *…the conduct…must be seen as so wrongful …or so unwarranted that the community itself should make a rule against it and respond when that rule is broken… (Davis 2012, 9).*

Tort law is limited to responding to wrongdoing through protection from interference that may cause harm. It protects, rather than facilitates, any aspirational and positive enhancement of autonomy.

The common law cases that have shaped the legal characteristics of consent have set out principles for the legal construct of incapacity. The principles of consent include that consent must be voluntary, not coerced; that the patient receives sufficient information about the treatment and the associated risks specific to the treatment; and that the patient 'appreciates and understands' the information (Kerridge, Lowe and Stewart 2009, 285). Exceptions occur in emergency or life threatening situations, where the doctor may avoid liability (Skene 1998).

Receiving appropriate information facilitates a person's decision-making capacity. Kerridge, Lowe and McPhee suggest that under Australian law risks must be disclosed, including the 'nature, consequences, harm and benefits, risks and alternatives to any treatment offered' (1998, 143). This basis arises from the 1992 landmark High Court judgement in *Rogers v Whitaker*,[3] which determined there was a 'paramount consideration that a person is entitled to make his own decisions about his life' (Skene 1998, 76). The outcome of this case is that the doctor has a duty of care to provide each person with information about the treatment choices and associated material risks relevant to their particular needs in decision-making (Davis 2012; Kerridge, Lowe and McPhee 1998).

If a person, because of mental impairment, does not have sufficient understanding of a matter to give consent to treatment, the law provides for substitute decision-making through the appointment of a proxy. The determination of capacity, or incapacity, therefore acts as the gatekeeper to the outcomes of either respect for autonomy or beneficence for the patient (Devereaux 1999) and is a highly significant concept. According to Kerridge, Lowe and Stewart 2009, the legal principles that provide a test for legal incompetence, and guide legal practice in this area are:

- that capacity is presumed;
- that incapacity is to be proven and related to brain impairment;
- that capacity is based on understanding the decision and not dependent on outcome;
- that capacity is decision specific and variable;
- that the threshold of capacity is to be commensurate with the gravity of the decision; and
- that the merits of the choice are to be evaluated if the choice might result in serious risk (Kerridge, Lowe and Stewart 2009).

The common law bases its test for decision-making capacity on the ability of a person to think rationally in order to understand the choices available to them. This conception reflects the ideal of rationality, and has a liberal, value-neutral approach towards the resulting outcomes of the person's decision. One exception to this notion of outcome neutrality arises from the British case *Re T (Adult: Refusal of Treatment).*[4] This judgment indicated that a test requiring the evaluation of choice was permitted if the decision was to result in a serious outcome for the person, such

---

[3] [1992] 175 CLR 479.

[4] [1993] Fam 195.

as risk of death. Such a test necessitates a higher threshold of capacity (see Appendix 1) than where the outcome has a low risk. This judgment has led to significant debate regarding whether the test for capacity should be outcome neutral (Kerridge, Lowe and Stewart 2009; Stewart and Bieglar 2004; Wicclair 1991).

Determining the legal test for capacity from these legal constructs to use in practice remains a controversial issue (Gillon 1985; Devereaux and Parker 2006; Charland 2008; Kerridge, Lowe and Stewart 2009). An overview of key debates will occur later in this chapter, however for now, the focus will move to legislation that is relevant to decision-making capacity.

Decision-making capacity in legislation

In Australia, legislation has become the most common source of law, allowing 'speedier amendment of the law, for the comprehensive treatment of a subject, or for a radical change' (Cook, Creyke and Hamer 2005, 151), and in response to social and economic changes in society (Blay 2006). There are four statutes in South Australia that deal with decision-making capacity,[5] with the two key Acts being the *Guardianship and Administration Act 1993* (SA), and the *Advance Directives Act 2013* (SA).

The *Guardianship and Administration Act 1993* (SA) protects persons who have mental incapacity, being 'the inability of a person to look after his or her own health, safety or welfare or to manage his or her own affairs'.[6] Such inability may be the result of either brain impairment or the inability to communicate due to physical illness. Unlike the common law, incapacity in this Act refers to the inability of the person to manage their health and affairs, rather than the specific capability to make decisions. Application to the South Australian Civil and Administrative Tribunal[7] can result in the appointment of public or private guardians, who have legal authority to make substituted lifestyle decisions on behalf of the person, leading to a global

---

[5] The *Mental Health Act 2009* (SA) and *Consent to Medical Treatment and Palliative Care Act 1995* (SA) also are concerned with decision-making but have less relevance to the focus on older persons with cognitive impairment.

[6] *Guardianship and Administration Act 1993* (SA) s 3(2).

[7] The South Australian Civil and Administrative Tribunal commenced in March 2015, replacing the Guardianship Board.

loss of that person's decision-making rights. The Act also contains the provision for the appointment of an Enduring Guardian to make future decisions.[8] The exercise of these powers commences when the person is 'mentally incapacitated',[9] encompassing the idea of global incapacity and therefore transferring full decision-making powers to the Enduring Guardian.

The Act contains principles that support autonomy, such as the requirement to consider the person's past or current wishes and preferences.[10] While the Act requires consideration of these autonomy-enhancing legislative principles by guardians and Enduring Guardians, the primary purpose of the legislation is to protect vulnerable citizens. The Act requires the presence of brain impairment as a cause of incapacity. Appointments of substitute decision makers who have global decision-making responsibilities results in reduced legal personhood for those who may have the ability to make some decisions. This legislation, along with relevant common law, comprises the primary legal landscape for the consideration of decision-making capacity.

The *Advance Care Directives Act 2013* (SA) is designed to 'enable competent adults to give directions about their future health care, residential and accommodation arrangements and personal affairs'.[11] In this Act, the definition of 'impaired decision-making' is congruent with the common law notion of 'understanding' of specific decisions.[12] The South Australian legislation replaces the previous provisions of

---

[8] This provision in the *Guardianship and Administration Act 1993* (SA) (s 25) was transferred to the *Advance Care Directives Act 2013* (SA) (s11) upon enactment in July 2014.

[9] *Guardianship and Administration Act 1993* (SA) s 3(1)

[10] *Guardianship and Administration Act 1993* (SA) s 5 (a)

[11] *Guardianship and Administration Act 1993* (SA) s 9 (a)

[12] For the purposes of this Act, a person will be taken to have impaired decision-making capacity in respect of a particular decision if-

(a) the person is not capable of –
    (i) understanding any information that may be relevant to the decision (including information relating to the consequences of making a particular decision); or
    (ii) retaining such information; or
    (iii) using such information in the course of making the decision
    (iv) communicating his or her decision in any manner *(Advance Care Directive Act 2013* (SA), s 7 (1)).

Enduring Guardian,[13] Medical Power of Attorney,[14] and Anticipatory Directions.[15] The Act was developed with the aim of reducing the multiplicity of different provisions, as existing advance directives for health or lifestyle decisions were ‘not well understood or optimally used by the community or by service providers’ (South Australian Government 2008, 1).

As well as providing criteria for the determination of decision-making capacity, the Act clarifies the legal power of the substitute decision maker to represent the person. The Act also makes it explicit that the autonomy of the person is to be maximised by substitute decision-makers despite the existence of fluctuations in capacity and short-term memory loss, regardless of adverse outcomes.[16] The legislative principles acknowledge the role by others in maximising autonomy though supportive decision-making: ‘a person must be…supported to enable them to make such decisions for as long as they can’.[17] This approach facilitates and supports autonomy of the person in contrast to a purely liberal position of non-interference. As this legislation only came into effect in July 2014, time will be required to see how the South Australia community utilises and accepts these provisions and the concepts underpinning them in practice. As Parker and Cartwright remark, the ‘existence of legislation enabling advance directives does not guarantee their use’ (2005, 83).

A legislative comparison of the notion of autonomy

Each area of law serves a different purpose. For instance, common law (torts) protects bodily inviolability in health care of the autonomous person; guardianship legislation protects persons who are vulnerable because of mental incapacity; and Advance Care Directives legislation supports the future autonomy of the person in relation to decisions about their medical and personal care and treatment.

---

[13] *Guardianship and Administration Act 1993*(SA) *s 25*

[14] *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 8

[15] *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 7

[16] *Advance Directives Act 2013* (SA)

> (a) *a person’s decision-making capacity will not be taken to be impaired merely because a decision by the person results, or may result, in an adverse outcome for the person.(s 7 (2))*

[17] *Advance Care Directives Act 2013* (SA) s 7(2)

These laws also define the legal person, which legal theorists often view as a pure abstraction, with the 'so-called physical person…not a human being but the personified unity of the legal norms that obligate or authorise one and the same human being' (Kelsen 1967 in Naffine 2009, 33). Legal personhood is without moral status and instead is defined by rights and duties (Naffine 2009). For instance, common law cases define the legal person by their autonomy in relation to bodily inviolability, with the treating doctor obliged to respect autonomy and not impose interventions without consent. In guardianship legislation, the person protected under legal guardianship loses their legal personhood, with guardians undertaking necessary decision-making in financial administration or personal guardianship, or both, with obligations to consider the relevant legislative principles in this task.

In South Australia, under the *Advance Care Directives Act 2013* (SA), the person making an Advance Care Directive can either bestow future decision-making on their behalf to another person, or give written instructions concerning key decisions, with the goal of extending their legal personhood for a time in the future when they may be incapable of making their own decisions. The types of decisions that may be subject to an Advance Care Directive include wishes and preferences for care and accommodation,[18] and binding provisions in refusal of health care.[19] The substitute decision maker, and any person providing care and treatment, has a duty to respect the instructions in the Advance Care Directive. These provisions may operate without the need to resort to the formal legal or court system, unless there is a dispute over the application or operation of the Advance Care Directive.[20]

Changes in legislation can result in different outcomes, even though the problem requiring a solution might be the same, such as where the role of substitute decision-maker in the *Advance Care Directives Act 2013* (SA) differs from, and supersedes, the role of the Enduring Power of Guardian in the *Guardianship and Administration Act 1993* (SA). For example, in the story I opened with, Faith had invested her future decision-making in her nephew. As an Enduring Guardian, he had the duty to make decisions on her behalf. Her nephew did not see Faith's wishes as representative of

---

[18] *Advance Care Directives Act 2013* (SA) s 11(3).
[19] *Advance Care Directives Act 2013* (SA) s 19.
[20] *Advance Care Directives Act 2013* (SA) s 48.

her needs, and made a decision for residential care. The *Guardianship and Administration Act 1993* (SA), asks the Enduring Guardian to 'observe' principles that include the consideration of her wishes and preferences, rather than require their application.[21] In contrast, the substitute decision-maker has obligations to make decisions based on the person's expressed wishes, or how he or she thinks they would decide.[22] In expressly stating the preference for home care, Faith's substitute decision maker, under the *Advance Care Directive Act 2013* (SA), would be obliged to try to obtain such services on her behalf. This example suggests that as guardianship legislation is the default legislation, in the absence of an Advance Care Directive persons may experience less protection for their personal autonomy than those who have made an Advance Care Directive.

The different obligations and duties on substitute decision-makers in legislation can therefore produce very different practical outcomes for the person. In another example, a person found to be unable to manage his or her affairs under the guardianship legislation and who has a guardian appointed, may, under common law, be found to adequately understand the aspects of the consequences of a specific decision for the same matter, and thus retain legal personhood for that particular purpose.

Besides the different emphases of law, other unique factors and dynamics also influence outcomes, including the decision-making by family members and health care providers, and the availability of community services that may enable instructions to take effect. These variables interact with law to produce different

---

[21] *Guardianship and Administration Act 1993* (SA) s 5 lists four principles to be observed:
(a) consideration (and this will be the paramount consideration) must be given to what would, in the opinion of the decision maker, be the wishes of the person in the matter if he or she were not mentally incapacitated, but only so far as there is reasonably ascertainable evidence on which to base such an opinion; and
(b) the present wishes of the person should, unless it is not possible or reasonably practicable to do so, be sought in respect of the matter and consideration must be given to those wishes; and
(c) consideration must, in the case of the making or affirming of a guardianship or administration order, be given to the adequacy of existing informal arrangements for the care of the person or the management of his or her financial affairs and to the desirability of not disturbing those arrangements; and
(d) the decision or order made must be the one that is the least restrictive of the person's rights and personal autonomy as is consistent with his or her proper care and protection.

[22] *Advance Care Directives Act 2013* (SA) s 35(1).

outcomes for each situation, with the resulting dynamic representative of the informal domain of law. I give attention to these legal relationships later, but for now give consideration as to how the liberal view of autonomy currently shapes formal posited law.

As set out above, decision-making capacity in common law has a focus on ‘understanding’, with the liberal reliance on rationality as the basis for autonomy. The value-neutral approach to outcome predominates in these cases, with attention given to the process of reasoning and understanding, and not the outcome of the decision. Common law has modified the ‘absolute’ nature of liberal autonomy through limiting consideration of decision-making ability to specific decisions. Glass considers that the decision-specific approach to competence in common law intrinsically supports autonomy, as it alters in relation to the specific decision and purpose (1997). However, the common law applies a higher threshold for capacity where such a standard is deemed appropriately commensurate with the ‘seriousness of the decision’,[23] and a person’s choice may therefore be evaluated if doubts about capacity are present (Kerridge, Lowe and Stewart 2009). This approach allows consideration of the effects of the decision, a move away from value neutral approaches of the liberal model, and has led to debate regarding threshold and risk considerations. This inconsistency may permit considerations of a moral nature, with the potential to be paternalistic in effect and hence diminishing a person’s autonomy.

Guardianship legislation, with its concern with the person’s ability to manage everyday life, does not provide objective criteria for the adequacy of a person’s health and safety. This lack of criteria may allow moral judgments of the best interests of the person to occur, with paternalistic intervention potentially occurring as a result. While the law allows for flexibility of operation in diverse social situations, justifications for intervention based on the presence of mental incapacity can potentially violate the liberty enjoyed more broadly by citizens (Carney 1991). These may include the freedom to administer financial affairs poorly, to live in a disordered home, and to neglect self-care. The threshold for guardianship intervention may therefore be subjective and contextual.

---

[23] *Re T (Adult: Refusal of Treatment)* [1993] Fam 95, 113 per Lord Donaldson.

Protective laws have 'a competing function in both removing an individual's legal rights, and in protecting and preserving their dignity and citizenship (Carney and Tait 1991). Margulies is critical of the general approach of guardianship law, with its focus on individual failure to manage personal affairs rather than an acknowledgement of systemic or family failure to support the vulnerable person (1994). He argues that the concept of incapacity is the result of the prevailing way society allocates resources, with some vulnerable persons not supported adequately (Margulies, 1994).

Guardianship legislation varies between jurisdictions,[24] but in general Australian guardianship law reflects liberal ideology and disenfranchises those who do not meet the autonomous ideal due to mental incapacity. For instance, when appointing a private or public guardian to make financial or lifestyle decisions on behalf of a person, all of the person's decision-making rights in that domain are lost. While the statute requires the substitute decision maker to give 'consideration' to previous and current preferences, the substitute decision-maker's views of the person's best interests will predominate.[25]

Guardianship law has been evolving to reflect changing societal attitudes towards persons with mental illness, mental disability or mental frailty (Wood 2005; Regan 1971). Guardianship legislation has its historical basis in the doctrine of *parens patriae,* where the state was responsible for providing care for mentally vulnerable citizens and their assets (Wood 2005). This past paternalism has been changing to demonstrate 'an increasing respect for individual civil rights, an increased understanding in human functioning, and the desire for the law to intrude as little as possible in the lives of people with diminished capacity' (Quinn 2005, 49). Human rights perspectives have shaped guardianship reforms in the United Kingdom with the *Mental Capacity Act 2005* (UK), and have led to greater support for autonomy and a review of guardianship legislation in Victoria (Victorian Law Reform Commission 2011). This indicates further evolution ahead for other jurisdictions,

---

[24] The Queensland Law Reform Commission Report 2008 compares the provisions of guardianship legislation in each Australian state and territory, showing commonalities and differences.

[25] *Guardianship and Administration Act1993* (SA), s 5.

with calls for changes in South Australian legislation (South Australian Office of the Public Advocate 2009).

In this section, I have compared how different laws can lead to autonomy being diminished or enhanced (Nedelsky 2011). The carriage of law in the formal domain is also shaped by the requirement to adhere to a range of legal principles. One such principle is that of procedural fairness, which is concerned with ‘decisions affecting *fundamental* (sic) rights, in particular rights to property, liberty and reputation’ (Katzen and Douglas 1999, 173). The law requires that any decision made which affects a person’s rights or interests has a fair decision-making process (the hearing rule) by an informed decision-maker (the no bias rule) (Katzen and Douglas 1999, 171). The ‘hearing rule’ requires that the process for making the decision is transparent and consistent, that all affected persons are afforded an opportunity to be heard on the issue and that reasons for the decision are given (Katzen and Douglas 1999). The ‘rule against bias’ requires that the decision-maker is neutral and ‘not so prejudiced in favour of a conclusion already formed’ (Katzen and Douglas 1999, 206). Procedural fairness as a principle of law, offers a relevant lens to review the processes of the capacity assessments in a later chapter.

This next section describes how these laws can be enacted to resolve human affairs without necessitating the use of formal legal structures.

In the shadow of the law

Human activities that may be regulated and enforced by statute or common law, but do not require necessarily formal processes in order to occur, are said to take place in the ‘shadow of the law’ (Galanter 1981, 8). While statutes and common law may influence them, these activities do not require any formal legal structures to occur. Faith’s story gives an illustration of this type of activity: Faith’s nephew Graham acts on his understanding of his legal role as Enduring Guardian and does not seek a tribunal to validate his decision for Faith to enter residential care. He acts within the shadow of the law, using his powers under the *Guardianship and Administration Act 1993* (SA) as Faith’s decision-maker. Faith’s doctor also acts in the shadow of the law using common law principles to assess Faith’s capacity when Faith refutes the need for residential care. The doctor also respects Graham’s authority as a substitute decision maker, enabled through provisions in guardianship legislation.

While these activities can occur in private settings and within personal relationships, without the supervision of law, the redress of formal law is available if needed. For instance, Faith’s nephew or her doctor could have applied to the Guardianship Tribunal if Faith continued to resist the idea of residential care. Her confusion and inability for self-care would have become substantial evidence of her need for alternative care, and the Tribunal could have made an Order that directed Faith to reside in a specified place, such as an aged care facility. In this way, formal law supports those activities that occur in its shadow. The extension of law into activities occurring in an informal arena serves the purpose of allowing society to resolve common matters, without reliance on formal legal processes.

Skene gives an example of doctors navigating informal processes of consent to treatment where the patient lacks capacity. She suggests that the accepted practice is to gain the informal consent of the carer, and while doctors may be seen as ‘acting without legal authority…it is assumed it is lawful for the procedure to be undertaken with the informal consent of the relative or carer, or even without any consent at all’ (Skene 1998, 137). Requiring formal legal processes to appoint substitute decision makers in each case of incapacity would be ‘so burdensome that doctors would be reluctant to use them and disabled patients may be denied access to necessary treatment’ (Skene 1998, 134). A resort to formal legal interventions would occur in relation to the threshold of risk: ‘courts and guardianship boards will not intervene in the care of an incompetent patient or appoint a guardian unless the person’s welfare is at risk’ (Skene 1998, 137). This example demonstrates a pragmatic but legal interpretation of law in the informal domain, which allows day-to-day business to proceed in an effective manner, with rare incursions into formal law.

Decision-making capacity also operates under the shadow of the law. For instance, while guardianship tribunals have powers to make an Order for a person to reside in a particular place, the legal procedure is not invoked every time an older person with dementia unwillingly enters a residential care facility. From a human rights perspective this result may be viewed as depriving a person of his or her liberty without formal scrutiny,[26] however it is commonplace for residential care facilities to ignore requests of the person to 'go home', and distract them in the hope that they will 'forget' and adjust over time to new surroundings. If the person consistently asks to leave, the facility may then invoke formal legal processes in order to gain the authorisation to continue to provide care and detain the person as appropriate. An assumption is therefore made about what the formal resolution would be if the legal system was to be formally invoked, and the perceived likely outcome of the legal process is then anticipated as a practical shortcut. This is a form of legal consciousness arising from 'practical experience with legal conventions' (McCann and March, 1996, 210).

However, there are some dangers in this approach. While informal processes may be expedient in managing the everyday care of older persons with mental incapacity, this leaves open the potential that paternalistic and prejudicial attitudes towards people with incapacity may prevail. The prioritising of day-to-day efficiency may in fact violate the older person's decision-making rights, such as a doctor imposing a decision on an older person who is competent, or health care professionals deciding that a person is to receive residential care, despite the person's wish to return home. Ongoing scrutiny is necessary to identify such violation of rights, but any challenge to prevailing approaches would rely on a high level of cultural and legal consciousness, and confidence, in the person sounding the alarm. The diversity in cultural values and norms and the desire to avoid risk for patients can result in limited consideration by those with power about the legal rights of older persons. This can create an environment that is disempowering or punitive to those who try to speak out on their behalf. Consequently, the reliance on informal safeguards to protect a person's legal rights in the legal domain has risks and limitations.

Similar concerns exist in relation to capacity assessment. Some commentators prefer the courts or tribunals to make capacity determinations, rather than relying on

---

[26] The *Mental Capacity Act 2005* (UK) has 'deprivation of liberty' provisions, where decisions for residential care are reviewed and authorised externally, as a safeguard for those incapable and without decision-makers (Victorian Law Reform Commission 2011a).

everyday informal actions as there is independent scrutiny by an objective third party (Moye and Marson 2007). In addition, the balancing of legal principles is a complex matter that 'can only be appreciated in the light of the body of case law' in contrast to simplified approaches to law in the everyday world (Donnelly 2010, 173). A court is also required to adhere to the standard of natural justice, giving a level of procedural protection to the person that may not occur in informal practices (Moye and Marson 2007). Sabatino and Basinger also consider that procedural rights are essential to protect autonomy in the instance of substantive standards in capacity assessment, and need to be 'recognized and enforced' (2000, 137).

Overall, 'the various parties generally "bumble through" extra-legally as best they can' in capacity assessment (Kapp 2002, 413). This increases the vulnerability of already disempowered persons. Improving health professionals' consciousness as to the aim and purpose of the law, of 'how and by whom the law is used' and the effect of culture, norms and values on practice, is one strategy to enhance the careful use of capacity assessment (Ewick and Silbey, 1998, 35). Different tests and approaches to capacity assessment which aim at a standard approach, are discussed in the next section, with autonomy-enhancing approaches with the potential to guide informal decision-making processes, explored in Chapter 3.

The application of the law is not without contention, particularly from different disciplinary worldviews outside of law. In the next section I present some of the broader debates regarding the concept of decision-making capacity that contribute to the dynamic interactions of the legal domain.

II Contentions and controversies arising from the legal approach

Legal approaches to decision-making incapacity, and in particular the common law, have led to decades of debate in the domains of health care law, ethics and philosophy (Charland 2008). Debates include concerns about the rational-cognitive approach, as discussed earlier, and disputes about procedural or substantive approaches towards assessment of capacity. In addition, there are tensions arising in response to the confusing proliferation of approaches to testing, concerns regarding lack of objectivity, and other contextual issues. The limitations of capacity assessment indicate that more is expected from the current approach to capacity assessment than is realistic.

Cognition, rationality and emotion in decision-making

Cognitive-rational thinking is the basis for determinations of decision-making capacity. While debated as a philosophical ideal, it is also a contested idea due to the contemporary understanding that persons do not necessarily use and rely on reason to make choices. This section discusses these two areas.

Neuro-scientists have found that everyday decision-making involves an automatic intuitive process that is based on fast unconscious interpretations of environmental cues (Wood and Tanius 2007). This process of thinking is tempered by another process which is ‘analytic, effortful, flexible, and slow’, enabling a person to quantify, calculate and retrieve information from memory (Wood and Tanius 2007, 92; Kahneman 2012). Wood and Tanius consider that a ‘good deal of everyday decision-making requires the dynamic involvement of both systems’ with different neural circuits involved in each (2007, 92). As the first form of thinking is automatic, persons habitually make choices without reasoned consideration of risks and consequences. Therefore, assessment based solely on rationality does not reflect human nature.

Researchers have also found that the two processes of thinking, intuitive and deliberative, are utilised differently with age. Older adults, in adapting to age-related changes in neuro-anatomy and reduced function in working memory, ‘rely more on affective processes in their decision-making …than on deliberative processes’, which may be a compensatory strategy to cognitive changes (Wood and Tanius 2007, 96). The increased reliance on intuitive decision-making by healthy older people challenges the validity of tests of capacity that focus on executive function, aligned to deliberative thinking. Wood and Tanius suggest that such ‘neuropsychological measures … may not correspond to …real-world decision making’ (2007, 97) and yet are the basis of many assessments of decision-making for older persons. As older people are a major client group of such tests, these test approaches can ignore and devalue the successful adaptations of the ageing person, becoming a form of unintended ageism. This new knowledge about thinking, while applied in other fields (Thaler and Sunstein, 2008), has been slow to infiltrate the legal domain.

The second area of debate is about the roles of emotion and values in cognitive decision-making. Post is critical of society as hyper-cognitive (1995), and Charland contends that values and emotions are part of the cognitive process that shapes reasoning (1998). Emotions ‘inform us about the meaning of an event’ which we assess against our ‘wants and aims’ and which results in an authentic personal outcome (Charland 2001, 143). He notes that models of capacity assessment assume the person is aware of this internal reasoning process, but that this may not actually be the case, making the reasoning process difficult to assess (Charland 2001). Other influences, such as biographical and historical experiences, add to those of emotion and values to impact on decision-making (Breden and Vollman 2004, 277). Christman suggests that the term ‘passionate reasoners’ is a more accurate concept as it acknowledges the role of other qualities as integral to the person (2003, 7).

Research has also illuminated the role of emotion in decision-making where, previously, theories in psychology ‘either minimised the role of emotion or discussed emotion as a distraction to rational decision making’ (Wood and Tanius, 2007, 93). These ideas were revolutionised following Damasio’s work on emotional intelligence (1994), which showed that damage to the area of the brain that processed emotional signals affected the ability to make appropriate decisions, confirming emotion as an essential factor in decision-making (Wood and Tanius 2007).

Not all support the inclusion of ‘emotional and valuational parameters’ in capacity assessment, as evaluating others’ personal morality can be perceived as too subjective (Kluge 2005, 296). Breden and Vollman, however, consider that there is a future requirement for research to find objective ways to evaluate these ‘authentic values’ in decision-making (2004). These debates are indicative of the desire by some to make the law more applicable to real life decision-making.

The rational cognitive approach to capacity determinations has flaws. This approach lacks a reflection of real life intuitive thinking processes, excludes the role of values and emotions in decision-making, and ignores idiosyncratic changes in thinking over the life cycle. As an unrealistic representation of decision-making, it may be unjust and diminishing of autonomy, deserving a rethink of the cognitive-rational approach. At the same time, facilitating reflective thinking gives the person the opportunity to consider a decision fully, with this attribute treated as essential in capacity tests.

Procedural and contextual approaches to assessing capacity

Another area of debate reflects concerns about the value-neutrality towards outcome. The procedural approach to capacity assessment is described by Charland as confining the capacity assessment to the process of reasoning and its necessary elements, such as understanding choices and insight into consequences, and being neutral to the content (2001). However, this purely procedural approach ignores the view that understanding the reasons and context behind a decision are important in determining decision-making capacity (Freedman 1981). Information about ‘why a person proposes to choose as they do’ indicates the role of values in authentic decision-making and is different to allowing the content of the situation to alter assessor views about the *ability* of the person to make the decision (Charland 2001, 143). In this way, the approach is still procedural in nature, but incorporates the factors that make up that choice.

In contrast, additional contextual information can become part of the assessment, providing a holistic approach. For instance, Moye supports assessment that takes account of the ‘environmental, contextual and situational factors’ as part of the process of determining capacity, combined with gathering information for solving the healthcare or social problem of the patient (2007, 187). Moye considers that contextual information assists not only with assessing decision-making capacity but also gives knowledge of the person’s environment and the ‘least restrictive alternatives’ in planning for care such as risk, medical aspects, cognitive function, everyday function and values, and options to enhance capacity (Moye 2007,182). Donnelly suggests that the legal requirement to assess capacity ‘without reference to the nature of the decision…is almost impossible to meet’ (2010, 3), while Higgs views that a ‘narrative understanding of the person’ is necessary: ‘if we must judge people, we must first struggle to understand them’ (2004, 308).

In this way, the divide between procedural and contextual processes can blur, with a risk that value judgments may influence capacity assessment. For instance, health professionals may assess the home care environment as providing inadequate support for the person, and may not include this option in the choices available, despite any procedural account that demonstrates that the patient understands this limitation as part of their autonomous choice to return home. Judgments by others on the person’s general function, such as in medical assessments, can be in tension with the capable person’s legal right to make the choice and be used as a justification to limit autonomy, rather than to enhance it.

The risk of harm is an example of a contextual consideration outweighing procedural processes of capacity assessments. For instance, Brock considers that the ‘standard of competence should vary’ based on the effects of the patient’s decision and concludes that possible risk of harm is a preferred basis for the threshold for capacity, rather than autonomy (1991, 105). In using the approach of the greater the risk, the higher the capacity threshold, Brock maintains that both ‘respecting a patient’s self-determination and protecting his or her well-being’ are held in balance (1991, 105), and argues that a variable level of capacity is necessary due to the ‘stubbornness’ of law to give validity to harm:

> *….the law makes a finding of incompetence a necessary condition for justified paternalistic interference with the patient’s choice… setting aside patient’s choices for their own good...requires that the patient be found incompetent’(1991, 106).*

This contextual approach moves the goal posts of capacity threshold to match the risk of harm. This tension reflects the pull between autonomy and beneficence, and places procedural and contextual factors in a fine and unresolved balance.

The assessment of capacity

Debates also occur about the method of assessing capacity. The significance of any capacity determination is its perceived ‘gatekeeper’ role, which decides whether autonomy or beneficence will take precedence for any particular patient where a conflict in treatment between the doctor and patient may occur (Faden, Beauchamp and King 1986; Devereaux 1999). ‘Competency resolves the impasse’ in that a competent patient will have his or her wishes respected, while an incompetent patient will have a decision made on their behalf, using the ‘best interests’ approach based on the patient’s good, after an analysis of the benefits and risks of the treatment (Devereaux 1999,77; Mendelson and Ashby 2006). The gatekeeper role therefore requires capacity to be a ‘black and white’ concept. The attempt to translate law into a practical tool to achieve this end has resulted in the development of a range of capacity tests, with subsequent debate about their reliability, and concerns about who conducts the test, and which test is used.

Tests and tools

There has been a proliferation of guides, tools and tests developed to assist practitioners in solving capacity decision-making dilemmas. The main tools are in the form of an interview, with structured or semi-structured questions, or as vignettes with questions based on a ‘hypothetical situation and treatment choices’ (Moye and Braun 2007, 213; Glass 1997). Appendix 2 lists some of the most commonly used tools, which have been ‘purpose-built’ for capacity evaluations. The discipline of neuropsychology has also become increasingly involved in capacity assessments and the development of tests, which have extended to tests on executive brain function and memory (Marson et al 1995; Sullivan 2005; Qualls and Smyer 2007). There have been comparisons of instruments, but any genuine comparison is difficult, because of the variable purposes of tests and tools, differences between legal and functional standards, and various diagnostic groupings (Vellinga et al 2004; Dunn et al 2006). The development and use of tests in capacity assessment is indicative of a strong desire for certainty. This positivist approach is strong in medicine and allied clinical fields such as neuro-psychology, and reflects the clinical reliance on objective assessment, with the ongoing search for a single standard approach to capacity determination (Kapp and Mossman 1996; Sullivan 2005). Kapp, however, warns against the pursuit of a ‘capacimeter’, due to the complexity and contextual nature of decision-making capacity (Kapp and Mossman 1996, 74):

> *The idea of a capacimeter ... resonates powerfully with relevant scientific findings and with modern society’s sometimes uncritical faith that human problems can be mastered through quantification’.*

Glass warns that such ‘instruments should not be used alone’ to determine incompetency (1997, 15) and Welie urges education about the purposes of such tests so they are used appropriately, rather than letting them ‘lead their own lives’ (2001, 145). For instance, neuropsychological tests designed to assess the cognitive changes that can affect capacity may become ‘substitutes for clinically based competence determinations’ (Grisso and Appelbaum 1998, 51; Marson et al 1996; Wood 2007). Welie suggests that ‘algorithmic’ measurements are illusory and misunderstand the normative nature of the concept of capacity (2001, 147).

Despite these concerns, there has been substantial energy directed into the development and evaluation of tests in capacity assessment (Marson et al1996; Grisso and Appelbaum 1998). The ageing of the population, with its prevalence of cognitive and neurological disorders and the need for a quick and effective test because of resource constraints, has some viewing ‘civil’ capacity assessment, being determinations of capacity outside of a court, ‘as a growing field of clinical practice and empirical research’ (Moye and Marson 2007, 3).

There is a view that interview methodology is more effective than test procedures to assess understanding as a measure of functional capacity. Welie considers capacity assessment requires a conversation with the patient about decisions that reflect his or her personal preferences and values (2001, 147). Church and Watts view that interviews ‘not only to allow the requirements of a legal test of capacity to be met, but also to test the potentially wide range of decisions necessary, provide properly tailored support and enable consideration of relevant evidence’ (2007, 306). A ‘capacity interview’ rather than quantification and measurement is used in Ontario, Canada to meet the stringent legislative requirements for decisional capacity, with the goal to interpret the degree to which ‘a ‘person’s level of decisional ability match[es] the demands of the specific situation with which they are faced’ (Ontario Capacity Assessment Office , 2005, II.1). Darzins, Molloy and Strang recommend an interview approach but provide a scoring tool to assist in the determination (2007).

Issues of objectivity in assessments

Capacity assessments occur in the context of assessors having variable levels of understanding of the law, the purpose of the tool, and a question of who is qualified to conduct such tests. One major group of assessors are clinicians, who undertake assessments for capacity either as part of informed consent requirements, or in discharge planning. In a medical context, they may occur in a strong culture of paternalism and significant cultural expectation for certainty (Fox, 2000; Quill and Suchman 1993). Research has found that ‘physician competency assessment is a subjective, inconsistent, and arguably idiosyncratic process’ (Volicer and Ganzini 2003, 1273). Capacity assessments in everyday health care settings have been found to lack scrutiny, with a risk to quality:

> *…determinations are also made within health care institutions for purposes of medical decision-making… without any assurance of reliability…(Glass 1997, 10).*

Capacity assessments can be misused for secondary purposes. In a study of patient refusal of treatment, Jourdan and Glickman identified a lack of understanding by physicians about their duty and the patient’s rights, with their research indicating that doctors requested formal capacity assessments as a guarantee in the case of any legal consequences against them (1991). Kapp found in his research that formal capacity processes were utilised to avoid legal ramifications to the doctor or the institution, as ‘a matter of legal self-protection for the health care provider…rather than primarily for the ward’s benefit’ (2002, 413). Such application is a misuse of capacity assessments, and unnecessarily imposes an intrusive assessment process on vulnerable patients.

Doctors may experience a conflict of interest in conducting a capacity assessment, if also providing treatment to the patient (Cutter and Shelp 1991; Donnelly 2009; Verma and Silberfield 1997). Karel suggests that doctors make judgments about a patient’s decision from their own cultural perspectives, and therefore ‘awareness of one’s own values attitudes and biases and how these may affect rapport and clinical judgement is critical’ (2007, 160). Erde proposes that having an independent person undertake the assessment using objective criteria to minimise this conflict of interest (in Cutter and Shelp 1991). Moye and Braun (2007) propose that values clarification tools[27] can be a valuable aid to the self-awareness of health professionals, but

---

[27] Value clarification tools provide checklists and exercises to aid a human services professional to become aware of personal values that may influencing their viewpoint and causing bias in particular instances, or of the values of the patient.

Donnelly suggests that many personal perspectives are unconscious and unavoidable (2009, 480):

> *Ultimately and inevitably, all capacity assessors come to the task clothed with their professional and personal values, motivations and beliefs. These factors affect how assessors engage with the people whose capacity they assess and may determine the conclusions they reach. Yet for the most part, the law operates as if these factors do not exist.*

Subjectivity arising from personal and professional norms compromises the objectivity sought by tests. Moye and Marson suggest that only courts and tribunals may ensure procedural safeguards through scrutiny by an impartial third party who applies natural justice considerations (2007). Skene, however, suggests that the volume of everyday medical assessments would overwhelm tribunals, and therefore informal assessments are a pragmatic necessity and reality (1998). To avoid ‘muddling through’ therefore, additional scrutiny and policies about practice seems appropriate.

This section has explored the various tensions arising from implementing the concept of capacity in practice. The next section gives attention to the application in Australian medical settings.

Australian approaches to capacity assessments

Three different approaches published in Australian literature illustrate the diversity in application of capacity assessment in healthcare settings with older persons in the Australian setting. These approaches span 15 years of scholarly and policy literature and also demonstrate changes in society over this time, as well as different emphases towards law.

The first approach by Finucane, Myer and Ticehurst (‘the ethical model’), being the earliest model, focuses on the practical ethical issues of capacity assessment, by recognising the increasing prevalence of conditions that can impair decision-making in older people (1993). The authors recognise the problem of the arbitrary, all-or-nothing phenomenon’ of capacity, but also acknowledge the cultural shift from beneficence towards autonomy, ‘even for those with reduced competence’ (Finucane et al 1993, 400-401). Their approach maximises autonomy through attention to a conducive environment, ensuring the patient’s mental state is medically stable, and addressing any concerns or factors such as anxiety that can affect decision-making. As older persons may require time to absorb relevant information, giving information gradually on different occasions may aid understanding (Finucane et al 1993).

The cognitive concepts used in the ethical model appear to align with the common law approach. The patient must be ‘aware of her or his condition and circumstances’; understand the issues; and be able to ‘process the relevant information and choose rationally’ (Finucane et al 1993, 400). Attitudes and values can influence the assessment and health professionals are advised to be aware of personal views that may affect their objectivity (Finucane et al 1993). As relationships with family and carers are ‘entwined’ in patient decision-making, the authors also recommend undertaking ‘a comprehensive interview with all involved family [for] invaluable information on facts, opinions, motives and family culture and beliefs’, as well as the degree of support available to aid functioning at home (Finucane et al 1993, 402).

This approach recognises the importance of enhancing the patient’s autonomy when conducting the capacity assessment. The ethical model considers that the doctor has a duty to promote the patient’s best interests as judged by the doctor (Finucane et al 1993). In this way, there is a mix of procedural and substantive consideration in the assessment approach.

The second approach, published seven years later, illustrates capacity assessment in the form of a ‘six-step model’ (Darzins, Molloy and Strang 2000). Darzins, Molloy and Strang view capacity as a social and legal construct that supports people’s rights for autonomy, and as a mechanism for establishing substitute decision-making if capacity is lost (2000). Their assessment of capacity adheres to the rational cognitive model and is value neutral to the outcome, aligning to key concepts in the common law. The authors acknowledge that as human beings are complex, and capacity not tangible, any tool has its limitations, ‘but a reliable and valid capacity assessment process’ can assist with resolving problems (Darzins, Molloy and Strang 2000, 6).

As capacity assessments are invasive, the six-step model requires a valid trigger or reason for assessment such as an identified risk as the first step. The second step is to engage the patient in the process of the capacity assessment and gain assent for participation in the assessment (as the ability to consent has not yet been established). The third step is to explore the issues leading to the assessment, the individual's 'values and goals', and relevant information from the patient and others about the context and choices available. The authors note that the 'problem' as identified by the trigger for the assessment can often be resolved from this shared information and discussion, including identification of the patient's wishes. If not resolved at this point, education of the patient regarding the choices available to them occurs as the fourth step, together with information about others' concerns. The fifth step is the capacity assessment test itself, utilising a template to measure the patient's functional understanding of their situation, choices, and consequences of those choices. Under this test, decision-making capacity is deemed present if the person understands all three areas, otherwise a substitute decision–maker is appointed to make the specific decision relating to the 'problem', as the sixth step.

The approach of the six-step model recognises the presumption of capacity as formulated in common law on decision-making capacity, and the requirement of functional understanding of the specific decision and its consequences. Contextual considerations have a place in the early stages of this approach, with capacity assessment taking place by procedure if the problem remains unresolved. The approach incorporates the goals and values of the patient as part of the information process. Further detail is in Appendix 8. This model is more representative of the common law basis of cognitive-rational decision-making than the first model, and, where assessment may be unavoidable, represents good practice.

A third, and most recent approach, is the 'Capacity Toolkit' developed by the Attorney General's Department of New South Wales (2008). This Toolkit was the result of extensive consultations regarding the rights of people 'whose capacity is in question', and was developed as a guide for families, advocates, health care workers and legal practitioners (NSW Attorney General's Department, 2008, 6). The Toolkit defines capacity in line with common law, being the ability to understand the facts, understand the main choice, weigh up the consequences of the choices, understand how the consequences affect them, and being able to communicate their decision

(NSW Attorney General's Department 2008, 18). The set of accompanying principles include the presumption of capacity, the decision-specific nature of capacity, and a focus on the decision-making ability and not the decision. This supports the procedural approach to capacity assessment. Decision-making, like the Darzins model, is decision-specific. The standard for capacity assessment in the NSW Toolkit is also procedural in approach and congruent with common law principles. This model reflects its legal authorship.

The NSW Toolkit contains ethical advice to the assessor regarding maintaining the privacy of the person, ensuring that the person has not been subject to undue influence, and avoiding making value judgments in the assessment (2008). A range of questions and tips in the booklet give capacity assessors advice on the process to use during the capacity assessment (2008). The NSW Toolkit recommends that the assessor seek a second opinion if, after assessment, the assessor still has doubts about the person's capacity (2008).

The booklet outlines the range of persons in the community who may have reason to assess capacity. This includes solicitors, professionals from the finance sector, medical or dental practitioners, community or social or allied health workers, enduring guardians, advocates or family members (NSW Attorney General's Department 2008, 54). This broad list, while indicative of the everyday requirements of society to know if a person can make a decision, raises the concerns expressed earlier about informal assessment and variable skills and knowledge.

The ethical, six-step and toolkit models all have a cognitive rational basis to assessment. Each seeks to ensure that autonomy is maximised through an enabling environment and through informing the person prior to the assessment about the facts of the decision, in a way that they can understand. The ethical model is designed with doctors in mind as assessors, the six-step model recommends assessment by any health professionals who can give adequate time to follow the six steps, and the NSW Toolkit lists a large number of persons in the community who may potentially make judgments about capacity.

The utilisation of contextual information differs in the three approaches. The ethical model gives credence to the doctor’s view of best interests, thus is at risk of being paternalistic. The six-step model incorporates contextual information in the third step of the model, exploring the issues of the problem, gathering information, and having dialogue with the different parties – family and health professionals – regarding their concerns and views. The actual capacity assessment in the fifth step is purely procedural, without judgment of the outcome. The NSW Toolkit maintains a purely procedural approach to the assessment.

The approach of the six-step model in integrating both contextual considerations and the procedural processes in the assessment allows the opportunity for the problem to be resolved without the need for capacity assessment. Consideration of the context is beneficial if it achieves resolution of the problem in a way that supports the person’s autonomy and life goals and does not force limited options onto the vulnerable person. Any success in resolving a particular problem in this way questions why the problem was not resolved through dialogue and exploration earlier, before a request for a capacity assessment. One possible reason is the weight given by health care professionals to views other than the patient’s, leading to an impasse as any departure from a procedural process is susceptible to professional values and cultural prejudices that diminish rather than enhance autonomy. If this is the case, it cannot be assumed that taking a contextual approach will be beneficial per se, as it can be influenced by the values held towards the person and their autonomy.

Limitations to the use of capacity assessments

Capacity determinations can significantly limit a person’s social and legal freedoms and require careful and sparing use (Carney 1997). However, with a flawed premise of rationality, an unrealistic desire for empirical objectivity, and with normative views towards outcomes, capacity assessments have limitations. Part of the difficulty results from the abstract notion of capacity and its black and white legal requirements in everyday life (Sabatino and Basinger 2000). The law aims for precision in an inexact world, declares Donnelly, by ‘seeking to impose a tidy structure on a much more complicated situation’ and relying on ‘bright-line, capacity based distinctions’ that do not fit real world experiences (2009, 475). This aspect presents the major source of contentions and confusion in applying theory to practice.

As a legal fiction, decision-making capacity is ‘a construct treated as a fact, whether or not it is really so, because it is recognized as having utility’ (Sabatino and Basinger 2000, 119). Sabatino and Basinger suggest that legal fictions have a legitimate purpose in aiding society’s functioning, and in this case are the ‘…trigger to tell us when a state legitimately may take action to limit an individual’s right to make decisions about his or her property…’(2000, 120).

Law and its legal fictions, are reflective of prevailing norms and political ideology (Sabatino and Basinger 2000). With a range of limitations in everyday application, and with the normative nature of the concept, Welie considers there is too much reliance on the fictional construct of competence to solve decision-making problems:

> *…incompetence cannot bear all of the weight put upon it; not all decisional dilemmas in health care for individual patients can be solved through this concept’ (2001, 147).*

Capacity assessments can also become tools of social conformity. Glass argues that the premise of autonomy relies on constructed boundaries ‘designed to empower or restrict the rights of persons for particular purposes’ in order for society to achieve its broader goals (1997, 7). She considers, however, that there is a risk of these boundaries being over-utilised in contextual settings with the ‘danger that competency will empower social institutions to “trump” an individual’s rights’ (Glass 1997, 8). This leads to the view that capacity assessments should be a last resort in solving the problems faced by older people. Glass and others suggest that pre-screening interviews can aid in establishing that a capacity determination is essential (1997; Silberfield, Corber and Checkland 1995). Darzins, Molloy and Strang suggest that appropriate time spent gathering information from key people can sometimes resolve the issue that has led to the request for a capacity assessment (2000). Giving sufficient time to clarifying the patient’s concerns can also lead to resolution, with Hurst of the view that understanding and respecting the patient’s choices ‘even when decision-making capacity is clearly absent’ can avoid the necessity for a capacity determination (2004, 1760).

Rather than invoking capacity assessments as a last resort, they can often and best be avoided altogether. Welie suggests that in interpreting capacity as a fiction of law, it ‘need not always be assessed, and hence not always be assessable’ with no duty of a professional to assess in order to seek a proxy (2001, 147). In ‘the presumption or fiction of law…justification could consist of other interests or principles prevailing’ above those associated with capacity assessment; therefore normative considerations of accepting the patient’s wishes can have precedence over that of decisional capacity affording the person power to decide (Welie 2001, 147). An alternative to capacity assessments in resolving care issues can be that of providing resources and supports that will enhance the person’s functioning (Glass 1997, 7):

> *If the principle of respect for persons operated optimally, society would function to maximise autonomy, limiting it only when necessary to protect persons from harm, in particular those unable to protect themselves.*

This reflects the view that incapacity results from inadequate social supports (Margulies 1994), and that capacity is contextual to the person’s environment (Nedelsky 2011). Therefore, appropriate supports can remove deficits, aligned with the political notion of positive rights (O’Connor and Purves 2009).

Capacity assessments, initially concerned with bodily inviolability and the necessity for legal protection in the patient’s inability to consent, have extended beyond health treatments to decisions on where to live and the care provided (Darzins, Molloy and Strang 2000). Given the contextual nature of many decisions of older persons with diminished capacity, there is the question as to whether it is appropriate or necessary to extend the capacity requirement to general life problems. Focusing on this area, the next chapter on personhood will extend the idea of alternative processes towards resolving problems where capacity assessment is currently used.

This section has been concerned with formal law regarding decision-making, activities that enact law outside of the formal legal system, and the challenges of applying the abstract notion of capacity. The next and final section explores how law and society, in relation to decision-making, interact and shape each other. To give context to this idea, I explore the idea of ‘law in the everyday’ and the socio-legal domain.

III Law in the everyday

Viewing law as written rules enacted in formal legal structures leads to a view of law as detached from everyday life. People may experience short incursions into the sphere of civil proceedings, such as contesting a will in court, resolving a landlord/tenant issue, or paying a speeding fine, after which they generally return to the usual tenor of their lives. Ewick and Silbey describe this domain as invoking ideas of law as:

> *…a remote...transcendent force governing human affairs from an all too distant plane, which from time to time is utilised but is mostly not impacting on common experiences…(1998, 15).*

An alternative view is that law extends into the dimensions of everyday life, influencing the behaviour of citizens in ways that they may be largely unaware of. Thinking back to the story of Faith in the introduction, law's underlying authority was present in everyday events in her life, shaping and facilitating Faith's choices and lifestyle. The protection of law gave Faith space to create her own unique life without unnecessary interference by others. She could utilise goods provided by the state, make everyday transactions, and navigate her relations with neighbours, businesses, and health professionals. The provisions in law enabled her to plan for alternative decision-making options for the future, in preparation for suspected future disability. Law exerted a subtle but undeniable influence on Faith's life.

The idea of 'everyday' law as constituting a broader legal domain than the events occurring within the formal legal system and its structures and activities carried out within its shadow, is one where law is understood as a socially constructed product of prevailing ideologies, values and culture (Sarat and Kearns 1994; Engel 1995). Within this mix, there are variations in the degree of consciousness with which its citizens engage with law. Complex dynamics therefore produce a legal domain in society that may be both overt and implicit.

Ewick and Silbey use the term 'law' to describe the formal realm of legal institutions and actors, and the term 'legality' to represent activities that respond to law in the informal domain: 'the meanings, sources of authority, and cultural practices that are commonly recognized as legal, regardless of who employs them or for what ends'

(1998, 22). In their definition of legality, the conformist use of formal structures of courts and tribunals are activities *before the law,* where law is a separate formal and impartial entity (Ewick and Silbey 1998, 45). Activities that engage the law are described as *with the law*, where the 'boundaries between law and everyday life are 'relatively porous', with 'new rules invented' in the application of law in the informal domain (Ewick and Silbey 1998, 45).

The idea of everyday legality also extends to those events where law is resisted: 'people may invoke and enact legality in ways neither approved nor acknowledged by the law', labelled as activities *against the law* (Ewick and Silbey 1998, 22). While resistance in Ewick and Silbey's schemata concerns those who are powerless, this thesis will extend the concept to include any individual or group who consciously or subconsciously opposes, subverts or ignores law, including those who may comparatively have more power (see de Certeau 1984; Harding 2006; Mezey 2001). Power is still central to the resistance, but the activities may be to maintain power rather than gain it, with power recognised as prevalent and based in 'local social relations' (Mezey 2001; Foucault 1982). Ignoring the law may also be a form of resistance in which 'people may reject the formal apparatus of law even as they create viable substitutes for its power and authority (Marshall and Barclay 2003, 625).

These interactions between law and society give a focus as to '*how* individual action and understanding is implicated in the production of legality' (Ewick and Silbey 1998, 39). Marshall and Barclay describe these activities as the 'push and pull' of the legal domain: 'the pull of the law on constructing and constraining individual action and decisions', and the push provided 'by individual's own interpretations of law…shaping new versions of legality' (2003, 617-618). McCann and March also view this area of activity as 'both a resource and a constraint… law is a variable social force that at once structures the spaces of social life and is reconstructed by citizens' activity within those spaces' (1996, 210).

This understanding of law as dynamic transforms the idea of law as remote to instead having a 'commonplace materiality' (Ewick and Silbey 1998, 16), with 'normative orders ranging from the “law” of the supermarket check-out line to the constitutional interpretations of the federal courts’ (Engel 1995, 125-126). Law no longer has distinct boundaries where citizens broach the walls to engage formally with the law, but consists of dynamic interaction between legal and non-legal activities in everyday happenings in society: ‘mutually constitutive processes through which law and everyday life construct one another’ (Engel 1995, 126). The production of legality from these interactions is therefore ‘an emergent feature of social relations rather than an external apparatus acting upon social life’ (Ewick and Silbey 1998, 17).

Ewick and Silbey use the concept of ‘schemas’ to describe the codes, values and conventions that exist in any context and which provide the premise for any interaction with the resources and structures in any given situation (1998). For example, the schema of decision-making capacity can include the formal posited law, the new rules developed for everyday use, the prevailing social and cultural values about older persons and of dementia, and the conflicts arising from the application of decision-making assessments. These norms and codes interact with personnel, institutions and structures, and produce legal activities that can be supportive or resistive, to law. In this way, law in everyday life is characterised by shape and form and has ‘its own distinctive logic’ (Engel 1995, 124).

In this understanding, activities that produce legality take place in a particular domain based in a specific time and space, and operate within a bounded community with different actors and a ‘plurality of normative systems’ (Engel, 1995, 133). For example, Faith’s experience was in a domain consisting of a hospital and her neighbourhood, with the doctors, social workers and neighbours as the actors. These events took place at a particular time and location, in which the ‘legal actors’, influenced by different norms and operating on personal values or codes within the setting and their profession, used their discretion to respond to and reflect these non-legal aspects, in a two way process (see Ewick and Silbey 1998, 18). In this way, the different elements of the domain were mutually interactive and iterative in an ongoing contextual dynamic.

Each domain contains interactions that shape and exert pressure on law to respond to social changes. This is particularly the case for activities that create innovations in law or resist the law. An innovation in law might occur when a doctor shifts the threshold of capacity in order to declare that a person is incapable of decision-making, because of the doctor's concerns about potential risk to the patient. In this instance, 'new rules' are created (Ewick and Silbey 1998, 45), aligning law with practice rather than practice with law. Therefore, law is utilised by individuals 'in order to elaborate their own conception of "truth"', and who are not necessarily concerned with the legitimacy of law (Harding 2006, 514). Hull places activities to achieve same-sex marriage equality in this category (2003), but the 'amendment of existing law and the construction of "new" law' is not seen by Harding as the conventional understanding of activities 'with the law' (2006, 518). Using this approach, the reform of advance care legislation in South Australia has amended rules to provide easier access by citizens to supports for future autonomy, in response to previous confusion and underutilisation (South Australian Government 2007).

Law is also resisted in this domain. An activity 'against the law' may be a doctor resisting law's support for autonomy, and making a decision for a patient based on perceived best interests, even though the patient may express other preferences and be legally capable. Resistance can also take an opposite form, where there is disregard for the conventions of capacity assessments due to their potential disenfranchisement of the vulnerable persons. Instead, the doctor or social worker may negotiate with different parties to provide supports that respond to the person's preferences, regardless of the patient's 'legal' capacity. Such stories of 'relationships of power and resistance' also have value in offering new understandings about legal consciousness (Harding 2006, 517).

An effective way for these interactions to be visible are through the use of narratives, which Ewick and Silbey consider to be a lens through which to study law in everyday life, and as a metaphor representing legal consciousness (1998, 29). Legal consciousness is reflected in the stories and activities of ordinary people as legal agents in the everyday: 'law is what people think it is, what they say it is, and what they do to implement the meanings they create' (Marshall and Barclay 2003, 621).

For instance, Faith’s nephew had a particular view of his legal authority, and by utilising it within his frame of meaning, created legality that shaped the direction of Faith’s life.

Legal consciousness represents both a traditional view where law is understood as a discrete set of activities relying on knowledge of legal conventions, being consciousness of the law, and a ‘systemic’ conception of law as a ‘form of social life’ (McCann and March 1996, 215). Nedelsky shares this social constructionist view of law, viewing law as in constant interaction with other norms and structures in society, and places relationships central in any analysis of the legal frame (2011). She indicates that the values of autonomy, freedom, dignity and equality require relationships to take effect, and that the quality of relationships are shaped by norms and culture in the societal domain (Nedelsky 2011, 375). As law is an integral vehicle for deciding what social norms should be by ‘giving effect to, and enforcing values’, Nedelsky views law as having potential in contributing to changing norms and restructuring relationships within these mutually constitutive dynamics (2011, 364).

In exploring concepts of the socio-legal domain, I argue that law’s activities occur in nuanced social environments well beyond the formal arena. The activities in the different spheres are ‘mutually constitutive’ within society, and can support law, adapt law for practical use, or resist law. These interactions create a system, and contribute to the evolution of law over time, which in turn influences and modifies behaviours and social structures. The perspective that relationships determine the expression of core values such as autonomy and equality, suggests a more deliberate role of law to analyse its participation in these dynamics and to maintain a focus on core values in these constitutive interactions. In this way the space provided by law, rather than being a vacuum for diverse norms in the liberal approach, offers potential for shaping the values and behaviours that enhance full personhood.

IV Conclusion

In this chapter, I have given an overview of formal law in relation to decision-making capacity, demonstrating that liberal ideology remains dominant with its focus on rationality and value-neutrality. I have introduced the idea of the legal person as consisting of rights and duties in relation to each piece of posited law, and of the concept of capacity as a legal fiction that aids the functioning of law. Law's history of supporting and protecting autonomy remains influential and continues to shape emerging directions in law, such as with advanced care directives legislation.

The rational-cognitive approach towards decision-making in law has limitations in application to real-world situations, and this has led to ongoing controversies and contentions. One major direction has been to seek certainty through a standard test approach, but these do not accommodate the complexity of human nature. As a black-and-white concept, the procedural approach does not take into account residual autonomy, or necessarily focus on factors that diminish autonomy, or provide opportunities for participative decision-making. The mix of procedural and substantive approaches has the latter being susceptible to cultural and professional prejudices, but also potentially sensitive to factors that can diminish rather than enhance autonomy.

Approaches based on the blurred boundaries between formal law and society have offered new dimensions in analysing how law interacts with society in everyday life and is in turn shaped by these dynamics. Activities in this domain lead to the creation of new rules, or can demonstrate resistance to law. Within the space created by law, a deliberate approach to facilitating values and relationships that support and enhance autonomy is possible. The legal domain provides opportunities and space for the legitimate expression and support of autonomy of vulnerable persons, without recourse to formal law unless this is unavoidable.

In finding the rational-cognitive approach to have theoretical and methodological limitations, I support an alternative approach to decision-making, with formal law as a last resort. Developing the concept of autonomy as empowerment, rather than non-interference, could reduce the limitations currently present in the capacity model and change the current process of ‘bumbling through’ in issues of decision-making. The challenge is to find an alternative or complementary model towards decision-making that enhances autonomy and is respectful of persons in the resolution of problems. Such a model of decision-making needs to be sufficiently congruent with law’s approach, so as to not disenfranchise those concerned with claims of negligence or battery, as well as indicate when it is appropriate to enter the formal domain to resolve problems as a last resort. The model needs to give confidence about law’s purpose, based on the enhancing of autonomy morally and legally, as to give weight to its legitimacy.

A needed goal of alternative decision-making methodology will be to place respect for the person and their autonomy foremost. Such a model would contribute to the activities within the legal domain that can shape the expression and development of law and social values that enhances personhood and empowers individuals despite impairments. Additional activities of raising the legal consciousness of health professionals and increasing awareness of prevailing culture, norms and values, may improve the informal expression of legality in enhancing autonomy.

The next chapter will explore the notions of personhood that entertain the values of the uniqueness and worth of individuals, as worthy of respect. It will offer a fuller understanding of the person than provided by liberal ideology in relation to the core values of autonomy. I will also consider personhood in relation to persons with dementia, and give further attention to decision-making approaches designed to respect personhood and maximise autonomy.

3 Personhood, dementia, and decision-making

This chapter gives attention to the concept of personhood and its relationship to autonomy and decision-making. The terminology of ‘person’ and ‘personhood’ are used in different ways and different contexts in the literature. This thesis takes a broad socio-legal approach to these concepts. In order to clarify this approach, some clarification of terms is valuable. In this thesis I use the term person to denote a human with the natural multi-dimensional attributes of humanity, which I describe as the ability to experience, think, feel, and value, in ways that are individual and subjective to that individual. This idea of the person connects to that of autonomy, as it both an attribute and a need of human beings. That is, to act in a self-determining way is a natural expression of the person’s internal thoughts, beliefs and values, and which comprise a sense of their unique sense of self, in response to their exterior world. I do not rely on judgements of ability for self-government, as argued in the liberal tradition, in acknowledging the significance of self-determination to every natural person.

In Chapter 1, I described how constraints on the expression of an individual’s self-determination can significantly reduce their psychological well-being, and how other external oppressions or constraints on choices and activities can also damage the individual’s sense of self, and subsequently affect their capacity to be autonomous. In this way, the person can be said to have their own sense of personhood, or sense of selfhood, of which autonomy is an attribute.

Personhood is also a term that can be used to denote the status that is bestowed or conferred on a person by others. Personhood status in this regard is linked to specific attributes of the person that are considered to denote that status. For instance, in the previous chapter, I described the attributes of the person given status by law in decision-making, namely that of the person of reason. In this instance, personhood is a formal legal status that relies on this attribute to be present.

These concepts intertwine, as the person’s own sense of selfhood can be deeply affected by the social personhood bestowed on them by others. To distinguish between these different uses, I have sought to use the term ‘personhood’ to describe the external bestowal of status, and the term person to recognise the individual, who along with a range of human attributes, has a sense of their own self, arising from their thoughts, beliefs and values, that can be subject to the effects of the status imposed or withheld by others.

In this chapter I extend this discussion on personhood to describe other worldviews of the person, defined by particular attributes that earn this status. The personhood status afforded to patients in medicine is explored, followed by consideration of the personhood status for those who do not meet the cognitive-rational threshold of competence, and the effect on this conferred status on autonomy and decision-making.

In particular, dementia has begun to challenge previous personhood concepts. As a group previously considered to be lacking decisional capacity, emerging new concepts of personhood in dementia give greater respect for decision-making, differing from the prevailing legal and medical approach. From this position, I outline person-centred decision-making approaches that recognise the contextual nature of capacity and the relational concept of autonomy, providing an alternative framework to the rational cognitive capacity approach. These contemporary approaches depart from the traditional models in that they aim to respect and enhance the autonomy of the person, rather than test it. Underpinning these approaches is the recognition of personhood as socially constituted, with value given to the person, their life meaning and their well-being.

The emerging challenge is how this understanding of the social and relational person, and the dynamic nature of decision-making, can align with the apparently incommensurable legal approach of capacity (O’Connor and Purves 2009; Naffine 2009). I conclude that a focus on the values of personhood can assist law in achieving just outcomes, such as inclusive decision-making, which currently appears to be elusive for persons who are vulnerable as a result of diminished cognition.

I Notions of personhood

‘Personhood’ refers to the status conferred on human beings in social settings. This status is defined by emphasis on particular attributes of the person and accompanying rights. Legal personhood is one such notion, but personhood concepts also include ‘popular, historical, political, moral, philosophical, metaphysical and theological approaches’ (Naffine 2009, 10).

Legal and philosophical notions of the person

Legal theorists, in particular positivists, view the legal person as a pure abstraction and as ‘the unity of a complex of legal obligations and rights’ (Kelsen 1967 in Naffine 2009, 173). From this view, law’s person is a construct that has no natural limits as long as it satisfies the purpose of any particular law (Naffine 2009). The abilities and characteristics of a natural person do not have any necessary bearing on the construct of the law in defining the legal entity of a person, which has no agency or moral status. In the absence of legal relations, no substance of the legal person remains (Naffine 2009).

This strictly technical and ‘within law’ approach to the legal person is tested in the area of decision-making capacity, where ideas of autonomy and self-determination blur the legal and non-legal, and challenge the legal concept of the person (Naffine 2009). Attitudes and beliefs about the attributes of a person, including their perceived level of autonomy, also have an influence on the social status that might be conferred onto the person by another. Reductions in personhood status can result in exclusions of the person from decision-making, diminishing the autonomy of the person.

Naffine has developed a taxonomy that describes the different metaphysical distinctions about personhood, providing a valuable framework in which to understand this complex philosophical area and its influence on law (2009). These worldviews have different emphases about human beings as thinkers, as sacred, as embodied and as relational, which influence and shape law and the legal notion of personality. These metaphysical views of the person create tension in the legal domain. In particular they are at odds with the positivist view of the legal person, who is defined only by rights and duties to specific contexts and has no necessary attributes of a natural person (Naffine 2009).

The idea of the person's status as consequential upon their ability to engage in reasoned thought was introduced in Chapter One. When this concept is extended into law the autonomous actor appears, aware and capable 'to bear legal duties and assert legal rights' (Naffine 2009, 60). Such a person has the autonomy to enter freely into social and legal relations through contracts, and take responsibility for his or her actions, for instance in the context of criminal law (Naffine 2009). Law is reluctant to depart from this approach, instead relying on protection and human rights as the alternative basis for those with diminished autonomy (Naffine 2009).

Where individuals suffer a complete absence of capacity, religious views and human rights approaches both give rise to claims about the innate worth of the person (Naffine 2009; Jones 2009). Debates in this domain range from the view that life should be maintained only where life has meaning and agency, to the religious view of the inherent worth and dignity of all human beings throughout life (Naffine 2009). Animal rights approaches also challenge the exalted position of humanity in relation to other biological species (Wise 2000).

Another view of personhood is that of the embodied person. Respect for the corporality of the body is implicit in law, with the body normally being inviolate, implying full legal personhood as equivalent to control over one's body, and typified by the doctrine for informed consent and tort law generally (Naffine 2009). In contrast, feminist and religious views accept the vulnerability and dependency of the human body as a shared experience of human life, but such images do not fit well with the rationalist image of the responsible and accountable person (Naffine 2009; Sherwin 1992).

An emerging vision of personhood is one that 'sees the person in law and society as formed by their relations rather than inherent characteristics' (Naffine 2009, 168). This social relational view (Taylor1985; Levinas 1981; James1952) understands the self in a dynamic and ongoing process of transformation, situated socially in a web of relationships (Naffine 2009). The idea of relational autonomy extends the basis of interconnectedness beyond the personal to the social, legal and political level, where structures, norms, rules and values dynamically shape each person and their autonomy in a form of ongoing social construction (Nedelsky 2011).

The different philosophical views of the person give dominance to particular human traits. However, the natural person, in having all of these attributes, is multidimensional. Nedelsky argues that an optimal conception of human selves would integrate the embodied, affective, and relational attributes, with an understanding of human beings, as socially constituted, as ‘in a constant process of becoming’ (2011, 38).

Naffine proposes that the legal concept of a person, if extended to social relations, would capture the normative model of the person, and allow the ‘multiplicity of personae’ that exists for each of us in reality (2009). However, in relationship to law, the different worldviews of personhood arise from different belief systems, and Naffine questions their ‘commensurability’ with each other (2009, 173). For instance, as social relations are free forming, the legal and relational concepts of the person do not align, as law does not recognise all relations. Moreover, the adversarial nature of law can lead to minimal obligations between parties, rejecting the relational attribute of interdependence (Naffine 2009).

The pragmatic nature of law, designed to solve problems, uses a different personhood typology to suit each purpose of the law, in a balancing act between competing belief systems and the application of law to achieve practical solutions (Naffine 2009). By embracing the flexible way our legal system works, Naffine considers that non-commensurable positions can be utilised to best effect by evaluation of the merits of each view of personhood in serving a just legal purpose (Naffine 2009). This legal flexibility towards personhood provides potential for broadening the concept of the person in law.

Personhood in medicine

Personhood is a concept that has applications other than in law. This section considers approaches towards the person in medicine, which are particularly relevant in relation to assessment for decision-making capacity as described in the previous chapter. Medicine has become increasingly powerful in society, as demonstrated by its increasing influence beyond disease to matters of everyday life:

> *…medicine is becoming a major institution of social control, nudging aside, if not incorporating, the more traditional institutions of religion and law. It is becoming the new repository of truth, the place where absolute and often final judgments are made by supposedly morally neutral and objective experts. Medicalising daily living in the name of health, gives labels to an ever increasing part of human existence (Zola 1972, 487; see also Illich 1975; Conrad 2007; Parens 2013).*

First, I describe the approach of medicine towards illness, being the process of constructing the idea of disease as deviant to the normal state of being healthy (Bond 1992). Foucault's insight about medicine's 'anatomo-clinical gaze', which understands disease to reside within the body, relies on clinical signs of disease to provide 'an objective, real and at last unquestionable foundation of the description of diseases' (Foucault 2000, 129). Definitions of normal health and deviance are created from this 'ascendency of scientific positivism' (Davis 2004, 370). The body is a 'public object' that undergoes observation and surveillance, and those with expertise in the dominant discourse establish the 'truth', with alternative sources of knowledge 'dismissed as non-objective, irrational, and unable to be verified by measurement of any kind' (Cheek and Rudge 1994, 41). Therefore, while the medical gaze can legitimise and manage illness, the dominant focus on the disease can socialise clinicians to practices which exclude the voice and perspective of the patient, and consequently ignore quality of life considerations important to them (Flegel and MacDonald 2008).

This dominant scientific/bio-medical discourse gives primary attention to the disease instead of to the person, with the phenomenon of the passive 'sick role' arising from the patient giving control of their body over to the physician with expert knowledge (Parsons 1951). In addition, institutional structures that serve the doctor's role result in a hierarchical hospital system, with the doctor at the top and the patient at the bottom, often ‘stripped of identity’ and with ‘emphasis on the client’s deficits and problems’ (Nay et al 2009, 108). In medical discourse, personhood aligns with the status of health, which is symbolic of attributes such as autonomy and agency. Personhood is lost when the person is ill. The goal of medicine is to restore health, and implicitly, personhood. The ill person is the host for the disease, and an object of assessment and surveillance for the anatomical ‘gaze’ (Cheek and Rudge 1994).

The dominant ‘gaze’ of medical discourse has extended beyond the disease in the body to ‘the domestic and social lives’ of persons, to control over societal norms (Robertson 1990, 431). In this way, medicine arbitrates social values about the social status of those with the illness, with the individual seen as the source of the deviant behaviour (Bond, 1992). Waitzkin suggests that medicine is powerful in achieving conformity to behaviour that conforms to this ideology:

> *In medicine, ideology and social control are closely related. When doctors transmit ideologic messages that reinforce social problems…they help control behaviour in ways that are defined as appropriate’ (1989, 225).*

This aspect was apparent in a case study of the files undertaken by Cheek and Rudge of two hospital patients (1994). The study mapped the ‘construction’ of the patient that occurred through depersonalising admission rituals, and scientific processes of ‘judging, evaluating, observing, and measuring’ symptoms of the illness, which obscured the person (Cheek and Rudge1994, 47). Those in surveillance roles made judgments about the patient, who was excluded from this process and was without opportunity for recourse. The researchers’ comment that this was ‘symptomatic of the loss of control’ and leads to disempowerment and depersonalisation (Cheek and Rudge 1994, 51.) Psychosocial aspects were ‘problematised’ and the exclusion of the person’s own experience and reality was a form of ‘epistemic authoritarianism’ by the powerful elite who control the ‘truth’ (Cheek and Rudge1994, 47-48). A similar study found that medical knowledge led to ‘a power imbalance in the relationship …causing professionals to feel justified in making decisions’, with information withheld or used in a way to ‘reinforce decisions already taken by others’ (Smebye, Kirkevold and Engedal 2012, 10). These activities led Illich to conclude that ‘[p]rofessionally organized medicine has come to function as a domineering moral enterprise’ (1976, 127).

This disempowering effect of authoritarian medical paternalism is of particular concern in relation to those stereotyped from gender, class, race, age and disability, with Sherwin (1992, 231) stating that :

> *It should come as no great surprise, that the health care system is least effective at providing for the needs of people who are multiply oppressed in society.*

The prevailing culture of scientific objectivity in medicine can also affect the attitudes and behaviours of allied healthcare professionals, who take on the dominant discourse through language and surveillance activities (Cheek and Rudge 1994), creating ‘power assymetry’ (Joffe et al 2003, 104). In a Welsh hospital study, health professionals were found to note the views of the carer rather than the person with dementia, giving little significance to the views of the patient in decision-making, thus suppressing their voice (Lamers, Gammon, Jones and Owen 2005). Health professionals caught in this web of medical discourse can become oppressed by it and, in becoming complicit in activities that depersonalise the patient, also become oppressors (Sherwin 1992).

Illness is a natural ‘thief of autonomy’ (Cassell 1977, 18). Prevailing attitudes towards dependency and interdependency exacerbate the loss of autonomy associated with illness (Sherwin 1992; Nedelsky 2011), and lack acceptance of interdependency as an unavoidable human experience (Illich 1976).

While the current health system is ‘closed to many innovative health strategies that would increase the power of patients’, Sherwin considers the appropriate direction is in empowering consumers in greater participation in their health (1992, 239). She suggests an alternative model of personhood as ‘a self who is both elemental and related, and who has a sense of herself making choices within a context created by community’, with the person’s choices reflecting his or her own needs (Sherwin 1992, 145). This model of the self would require recognition of the patient’s ‘social world’ within the medical culture and the inclusion of significant trusted others in decision-making (Sherwin 1992, 156).

This image aligns with the view of autonomy as constituted and maintained in relationships (Nedelsky 2011), with the understanding that decision-making by the patient occurs in the context of personal values and meaning (Veatch 2009). In this way, the understanding that 'contemporary medical practice involves a great deal of uncertainty and intuitive reasoning' (Sherwin 1992, 147) challenges the objective certainty resulting from scientific positivism. Veatch describes this current shift in medicine as moving from the belief that scientific knowledge can indicate what is 'best' for the patient, to a new medicine where it is acknowledged that 'every medical choice requires non-scientific value judgments' (2009, 4):

> *The conviction of the new medicine is that the patient knows best– that is, the patient usually knows the patient's own interests better than the physician… The new medicine exists in a world in which the doctor's expertise in medical science will have to be combined with the expertise of others –especially the expertise of the patient– in knowing the values upon which literally every decision in medicine must be based (2009, 5).*

Some sectors within medicine are reclaiming medicine's historical approach towards the holistic person, renewing 'the ethical imperatives connected to promoting the autonomy, responsibility, and dignity of every person involved' (Mezzich and van Weel 2009, 1). Shared decision-making relationships between physician and patient have emerged, with a range of variations dependent on the degree of recognition of patient autonomy and the moral agency of the doctor (Kerridge, Lowe and Stewart 2009; Emanuel and Emanuel 1992).

Policy shifts towards patient-centred care have become evident in recent years (Moulton and King), being 'healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers' (Australian Commission on Safety and Quality in Healthcare 2011, 1). Core concepts include respect for patients' values, emotional support, physical comfort, information, access to and coordination of care, and the involvement of family and friends (Picker Institute 2008 cited in Australian Commission on Safety and Quality in Healthcare 2011). Person-centred practices for older persons in health services aim to enhance personhood by recognising the person beyond their diagnosis, and sharing power and responsibility in treatment goals and decision-making (Victorian Department of Health 2012).

In summary, traditional scientific medical discourse focuses on disease in the body, and objectifies the person. While illness and dependency naturally reduce autonomy, further diminishment of personhood occurs from the ‘sick’ role, stereotypical attitudes and depersonalising environments, with the patient experiencing passivity and diminished autonomy. Such norms about illness and personhood have also become influential in mainstream culture. Person-centred policies and approaches that place the natural person and their broader interests as central are gaining some traction in some sectors. Nonetheless, the view that the doctor is the expert and the patient’s views are of limited importance is still common in the medical environment. The status afforded to the person who is a patient affects attitudes towards the person’s autonomy, and subsequent practices, such as respect for choices or paternalistic approaches, illustrates the socially constitutive nature of autonomy in this setting.

This general discussion on personhood shows that different views can exist concurrently with some more responsive to autonomy than others. Different groups and disciplines can develop their own norms about personhood. In the next section, I extend the notion of personhood into the domain of dementia.

II Personhood and Dementia

Dementia provides particular challenges to personhood and decision-making practices. This section explores the phenomenon of dementia and its medicalisation, the stigma of dementia, new approaches to personhood in dementia, and the relationship of personhood and autonomy. These latter emerging ideas indicate important shifts in concept and understanding, though are not widespread in adoption.

Dementia in society

Dementia poses challenges due to both the symptoms resulting from the disease and to the resulting stereotyping (Alzheimer’s Australia, 2012a). Bio-medical descriptions define dementia as:

> *…a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension,*

> *calculation, learning capacity, language and judgement…Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease and in other conditions primarily and secondarily affecting the brain (World Health Organisation, 1992-1994, 7).*

This description can scarcely give a bleaker picture of the syndrome of dementia. Progressive loss of cognitive function and associated changes in personality lead to stigma, being the 'prejudicial views or negative stereotypes that individuals may hold about people with certain distinguishing characteristics or attributes' (Phillipson et al 2012, 5). The Australian community holds significant negative beliefs about people with dementia, with sixty-three percent of Australians afraid of getting dementia more than any other health condition (Alzheimer's Australia 2011). There is also evidence of social avoidance, with twenty-two percent of persons in a survey describing they would 'feel uncomfortable spending time with someone with dementia' (Alzheimer's Australia 2011, 4). Shame, humiliation and fear emerge as reactions from people in a survey as to the scenario of being diagnosed themselves (Phillipson et al 2012, 9).

Stigma affects personhood status. Goffman suggests that stigma results in the person being 'reduced in our minds from a whole and usual person to a tainted, discounted one' (1963, 12) with a belief 'that the person with the stigma is not quite human' (1963, 15), leading to a reduction of the social status of the person, and associated rights. Such attitudes can affect the behaviour, emotions and beliefs of the person (Major and O'Brien 2005). Stereotypes about the inability to make decisions in dementia lead to attitudes and practices that act to confirm assumptions of incapacity (Phillipson et al 2012, 10). The importance given in society to cognitive ability enhances anxiety about its loss: '[O]f all forms of loss or weakness, the one that many people fear the most is the loss of their reason' (Jones 2009, 15). The term 'living death' exemplifies this total loss of personhood (Woods 1989). The resultant fear of such vulnerability leads to 'an exaggerated and harmful kind of sympathy', where those in this predicament 'are in danger of being classified as non-persons' (Jones, 2009, 20), resulting in changes to self-image and identity.

A study on the decision-making of persons in early stage dementia found the person's opinions were 'often overlooked and their rights to information and free expression [as] fragile' (Tyrrell, Genin and Myslinski 2006, 496). Such labelling of persons with dementia as 'lacking insight' contributes to 'depersonalisation, loss of independence, [and] loss of social and political rights' (Bond et al 2002, 313).

With the increasing prevalence as the population ages,[28] dementia is a common-place threat to personhood. However, with one in three people over eighty-five years having dementia, Katz questions whether dementia is deviant, or in fact a 'normal' condition of later age (1996). Herring (2009, 26) suggests there are advantages in viewing dementia as a common experience of later life:

> *…with old age comes brain ageing which affects all of us in different ways. The social narrative of dementia…which is widely feared, has meant that the truth, that brain deterioration is extremely common in old age and is a natural part of ageing, has been lost…and needs to be regarded as part of being human, rather than a humiliating disease.*

A different view is held by Alzheimer's Australia, the peak consumer body for dementia, whose research foundation views the disease as something to 'fight', embracing the bio-medical framework for prevention and cure, stating that 'science holds the key to defeating dementia' (Alzheimer's Australia Dementia Research Foundation 2014). This approach seeks to distance dementia from age. As ageing is an inevitable part of life, this could convey an acceptance and ordinariness about dementia, and possibly fail to achieve political interest to achieve a cure.

Dementia has become 'medicalised' over the past two decades as the bio-medical model of dementia has become dominant (Bond 1992; Lyman, 1989). Dementia creates a 'problematic' issue in the medicalisation discourse, due to dementia being a form of degeneration that is understood as separate to, but also part of, the ageing process, making the 'aged body… both normal and pathological' (Katz 1996, 44). Lock suggests that the biological and social processes are inseparable from biological

---

[28] In 2014, there are estimated to be over 332,000 Australians with dementia, and is expected to increase by a third in the next decade, with 1700 new cases every week, which is one every six minutes (Alzheimer's Australia 2012b). Dementia is the third leading cause of death in Australia, and three in every ten people over 85 years have dementia (Australian Institute of Health and Welfare 2013).

ageing, with researchers ignoring these intertwined factors in the frenzy to establish a single medical cause of Alzheimer’s disease (2013). Both dementia and ageing carry stigma, and when combined together may lead to further loss of status of the person.

The medicalisation of dementia has been both beneficial and disadvantageous to people with dementia and their families. Of major benefit has been the legitimation of the condition and ‘the bringing of order to dementia care’ (Bond 1992, 401), reducing uncertainty through diagnosis, labels, and providing a model of stages for a disease which has an ‘uncertain trajectory’ (Strauss 1975 in Lyman 1989, 599). Less favourably, medicalisation reduces the social status of those with the illness, as the individual is the source of deviant behaviour (Bond, 1992). As a result, social aspects such as caring relationships and structural resources receive limited focus (Bond 1992), although greater attention has been given to the needs of people with dementia and their caregivers over the past decade (Australian Department of Social Services 2015).

The concept of personhood in dementia

Dementia has a broad and often long trajectory of 5-20 years, with brain changes occurring ‘years, if not decades’ before the clinical diagnosis is made (Sperling et al 2011, 280). The progressive loss of functional abilities varies greatly for individuals, but can often be generalised, which can contribute to stereotyping.

In a society that had the prevailing view of dementia as the ‘complete loss of self’ (Cohen and Eisdorfer 1986), Kitwood was radical in attributing personhood to people with dementia: ‘a person in the fullest sense… he or she is still an agent in the world, a sentient, relational and historical being’ (1993, 541). Kitwood challenged the existing social construction of personhood in dementia, making the claim that attention to personhood required recognition of ‘the centrality of relationship, the uniqueness of persons, [and] the fact of our embodiment’ (1997, 7). He defined personhood as (1997, 8):

> *…a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.*

This understanding of personhood is in marked contrast to the rational-cognitive idea of personhood. Symptoms that had previously been considered to result solely from neuropathological damage have instead been identified as resulting from the interactions between personality, biography, physical health, neurologic impairment and social psychology (Epp 2003, 16). Understanding that a negative social and psychological environment could compound symptoms of dementia, Kitwood developed the phrase 'malignant social psychology' to identify attitudes and practices that reduced personhood and affected the identity and self-esteem of people with dementia (Kitwood 1997, 45). To alleviate such effects, Kitwood proposed cultural transformation to enhance well-being through the provision of supportive social environments that acknowledged and responded to emotion, and nurtured the person's abilities and skills (1997). This model has created the foundation for a 'person-centred' system of care that is now international in its application and ongoing research (Brooker 2004).

The status of personhood and the role of relationships and environment in constituting the self in dementia have received ongoing attention (Sabat, Fath and Moghaddam 1999; Thorngate 1999). Epp views personhood in dementia as comprised by the person's social history and relationships, valuing 'an individual's life experience, unique personality and network of relationships' (2003, 15). Various writers have argued that the person with dementia has attributes denoting full personhood, such as 'self-awareness, subjectivity, meaning-making, meaningful talk, sexuality, expressive behaviour, autonomy, social and cognitive abilities, an intact sense of social and personal identity, humour and individuality, and agency and the capacity to value' (Epp 2003, 15). This is in contrast to bio-medical descriptions of the person with dementia, where attributes of the person are generally given attention as deficits.

Post states that attention to personhood requires an understanding of the experience of people with dementia, and recognition that 'all lives count equally' (2006, 223). Meaning and identity, constructed through the person's social encounters (Hughes, Louw and Sabat 2006) supports the concept of personhood in dementia as the person being a situated-embodied-agent, with the person's life narrative embedded in time and social context (Hughes 2001, 88):

> *... that the person is situated in a history; which is both physical , emotional, conative and cognitive…embedded in a context of care, which might be familial, social or professional; and finally, that the person is an agent and that the person's agentive capabilities …should be encouraged.*

These different accounts about the person with dementia recognise a full range of attributes that comprise the person, broader than cognition, resonating with the idea of the person as multi-dimensional (O'Connor and Purves 2009; Nedelsky 2011). Narratives of people with early dementia have further contributed to the understanding of the person's experience and insight in living with the symptoms of dementia (Friel-McGowin 1993), with Bryden, diagnosed with dementia at age 46, describing her life as continuing to have meaning and purpose (2012).

While the relegation of the symptoms of dementia to biological pathology can result in a disregard of the effects of social pathology and a lack of validation of residual abilities, new approaches have enhanced the autonomy of persons with dementia and enabled them to have a voice. People with dementia are now in representative roles on consumer advisory groups and research committees, which was rare a decade ago (Alzheimer's Australia 2010). One person with dementia has recently spoken out on behalf of people with dementia (Swaffer 2014, 1), saying:

> *…please don't call us sufferers…we are just changing in ways the rest of you aren't… [We] desperately need others to enable us, not further disable us!*

The beneficial results obtained from a person-centred environment for people with dementia have also revised knowledge about cognition in dementia. Empirical studies have shown that with appropriate psychological support, people with dementia can experience learning and improved cognitive functioning, validating the importance of the social environments and social relationships (Kitwood and Benson 1995; Woods and Pratt 2005). This redefined understanding of the autonomy of persons with dementia, with the belief that the person is the best 'expert' on themselves, has led to involving people with dementia in the decisions affecting their lives (Brooker 2004). Inclusive practices, previously denied the person, include informing people of their diagnosis (Maguire et al 1996), empowering them with knowledge about how to live with the disease (Alzheimer's Australia 2014), participating in feedback about services (Epp 2003, 16), and seeking their views regarding their end of life care (Downs 1997).

The recognition of other valued attributes besides cognition challenges the boundaries of the rationalist model. While giving particular emphasis on the social and psychological aspects of the person, this approach reclaims multi-dimensional personhood for people with dementia. The person is embodied, with physical desires and needs; sacred, having intrinsic worth; cognitive, expressing preferences and desires and acting on them; and relational, with identity formed from relations with others, and requiring nurturing social relationships and environments in order to thrive and develop. The emerging and strengthening concept of personhood for people with dementia is an inclusive and holistic one, gaining further credence from the growing empirical base and the voices of people with dementia. This model is relevant across the dementia trajectory.

Such shifts in thinking have softened the blunt bio-medical description of dementia by the World Health Organisation: eighteen years later the updated definition acknowledges the person and those that care for them:

> *It is overwhelming not only for the people who have it, but also for their caregivers and families. There is often a lack of awareness and understanding of dementia, resulting in stigmatization and barriers to diagnosis and care. The impact of dementia on caregivers, family and societies can be physical, psychological, social and economic (World Health Organisation 2012, 1).*

Openness to fuller personhood has implications for the concept of autonomy. The emphasis on 'cogniser' is replaced with respect for the aspects of the person as a 'valuer' (Jaworska 1999, 130), with emotions, intuition, will, sense of self, and life meaning, given recognition. The person's ability for self-determination is understood to be undermined by social norms, stereotypes and practices (Davis 2004; Kitwood 1997) and enhanced by recognising each person as unique, focusing on their strengths and abilities, ensuring choice, supporting their decision-making, and 'providing unconditional positive regard' (Nay et al 2009, 110). This is representative of the socially constitutive person and the dynamics of relational autonomy, with the importance of providing ‘an environment that is always… conducive to the articulation of one’s unique personhood’ (Davis 2004, 376).

While the person-centred approach pioneered by Kitwood is concerned with cultural and psychosocial realms, rather than law, it offers an approach to personal autonomy that is not reliant on capacity measures, but on supporting autonomy to the greatest extent possible. This view is not dominant, but has merit in recognising the strengths and attributes of the person, rather than just the effects of the disease. The challenge that remains is the relationship between the requirements in law and the relational person in dementia, as, according to Herring: ‘the law must find ways of interacting’ with those who do not meet the threshold of legal competency’ (2009, 29).

III Approaches to person-centred decision-making

Understanding the person as social and relational, including those with dementia, rather than defined solely by their cognition, requires a different approach to decision-making than that currently reflected in law. This includes recognising the person as multi-dimensional, autonomy as relational, and capacity as contextual. In this section, I build on my discussion of capacity assessment limitations in Chapter 2 and explore alternative social approaches to decision-making that are more responsive. Different approaches found in literature are grouped according to their major emphases, being the combined contextual/procedural model; the supported decision-making/partnership model; the presumption of capacity approach; and the hermeneutic/narrative approach. Each approach has a different nuance and together they provide some basis for the development of a person-centred model. The first approach is part of a capacity assessment process, indicating an attempt to straddle legal and social constructs, whereas the remaining three groups focus solely on enhancing rather than assessing capacity of those with diminished autonomy. These approaches contrast with the current prevailing approaches but are congruent with the person as social and relational.

The combined contextual/procedural approach

This approach is where contextual considerations are incorporated with the procedural cognitive test, with the purpose of integrating ‘subjective meaning-giving' of the patient with assessment of reasoning (Breden and Vollman 2004, 280). There is recognition of the role of emotion and values and 'biographical, social and contextual factors' related to the decision, but with the goal of achieving objective measurement, indicating their confidence in the measurement approach of capacity (Breden and Vollman 2004, 281). A similar approach is taken by statutory capacity assessors in Alberta, Canada, who assess psychosocial factors to aid the understanding of the effect of person's social functioning on decision-making (Newberry and Pachet 2008).

Another variation is integrating the procedural and contextual aspects of the situation without the use of objective measurements. Margulies, a lawyer, proposes this mix in his 'contextual capacity' model (1994). This approach retains a focus on concern for 'legal interests', but also understands the client 'as situated in a web of relationships' (Margulies 1994, 1075). Margulies recognises that autonomy is relational and impacted by roles and culture: 'our membership of groups, whether as family members, citizens, professionals or others, shapes our action in the world' (1994, 1077-78), and that capacity is contextual to the person and their situation, being 'a shifting network of values and circumstances' (1994, 1083). '[S]eparating substance from process in decisions about capacity is both wrong and impossible' says Margulies (1994, 1083), as 'any consideration of process inevitably involves some background assumptions about substance' (1994, 1084).

Margulies gives attention to factors such as fluctuations in cognition, the ability to articulate reason, appreciation of consequences, irreversibility of the decision, the contextual fairness of the transaction, and consistency of lifetime commitments (1994). The last three are contextual and reflect some legal concepts. For instance, if a potential decision cannot be reversed, Margulies suggests caution and preservation of the status quo, which is a 'historical legal position' (1994, 1087). Margulies argues that the use of both contextual and procedural approaches allows both an 'overlapping dialogue' and the use of 'intuitive judgments' (1994, 1084). This mixed approach is holistic and incorporates social and relational aspects, but it relies upon strong notions of the rational person.

A third variation on this model is that of engaging with the contextual information to negotiate a solution, and if successful, avoiding the procedural assessment. Darzins, Molloy and Strang, in their six-step model described in Chapter 2, usually finds the problem triggering the capacity referral related to ‘conflict between the allegedly incapable person and those who question their decision-making capacity’, and the ‘differences the various parties place on certain values and outcomes’ (2000, 24). The role of the assessor is to gather views on the problem from the treating doctor and family, seeking options consistent with the person’s values and to ‘frame the issues so that disagreements can be resolved’ (Darzins, Molloy and Strang 2000, 24). This is a practical approach to impasses in the medical setting, and where possible facilitating informal resolution that is acceptable to the parties, especially the vulnerable person. If unresolved at this stage, the assessor proceeds with the capacity assessment, with procedural focus. It does, however, introduce aspects of relational personhood and navigate resolution in the medical setting without becoming adversarial.

Overall, these variations within a combined contextual and procedural approach, seek to enhance autonomy and decision-making of the person, but use the structure of the rational-cognitive approach, and work within the ‘shadow of the law’. In comparison, the following approaches operate independently of the concept of capacity.

The partnership/ supported decision-making approach

The supported decision-making approach recognises that the person has some residual autonomy but may not be able to make the decision without assistance. Partnering with the person includes bringing information to their attention, talking through options and consequences, and reminding them of facts of the current situation. From a relational viewpoint, involving significant others is the way most people usually make decisions, understanding that humans do not usually make decisions in isolation from others (Nuffield Council of Bioethics 2009). The supported decision-making approach for those with cognitive impairment is a natural progression of this human characteristic. Supported decision-making is also valued in the rights approach, as respecting the person and maximising autonomy (South

Australian Office of the Public Advocate 2009). Nuances within this broad approach give different emphases of relationship, advocacy and rights.

Donchin proposes a relationship model for health care that recognises the ‘relational aspects of individuality’ (2001, 365). From the basis of feminism, she uses metaphors of ‘mothering’ and ‘friendship’ to advance the relational approach to autonomy (Donchin, 2001, 365). The mothering role is symbolic of helping another being to develop agency and autonomy (Held1993) and fostering the ‘development of capacities’ while the metaphor of ‘friendship’ is more representative of equality between persons (Donchin 2001, 381). While these metaphors are instructive in the practice of medicine for advancing the good of others, and in ‘generating continuities and interconnections’, Donchin considers that moral principles are also needed, such as autonomy and equality, as the ultimate basis to relationships of care (2001, 382). Extending this approach to decision-making would be to focus on enhancing capacity and personhood through supportive relationships, and shared decision-making.

A different emphasis exists in the ‘assistance/advocacy’ approach, which includes providing the person with information, helping them to understand concepts, and giving advice (Glass 1997). The advocate can help the person ‘understand the implications of the possible choices and to appreciate the consequences of the alternatives chosen’, knowing that ‘decision-making itself belongs to the patient’ (Glass 1997, 31). This model seeks to ‘preserve and maximise a person’s decision-making capacity, while at the same time protecting that person from harm’, which Glass sees as including being prevented from making a harmful decision, or making an ignorant decision (1997, 31). The advocate can also speak on the person’s behalf, and facilitate communication between the older person and their family members, providing information and possibly ‘negotiating’ a treatment decision (Glass, 1997, 31). This advocacy model has elements of empowering the person with information in ways they can understand, and helping them think through the implications of their preferred choice. However, it has a risk of imposing another’s account of harm, which may lead to paternalistic responses. Overall, its primary focus is on facilitating decision-making to solve the problem, whereas Donchin’s primary focus was on the quality of the relationship.

The last type of supported decision-making in this set has a philosophical emphasis on rights. The United Nations Convention on the Rights of Persons with Disabilities confirms the ‘legal capacity’ of all persons regardless of decision-making abilities, and therefore Flynn and Arstein-Kerslake argue that every person has legal status and is an actor in law (2014). They link this right to the idea that ‘almost every person is capable of expressing her will and preferences with the right support’ as part of ‘a holistic and inclusive notion of personhood’ (Flynn and Arstein-Kerslake 2014, 84). In support of this philosophy, Gooding proposes that society ‘discard any notion of incapacity as it is understood in common law jurisprudence’, and instead substitute ‘disability-neutral’ tests to determine the level of decision-making support required by an individual (2013, 438). Measures that support all citizens’ to ‘exercise their legal capacity’ include advocacy, information, tools to assist in the expression of will and preferences, and access to advance directive mechanisms enable the person on this continuum of decision-making (Flynn and Arstein-Kerslake 2014, 88).

This rights model is designed to ‘augment an individual’s existing strengths’, with the person to be given the necessary supports by the state to express their choices, and to have their choices affirmed (Flynn and Arstein-Kerslake 2014, 94). A person may be able to make a decision independently if given needed information in an appropriate way, or may require a circle of support of trusted persons to assist with decision-making (Flynn and Arstein-Kerslake 2014). Where this is not possible, a facilitator makes decisions on behalf of the person, ‘with the will and preferences of the individual at the centre of the decision-making process, and in the manner which best augments the person’s autonomy and decision-making capability’, rejecting any best interests approach (Flynn and Arstein-Kerslake 2014, 95). This approach requires fundamental shifts in status of the person with decision-making disability in order to protect legal capacity (Quinn 2011, 11):

> *Legal capacity is only the tool by which the ‘person’ asserts him or herself in the lifeworld…in the myriad of tiny transactions that makes up who we are. It protects…the integrity of the space in which the person conceives of the good for themselves…and its expression in the lifeworld…. The war over legal capacity is a proxy war over personhood.*

This approach shares a similar philosophical basis of relational personhood with Donchin’s approach (2001) but uses rights language and a broader legal framework.

All of these approaches build on the natural human inclination to involve others in significant decision-making, which extends to persons with dementia. Approaches in the next section respect personhood by assuming the person is competent.

The presumption of capacity approach

Presuming capacity in decision-making is at the other end of the continuum to that of capacity assessment. One approach, by Dubler, is to act on the basis that the person has decision-making capacity, regardless of any capacity threshold, in order to 'amplify diminishing voices and support residual autonomy' (Dubler, 1985, 249). This approach treats 'once successfully functioning adults …as currently competent' (Glass 1997), based on 'their demonstrated and documented life preferences' and 'clear value system' despite diminished cognition (Dubler 1985, 250). Dubler considers that a person's consistent choices indicate the persistence of enduring strong preferences, beyond any losses to cognitive function (1985). These 'sedimented life preferences' are consistent themes built up over a life time by actions, thought, and behaviour, and are a valid expression of autonomy:

> *…these themes are so strong and fundamental to a human soul that they survive intellectual and physical decline. When this sort of theme emerges, buttressed by surprisingly articulate statements… and supported by confirmatory statements of family and friends, it deserves great weight and respect; in some cases…it should be permitted to override issues of present incapacity, if this solution is even marginally possible (Dubler 1985,150).*

Glass comments that this approach promotes 'maximum respect for persons with diminishing intellectual capacity', with the view of capacity as broad and malleable rather than a 'fixed attribute' (Glass 1997, 29). Recognition that personal emotions and values by the person with dementia endure beyond cognitive changes aligns with the view of persons as 'valuers' (Jaworska 1999, 130; van Leeuwen and Vellinga 2004).

Herring echoes these sentiments in treating the person as having decision-making capacity regardless of legal actuality (2009). He gives attention to those in the grey area of borderline capacity: 'those who are assessed as having capacity, but only just, and those who are assessed as lacking capacity, but only just' (2009, 4). By using capacity as a fixed point, Herring acknowledges the rational-cognitive framework, but prefers to place personhood as the priority in decision-making, giving status to 'a person's views and feelings' (2009, 16). Herring bases his approach on principles of the right to dignity and the right to liberty as principles that have primacy where autonomy diminishes. He argues that any treatment forced onto an objecting person, even if they lack capacity, 'contravenes their dignity' (Herring 2009, 14). He states:

> *…the views and feelings of the incompetent person should carry some weight. The argument is not that an incompetent person's wishes should be followed regardless of the consequences. Rather, the wishes of the incompetent person should be followed unless there is a good reason for not doing so (Herring 2009, 16).*

Herring holds that intervention is justified if the person is making a choice that is at variance with their lifelong values, unless there is a reason for this change, or if the person is making a choice that will result in serious harm, and reduce their future autonomy. In the latter, Herring considers intervention justified, if it preserves the person's autonomy for the future, 'in the richest sense' (2009, 10). This model also allows interference on the basis of significant harm, which can be subjective.

The 'presumption of capacity' approach recognises the legal and moral right to decision-making, and respects the wishes and preferences of the person unless significant harm may result. The final group of person-centred approaches is also concerned with the life meaning of the person, with particular emphasis on enhancing personhood.

The hermeneutic/narrative approach

This fourth type views capacity as related to events rather than being primarily about reasoning, with tests of cognitive capacity 'too crude to do justice to the actual way in which people live their lives' (Benaroyo and Widdershoven 2004, 299). This approach demands respect of the person and their life meaning, requiring understanding of how the person can 'interpret the world and respond to it' (Benaroyo and Widdershoven 2004, 298). As illness impedes capacity with its challenge to identity and practical agency, the hermeneutic response recognises the experience of vulnerability as a moral issue and takes steps to modify the environment and empower the person in their situation, thus enhancing autonomy (Benaroyo and Widdershoven 2004).

In the clinical setting, this approach aims to ‘bring various perspectives into contact with one another and create a space in which they can merge so that new views and practices can be developed’ (Benaroyo and Widdershoven 2004, 296). The hermeneutic approach relies on the clinician to understand the patient’s life meaning and the impact of the illness, with mental capacity:

> *…not just as the exercise of an arbitrary power of choice…but as lived out in an attempt to choose well in the context of one’s life story, with its own plot, aims and values’ (Benaroyo and Widdershoven 2004, 297).*

Benoroyo and Widdershoven view the task of health providers as helping the ill person to ‘reconstruct meaning’, which requires ‘effort and care, imagination and perceptiveness’ (2004, 297). This can be contrasted with the utilitarian approach of the biomedical model, which is designed to ‘find a solution’ to the problem as perceived by the medical team (Benoroyo and Widdershoven 2004, 301). To achieve the reconstruction of meaning, they recommend ‘making all views explicit in case histories’, and for the doctor to become aware of his or her own values and feelings shaping their perspective, challenging any prevailing view of ‘right’ behaviour or an ‘absolute standard’ in rationality, action and morality (Benoroyo and Widdershoven 2004, 300). The hermeneutic approach shares similarities with the person-centred approach, as it seeks to see the world from the patient’s view and in the context of their life story (Tetley, Grant and Davies 2009). Modifications of the environment enhance selfhood, capacity and autonomy, with the goal to seek solutions that are meaningful to the patient and their life story.

Viewing the person from the narrative of their life story is also supported by Hughes, Louw and Sabat, as it ‘provides unity that is prerequisite for our sense of self, with this critical for our functioning as persons (2006, 15). Their approach is one of ‘empathic understanding’ and ‘moral engagement’ with the person with dementia, which requires trying ‘to inhabit their world’ in a phenomenological way (Hughes, Louw and Sabat 2006, 18). This approach aims to understand the world from the person’s view, rather than from institutional or discipline perspectives, or from an objective reality, and in this way aligns with the person-centred approach to decision-making.

This section has offered some alternative approaches to decision-making and autonomy than the capacity approach. In particular, the latter three models – the partnership/supportive approach, the ‘presumption of capacity’ approach, and the hermeneutic /narrative approach, share the central themes of respect for the values and feelings of the person, understanding their life story as part of their identity, and empowering the person. They demonstrate characteristics of a person-centeredness approach, with a focus on the person and their strengths, not their disabilities (Kitwood 1997), and drawing on the person’s life history (Edvardsson, Winblad and Sandman 2008). The person’s ‘rights, values and beliefs’ are respected along with their choices, and there is a goal of ‘maximising potential and providing shared decision-making’ with primary focus on the well-being of the vulnerable person (Nay et al 2009,109-110).

The person-centred approach to decision-making responds to the limitations of the traditional liberal model discussed in Chapter One, through the recognition of autonomy for persons who may not meet the traditional threshold of capacity. These approaches therefore include previously disenfranchised persons in legitimate decision-making processes. While reclaiming some rights to decision-making, they do not provide the ultimate freedoms resulting from the liberal model that remains for the person with capacity, as interference is seen as valid in cases of serious harm. However, they do provide protection against assumptions and prejudices about the person based on age and cognition. A person-centred approach reclaims the personhood of those with diminished cognition, broadens the concept of autonomy and is indicative of new horizons in decision-making for this otherwise vulnerable group (O’Connor and Purves 2009).

Overall, while these different approaches to decision-making vary in nuance, they operate within a personhood paradigm, recognising the multi-dimensional attributes of the person despite their impaired cognition, and conferring an accompanying respect for the person’s autonomy, with support to maximise it. They indicate a way forward that is more respectful of personhood than approaches based on the ability to reason. There has been no empirical evidence supporting or building on these ideas identified by the author, indicating an area for further exploration and research. The next section considers how such person-centred approaches align with ethical concerns in relation to risk of harm, and the connection with law.

IV The ethical and legal interface of personhood

In this final section, I return to the area of ethics and law, to explore areas of alignment with the fuller conception of personhood. First, I propose that 'respect for persons' becomes the primary ethical principle, which incorporates respect for autonomy. I illustrate this by reference to Faith's story. Secondly, I explore different responses to perceptions of risk, which form a major barrier in supporting a person's preferences, and recognise those situations where greater certainty for accountability requires legal notions of autonomy.

A review of ethical principles

This chapter has given recognition to multi-dimensional personhood, with approaches aimed at maximising autonomy and well-being in decision-making processes and outcomes. Respect is at the heart of this approach. As a term 'strongly embedded in our cultural psyche', respect for another is:

> *...to regard her or him highly…a sense of deferring to the other, considering the other's interests and feelings, attending to his or her needs, looking out for the other's well-being…To treat another with respect then, is to put them above and ahead of ourselves (Lysaught 2004, 665-6).*

The obligation to treat others 'with deep respect' has a strong ethical discourse (Kitwood 1997). Using a modern ethical framework, this description can align with the principle of beneficence, as supporting of another's autonomy (Gillon 1985), and is the point where autonomy and beneficence co-exist (Nuffield Institute of Bioethics 2009). The principle of 'respect for persons' differs however, in that it gives primary focus to the person, rather than a focus on separate moral attributes.

The term has lost popularity in medical ethics, with Lysaught pinpointing the time to when Beauchamp and Childress launched their landmark work on ethical principles, changing 'respect for persons' to 'respect for autonomy' (2004, 675). Lysaught understands the term 'respect for persons' to symbolise an entwined relationship between promoting autonomy, doing no harm, and protecting the vulnerable (2004). This integrates these activities around the value of the person, instead of giving primary focus to separate ethical principles. There is significant value in reclaiming this term as representing the fuller understanding of the multi-dimensional person and enhanced personhood status for associated attributes. Respect for persons also supports acknowledgement of the relational aspects of autonomy, being the ability of others through their actions to either enhance or diminish another's autonomy. Broadening the focus of respect beyond autonomy to the full person is understood to encompass respect for dignity and equality of persons (Nedelsky, 2011; Neal 2014).

Application of the principle 'respect for persons' to Faith's situation, for example, involves the promotion of autonomy, support for well-being, and avoidance of harm. To understand Faith's life story, is to recognise the importance of her home environment in offering security, meaning and occupation, and as a major source of her psychological identity. In respecting her autonomy regarding her wish to stay in her home, potential harms needed to be addressed, such as issues of hygiene, nutrition and personal safety. These were not apparent concerns for Faith and she was content with her independence. However, her nephew and doctor saw her deterioration in capabilities as dependency, and potential physical risks, with residential care to be in her best interests. This option had the risk of causing psychological harm, by both imposing the decision for Faith to live in a care situation against her wishes, and in losing all that was familiar and meaningful to her.

While the previous approaches of maximising autonomy in decision-making and respecting personal preferences did recognise potential harm as a valid reason for intervention, this requires consideration of the seriousness of risk of harm, and identification of different accounts of risk that may not congruent be with Faith's values about risk. In this instance, the harm associated with Faith losing the familiarity of her home as the centre of her existence would carry considerable weight in relation to the possible risks to her physical safety, and would be congruent with her preferences. Respect for Faith's full interests, as understood and experienced by her, would be to support her to stay at home, while minimising the risk of physical harm. This could have included dementia support services to provide home care services to maintain hygiene and nutrition, to ensure appropriate heating and cooling in extreme weather, along with the provision of an identification bracelet in the instance of her losing her way, and the opportunity for social contact with others. These actions would have met the duty of care and negligence concerns, as part of the 'broader societal contract' (Flynn and Arstein- Kerslake 2014). Her physical and psychological well-being would then require regular review as the disease progressed, adjusting supports to suit. Implicit is the requirement for resources to be flexibly reconfigured to support this approach.

Faith's story illustrates how different views of personhood can be translated into interventions around conceptions of autonomy and the 'contested territories' of the person's good, leading to different outcomes, and profoundly affecting well-being (Clarke et al 2010, 102). A 'respect for persons' approach enhances relational autonomy and promotes personhood, in contrast with the prevailing approaches of risk-aversion and paternalism.

The remaining task in this chapter is to give particular attention to issues of risk and the interface with law.

Perceptions of risk and the legal interface

One of the major reasons that a vulnerable person's choices may be discounted is because of perceived risk to the person's health and safety. Risk of harm can justify a restriction of choice, or imposed solutions, despite the presence of legal capacity and associated freedom of the person. Older people are particularly vulnerable to having their freedoms curtailed due to stereotyping and associated protectionist attitudes. These prevailing attitudes in society set levels of risk thresholds in the community and reinforce practices that can be unnecessarily restrictive of personal freedom:

> *The risk discourse permeating post-industrial society is an example of a powerful cultural norm influencing the practice of medicine, especially geriatrics (Kaufman 1995, 486).*

Risk of harm becomes emphasised where the older persons has cognitive changes and are seen as unable to take responsibility for their choices, and becomes an area of 'contested territories' (Clarke et al 2010, 102). Strang, Molloy and Harrison consider that society should also be protected from harm arising from 'the consequences of choices made by incapable people' (1998, 28) and that society sets standards that need to be taken into account. However, this standard is contextual and morally pluralistic, and therefore not easily determined:

> *A limit could be placed on autonomy if [the person] harms or endangers others or if society decides that he is incapable and at unacceptable risk. The problem lies in defining unacceptable risk (Strang, Molloy and Harrison 1998, 28).*

In clarifying issues of risk, it is important for concerned individuals to become aware of the personal value judgments about risk that they may inadvertently, or consciously, impose on others (Flynn and Arnstein- Kerslake 2014). This requires an understanding that risk is unavoidable in life, and that people have different values and priorities about risk. Gooding suggests that a positive focus on ways to reduce risk can aid those providing care with ‘more room to move’ (2013, 436). The prevailing approach in medicine is in contrast to this, where, in assessing the lifestyle of older persons, judgments are made about what is appropriate from a position of elite and expert authority, with a focus on physical concerns.

Where there is risk of harm, it is important to understand the person’s life values and current meaning. Herring suggests that decisions that are uncharacteristic of the person and their previously demonstrated values, and carry a risk of harm, justify intervention, compared to choices which reflect the person’s values and identity (2009, 7). In the latter, he considers that intervention is not justified. Flynn and Arnstein-Kerslake have an alternate approach in giving primacy to the will and preferences of the person, despite some choices potentially leading to harm (2014), a concept known as respecting ‘dignity of risk’ (Nay 2002). Where choices appear self-harming, Flynn and Arnstein-Kerslake’s preferred approach is to provide support to the person, and make environmental changes that may meet the person’s needs and potentially lead to a change in choice or behaviour (2014). They consider that it is ‘more morally dangerous to impose outside decision-making on an individual than it is to support an individual in her decision-making’ (2014, 100). Both of these writers have a person-centred approach in understanding what is important to the person, but have different solutions, with Herring focused on congruence of values and behaviour as a guide to intervention, while Flynn and Kerslake take a rights-based approach to the person’s freedom.

Descriptions of risks can often be generalised and vague, and based on unjustified assumptions. Potential harms require articulation in order to understand the type and perceived level of risk, and weighed ethically against the benefits of the proposed action (Nuffield Council of Bioethics 2009). For instance, the risk to Faith's psychological well-being in entering a residential care facility against her will may have been far greater than any risk to her physical health in staying at home (Zarit and Goodman 1990). However, Huby and colleagues suggest that risk is an 'ideologically loaded concept… with political consequences in screening out certain courses of action and narrowing down the considerations upon which decisions are made' (2004, 116). In extending this idea, they suggest that as risk is perceived in different ways, understanding others' perceptions is more significant to resolution than objective measures of risk (Huby et al 2004).

Implicit in debates on risk is that health professionals may assert their views as predominant within a risk-averse paradigm due to their expert status, often excluding the priorities of the vulnerable person (Denson 2006) and indicating the relationship between role and values (Denson, Winefield and Beilby 2013). There is a tendency for risk to be equated with physical harm, rather than including psychological aspects, biasing perception and outcome. In her research, Denson found that concerns by health care professionals for the physical safety of the person far outweighed consideration of psychological harm from imposed choices (2006). Glass makes a similar conclusion (1997).

It can be oppressive to the vulnerable person if there is not more than one choice made available in decision-making (Donnelly 2010). When several choices are identified, a benefit/risk analysis can be made for each option. For instance, while concern for falls at home may be a risk, falls are also common in aged residential care facilities. If admission to a facility will not avoid falls, then further attention can be given to the benefits of the other options. It is important to include the person in discussion on the consequences of risks in order to inform choice. Where the person does not have the ability to comprehend the consequences, health professionals can give information about risk minimisation, and support the substitute decision-maker to weigh up the harms with the benefits, in the context of what outcome is most important to the vulnerable person.

Apart from risk to self, perceived risk of harm to others can also impose restrictions on personal freedom. Strang, Molloy and Harrison consider that society should be protected from harm arising from ‘the consequences of choices made by incapable people’ (1998, 28). Potential harms need to be specifically identified to ensure that prejudicial views are not causing restrictions on freedom. For instance, is it harm to society if an older person has several admissions to hospital following falls, thus using scarce resources? How does this compare to the repeated hospital admission of persons caused from alcohol abuse or by driving dangerously? Families can find it stressful when vulnerable older people live alone. Is it causing harm to family members if they are worrying continually, or it is part of our relational inter-dependency? These instances require a balancing of needs but may be alleviated by a plan of services to minimise risk and give support.

The prevailing paradigm of risk-aversion may influence professional views and not necessarily reflect actual legal requirements. Kennedy suggests that the professional duty of care becomes distorted where organisations are concerned primarily with their own protection and not that of the vulnerable person (2009). Where agencies and health and community care workers are risk averse, organisations become ‘defensive rather than responsive, and more inclined to limit client independence and choice’ (Kennedy 2009, 13). This has led to ‘care …redefined as risk aversion and protection’ (Phillips 2007, 144). In an investigation of risk management for older persons, Taylor found there was more concern by agencies with what was ‘defensible’ than what was ‘right’, leading him to conclude that issues of risk were less ‘about probabilities, and more about aspirations, fears and justifications’ (2006, 1424). Risk management policies can support staff in this challenging area, and ‘weigh up conflicting and competing imperatives’ (Kennedy, Richards and Leiman 2013, 35; Taylor 2006). Waugh suggests that a focus on the worker’s relationship with the client, supported by resources, is effective in achieving a person-centred approach towards risk (2009). Overall, the impact of perceptions of risk on decision-making and autonomy suggests significant future attention is required.

Law may be invoked if issues of risk are unable to be resolved informally: ‘a last resort’ when less restrictive alternatives have failed’ (Strang, Molloy and Harrison 1998, 29). Flynn and Arstein-Kerslake, with their focus on rights, acknowledge the duty to intervene or safeguard a person as set in broader ‘social contract’ of law, such as civil or criminal negligence (2014, 99). The area of negligence in human services is considered a complex and ‘uncertain’ area, requiring some precedent to be set in case law to assist practice, but with over-protection being simplistic and not doing justice to this area of law (Kennedy, Richards and Leiman 2013,156).

Hall suggests that ‘risk can never be eliminated’ (2009, 120). However, she describes law as intervening where there are recognised consequences, such as in relation to property transfer, or when concerns about decision-making and best interests exist (Hall 2009). As society requires a certain level of certainty in legal and commercial transactions, as derived from clear legal capacity (Quinn 2010; Donnelly 2010), the area of legal contracts, wills and advance directives are outside the gamut of person-centred approaches to decision-making.

V Conclusion

This chapter commenced with the exploration of notions of personhood. While the concept of the legal person is morally neutral, metaphysical worldviews of the person pervade the practice of the law (Naffine 2009). These worldviews construct the social and normative views of the person, endowing a particular moral status on the person. Law uses these personas to suit the particular purpose and relations under consideration, and therefore provides a versatile tool that can be used flexibly to affirm personhood and achieve a just legal purpose (Naffine 2009).

The conferral of social personhood onto people with dementia is based on recognising the many attributes of the person other than cognition, and respecting what is important to them, and their ability to indicate this meaning through participation in decision-making. There is an understanding that relationships can enhance personhood through supporting the person in decision-making. Creating an environment of well-being for people with dementia is empowering, increasing their sense of identity and functioning. In this way, the conferral of personhood overlaps with the expanded notion of autonomy.

Personhood applied to the medical culture shows the influence of the bio-medical focus on disease, and the quest for certainty in scientific facts. In the medical context, personhood and autonomy tends to be diminished, with this dominant medical discourse also influencing broader social norms about persons in relation to health and disease. The emerging focus on patient-centred practices in medicine indicates broader understandings of personhood. The person-centred approach aligns well with the ethical principle of 'respect for persons', which requires reclaiming as a primary principle.

A range of approaches towards decision-making illustrates the different nuances towards enhancing autonomy and personhood, such as supported decision-making, presumption of capacity and hermeneutic understandings. These can be further developed to provide valid alternatives to the capacity approach.

Assumptions about risk, lack of analysis of harms, and a risk adverse culture and policies in organisations can unnecessarily reduce autonomy. Physical and psychological risks require analysis and balancing of the possible benefits to the person with strategies to minimise risk. This may moderate others' behaviour in making assumptions and imposing value judgments about risk on decision-making. While negligence laws are complex and lead to uncertainties in practice, organisational policies about risk can assist person-centred practice. Increased knowledge of duty of care may keep law as a last resort, but specific aspects such as wills and contracts may require legal approaches to have priority. Otherwise, the space provided by law for everyday activities can support person-centred decision-making:

> *…the whole point of our political and legal order is to create an uncoerced space for the self…to allow individuals to create their own mini-legal universes in free association with others', including those with disabilities (Quinn 2011, 12).*

Values are central to whether recognition of full personhood for people with diminishing cognition occurs. Nedelsky reminds us that law is 'a central means of giving effect and supporting values', and that in promoting freedom, which includes autonomy, dignity, and equality, law also fosters structures and relationships that may facilitate or limit their achievement (2011, 364). Naffine adds justice to this list, with the focus on how each personhood approach serves a just legal purpose (2009). In addition, I add empathy, respect, and toleration of difference as values that can facilitate the recognition of full personhood. These cultural elements remain the most challenging in our pluralistic and complex liberal society, but Nedelsky holds that law can shape these values, just as society can shape law to be more inclusive of broader understandings of autonomy and personhood (2011). The focus on the values of personhood can assist law in achieving just outcomes, which are currently elusive for persons vulnerable from diminished cognition.

This chapter, and the previous two chapters, have given attention to the notion of autonomy, legal and moral approaches to decision-making, and the concept of personhood. New understandings about decision-making, autonomy and personhood challenge the exclusionary features of the traditional approach, with new concepts of autonomy emerging. A broader understanding of law, incorporating the socio-legal domain, also recognises that law, within a liberal polity, supports a space for pluralistic responses to the autonomy of older persons vulnerable from cognitive changes, which can be enhancing or diminishing of their autonomy. There is an understanding that the individual context of each person shapes and contributes to their personhood. Law can also be invoked, avoided or adapted to achieve ends other than the interests of the individual.

From this background, the thesis seeks to explore the phenomenon of how law is applied in real life to the decision-making of older persons whose capacity is in question, the informal practices of decision-making that appear prevalent, and the values and assumptions that such practices indicate. The next stage of this thesis is the methodology for gaining a broad understanding of approaches to decision-making of older persons as seen by advocates and guardians, and exploring decision-making in the real life context of a hospital setting, to contribute useful knowledge about the interface between decision-making, personhood and law in everyday life.

4 Methodology

The review of legal theory and literature undertaken in Chapters 1–3 has revealed a range of discourses on decision-making capacity for people with dementia. The liberal notion of autonomy, while protective of personal freedom, excludes some persons who do not meet the cognitive ideal. This extends the approach by law towards capacity, and exposes the conundrums that result implementing a legal fiction in practice. The dynamics of attitudes and consciousness about law and capacity demonstrate the interactive nature of the domain of everyday law, and of society and law as mutually constituted. Notions of the legal person and metaphysical views of the person that influence law were used as a basis to explore how the person is viewed in medicine, and of new understandings of personhood in dementia. The interface between formal legal approaches, the dynamic nature of everyday law, and relational approaches to autonomy and personhood set the stage for exploration of these concepts in real life settings.

With this framework as a base, the research question that emerges is ‘how is law applied in real life to decision-making of older persons whose capacity is in question, and what values and assumptions underlie such practices?’ A qualitative approach offers strategies to gain a range of perspectives towards decision-making by persons with changing cognition. This chapter contains an outline of the recruitment, data collection and data analysis processes. The worldview of constructivism establishes the epistemological basis of this research methodology, and a hermeneutic approach has been chosen as the most effective method with which to collect and interpret the nuances of meaning towards decision-making capacity in real world.

I The research methodology

A qualitative research approach provides a range of methods to assist in observation and reflection of the real world (Creswell, 2007, 43) and facilitates an interpretative approach (Denzin and Lincoln, 2005, 3):

> *Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretative, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations,*

> *photographs, recordings and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.*

This form of social inquiry has developed from a broad range of disciplines and perspectives, with ongoing philosophical debates about the nature of truth and reality, and the means by which these are explored and understood (Denzin and Lincoln 2000; Lincoln and Guba 2000). The 'truth' held by any social inquirer has an influence on the form of interaction, methods and interpretation of that social inquiry, with connectivity between the activity of social inquiry and the underlying theories (Schwandt 2000, 190-1):

> *As one engages in the "practical" activities of generating and interpreting data …one inevitably takes up "theoretical" concerns about what constitutes knowledge and how it is to be justified…'.*

Beliefs about 'truth' and knowledge exist within a paradigm of connected concepts of ethics, epistemology, ontology and methodology, which shape the approach to the social inquiry (Lincoln and Guba 2000, 175). The nature of this research study, in exploring the nuances of decision-making and dementia in the natural world, uses the 'constructivism/ interpretivism' tradition, with an acknowledgment that 'reality is viewed as socially and societally imbedded' (Grbich 2007, 8). This approach rejects the empiricist and 'fixed reality' approach of positivism (Schwandt 2000, 201), to one where knowledge is constructed from the subjective interpretations of the researcher in relationship with the participants, all of whom are shaped by the social context and culture within which the events occur (Grbich 2007; Patton 2002).

The evolving discussion and debates in the literature regarding the concept of decision-making capacity reflect the use of socially constructed ideas in disciplines such as medicine, philosophy, psychology and law. These disciplines also operate within their own constructed worlds, with varying awareness of the historical and cultural ideologies that have shaped the development of thought in society. The social context, with its historical development and ideologies in current place and time, continues to wield hidden influences on human thought, which is unable to be free from the subjective experiences of what constitutes reality for each individual. The interpretivism/constructivism paradigm acknowledges the 'multiple realities' of this construct on both the subject under consideration, and the interpretations of the researcher (Grbich 2007, 8).

Complementary to this approach is the use of the hermeneutic form of inquiry, which provides the structure for analysing meanings created in the range of human activities (Grbich 2007; von Zweck, Paterson and Pentland 2008). Hermeneutics has evolved to become a 'core discipline' for all scientific inquiry into human activity (Dilthey 1924 in Kakkori 2009, 23). Today, hermeneutics is considered as both the 'art' and 'science' of interpretation (von Zweck, Paterson and Pentland 2008), and embraces all human activity such as language, events, activities, cultural systems and organisations (Crotty 1998; Kakkori 2009).

There are epistemological differences between philosophical hermeneutics and interpretivism/constructivism views, particularly in the role of the researcher's filters and prejudices that they bring to any interpretation (Gadamer 1988). In the constructivism/interpretivism approach, biases are a potential barrier to objectivity, whereas in hermeneutics, they are unavoidably influential, and are dynamically engaged to develop the new understandings, or the 'future horizon', therefore requiring exposure and transparency (Schwandt 2000; Kakkori 2009). Both approaches share an understanding of interpretation as influenced by the 'lens of the researcher's perception and experience' (Kinsella 2006, 5). This is representative of the 'montage' of approaches to be considered by researcher, who pieces together a quilt from the 'competing and overlapping perspectives and paradigms' (Denzin and Lincoln 2000, 6).

The hermeneutic circle is a key aspect that shapes the research inquiry (Kinsella 2006; von Zweck, Paterson and Pentland 2008). With its early derivative from Schleiermacher (1768-1834), Kakkori (2009) describes this aspect of 'circular understanding' as developed further by Dilthey (1924), and later by Heidegger (1992) and Gadamer (1998). As researchers commence an inquiry into a phenomenon, they bring to that research their own 'history' or 'pre-understanding', and through immersion in the inquiry, develop new insights that change them irrevocably, impacting on their future understandings of the phenomenon, thus closing the circle (Crotty 1998; von Zweck, Paterson and Pentland 2008; Kakkori 2009). This dynamic nature of the interpretation of text and responding contextual insight has also been viewed as a spiral, where there is an iterative process of interpretation and synthesis: ‘an open ended movement from the horizon of the text to the horizon of the reader…spiralling nearer and nearer to the text’s meaning’ (Osborne 1991, 6).

The hermeneutic circle also offers a method to assist interpretation of human activity, being that of requiring understanding of each part and the whole of the phenomenon under study, of which Geertz’s describes moving between ‘the most local of local detail and the most global of global structure’ (Geertz 1973 in Schwandt 2000, 193).

The approach used in research inquiry guides how research is conducted, analysed and reported (Creswell 2007), and hermeneutics gives shape to both research design and data interpretation. For example, the importance in hermeneutics of viewing both the parts and the whole of the phenomenon, gives weight in research design to capturing a range of different viewpoints. This takes form as ‘data triangulation’, which Patton describes as gathering data from a number of different sources (1990). The complex natural world of human activity in hermeneutics is interpreted through ‘representations’ of the written word, therefore field notes from observations, transcripts of interviews, and document analysis are key modes of data for interpretation of meaning (Liamputtong 2009).

The researcher’s perspectives and worldview influence these interpretations. Therefore, the self- awareness of the researcher’s previous lived experiences and prejudices brought into the inquiry is important. Acknowledgement of his or her unique viewpoint, which influences and shapes their understandings during data collection and analysis, emphasises the value of journal keeping by the researcher. The processes of data collection are empathic and relational in the hermeneutic tradition, with the personality of the researcher a dynamic in data collection. In-depth semi-structured interviews are one expression of this approach (Van Manen 1990).

The circular, iterative nature of hermeneutic data collection requires an ongoing review of data, with initial preliminary data analysis identifying themes, and gathering further data in a ‘continuous stream’ until the researcher is confident that the circle of understanding has reached a completed state (Kinsella 2006; Grbich 2007). Analysis and reanalysis of themes takes place through immersion in the data, in ‘a recurring process of asking and answering questions’, recognising the dynamic nature of the hermeneutic circle (von Zweck, Paterson and Pentland 2008, 119). The reporting of the data needs to reflect the dynamic nature of interpreting meaning in complex human phenomenon, therefore accepting the inevitability of ambiguity in interpretation, and that findings are not conclusive and bounded (Kinsella 2006).

Qualitative research supports the understanding of subjective reality by offering methods designed to explore multiple realities. As a method that facilitates the voices of the ‘silenced, othered and marginalized by the dominant social order’ (Hesse-Biber and Leavy 2005), qualitative research is a valuable approach with which to explore the different realities and perceptions of decision-making with vulnerable older adults in the everyday world.

II Study methods

A multi-method approach using focus groups, case studies and interviews was developed to gain different viewpoints and perspectives of the phenomenon of decision-making capacity, in order to capture both the ‘parts and the whole’.

Focus Groups

Two agencies which worked on the ‘frontline’ in the community with those who were vulnerable and often ‘invisible’ to society were chosen for the focus groups (Creswell 2007; Liamputtong 2009). One agency provided advocacy services for older persons, while the other agency had a statutory function in providing protective services to adults with impaired mental incapacity, of which a large percentage were older persons. Exploring these agencies’ observations, perceptions and experiences through focus groups was a valuable starting point in the inquiry about decision-making by vulnerable older people (Morgan 1997), and a valuable means from which ‘to gain understanding of a particular issue from the perspective of the group participants' (Macnaghten and Myers 2004, 65). The focus group approach facilitated the gathering of information about the difficult situations experienced by the staff in these agencies and their approach, and their perspectives on societal values and of the role of current legislation in supporting their work.

The focus group structure permits participants the opportunity for reflection and interaction with their co-workers on these complex and sensitive issues, with the opportunity to elicit additional information that may not have been forthcoming in individual interviews, also making them time effective (Creswell 2007).

Preliminary Scoping

When approached, both agencies were interested in the opportunity the focus group gave officers in the agencies to reflect on the issue of decision-making capacity. Meetings with the senior staff member in the guardian agency and the director from the advocacy agency enabled the development of a strategy for applying the ethical considerations and methodology in each agency. Documentation of the resulting methodology was provided to each agency for consideration, and subsequently both agencies agreed to participate.

Ethics approval- focus groups

Documentation of the research process, information and consent forms, and a support letter from the agency was submitted to the Southern Adelaide Health Service/ Flinders University Human Research Ethics Committee. A copy of the ethics approval is appended (Appendix 3).

Sampling and recruitment

Recruitment was by invitation. The director of the advocacy agency, and the senior officer in the protective agency, were provided with a written invitation to participate in the focus group, which they distributed to all staff in the agency. A support letter from the relevant heads of each agency accompanied the invitation, with information about the focus of the research, the voluntary nature of attending, aspects of confidentiality and privacy, use and storage of data, and a request for permission to audiotape the group session. Consent forms were included (see Appendix 5).

Focus group invitees indicated their interest to participate to their liaison person, who proposed a suitable time for the focus group to occur, based on staff schedules. This aspect varied from the proposed methodology, which had involved each person being contacted directly to discuss a suitable time and location for the focus group. There was high interest in the focus groups and all those invited in both groups attended, with eight and seven participants respectively. Each participant signed consent forms before the commencement of the focus group. There were several team leaders in each group which indicated some power differentials between participants.

Data collection

I facilitated each focus group, assisted by a note taker/co-facilitator[29] who took notes of the interview. An audiotape was made of each session for later transcription to ensure accuracy of the data. There was a discussion on confidentiality and the timing of the session at the commencement of the group interview. After I introduced myself and the co-facilitator to the group, each participant introduced herself or himself. The focus of the group interview, outlined in the information sheet, included aspects such as the environment within which the group participants worked, the types of difficult situations that vulnerable older people encounter, the participants' approaches towards the decision-making of older persons, and the group participants' relationships with other agencies and health professionals in promoting the rights of older persons. In moving through this range of topics, each participant had the opportunity to respond before moving to the next question. Several times in both groups dialogue moved away from the focus and I facilitated the discussion so that it was back on 'track'.

Each session was ninety minutes with a break in the middle. The advocacy group extended by fifteen minutes due to the interest and preparedness of the participants to continue longer, but time pressure did not permit an extension for the second focus group.

---

[29] Margaret Brown, Adjunct Research Fellow, Hawke Research Institute, University of South Australia

Study settings and participants

The first focus group (FG1) took place in the boardroom of the agency. All participants in the group sat around a large table that had been set up earlier. Refreshments were served in a midway break during the focus group interview and informal conversation ensued.

The discussions were energetic and often passionate, and several times the discussion had to be brought back to the specific questions, to ensure that all participants had the opportunity to make comment. Initially the participants answered a question in turn, but as the interview progressed, conversation ensued between numbers of the participants, reflecting one of the interactive benefits of the focus group method (Creswell 2007). One participant was particularly dominant in expressing their view, and one participant was particularly quiet. At the conclusion of the focus group interview, the participants were thanked for their time, and participants indicated their enjoyment of the session as a rare opportunity for discussion and reflection.

Table 1   Focus Group 1 Participants

Name (pseudonym)	**Role**	**Years with agency**
Lauren	Advocate and team leader, residential care	12 years
John	Advocate, abuse prevention	7 years
Sarah	Team leader, abuse prevention	7 ½ years
Sophie	Advocate community services	3 years
Harry	Advocate, residential care team	4 ½ years
Rebecca	Advocate, abuse prevention	2 years
James	Advocate, residential care team	3 ½ years
Emma	Team leader, community services	14 years

The second focus group (FG2) took place in the premises of the agency, but a separate room was not available so participants sat in a circle around a coffee table in a large area that also had some ‘people’ traffic to the kitchen and other rooms. The same list of questions used in the first focus group also created the framework for this discussion. The conversation of this group was more constrained in comparison to Focus Group 1, with most people contributing equally with the exception of one person who contributed frequently. A break occurred midway, with coffee and a light lunch provided at the conclusion of the focus group interview. The length of time in the role was gathered, but information on professional background did not ensue in the second group.

Table 2   Focus Group 2 Participants

Name (Pseudonym)	**Role**	**Years with agency**
Kate	Senior advocate guardian	4 years
Mary	Guardian advocate	4 ½ years
Eleanor	Guardian advocate	1 ½ years
Anne	Guardian advocate	5 years
Joanne	Senior guardian	6 years
Laura	Guardian advocate	1 year
Nicola	Assistant director	1 ½ years

Data analysis

Transcripts were made from the audiotapes from both focus groups. To achieve anonymity, participants were given anonymous identifiers in the material. Participants of focus groups received the de-identified transcripts, and each participant was individually emailed with their identifier code, inviting them to check the transcript. None of the participants requested any change to their contribution in the transcripts. All data was stored in a secure setting.

Processes for analysis included listening to the interviews and reading the transcripts several times in an ‘immersing’ in the data in ‘a recurring process of asking and answering questions’, recognising ‘the dynamic nature of the hermeneutic circle’ (von Zweck, Paterson and Pentland 2008, 119). I made notes alongside the text, describing details and significant features, identifying possible contexts and reasons, and recording thoughts that emerged in response to this process (Grbich 2007). I noted and extracted the language that the participants used to describe the target group, their own role, and others, such as family members, health and welfare professionals.

Themes and theories from the literature were considered in this process, particularly the language of rights and reference to legislation that had impact on the practices of these two groups, and the models of personhood utilised in their work. Notes were made of areas of literature that would merit further investigation in response to the data, and questions to which more information would be useful in latter interviewing. I had an aim of ‘letting the data speak’ before bringing the main focus of the study into consideration (Grbich 2007).

Analysis and reanalysis of themes takes place through immersion in the data, and Grbich describes the process as one of separating, grouping and relinking data to ‘consolidate meaning and explanation’ (2007, 21). The next stage to assist this process was that of thematic analysis, classifying and interpreting these notes several times, and setting up broad codes for different categories. Codes were condensed to major themes, and a block and file approach assisted in developing major themes in the texts. I developed a conceptual map of the themes and relationships, acknowledging both the role of intuition and the social constructs implicit in the data (Creswell 2007; Grbich 2007).

A comparison was made of the data from the two different agencies, to identify variations arising from the contextual issues of client base, professional role, and the social or legal power of each group. For instance, the guardians work within the framework of protective laws, while the advocates use a rights-based approach. One group works with people who have legal capacity, while the other group act as substitute decision makers for those deemed, under protective legislation, to no longer have legal personhood. Differences arising from the themes between the data from each group were identified, while recognising the ambiguity from such a complex context (Kinsella 2006).

Case Studies

Hermeneutics places importance on exploring each part of the phenomenon as well as the whole. The focus group interviews enabled the gathering of broad perspectives of decision-making with older persons, while case studies are an ideal method for in-depth exploration of fine contextual matter. Analytical processes within each method facilitated the interpretation of minute detail of the parts, while also allowing a global picture of the phenomenon to emerge.

Case studies have a distinguished history as a methodology in psychology, medicine, law, and political science, rendering them suitable for the multi-disciplinary aspects of decision-making capacity (Creswell 2007). While there is debate about whether a case study is a method, a research design, or a focus on an issue (Yin 2003; Denzin and Lincoln 2005; Liamputtong 2009), this study utilises the latter understanding. This is described by Creswell as exploring the problem or issue intensively through a small number of cases in a bounded system, with 'detailed, in-depth data collection to explore these potentially sensitive interactions in a 'complex and nuanced environment' (2007, 73). Gathering data from multiple sources, such as interviews, observations and texts provides triangulation of data (Creswell 2007), giving 'multiple perceptions… in the clarification of meaning' (Stake 2000, 43).

The case study is seen as the research strategy of choice in exploring the 'what', 'how' and 'why' questions of a phenomenon in the uncontrolled environment of the natural world (Liamputtong and Ezzy 2005, xi; Yin 2003). Liamputtong suggests that case studies facilitate the discovery of Popper's metaphoric 'black swans', being the unexpected or hidden aspects of a phenomenon (2009, 197).

As places where health and care decisions are made, and with a high percentage of older persons as patients, a hospital setting was chosen as the setting for the study. Furthermore, the concept of decision-making ability and its assessment have its foundation in health law, with the latter an identifiable activity in hospitals. Hospitals also offered relative ease of access to the subject group chosen, and two different hospitals eventually participated in the study.

Preliminary scoping

The original plan was for the recruitment of case studies to occur in the psycho-geriatric unit of the hospital, and there had been several meetings with a consultant psycho-geriatrician interested in the study area. A subsequent change in detention practices reduced these recruitment opportunities, with the scope of recruitment needing to be widened. After making contact with the Director of the Geriatric Services of Hospital 1, I attended a meeting of geriatric consultants in the hospital, and met with the senior social worker at the hospital and the geriatric liaison registrar. The latter had a role in capacity assessments in the general wards, and indicated her interest in recruiting cases for the study.

Flow charts of the recruitment process for the psycho-geriatric and general hospital areas with a description of the study were provided to the Director of Geriatric Services and the consultant psycho-geriatrician, who supported the research approach.

Ethics approval – Hospital 1 and 2

Clinical ethics approval was required due to the nature of the research. Advice was sought from the Chair of the Southern Adelaide Health Service/Flinders University Human Research Ethics Committee prior to submitting the documentation regarding the consent/assent issues for the patients recruited to the study. I was advised that persons whose capacity was in question would only be able to assent, rather than give consent to involvement in the research. For this reason, involvement of the case study participants was limited to access to their case files and observation of the capacity assessment, with consent also required from their relatives for the vulnerable person's involvement. The subsequent documentation of methodology and ethical considerations were submitted along with a support letter from the clinical director of the region. Indemnity/Participant Compensation was obtained from Flinders University for the research project as an essential aspect of ethics approval. Midway through the study, due to limited referrals, recruitment was extended to a second hospital and I submitted a modification of the study to the ethics committee, along with the support letter from the Director of the region. A copy of the second approval is appended (Appendix 4).

Sampling and recruitment

The multiple case study approach enables exploration of a problem through different perspectives arising from a number of cases. There are a number of considerations to take into account in this method, such as ensuring that cases are of value to the topic, and developing a rationale for sampling and selection (Creswell, 2007). Having cases with a variety of different aspects, while ideal, is subject to the availability of cases for recruitment. The trigger for recruitment was the decision of the medical team for a decision-making capacity assessment of the patient to be undertaken, and cases were to be drawn from this population. There were variations in how the assessment process occurred in the different areas of the hospitals. In the specialist geriatric units, the consultant geriatrician conducts the capacity assessment when they appear straightforward, with a referral to the neuropsychologist if complex, and he or she makes a recommendation to the medical team regarding decision-making capacity. In the psycho-geriatric unit, the registrars conduct capacity assessments, with the consultant involved if necessary. In the general wards, a geriatric registrar makes the initial capacity assessment, gathering information about the patient and the area of decision-making, and then asks the consultant to meet the patient with the registrar to make the final assessment. A document to cover the different procedures in the different areas of the hospital and an information kit containing consent forms was given to those medical staff participating in the study.

The first phase of recruitment was from November 2010 to May 2011. Three cases were recruited, one each from the specialist geriatric unit, the rehabilitation unit, and the psycho-geriatric unit. The first case recruited was a patient residing in the geriatric ward, under the treatment of the general medical team, and the registrar covering these general wards notified me and then contacted the family for consent. The consultant geriatrician gave consent to being observed and interviewed. The registrar, who had met with the patient and talked with the family in the days preceding the assessment, obtained the patient’s assent.

In the second case, the psycho-geriatrician advised that a potential case had arisen, and then obtained the appropriate consents, firstly from family members and then the patient. The psycho-geriatrician, who knew the patient well, gained his consent prior to the observation, and introduced the family to me at the hospital. The patient in the third case was in the rehabilitation unit, and the geriatric consultant gained the consent of the patient to be involved in the study and from the family, who resided interstate.

Following these case recruitments, there were no further case recruitments over a three month period, despite a meeting with the new liaison registrar and the clinical team of the geriatric ward, and distributing information in the ward meetings about the study. Consequently, I decided to extend the study to a second hospital in the region. I met with the social worker and multi-disciplinary team leader of the geriatric unit of the second hospital, and developed a recruitment strategy for that setting, with approval received from the Director. The social worker explained the study to other team members, and I was introduced at a clinical team meeting.

The second phase of data collection occurred from November 2011 until May 2012 in Hospital 2. In this phase, the social worker of the geriatric unit sought to identify potential cases that met the criteria from her caseload. As she worked intensively with the patients and families, she had a prior relationship that facilitated recruitment. The first case in this setting, Case 4, had an assessment by the neuropsychologist, and while this assessment was not observed it was kept in the sample due to the social aspects of the case, and the availability of detailed information from the assessor. An observation of an interview of the patient by the social worker gave nuanced information about the patient. Case 5 was recruited and the consent of the family member obtained, but the proposed formal capacity assessment did not eventuate. The patient died before the interview with the family member took place, but with unique data regarding end-of-life issues, the case was retained in the sample. The social worker was interviewed to obtain additional data.

At this stage of recruitment in Hospital 2, a review of the diversity of cases occurred showing it to be appropriate to have a further case where the subject was a woman, to balance gender. The social worker proposed a case involving a male patient but this was not pursued. The final case recruited was Case 6 and met the gender requirement. The family member gave consent for participation in the study and the patient also consented to having the capacity assessment observed. The neuropsychologist gave consent to both the observation of the assessment and to an interview. The family member was interviewed by phone as he lived in Queensland.

There was some urgency around assessments in the geriatric and general hospital areas, as a capacity assessment could occur if affecting the discharge planning for the patient. The tight timelines made the gathering of consents challenging, particularly from family members, who required the courtesy of receiving the information about the study and having the opportunity to reflect on participation of themselves and their relative. In one case, the assessment was delayed to allow the family sufficient time to consider the information.

Attendance at the clinical team meetings in the geriatric unit in the second hospital aided proved a successful strategy in identifying potential cases early and making the research study visible, in an otherwise time-pressured environment. Basing the recruitment in one hospital unit in the second phase also assisted due to continuity of staff and a health professional in a key position willing to support the study and give additional time to recruitment.

Data collection

A range of methods aided in gathering data from different perspectives to achieve an in-depth understanding of the uniqueness of each case, and a range of perspectives. These methods consisted of general observations and four types of case related data: observations, interviews, documents and audio-visual materials.

General observations

There were regular visits to the two hospitals during the two data collection periods for recruiting, observing assessments, interviewing and accessing file notes. Journal notes of observations and casual conversations were made from these visits. Observations were noted during attendances at clinical meetings in both of the geriatric units of the two hospitals, which were multi-disciplinary in nature, and had a discharge planning focus.

Direct observation of assessment

At the start of each observation session, I was introduced and then sat out of line of sight of the interviewee when able, making observation as discreet as possible. With different competing aspects to be observed at any one time, I took comprehensive notes, which were written up as soon as possible after the observation. I sought to be conscious of the process while also attending to the content that was forthcoming

(Creswell 2007; Seidman 1991). The notes were later transcribed. The assessment was not observed in Case 4, but full assessor notes were available.

Interviews with assessors

The interview of each professional who conducted the capacity assessment took place as soon as it was practicable. One interview occurred immediately after the assessment, but the remainder occurred later to accommodate the professionals' schedules. All of the interviews took place in offices or private staff space at the hospital. I outlined the consent provisions at the beginning of each interview, and gained consent. The focus of the interviews included the process and outcome of the assessment, the overall aspects of decision-making in the case, aspects of the case that are seen as difficult, unusual, or challenging, and to what degree the assessment helps resolve the decision-making dilemma.

The interviews with the professionals who conducted the assessments were generally short and structured in acknowledgment of the time constraints of the professionals. I took notes of the conversation during the interview and afterwards made additional notes regarding her observations and reflections. The interview was transcribed and a provided a copy to the assessing professionals for checking for accuracy. As there was no formal assessment in Case 5, data was not available in this instance.

Interviews with family members

A semi-structured interview protocol was individualised for each interview, listing open-ended questions as a guide (Appendix 7). The focus of the interview with each family member was concerned with their relationship with the patient, their understanding of the needs of the older person, their understanding of capacity and the process of assessment, and their views on the outcome of the capacity assessment.

Flexibility in the flow and direction of the interview had the aim of facilitating the gathering of rich data from the interviewees from their unique viewpoint and life experience (Liamputtong 2009). In this approach, I became a 'co-participant', actively engaging with the interviewee, and encouraging them to talk about the research issue, demonstrating the relational aspect of hermeneutics. In this way the semi-structured nature and flow of each interview becomes idiosyncratic to the person's context and meaning, and is not possible to standardise (Denzin 1989).

Specific skills were required in order to offer a seemingly relaxed conversational style but also become a 'constructor of knowledge' during the interview process (Holstein and Gubrium 1995, 4). This included a focus on the context and meaning for the interviewee within a conversational form, considered an essential skill and discipline in interviewing (Liamputtong, 2009). My social work skills were utilised in the interviewing process to elicit the story of each person in relation to their understanding and meaning of decision-making and the context of the current situation. An example of an individualised interview protocol is in Appendix 7. The interviewees chose their preferred location for their interview. Two interviews occurred in the family member's home and one in the home of a friend, one in the office of a transitional care facility, and one interview over the phone. Time was taken at the beginning of the interview to ensure the participants understood the consent provisions, and to gain consent. The interviews kept to the time proposed, except when otherwise negotiated with the interviewee. Observing the interviewee in all but one interview gave valuable data, with non-verbal observations noted, adding further notes following the interview.

Case file data

Notes were made from the case files of each patient in the study. In some instances, space was found in the busy workstation of the ward, but in three cases, the doctor or social worker made a room available. I asked to meet the ward clerk in three of the units in the study, in order to facilitate access to the case notes on a return visit. The case files in the case study consisted of reports, assessments, results of medical tests, the previous discharge summary, and progress notes for the current admission. Entries in the progress notes included medical notes by interns, registrars and consultants, and specialists from other medical specialities, social workers, physiotherapists, and occupational therapists, dieticians and speech pathologists, with nursing notes constituting a considerable proportion. Initially notes were made of all contributions in the file, but as some of the latter cases had large case notes, nursing notes were excluded unless offering a viewpoint of the patient in relation to the decision-making affecting the capacity assessment. The notes were later transcribed.

Additional Case Information

Additional information about cases arose from supplementary interviews, phone information from staff involved in the case, and observations in the ward. In each case the information was noted and transcribed.

Data collection matrix

Each type of data was transposed into text, resulting in a rich variety of data for interpretation and analysis. The resultant text comprised the notes about patient information provided at recruitment; notes on the direct observations; notes from assessor interviews; audio-visual materials and transcriptions from family interviews; written notes from case note documents; and notes from additional information received. The different types of data collected in the case studies form a 'data collection matrix' (Asmussen and Creswell 1995) and the type of data collected and their text form are summarised in the matrix below.

Table 3 Case Study Data Collection Matrix

Case	**Recruitment information**	**Assessment observation**	**Assessor interview**	**Case notes**	**Family interview, location**	**Additional information collected**
1	Supplied by registrar, notes taken	In shared ward, notes taken and transcribed	Consultant geriatrician; notes taken and transcribed	Nurse's station; notes taken and typed	Son and daughter in law in their home; audiotaped and transcribed	Registrar interview; notes taken and transcribed
2	Supplied by psycho-geriatrician, notes taken	In single room, notes taken and transcribed	Psycho-geriatrician; notes taken and transcribed	Consultant's office; notes taken and transcribed	Wife and son in their home; audiotaped and transcribed	–
3	Supplied by consultant geriatrician, notes taken	In Interview room, notes taken and transcribed	Consultant geriatrician; notes taken and transcribed	Ward interview room; notes taken and transcribed	Nephew and niece in law in a care facility; audiotaped and transcribed	–
4	Supplied by social worker, notes taken	–	Neuro-psychologist; notes taken and transcribed	Nurse's station; notes taken and transcribed	Partner in his friend's house; audiotaped and transcribed	Observation of social work/patient interview; notes taken and

						transcribed
5	Supplied by Social Worker, notes taken	–	--	Social worker's office; notes taken and transcribed	–	Social worker interview; notes taken and transcribed
6	Supplied by social worker, notes taken	In interview, room notes taken and transcribed	Neuro-psychologist; notes taken and transcribed	Nurse's station; notes taken and transcribed	Son over phone ; audiotaped and transcribed	Social worker over phone; notes taken and transcribed.

Study setting and participants

The case studies took place in two hospitals. The first hospital had old four-bed wards, as well as a newer rehabilitation building, and a recently constructed psycho-geriatric facility, which were all single storey buildings. Interviews occurred in all three of these settings. The second hospital was multi-storey and modern.

Of the four capacity assessments observed, two occurred in the patient's room. The first of these was in a shared room with some privacy from a pulled curtain. The patient was in bed and had just finished his breakfast. There were a number of disturbances during the interview from the ward orderly collecting the breakfast tray, and a nurse called to attend the other patient in the room, who vomited while the interview was in progress. The consultant also answered his phone briefly during the interview. The second ward interview was in a private room without interruption, and the patient chose to recline on his bed rather than a chair. The other two capacity assessments interviews took place in hospital meeting rooms without external distractions. There was a relationship between the environment and interview styles: the interviews in the meeting rooms saw the two professionals conducting the assessments initially chatting and establishing rapport with the person, while the style of the professionals conducting capacity interviews in the ward situation was more formal and brusque.

The patients

While all of the subjects of the cases shared the commonality of hospital admission and a focus on their decision-making abilities, there were unique characteristics relating to social and health factors in the six cases. Four of the patients were in their late eighties and two were in their late seventies. There were four men and two women. Four of the patients were widowed; one was married but resided separately in a residential care facility, and one was in a long-term gay relationship. Of those widowed, one shared a house with his son, two lived alone, and one lived in supportive accommodation. The table below summarises the gender, age, living arrangements and unique aspects of each subject, with a pseudonym for each person.

Table 4 Age, gender and diversity of subjects

Case	Pseudonym	Age	Gender	Unique aspects
1	Andrei	87	male	Born in East Prussia; English was a second language; blind; widowed with children; lived alone until admission
2	Lewis	77	male	Korean war veteran, previous post-traumatic stress; chronic diseases; married but residing in an aged residential care facility
3	Kathleen	88	female	Lived independently; widowed, no children
4	Tom	78	male	Lived in a long term gay relationship until admission
5	Reg	87	male	Had a life-limiting illness and was in the last few months of life; widowed with children; lived with son
6	Daisy	89	female	Widowed with children; lived in supportive accommodation until admission

The assessors

The interviews with the assessors comprised of a consultant psycho-geriatrician, three consultant geriatricians and a neuropsychologist, and all occurred in hospital offices or staff rooms. The interviews ranged in length, with the interview with a consultant geriatrician being of 15 minutes duration, while one interview with the neuropsychologist went for an hour. The other interviews were of approximately half an hour in duration.

Table 5 Assessors conducting capacity assessments

Case	Pseudonym of assessor*	Profession	Gender	Observed	Interviewed	Length of interview
1	Dr Harris	Geriatrician	Male	yes	yes	15 minutes
2	Dr Royal	Psycho-geriatrician	Female	yes	yes	35 minutes
3	Dr Windsor	Geriatrician	Female	yes	yes	30 minutes
4	Tanya	Neuropsychologist	Female	no	yes	60 minutes
5	(Not applicable)					
6	Tanya	Neuropsychologist	Female	yes	yes	35 minutes

*The pseudonyms reflect the hospital conventions with the use of titles for medical staff.

The family members

The interviews with family members occurred in a place of their choosing: most were in the person's home, and one took place in a pre-arranged interview room at a transitional care facility. In a number of cases, there was a delay in the interviews taking place due to the personal circumstances of the family members. Out-of-pocket expenses were available for transport and parking but the interviewees did not utilise this provision.

At the beginning of the interview, I summarised the purpose of the study, gained consent for interviewing and taping the interview, and explained the use and protection of data, including confidentiality. Family members gave consent for each of the interviews to be recorded. In each case, the family member had significant stresses occurring due to their relative being in hospital and particular issues still to be resolved. However, all of the family members were very willing to discuss their situation, seemed to appreciate the interest in their situation, and became more relaxed as the interview progressed.

Table 6 Family member relationship and place of interview

Case	Pseudonyms	Relationship	Place of family interview	3 month follow up
1	Greg and Rose	Son and daughter-in-law	Family's home	phone
2	Jenny and Simon	Wife and son	Family's home	phone
3	Brian and Joy	Nephew and wife	Interview room, transitional care facility	Coffee shop

4	Jay	Partner	Home of friend of family member	phone
5	Michelle	Daughter	-	-
6	Andrew	Son	phone	phone

A follow-up interview was arranged three months later, and most family members chose a phone interview, with one follow-up interview held in a coffee shop. The follow up interview explored the events that had taken place since the first interview, and the impact of the assessment and its outcome. Notes from this interview were added to the original transcript for perusal. Each case concluded at this point, and the family members received a copy of the transcript from the initial interview, and notes from the follow-up interview, to check for accuracy. One family member requested a small modification to their transcript. All data was de-identified and stored in a secure location.

Key informants

During the study, I also interviewed a range of people who had relevant roles or useful perspectives on the study topic. These interviews were primarily of an iterative nature, seeking information about gaps or issues that had arisen in the data along the way. Each participant was provided with information about the study and how the data would be used. Agreement to be interviewed was taken as consent. Notes were taken in all the interviews, with one audiotaped, and the material de-identified.

The psycho-geriatrician, liaison registrar, neuropsychologist and social worker involved in the case studies were interviewed in relation to a more general understanding and views about decision-making capacity. A second neuro-psychologist in mental health services was interviewed regarding the role of the profession in capacity assessment, and a geriatrician in a different region was interviewed to identify different approaches towards capacity assessment. Notes of these interviews were transcribed into an electronic form. A risk manager from one of the hospitals was interviewed regarding issues of patient risk, and this interview was audio-taped and transcribed. The key informants are listed in the table below.

Table 7 Key informants and professional role

Interview	Name (pseudonym)	Role
1	Dr Royal	Psycho-geriatrician, Mental Health services
2	Dr Thomas	Registrar, general wards
3	Ms Hughes	Neuropsychologist, geriatric medicine
4	Dr Isaacs	Geriatrician, different region
5	Marta	Neuropsychologist, psycho-geriatrics
6	Jane	Social worker, geriatric medicine
7	Ellen	Risk manager of hospital

*The pseudonyms reflect the health care conventions of using titles for medical staff.

Data Analysis

At the conclusion of the data collection, the data was collated for each case, which consisted of the record of the observed assessment, the case file notes, and transcripts of the interviews with the assessor and family member. In two cases, this included interviews with the social worker and liaison registrar. Each item was investigated initially separately, and then together, for a detailed description of each case ('within-a-case analysis'), followed by comparing issues and themes arising from each case as a 'cross-case analysis' (Yin 2003, 167). Both instrumental and intrinsic aspects were analysed (Creswell 2007).

I listened to the interviews and read the transcripts and notes, 'immersing' myself in the data, and becoming familiar with the nuances of each case. Notes were made alongside the texts, identifying items of interest and creating questions about the content in a 'block and file' approach. A number of different filters were used to examine the material in each case, searching for hidden meaning, and the resulting findings were analysed in a cross case comparison.

Narratives are a powerful lens through which to study everyday life (Ewick and Silbey 1998). The 'story' of each case was developed from the different perspectives of the case files, and the family and assessor interviews, and described in a narrative (Patton 1990). I examined the factors comprising the context for each case and developed domains, comparing these across cases and identifying some common themes. The next process was of identifying the decision-making events and a subsequent chronology, compared across cases, concluding with the development of a matrix. A thematic analysis occurred through identifying and regrouping themes, and ‘cut and pasting’ data to sit within the themes.

A filter of law was applied to the data in each case, particularly about the capacity assessment interview. The trigger, process, outcome and implications of the assessment were analysed for each case and themes identified. I also extracted aspects of legal personhood and compared themes relating to law and legislation in the cases. Themes from the viewpoint of everyday law were developed (Ewick and Silbey 1998).

Aspects relating to the person’s identity and selfhood were identified and analysed. This filter included the language used to describe the person, values that were implicit in language or interactions, and ethical considerations in the texts. Statements of recorded patient preferences, and the professional who wrote them, were identified as symbolic of the varying views held by others regarding personhood. Interactions and language relating to power by others was analysed. Observations in the hospitals, informal discussions and additional interviews were analysed to provide further insights and validations to the themes emerging and added to give a broad picture of each case. Following the detailed in-depth study of the case material, and comparisons between cases, there was a process of looking at the information as a whole, with a broader perspective. Finally, there was a summary of the intellectual insights gained and the ‘lessons learned’ from the case studies, that could be of benefit for practical application in the natural world (Guba and Lincoln 1988). These activities of analysis and interpretation aimed to assist the ‘heuristic inquiry’ valued by Patton in qualitative research (1990), which Moustakas summarises as immersion, incubation, illumination, explication, and creative synthesis (1990). These aspects will be further discussed in the following section on the personal experience of being a researcher.

III Methodological Considerations

The aim of the research has been to explore the approaches to decision-making by professionals in the social, legal and medical context, towards older people who are vulnerable from diminishing cognition. Already, in the expressed aims of the study, are inferences about worldviews, principles and values. For example, giving attention to this group, who have a low status in society, is a statement about intrinsic worth of persons. The selection of decision-making implies there is a problem or an issue worthy of attention. Underlying these topics are profound philosophies about autonomy, personhood and concepts of ‘good’, and tensions between individualism and community interests.

A survey of literature had exposed decision-making capacity as a contentious concept, and a constructionist view of law ‘in the everyday’ suggested immense diversity was possible. The overlay of theories from a range of disciplines, such as law, medicine, philosophy, and ethics, indicates the complexity and nuances towards this topic, and the infinite choices available in approaching and justifying the research slant.

The phenomenon of decision-making is a mix of semantic/conceptual knowledge from a range of disciplines and worldviews, which take place in practice in complex and contextualised situations. The constructivism/interpretivism frame recognises that knowledge, truth and reality are situated in time and place, imbedded in prevailing culture and worldviews, with a rejection of the ‘fixed reality’ of positivism (Schwandt 2000). From this approach, qualitative research supports the understanding of these multiple ‘truths’ about decision-making, with the research methodologies chosen needing to be congruent to this worldview, and to reflect different perspectives.

This research has used a multi-method qualitative approach to explore a social phenomenon. As such, it is open to observing, reflecting and interpreting human activities, which is not a precise activity. Traditional procedures in quantitative data designed to ensure quality do not always translate to qualitative approaches, but some have been adapted (Flick 2007). For instance, the criteria approach is utilised by Lincoln and Guba to apply to the process of the research method, with strategies to ensure trustworthiness, credibility, dependability, transferability and confirmability (1985). Huberman and Miles extend this idea further with a focus on the relationship between the process and the findings, such as concern for the method of collecting data, and showing logic between the findings and inferences (1998). Charmaz is concerned with process, but also adds originality and usefulness as features of quality research, with questions that aid the researcher to identify new insights and conceptions from the findings, and ascertain the contribution to new knowledge or practice, among others (2006).

A holistic approach to research quality, instead of the criteria approach, is suggested by Flick (2007). In recognising the complexity and contextual nature of the subject matter in this inquiry, within a constructionist/interpretivist approach, three-way triangulation ensures quality is enhanced (Flick 2007). Denzin applies triangulation to data collection, investigator perspectives and theory development, in order to reduce bias (1970).

Triangulation of data involves gathering a range of different perspectives to the phenomenon, recognising the constructivist understanding of different worldviews, and being able to ‘produce knowledge at different levels’, beyond what would be possible by any single method (Flick 2007, 41). Data gained in this way is conceivably more robust as the diverse approaches can validate different aspects of the phenomenon, and test the emerging theoretical frameworks for consistency. In studying ‘the same phenomenon at different times, in various locations, and with different persons’ (Flick 2007, 42), this study explored concepts of autonomy, decision-making and capacity in focus groups and case studies.

The second aspect of triangulation has the aim of removing bias emerging from a single researcher, by using a number of researchers. This aspect was not appropriate in this inquiry, but instead there was a focus on developing the trustworthy nature of accurate and diverse data collection and recording, and transparent reporting. Raw data also remains available for any future independent scrutiny. The constructivism approach recognises that findings are not conclusive and remain unavoidably ambiguous. Nevertheless, by separating the presentation of observations and realities from theoretical conclusions, the reader is free to make up his or her own mind about the interpretation made on the data collected within the context.

Reducing bias in theory formation forms the third aspect of triangulation, with data approached from ‘multiple perspectives’ (Denzin 1970, 303). The data from the focus groups and case studies was considered from a number of lenses and interpretations. These included the philosophical notions of personhood and autonomy, clinical processes of assessment and problem-solving, legal principles and the use of formal law, and the dynamic phenomenon of law in ‘everyday life’. In particular, these largely non-commensurable, ‘multiple realities’ were tested for potential connecting relationships within a decision-making framework.

Of particular note is the merit afforded to case studies in enabling nuanced exploration of a phenomenon, which was the major method used in the inquiry (Creswell 2007). The use of stories in our culture is well integrated. Developing narratives from case studies illuminates aspects of the decision-making phenomenon and demonstrates the uniqueness of humanity within different contexts. Decision-making is a concept with different understandings in law, medicine, philosophy and general society. A broad approach to personal autonomy and decision-making was taken, including formal assessment and informal attitudes towards a person’s wishes and preferences, discussions with the person and involvement in meetings as signs of intent to involve a person in decision-making about their life. The interplay of family members, health professionals from different disciplines and the person themselves, were all part of the unique context of each case. The inquiry required methods to facilitate the gathering of data of these aspects, and other dynamics of the phenomenon.

Lincoln and Guba suggest that the ‘rhetoric’ quality of the case study includes a well-organised story, written simply and clearly, crafted to be able to include new ideas and interpretation, and displaying the passion and risk of the researcher (2002). The case studies, developed as stories, are placed under different lenses to illuminate the actors, the environment, and values that influence attitudes and practice. These contextual elements ultimately create the outcome for each person who is central to the story.

The contentions and complexities about decision-making capacity, and the need to give respect for the person's story, were evident in the process of gaining research ethics approval. The older person subject to a capacity assessment was considered vulnerable and I was advised by the chair of the research ethics committee that it would be inappropriate to interview these individuals. This perpetuates the capacity/incapacity divide challenged in this thesis. There was also a contradiction in the ethics logic, in that the same individual's assent, with proxy consent to having their assessment observed and their files accessed, was deemed adequate, but proxy consent to interview them was not. An interview with the individuals subject to the capacity assessment would have added significant richness to the study by capturing their voice. In future studies I would argue strongly for the person's voice to be included, and provide empirical and moral justification.

The ultimate goal of research is of lessons learned, and these case studies contain within them a range of lessons about decision-making and personhood in both legal and moral frameworks. The in-depth information captured in the case studies, provides a base line for the particular hospitals concerned in consideration of future practice, and the methodology used provides a framework for future evaluation.

Generalisation and transferability are two standards of traditional research. Creswell suggests that the role of qualitative research is not to generalise but instead to 'elucidate the particular, the specific' (2007, 126). Bearing this in mind, the data collected from the focus groups and case studies is valid for the time of collection, and unique to the persons, place and time. Two focus groups and six case studies cannot capture the full picture of approaches to decision-making in the real world. However, while the details in qualitative research are not generalisable, strong themes emerging from the data about the phenomenon of decision-making, confirmed by multiple perspectives, are transferable to 'other similar individuals, groups or situations' (Liamputtong 2009, 22). The theoretical or analytical knowledge gained, with the lessons learned, can contribute to both thought and practice in this ongoing area of human activity.

The role of the researcher

The researcher unavoidably influences the research, both from having an impact on participants, and by the filters brought to the activity. In this section, I reflect on my experience in conducting the research, and then use the concept of the hermeneutic circle to describe the changes resulting from involvement in the inquiry.

The focus groups

My earlier professional knowledge about relevant agencies led me to the particular choice of focus group participants, and my previous network relationships facilitated access to two agencies. I drew on my professional group work skills in conducting the group interviews but in reflection, recognised that a more formalised approach would have enabled greater contribution by the quieter individuals in the first group. As there was a power differential with both staff and team leaders together, in hindsight it would have been beneficial to have met with team leaders separately. I found the focus groups to be a positive event for the participants, giving them a rare opportunity to interact and reflect as a group about their role and the resulting dilemmas. While commencing the focus groups with some knowledge of the different roles and issues, I was surprised by the extent of new insights emerging from the disciplined process of immersion and analysis of the data.

The case studies

Basing my case study in hospitals offered rich data, but I was also concerned that I might find it difficult as an ‘outsider’ in a busy and medically orientated setting. It also brought memories of my challenging experience as a new graduate Social Worker in one of the hospitals, and of illness and death of several family members in this setting. I was aware that I needed to control any reactions arising from observations and consciously suspend judgments, so as not to cause selective perception, but at the same time, used these filters to sharpen my observations.

I was surprised at the ease of basing the research in the hospital setting, and the general support to the study by the group of clinicians that I met with, given that I considered the research topic controversial and one that would expose practice. I found that research studies in this setting were commonplace, and consequently staff were desensitised to the regular presence of research students. This required a degree of assertiveness in recruitment. One doctor and several health professionals were very helpful in assisting with recruitment and interviews, while others gave me minimal assistance, such as not returning calls. I grew in confidence during the data collection period and learnt how to intercept the hospital processes to gain what I needed.

I understood that my presence during capacity assessments would naturally influence the proceedings. However, the majority of the assessors ‘got down to the task’ of interviewing with the older person engaged in the process, giving an impression of minimal interference by my presence. There were two exceptions. One older person tried to engage me several times during an observation, and consequently I moved position to reduce this opportunity. In another assessment, the interview was prolonged and confrontational for the patient, as if the assessor was trying too hard to demonstrate the process. I was concerned for the patient, and about the clinician’s ethics. From a later family interview, it seemed that the patient had not experienced any significant distress from the process.

I found the interviews with the assessors intellectually demanding because of time pressure and status imbalance, as well as a self-expectation to present as competent and on top of my topic. Upon reflection, there were questions I wished I had asked.

In the family interviews, I was able to use my skills of empathy and listening to understand the relative’s own experiences and perspectives. These interviews were less formal, with rapport established and built on in the follow-up contact. These interviews gave a new perspective picture of the patient not apparent from the case files or observation. Interviewing the older person would have added to the richness of the data, but I had excluded this method due to the ethical advice that genuine consent from the case participants could not be gained as their capacity was in question.

The recording of case file notes was long and often required a number of visits, and meeting with the ward clerk facilitating access to files. There were two wards where I sat writing in the nurse's station for long periods, seemingly invisible, enabling me to observe ward activity.

I had a personal reaction to some information in the files, such as when professional communication was poor and important information seemed missed, to the potential detriment of the older person. In the last case, I witnessed the lengthy containment of a person in hospital against their regularly expressed wishes, with behaviours of decompensation, which was emotionally difficult.

Additional interviews and attendance at clinical meetings gave me the opportunity to observe day-to day dynamics. Keeping a research journal was of assistance in noting my reactions, thoughts and biases, as part of my 'past horizon' and new perceptions influencing the inquiry. I describe this hermeneutic experience in the next section.

The hermeneutic journey

The hermeneutic inquiry has the premise that each researcher brings to the research project influences from their lived history and accompanying unique perceptions and biases of the subject matter. This 'past horizon' is dynamically engaged to enrich the process of data collection and analysis, fusing with the 'new horizon' of emerging new insights and self-understanding.

The past horizon

The choice of subject matter reflects in part my history as a Social Worker, with professional values of respect and acceptance for the individual, whatever their situation and life choices. Self-actualisation and self-determination are important social work philosophies, applicable for all stages in life, including later age (Erikson, Erikson and Kivnick 1994). My professional roles in empowering and advocating on behalf of people with dementia and their families was congruent to my worldview of the value of each person, and the importance of psychological and physical well-being.

From my previous advocacy activities at the individual and systems level, I was aware of some attitudinal and structural barriers that impeded just outcomes for this group of vulnerable people. The interface with legislative systems affecting people with dementia had also became a specialised focus in my work and academic study[30] and I had facilitated the publishing of a book on capacity assessment [31] Previous seminars about this book had confronted health professionals with the idea of suspending value judgments about another's decision, and this apparent dissonance was a motivation to make further inquiry.

Prior to the study I understood the law, somewhat naively, as rules for obeying, and containing some implicit wisdom, even though I had also been critical of the implementation of some law. I had a view of 'the law' as relatively fixed, with citizens largely passive. This view was challenged by the field of legal theory, and the different worldviews between those working 'within' the law' and those who observed law as a social construction. 'Law in the everyday' became a helpful new concept. This required me to accept different worldviews as 'competing and overlapping perspectives and paradigms', and I recognised my own preference for certainty, but the necessity to journey without it.

As I immersed myself in the case study data, the nuances in each case took on significance as I applied different filters to the texts. I also had to step away from this close view of the minutiae of their experience connection to analyse different meanings in the texts and look for overall themes– demonstrating both the global and local aspects of the hermeneutic circle. I became more aware of health professionals as shaped and constrained within the medical 'system' in contrast to my earlier prejudices about their behaviour. To ensure that such biases did not lead me to interpret the data incorrectly, I rechecked data a number of times for the possible meanings of the texts, aware of the limitations and inherent ambiguities. The illumination of the texts, and the reflection and analysis of aspects from the data, was

---

[30] Unpublished thesis titled 'Soft Law, Hard Decisions: the Implementation of Guardianship Legislation in South Australian, Flinders University, 1998.

[31] I approached the Board of Alzheimer's Australia SA who agreed to underwrite the publishing of the book by Darzins, Molloy and Strang: 'Who Can Decide? The six step capacity assessment process' Memory Australia Press 2000. Justice Michael Kirby launched the book at a national conference in Canberra in 2000.

an ongoing iterative process, and from this discipline, I found emerging new insights. For instance, a focus on language exposed some hidden attitudes, and analysing the decision-making in the chronology gave a different picture in some instances to what I had first realised.

The new horizon

The intellectual and reflective journey over the life of the study has provided new perspectives and understanding. I have a greater understanding of the ways beliefs are constructed and influence attitudes and behaviour, and the ways social structures contribute to these attitudes, most notably in reducing or enhancing autonomy.
One significant and unexpected issue that emerged from the study was the insidious and prevalent nature of ageism based on negative stereotypes. While aware that ageism is active in our society, I did not expect to see its effects to the extent that emerged, in subtle but pervasive ways, in the healthcare practices observed in the case studies.

I have recognised more layers of knowledge compared to my initial comprehension, and how such knowledge ‘fits’ in the larger world of ideas. I have a better understanding of my values in relationship to this knowledge, and greater confidence in positioning myself within that framework, while remaining open to new ideas. I am more accepting of the pluralism in ideology in a post-modern world, with each discipline having a dominant view and truth. I have greater appreciation of the limitations of law and how law and society interact subtly as part of societal change.

I have awareness of how ideas are subject to social construction usually beyond our conscious awareness. I recognise my earlier desire for certainty and understand more about the dynamics of ‘multiple realities’. I am aware of the interplay between my own view of the world, new ideas, and the interactions with others, in synthesising my learning to create a new understanding of the topic, and to shape others’ ideas. This has built my confidence to engage with change dynamics to promote an approach to decision-making that is respectful of persons, understanding the presence of opposing social paradigms.

IV Conclusion

This chapter has described the research approach as qualitative and based on the tradition of constructivism/interpretivism. This approach recognises that the social context, culture, and past and present ideologies shapes the construction of knowledge, and that the research is subject to individual interpretation by the researcher within these socially constructed paradigms. The iterative nature of research is an essential characteristic of the hermeneutic form of inquiry, where the researcher's perception and understandings undergo irrevocable change as the result of new insights.

The study methods of focus groups and case studies have been outlined, including the initial scoping, ethics approval, sampling, recruitment, data collection and data analysis. Research settings and features of the participants have been described. I have outlined methodological considerations, and identified the development of new horizons as a researcher, resulting from the process of inquiry.

The next three chapters outline the findings from the data analysis.

5 Ageing and society

Autonomy, selfhood and the law are three related concepts explored in the earlier chapters of this thesis. This chapter presents findings about these concepts and related issues in the everyday world, through the methodology of focus group interviews.

Focus group interviews were conducted with two agencies that work on the frontline of society with vulnerable people. The aim of the focus groups was to gather information about approaches towards decision-making. The ‘advocates’ support older persons who are experiencing restrictions of their rights, while the second group, the ‘guardians’, provide statutory substitute decision-making for people who have mental incapacity. Both groups had significant experience, and exploring the perspectives of staff in these two agencies offered important insights about the moral and legal personhood of older persons in the real world.

Semi-structured questions (see Appendix 5) guided the focus group interview process. This section presents findings from the interviews across five themes pertinent to this study: the worker role and clientele, approaches to personhood, prevailing attitudes and values towards older persons, perspectives about decisional capacity, and interactions in the socio-legal domain.

I The Advocates

The advocates work with older persons to promote and support their rights, and the goal of the focus group interview was to capture their perspectives about autonomy and personhood. The focus group adopted an intense non-verbal tone, which appeared to express the frustrations experienced by this group in their work.

Role and clientele

At the time of the focus group, the eight advocates had a total of 53.5 years of work in this agency, with 1500 clients in the year of the study.[32] The advocates described

---

[32] The Aged Rights Advocacy Service provided individual advocacy assistance to over 1500 persons in the financial year 2009/2010: ARAS Annual Report 2009/2010.

their main role as preventing elder abuse and promoting the rights of older persons who receive government services. They spoke of supporting, educating, empowering, and advocating, with a social justice ethic:

> *…we can assist people, and advocate and stick up for people.* *Sarah*

> *...people present to us with issues that are of deep concern to them and we're able to help resolve them.* *Sophie*

The advocates spoke of the positive aspects in their work as 'rewarding' and 'interesting'. Their language in the interview indicated a group of people deeply engaged with their work, who found it meaningful, and had a shared understanding and approach with their colleagues. The advocates also talked about significant challenges in carrying out their role, describing some aspects as 'difficult' and 'frustrating', but remained motivated about their purpose.

Advocates became involved when an older person contacted the advocacy service. The advocate would meet with the older person, explore the problem and reach a mutual agreement as to the desired action and outcome. The advocate would support or represent the older person in discussions with relevant others such as family members, residential care or community care staff, or health professionals.

The advocacy service required the older person to give consent to their involvement. In the situation of a concerned family member or a service provider contacting the agency without the older person's consent, the advocates could not respond:

> *…that can be very frustrating if the person does not really want ...to speak to us directly, and you know that you can do something about their particular situation.* *Sarah*

The advocates described the requirement for their clients to have decision-making capacity as being capable of giving consent for advocacy intervention and being able to instruct the advocate. If the capacity status of an older person were unclear, the advocate would request an assessment through a service provider, and take the case only if capacity was confirmed. Obtaining this information was difficult at times, limiting intervention:

> *The area of capacity is a particular issue for us in our team…where it is unclear whether someone still has capacity or not, and that poses quite a few dilemmas for us in our work.* *Lauren*

Decision-making capacity was therefore a significant client designation. Where the older person did not have capacity, the advocate would advise the third party to contact the Office of the Public Advocate for ongoing advocacy or to make an application to the Guardianship Board. The advocates explained that there is a general disinclination by service providers to take this latter action:

> *Service providers are very reluctant …they don't like the guardianship process and it's time consuming…there appears to be a person at risk but we're limited in what we can do.* John

In these circumstances, advocates were not able to ensure that intervention occurs.

Notions of personhood and autonomy

The requirement of capacity and consent to receive advocacy services denotes the utilisation of the traditional liberal model of autonomy. Personhood is a concept that is interrelated with autonomy, and advocates' perceptions about the attributes and status of the older persons were analysed from the interview transcript.

The advocates shared a view of the person as having intrinsic worth, and gave importance to maximising autonomy and self-determination:

> *…it is important to continue engaging whoever it is, wherever they are, in their decision-making so that they are …still able to, as long as possible, be involved in the decisions about their lives.* John

Empowering the person through participation in all decision-making was important to the advocates, from significant life decisions through to everyday decision-making:

> *…if people don't respect the humanity of the individual to make the smallest decision …they're ignoring the totality of who we are as human beings…and (the) …quest for individuality and significance.* Harry

Advocates spoke of the intrinsic value of personal autonomy, with this extending to people with diminished cognition, acknowledging their residual autonomy:

> *We don't want to be told at times they don't have capacity when you really do know that they actually have some …insight about their care and care arrangements.* Lauren

Advocates viewed autonomy as an attribute to be respected and enhanced throughout life. They indicated that self-determination could be supported through their work:

> *…it's about increasing the empowerment and maximising control for that person throughout their life span, rather than the current model that is quite often focussed on removing it.* *James*

While autonomy and personhood of older persons are key values to the advocates, they found different views in play in broader society, and the next section describes their perspectives in this regard.

Prevailing values, attitudes and structures

The advocacy service worked to facilitate relationships and resolve difficulties experienced by the older person in receiving aged residential and community care services. This work had the tendency to expose the culture and practices of service agencies towards vulnerable older persons. In this section, perceptions of prevalent community and professional values and structures arising from the focus group interview are presented, as are the advocates' views on the influence of the service structure.

The service structure

One advocate described the complex web of aged care and health services as a 'system' in which the services interact with their clients and each other. This was a common view of the majority of the advocates, along with their assessment that this system lacks forward planning and review, and they spoke of significant gaps between services. For instance, one advocate gave the example of a person receiving services at home through a low care package, who required additional services that were not available, and subsequently unable to stay at home, despite support by family:

> *…against their will, they end up in (residential) aged care… The system does not help them, it actually works against them…the whole system is just reactionary and counterproductive.* *Harry*

Advocates explained that the structure and funding of services requires people to fit rigid categories of care, when in reality their needs require an individualised response. People were therefore categorised according to service boundaries:

> *All the time, labels labels, labels...* *Lauren*

The advocates expressed the view that many service providers made care decisions about clients that give priority to organisational efficiencies. They described the result as a lack of consideration of the needs or preferences of the older person, and suppression of their voice:

> *…very often…the person's perspective is lost in the expedience of getting the task or decision done…* *Harry*

They spoke of busy workloads restricting care staff in carrying out care duties in ways that maximise a person's functioning and independence:

> *… the carers don't have the time to let the person dress themselves…they've got another client in 15 minutes…so the older person doesn't have that opportunity …they just become this person who's having things done to them all of the time.* *Sophie*

Overall, the advocates had the view that the service system did not function in a way to support the holistic needs of vulnerable older persons. They spoke of the lack of an integrated approach, restricted services, and inadequacies in responding to individual needs. Consequently, support tended to be minimal and the older person's options limited.

Prevailing attitudes and values

The advocates indicated that their values often differed from those of family members and service providers. For instance, one advocate commented that service providers preferred the older client to be passive and compliant, and when not, they would blame and label the older person:

> *…if they are not compliant, or not happy with a particular thing…they are labelled as 'problematic', or having dementia...* *James*

The advocates observed that service providers gave precedence to their own opinions of good about the older person, and often ignored or suppressed the older person's voice. The institutional setting in particular exemplified these power and control issues, with several examples given where the older person's autonomy, or that of the family, was eroded:

> *…the wife wanted her husband to come back home and she was going to care for him...but the hospital had decided that he wasn't going back home.*
> *John*

The advocates described that their own advocacy is limited in situations where the views by service providers were entrenched:

> *…the hospital had made the decision…they were absolutely determined about this- that patient was going into a nursing home.* *John*

The advocates referred to ageist attitudes and behaviour throughout the group interview. They reported service providers as applying 'false conceptions and assumptions' about older persons, with less tolerance towards the choices of older people in comparison to the rest of the adult population, especially where risk is concerned. The advocates described ageism as extending to decision-making, reducing the older person's freedom to participate, with older persons vulnerable to having their behaviour scrutinised and controlled, unlike other age groups.

> *…there's a societal attitude towards age – and it becomes ageism… because you've become an older person then suddenly it's become a bigger risk… and therefore [they] must be stopped from doing what they've always done all of their life, because they've become old.* *John*
>
> *There's still a lot of ageism…a lot of paternalism, operating within aged care…taking away a person's self-determination… people are telling them how to live their lives, how to run their lives...it is not applied to other age groups in the same way. There is just this inequity…* *James*
>
> *It's a bit paternalistic, isn't it.* *Deborah*

The advocates pronounced residential aged care to have an institutional nature, where basic freedoms of the resident disappeared, in marked contrast to their life before they entered the facility:

> *…a person goes …from their home where they've been caring for themselves for 80-odd years, that they end up with being totally disempowered to the point that they can't even make a cup of coffee or tea for themselves even if they're capable, because someone says there's a risk and we have a duty of care.* *Harry*

Advocates spoke critically about the lack of holistic care in hospitals, with their view being that the older person's function declined within that environment. They described a singular focus on the specific medical issue to be solved, followed by prompt discharge. The advocates expressed the view that doctors were not respecting the self-determination of older persons, or not appreciating their right to take a risk, and that this was evidenced by the paternalistic attitudes in the hospital:

> *…there's the inability of the medical staff and social workers at the hospital to appreciate that the older person, and in this case, the carer, have a right to give it a go…* *John*

Several advocates described that both a supportive family network and intact cognition were necessary for an older person to return home from hospital. Being without family, or having cognitive impairment or delirium[33] were risk factors for institutionalisation.

The advocates described case examples in the group interview that highlighted the vulnerability and dependence of the older person on others to achieve their life choices. They explained that prevalent values and attitudes of healthcare staff resulted in the imposition of their views onto the older person, restricting the older person's autonomy. Confusion, delirium or symptoms of dementia, such as memory loss, were in their view, also prejudicial in affecting outcomes.

Risk and duty of care

Linked to ageism is the issue of protection, and the advocates commented that service providers were over-protective in their approach and, by trying to 'wrap the older person in cotton wool', impacted on the identity and well-being of the older person:

> *…they're layered with further feelings of disempowerment by people assuming to take control because they want to treat them like an infant…*
> *Harry*

The advocates expressed the view that this over-protectiveness often resulted from service providers being ignorant of, or misunderstanding, the legal concept of duty of care, including the concept of 'reasonable' prevention of risk:

> *…duty of care is not being over-protective, it's taking reasonable steps to provide that person with protection.* *Emma*

---

[33] 'Delirium is a transient mental disorder, characterised by a disturbance of consciousness with a reduced ability to focus, sustain or shift attention. It also involves a change in cognition (such as memory deficit) or the development of a perceptual disturbance. Delirium develops over a short period of time and the disturbance fluctuates during the course of the day. Delirium usually only lasts for a few days but symptoms may persist for weeks or even months'. From the 'Best care for older people everywhere: the Toolkit', Dept. of Health Victoria at <http://www.health.vic.gov.au/older/toolkit/07Cognition/01Delirium/index.htm>.

Some advocates explained that as a result of this limited knowledge, service providers translated their duty of care responsibilities into avoiding, rather than minimising, risk:

> *…service providers out there think that duty of care means they can't do something…it's very dictatorial.* *Emma*

> *…they always go above and beyond what is required, to the point of infringing on someone's self-determination.* *James*

Service providers concerned about a risk situation would often contact the advocates about the problem, which the advocates described as having the goal of passing on their responsibility:

> *…by ringing us and telling us about the problem they don't have to take responsibility for it any more but hand it over.* *John*

> *It's 'can you put that in your notes'… and if you hear about 'duty of care' one more time, sometimes you think that you will scream…* *Sophie*

Several advocates spoke about service providers giving greater priority to the organisational needs of avoiding legal implications that might result from risk, rather than focusing on the needs of the person and managing potential risk:

> *They're not really concerned about what happens when they're not in their care, it's more about 'this is our principal interest… we don't want them to come to harm while they are legally deemed to be under our care'.* *John*

In one advocate's view, adherence to funding regulations and audits added to risk aversion practices. He explained that some service providers cited regulations as the reason to prevent older people to undertake 'risky' behaviour:

> *…they see it in terms of compliance – to standards – and regulations…rather than a duty of care to care for that person within what's reasonable … the 'duty' part takes over from the 'care' part…* *Sophie*

Advocates described the culture in hospitals as risk-averse, with potential risk of harm to the patient a barrier to choice:

> *…the wife might say, 'I want to care for my husband… he might have another fall … but I'm willing to take that risk because we want to be together as a couple …as long as we possibly can' … but they're not being allowed to take that risk.* *John*

Several advocates expressed concern about the focus on physical risk in both hospital and community services, with little recognition of the psychological harm to the older person that can result from over-protective behaviours and suppression of autonomy:

> *…when we're talking about 'harm' it's always in a physical sense… it is all about protecting the person from …physical injury – and there's no consideration of psychological harm caused by the intervention. James*

In general, the advocates viewed service providers as over-protective towards older persons and reflective of a risk-averse culture. Lack of knowledge or misunderstanding about the law, and a desire for expedience, were reasons given by the advocates to explain the causes of this prevailing approach. These prevailing attitudes influenced responses to autonomy and decision-making, the focus of the next section.

Perceptions of decision-making capacity

This section examines the perspectives of advocates towards the concept of decisional capacity in their own work, and of the use of the concept in community care, aged residential care and health sectors.

Advocates described decision-making capacity as variable, with fluctuations arising from illness, medications and delirium. They saw capacity as a continuum and influenced by the context:

> *…there can be gradual decline. Other people seem to think that it's either this or that - 'she's OK' or 'she's not OK.' Sophie*

> *…people …over-simplify the whole issue of capacity… talking about it in black and white… you've got moral issues, you've got ethical issues, social issues. It creates a very complex sort of environment. James*

The advocates articulated a desire for decision-specific decision-making but did not see it as realistic to apply in practice:

> *I suppose in an ideal world it would be all very contextual to assess a person's capacity to make that decision today about that issue and then tomorrow assess their decision tomorrow. How realistic that is - that is the question. Sophie*

One advocate also expressed uncertainty about determining the relationship between the threshold of capacity and the complexity of the decision:

> *…if it's …… about some simple life-style choices – then I would say that [its]right for that person to keep making those decision, but… how you decide what is complex and less complex – I don't know. Sophie*

The advocates' views of capacity as decision-specific were not necessarily consistent with the agency policy, which required clients to have capacity as assessed by others. With variable approaches to assessment, such determinations could construct the concept of capacity as global or defined by cognitive impairment, rather than decision-specific understanding.

In their discussion, the advocates described approaches to capacity as varying in the informal domain, with their support for formal capacity tests suggesting confidence in professional authority:

> *…all these different perspectives of whether or not this person has capacity and yet there's no professional diagnosis of that person's capacity……John*

While relying on these tests, the advocates expressed concerns over outdated assessments used as a basis for decision-making, or over-simplification of the concept of capacity. One advocate described the myriad of different tests for capacity as confusing, with some doubts about their accuracy:

> *…there are so many different assessments- medical capacity assessments…they're not even consistent so obviously they're going to be giving different reports …I just find it very frustrating. Sarah*
>
> *…if there's a specialist or a doctor giving commentary on someone, it's assumed that it has to be correct. Harry*

The different views held by advocates towards the concept of decision-making capacity, and its application and assessment, demonstrated the practical difficulties in operationalising the concept in practice.

The focus group interview also elicited information about service provider responses to capacity issues. Advocates gave examples of medical staff in a hospital using a determination of incapacity to confirm that the person was unable to return home to live, and of families utilising decision-making capacity to justify a preferred decision. In this way, capacity status came to reflect the competing interests of others, in order to achieve certain outcomes, rather than consideration of the older person's actual decision-making abilities:

> *… I guess it can be best called a 'diagnosis of convenience'…it's convenient to pursue whether they have capacity or not…they want mum to change her will, so 'Oh yes, mum's got her capacity', but when it comes to decision-*

> *making by mum, it's 'Oh no ... mum can't make her own decisions'... it's more about people's agendas.* John

Advocates spoke of service providers assuming incapacity when the person had confusion or dementia, and a reason not to facilitate the person's preferences or include them in decision-making. The advocates also described assumptions about risk when incapacity is present, and vice versa.

Several advocates commented that cognitive assessments in aged residential care facilities had become a form of disempowerment of the older person:

> *...it's 'we may need to think about getting their cognition and everything else assessed' and then that's a slippery slope to disempowerment...*
> *Harry*

With evidence of the person's inability to make decisions, one advocate explained that there was a justification for the staff of the facility to seek substitute decision-makers to make decisions, which resulted in unnecessary disempowerment of the older person:

> *...if there is any confusion about the older person... they then start taking directions from people who have absolutely no authority to give directions about the person's life. The person is already going through huge issues of grief and loss ...and they're layered with further feelings of disempowerment.* *Harry*

One advocate gave an example of a hospital setting where decision-making capacity was used to achieve a particular outcome, reiterating a dimension of social control:

> *...this lady ...is in hospital, she is deemed to have capacity. She doesn't want to go into aged care ...and yet ...ACAT*[34] *and other people, are now saying she doesn't have insight, she doesn't understand that when she's home she has these falls and she's not ...understanding ...so they're building a case.*
> *Lauren*

The advocates also described several instances when the reason of temporary incapacity was used by family members to organise residential care for the person while unwell, which then became permanent residential care. When the older person recovered and wanted to leave the facility, they had reduced options as the family had sold their home.

---

[34] The Aged Care Assessment Team (ACAT) assesses older persons for eligibility for residential aged care and community care packages.

Overall, the advocates described many situations where their approaches to capacity were variable and contradictory. For instance, advocates explained that capacity determinations were used to designate clients, which potentially excluded the recognition of residual autonomy, but at the same time, gave examples of utilising residual autonomy with some older persons in residential care. The advocates questioned the reliability and variability of some assessments, but still gave authority to capacity assessment determinations.

Variability was also evident in the broader domain. From their discussion, the advocates saw service sector and family members assuming incapacity of the person at times to justify their decisions about an older person's good. Advocates had the perception that service providers and families made assumptions about incapacity when cognitive changes in the older person were present, and that the pairing of incapacity and risk subsequently reduced freedoms for the person even where there was little basis for this.

Respect for autonomy and freedom for decision-making are also legal concepts. The next section presents findings from an analysis of the advocates' interactions in the socio-legal domain.

Interactions in the socio-legal domain

The socio-legal domain is a sphere where law is interpreted and enacted by citizens in everyday life. Activities in this domain occur in time and place, shaped by broad prevailing ideologies and the most local of norms. This section explores the legal agency of advocates in relation to their interpretation of formal law and their day-to-day activities in the broader socio-legal domain.

The advocates articulated the basis of their authority as ranging from citizenship rights in the constitution, consumer rights in the Aged Care Act and community services legislation, and of the (United Nations) 'Convention'. The use of the term 'rights' by advocates reflected the generalised compilation of moral, civil, legal and consumer rights that are the stated basis of their organisation's work. They respected the values espoused in these charters but described the authoritative use of them as tenuous:

> *...so we're really basing it on people's good nature and...humanity to abide by the people's rights that we promote… John*

The advocates did not appear aware of how law influenced their values and practice. For instance, respect for autonomy and self-determination was central to their *modus operandi,* but they identified this with human rights charters rather than with legal rights. The guardians integrated two legal constructs, the presumption of capacity and the freedom for competent adults to make unwise decisions, into their approach, but did not articulate them as having a legal basis.

Advocates were conscious of different laws pertinent to their work, such as health law (consent and capacity), tort law (negligence and duty of care) and guardianship law. They spoke of law as often inadequate in safeguarding older persons' rights. For instance, one advocate considered law reform necessary to make elder abuse a criminal offence, while another stated that legislation does not take into account the unique vulnerabilities of older people:

> *…we advocate for people to have legal advice …it gets so far and then the injustices appear… they're just lumped in with everybody else and yet they do have specific barriers and vulnerabilities that need…recognition.*
> *Rebecca*

Advocates worked in the shadow of the law by encouraging service providers to make applications to the Board when appropriate, thus supporting the legal role of the Guardianship Board. However, while the advocates expressed confidence with complex legal abstractions such as duty of care, this confidence did not extend to using the law to reinforce this authority. The advocates found age discrimination by service providers to be prevalent but did not refer to discrimination law, or utilise it formally. Instead, they used informal education and persuasion about the legal concepts of duty of care with service providers, but described this approach as having limited effectiveness in changing behaviour.

The advocates accepted capacity as a legal construct, and gave the concept authority. They also created new rules about this law, such as generalising the concept of capacity to place boundaries around their client group, and in this interpretation were producers of law. Advocates gave authority to doctors and service providers to translate the law, but did not recognise the range of legal interpretations by others. In this way, they supported others' production of law.

Understanding themselves as producers of law in the everyday could have enhanced the advocate's effectiveness in operating more confidently to achieve their aims. One area for greater effectiveness was in relation to consent law. The coercion of an older person to enter residential care, when they had capacity to make the decision themselves, was a breach of consent law, with different legal actions possible. Consent law also used a decision-specific approach, but the advocates were not familiar with this legal approach. Such knowledge could have aided the revision of rules to expand access to the advocacy service, as well as maximising the autonomy of their clients in response to others who are claiming global incapacity of the older person.

The advocates could have also utilised the principles in the *Guardianship and Administration Act 1993* to further support person-centred decision-making of substitute decision-makers, including making applications to the Board when persons seriously breach their duties. The principles could have been utilised with health professionals to support least restrictive alternatives for the older person, and to respect the substitute decision-making authority of the family.

The advocates carried less status than health professionals and service providers, who could bring resources to bear on achieving their legal objectives within their field. Greater legal consciousness in knowledge of the law, and recognising their own freedom to initiate and utilise law in the legal domain, had the potential to increase the power of advocates to achieve autonomy-enhancing goals, including enhancing access to their own service.

Overall, the advocates shared the aim of law in supporting the autonomy of persons. While the advocates had a degree of legal consciousness, they did not distinguish some broader ways in which to use law effectively, as actors in the legal domain of the everyday. This included new interpretations and invocations of law. Understanding power struggles in the socio-legal as resulting from different uses and interpretations of law, of which the advocates’ interpretations were equally valid, could have potentially strengthened the advocates’ confidence to achieve greater social justice for their clients.

In summary, exploration of the advocates’ perspectives has given an insight into the everyday challenges of advocates in promoting the rights of older persons. While advocates attributed full personhood to older persons, such as participation in decision-making, this was not matched in some sectors of society. Prevailing attitudes of service providers indicated limited consideration of the older person’s preferences and life meaning, with the imposition of views and choices. Regulations and duty of care considerations often justified protectionist care models, with little demonstrated respect for the intrinsic value of autonomy. There was a focus on the physical safety of the older person and exclusion of psychological needs, indicating a narrow view of their selfhood. The existence of confusion or dementia presented as prejudicial to outcomes of the older person and highlighted the dependency of older persons on others to achieve many life choices. Bounded and limited services also affected choices. Their experiences indicated complex layers of insults to the autonomy of the older person, which also reduced the advocates’ success. The advocates were aware of formal law, but did not fully utilise it to achieve their aims. Increased understanding of the opportunities to interact in the informal legal domain has potential to increase their future effectiveness.

II The guardians

The guardians work with persons deemed as having mental incapacity, providing different perspectives towards decision-making capacity. This section describes their view of the protected person, the challenges of their role, and the broader societal context within which they worked. The group interview was relaxed in tone.

Role and clientele

The seven guardians had a total of 23.5 years of combined experience in their agency and there were 705 persons under guardianship in the same year, of which dementia was the largest category.[35]

Appointed by the Guardianship Tribunal as a substitute decision-maker, guardians have a ‘compulsory’ aspect to their role, and the person under appointment and their significant others are required to accept the substitute decisions made by them. The tribunal can make special orders in relation to a protected person, such as requiring them to reside in a specific place, or that they receive medical and dental treatment,[36] which guardians have the responsibility to organise. Their role as substitute decision-makers includes making decisions on medical treatment, resuscitation orders, care, and accommodation.

The Tribunal places persons under guardianship when they are unable to look after their ‘health, welfare and safety’[37] because of some change or injury to the brain. The largest diagnostic group of protected persons is that of older persons with dementia.[38] Some factors contributing to guardianship appointments are the lack of family to take on a substitute decision-making role, while others result from suspected abuse or conflict, giving the guardians a protective role.

The guardians described their role as ‘rewarding’, ‘privileged’, ‘liberating’, and ‘fantastic’, while words with negative connotations included ‘hard’, ‘distressing’, ‘difficult’, ‘exhausting’ and ‘heart-breaking’. Overall, the guardians found satisfaction in their role:

> *…it’s a privilege to be part of such personal knowledge of our clients’ lives and to be able to assist them to achieve the things that they want if we can possibly do that.* *Mary*

> *…the most rewarding part of my job is seeing the difference guardianship can make in …very vulnerable people’s lives… and being very privileged to be involved in some very personal decisions with people.* *Karen*

---

[35] The Office of the Public Advocate had 705 active guardianship cases in 2009/2010, with clients with dementia being the largest category- OPA Annual Report 2010.

[36] *Guardianship and Administration Act 1993* SA s 32.

[37] *Guardianship and Administration Act 1993* SA s 3(2).

[38] Diagnostic Profile of Guardianship Clients, OPA Annual Report 2011-12, 149.

The Act provided distinct client boundaries for the guardians, with challenges in applying the legislative principles in a complex environment, and with ultimate responsibility for the person's welfare, in a setting of public scrutiny.

The next sections explore the guardian's perspectives towards these challenges, beginning with identifying their views towards the personhood of their clients.

Notions of personhood and autonomy

Concepts of personhood emerged throughout the group interview with the guardians. One dominant perspective was a positive view of aging and quality of life for those with cognitive impairment, such as:

> *…age or deteriorating cognitive capacity (doesn't mean) that people can't still have an enjoyable, appropriate, pleasant life for themselves…* Laura

There was respect for the uniqueness of each individual, and as substitute decision-makers, guardians sought to learn about the person, to ascertain their wishes and preferences, and to maintain their identity as much as possible:

> *…who is this person, what do they like doing, what enables them to continue to be themselves?* Nicola
>
> *That starting place is always to know the person. If they can't give you their history or their views, then to gather information about who they are and who they were, and what capacity do they have…* Mary

The guardians took account of the person's view of life, and sought to understand the previous lifestyle of the person. They disliked the labelling of vulnerable persons by others, and the associated discrimination. Rather, guardians gave value to each person and their voice:

> *I think it's … their right to be heard – it's not about their family, it's about them, and just that basic right that we have to express our opinion, have it listened to, and considered and valued.* Joanne
>
> *…this Office really supports … individual decision-making for a person.* Laura

The guardians spoke of receiving guidance from legislative principles that recognise personhood beyond the finding of mental incapacity, such as maximising autonomy, maintaining the familiar environment for the person, and minimising restrictions.[39] One guardian offered the view 'that working to the principles was very important', and another guardian stated that the first legislative principle offered significant guidance in their substitute decision-making, especially when there was disagreement by others:

> *…consideration to the wishes of the person is something that I bring out in just about every contact I have… our starting point is the wishes of the individual, regardless of the degree of mental incapacity, so…the principles give me that will and strength to be able to say 'I understand your concerns, but this is where we're starting'.* *Mary*

The guardians expressed the view that the use of these principles separated them morally from many others involved in the person's life. They described taking the harder road and withstanding significant opposition to represent the wishes and preferences of the person, even when it took an emotional toll on them:

> *…we're very open-handed …we look at every aspect but then we come back to the wishes of the individual, and that's the difference.* *Mary*

> *…like driving into a hospital once I kept thinking to myself 'well I'm taking all of this for him so that he's fine, and that's the reason for it', but it can be exhausting.* *Eleanor*

Discussion in the group interview identified significant congruence between the personal values of the guardians and the legislative principles that guide their work, with collegiality based on these shared professional and personal values.

The guardians described how the formal statutory authority for decision-making gives them significant power in maximising self-determination. One example given was a hearing where the tribunal made an order for full public guardianship of a person in hospital. The patient wanted to go home but there were strong objections from the hospital representative, who was not willing to extend the patient's stay in hospital while the services were organised:

> *…the hospital said 'sorry, that will take too long, he needs to go to residential care, so that we can discharge him.* *Joanne*

The guardian used her authority in this situation to pursue the return home:

---

[39] *Guardianship and Administration Act 1993* (SA) s5.

> *… our intention would be for this man to return home…that's where guardianship can be liberating…he would probably have gone to a facility…   Joanne*

Guardians spoke of developing strong relationships with their clients over time, and finding some decisions hard to make when it did not meet the protected person preferences:

> *…the hardest thing that I find is having to tell somebody who wants to remain in their own home that they're no longer able to do that. That's – I find that heart breaking…and they say 'can't we just go home?' – and I find that really hard…   Joanne*

Overall, the guardians described getting to know each client as a unique individual, of understanding the person's preferences, and of working to achieve them. These views represented recognition of the personhood of their clients, regardless of loss of legal rights and cognitive ability, often not matched by prevailing views in society. The next section describes the broader societal values, attitudes and service structures that often created tension for the guardians in their work with vulnerable persons.

Prevailing values, attitudes and structures

The guardians work with family members and services to achieve the appropriate care and support for the protected person. They talked about the structure of services, and the attitudes of those providing services, as affecting the experiences and options of the vulnerable person.

The service structure

The guardians expressed concerns that services were inadequate in relation to the needs of clients, with service rationing inequitable, particularly for older people living in the community, who they saw as often receiving less in comparison to other groups:

> *… the lack of services… you see such disparity as well… but this person's just old so they get very little…   Sophie*

The guardians spoke of the inadequate supply of home care services, which resulted in hospitals pursuing residential care options for the patient to achieve discharge.

This limited availability and level of community services affected the guardians' ability to maintain some protected persons at home.

A common theme in the focus group discussion was that care services had a primary pre-occupation with their task of allocating scarce resources, with insufficient consideration of the actual person:

> *…their job is to make sure this allocation goes this far, and so they're not thinking about the person, so I think it's the way they're perceiving their role, understandably, in their organization with all the constraints, and it doesn't have a focus on the person.* *Nicola*

Overall, the guardians described a service network under pressure to match the needs of persons adequately, and with unequal resource allocation, which limited the choices of older persons, and led to residential care being seen as the default option.

Prevailing attitudes and values

The guardians explained that respect for personhood, and giving attention to the preferences and wishes of the person, were values not always shared by service providers. Guardians expressed views that without their appointment, some outcomes for older persons may be very different:

> *…recently I've returned a lady home. It took me a long time to get her home, but the services throughout that process were saying 'it's just too hard… it's easier to put her in a nursing home'. So it's also about what people are willing to do, and without the guardian…she would have gone into an aged care facility – and she's at home and she's doing extremely well…* *Anne*

This example highlighted the extreme vulnerability of some older people to the attitudes of others determining their life outcomes.

Guardians, in carrying out their duties, also experienced significant conflict from both family members and service providers in response to their role, indicative of different perspectives, priorities and values:

> *…my worst days…are probably related to family conflict type situations…but the ones that really surprise me is the amount of aggro that we get from service providers, or from the systems…* *Eleanor*

Guardians spoke of some service providers viewing themselves as having authority in relation to case management of the protected person, and it was a common experience of guardians to be told what they needed to do in relation to the protected person. Guardians resisted this pressure but found it difficult:

> *I have …a list of the amount of times a week I get told …" you are the guardian so you will do this.' I got frustrated and so I started counting it… Eleanor*

The guardians described service providers as having expectations of the guardian role, through making comments such as 'we can't get this person to do it, so you will'. One guardian expressed this assertion of power as a lack of understanding by the service providers of the guardian role, with subsequent resentment by service providers if the guardian did not agree on the action:

> *And I think some of them just expect that… you'll just tick the box that they want you to tick and you'll place them in the first placement that's offered, and when you say, 'no we're not accepting that placement, because it's not appropriate for our person' …they get really cranky. Anne*
>
> *…people can take that very, very personally and say 'you're questioning my professional judgement' … Eleanor*

The guardians described situations where service providers used the guardianship system to achieve their case management goals where their client was not compliant:

> *…the client wouldn't do what she (social worker) wanted – therefore she came to the Board to get guardianship… it's about the honesty that comes through – what's behind the application – in some cases. Anne*

These examples are indicative of social control. Similarly, the guardians reported being the subject of manipulation, with service providers using the guardian to achieve their own ends. In one instance, a guardian described how a service provider provided inaccurate information in order to achieve a particular outcome, which was damaging to the protected person:

> *…the information (on a case) that we were given was incorrect, and that weighed heavily on me, because I'd been responsible for a huge infringement on the rights… it was a dreadful, dreadful situation, and it still is there … Mary*

The guardians were responsible for making health treatment decisions on behalf of the protected person. They described a lack of understanding of this responsibility by others, as demonstrated by a doctor who rang for consent to undertake planned surgery for a protected person, and reacted to the guardian's question about the risks from the surgery:

> *Well, I heard…how preposterous it was that I should ask such a thing, that he would have to write out the equivalent of a telephone book worth of details of all the risks of anaesthetics and things like that, and when I tried to say to him 'surely you would just understand that this needs to happen' he said 'well, ... I don't need to do that for you'.* Laura

This example not only indicated a lack of understanding of the guardian's responsibilities, but also of lack of understanding of the doctor's legal requirements of consent, which the requirement of communicating the relevant material risks of the treatment for that individual. The guardians explained that at times they do not give consent for treatment, based on person-centred considerations of the protected person's wishes:

> *I had a 92 year old lady with a diagnosis of mental illness. She had quite a very nasty cancer on her ear and … she wanted to die with two ears. So I refused the surgery and I had two hospitals just up in arms about that, saying, 'but she has a mental illness and she can't make these decisions, and that's why we appointed you and we wanted you to say yes.' However she stabilised and four months later …between herself and her GP – she got part of her ear removed, enough so she could still wear her glasses and she's been home nearly a year now.* Anne

The guardians spoke of the challenges of working with family members of the protected person, with family relations at times a reason for the guardian appointment. The guardians expressed the view that grief and guilt are common emotions affecting the behaviour of family members; however, in some instances they attributed family conflict to self-interest, such as greed in relation to property of the protected person, or a desire for power:

> *…so many conflicts …aren't actually related to the [protected] person themselves… in every single situation it's come back to greed, or power and control. Laura*

The guardians explained that many conflicts within the family remained unresolved or exacerbated during guardianship, and were intensified by limited knowledge and understanding about cognitive impairment and the guardian's role in using substituted judgement based on the person's wishes:

> *Getting the families to …acknowledge that it's not about them, that it's actually about the protected person …I think that's the hardest thing… Anne*

The guardians asserted that increased knowledge about the principles in the guardianship legislation and the guardian role, prior to guardianship appointments, by families, health and aged care services, would be helpful:

> *…if we had people who knew that everybody has the right to make their own decisions, knew about the principles of the Act, we wouldn't have a lot of barriers that we now reach, because people don't hear about it until they're already here.   Mary*

While guardians experienced barriers and resistance to their substitute decision-making, they also gave examples of where health professionals and service providers appreciated their involvement, and how they valued this support:

> *…doctors would ring in saying 'this is where we're at now, what else can we do?'   Anne*

> *…an appreciation by service providers – 'thank goodness you're here…you can actually do something about it.' So that's a very positive thing.   Mary*

> *'there are some brilliant workers …who will come alongside and will be so glad that you are able to accept risks, or… to authorise services, and they make such a difference to the person…   Joanne*

From the perspective of the guardians, decision-making for protected persons occurred within a complex environment of service restrictions, with differing values, expectations and often-conflicting views about the desired outcomes for the protected person. The next section gives specific attention to the issue of risk of harm in this domain.

Risk and duty of care

In having a substitute decision-making role, guardians spoke of issues of risk of harm for their clients as confronting them regularly. They described seeking to minimise risk and balancing it with other benefits to the protected person, observing significant benefits to the well-being of the protected person as a result:

> *One of my favourite parts has been the ability to take on risk as an Office and how that can liberate someone living in the community…   Eleanor*

The guardians expressed the view that decision-making when risks are present is not straightforward, however, and a source of significant challenge:

> *When I think we really start to really flounder is if (the person) is wandering outside, if it's …that direct harm – they're very vulnerable to somebody else out in the community…   Joanne*

They explained that duty of care requirements is foremost in their minds as they aim to follow the person’s preferences. They talked about not everyone agreeing with their decisions, and that the sense of responsibility and the lack of support was emotionally taxing:

> *…she was living at home with motor neurone disease and she was immobile, and I used to think ‘this is awful’, but she would write to me ‘…this is my house – don’t dare …make me go out of this house’… A new provider would come on …and they’d go ‘this is disgusting’, and then another worker would say ‘yes, yes, we need to keep her home’… it was a real heart-wrencher…*
> *Joanne*

Guardians spoke of service providers and health professionals as having strong views on what is appropriate for the person, and different levels of risk tolerance in comparison with guardians. More positively, guardians spoke about finding the appointment of a guardian as offering some security and accountability to those services providers who are concerned about the perceived risks to the person. In one instance, where a service was considering withdrawing their services due to their view of the high level of risk to the person in that situation, the guardian described how the statutory responsibility of the guardian relieved this pressure, with the service personnel telling the guardian:

> *...oh, that’s good then –we can still continue to provide a service... Joanne*

Overall, guardians expressed seeking to balance risk of harm with the other important needs of the person, but found that this often differed from service provider’s tolerance for risk, creating tension and conflict for the guardians.

Perceptions of decision-making and capacity

Protected persons have mental incapacity that is the cause of their inability to manage their own health and welfare. One might expect that this would lead to a reductionist view of autonomy; however, guardians expressed views that the presence of cognitive impairment did not reduce their respect for the person’s autonomy:

> *… many people, even with a mental incapacity, can still be very, very clear about their underlying principles and positions on a lot of things’ Mary*

They asserted that this approach differentiated them from many others working with the protected person:

> *…we look at every aspect but then we come back to the wishes of the individual, and that's the difference.* Mary

The guardians described their goal as ascertaining the person's preferences and involving them in decision-making as much as possible:

> *…we will, where we can, involve the person in the decision…so that there's that respect there.* Nicola

They spoke of looking for consistency in the wishes and behaviours of the person to guide their decision-making. At the same time, guardians explained that these were not always congruent for a person with cognitive incapacity, and with an understanding of capacity as fluctuating and variable. While seeking to ascertain and act on the person's preferences, the guardians spoke of the different dilemmas arising in their substitute-decision-making role:

> *I find it really difficult ... when the person themselves, either for ... the difficulty of the decision that needs making or because of their incapacity, fluctuate so much ... and just where do we balance any of that…on that day they're so adamant for one way or the other and the next day they can completely be the other.* Laura

From the group discussion, the approach of the guardians presented as person-centred, where they got to know the protected person and included them in decision-making processes for each decision made, taking their wishes and preferences into account. In contrast, they described that others in the care domain made generalisations and assumptions about the incapacity of the protected person, in ways that inferred global incapacity.

One example was of how the presence of cognitive impairment contributed to service providers thinking of guardianship as a solution to decision-making:

> *…a person with capacity can say yes or no…when you lose capacity then it's like, 'well you can't make your own decision' and 'this is what you have to do, so therefore we'll get a guardian to consent for us.* Anne

The guardians expressed views that this was an unnecessary response in some situations, where they prompted service providers to give attention to the residual autonomy of the person by attempting to ascertain the person's wishes:

> *'...we need to get a guardianship order' I was told, because this person is in hospital and he's not well ...and I said 'well, what does he think about it, what does he understand?'…there can be an assumption that, because a*

> *person has a mental incapacity of some kind… it's not even worth asking…*
> *Nicola*

This tendency of service providers to discount the person's view indicated assumptions of incapacity in the presence of cognitive impairment, rather than a decision-specific approach to autonomy and recognition of residual autonomy.

Guardians expressed concerns that decisions can be based on inaccurate assessments of capacity:

> *I think we've all seen a situation where a doctor will do a mini-mental of someone and …they're fine – and we know that that person has got really significant judgement issues and executive function… Eleanor*

They also described that contextual issues such as environmental conditions, emotional state and physical illness can affect the person's function, and assessments made at this time can give a biased view of the person's ability to cope at home:

> *…their ability to cope at home may be not able to be accurately assessed because they're in crisis, they're in a strange environment, they're not well, so they're not going to be functioning at their best. Nicola*

The guardians viewed that health professionals made assumptions about the person's decision-making ability by not supporting decisions of the person that they consider might have unwise consequences. Guardians asserted this as prejudicial:

> *…we're all allowed to make bad decisions but somehow when you …start to have a cognitive issue then all of a sudden you can't make bad decisions, so you've got to make what society wants you to do … Joanne*

Overall, while guardians respected the residual autonomy of the person with cognitive impairment, they also found that it was common for others to assume that the person with cognitive impairment lacks all autonomy. Guardians did not utilise the traditional liberal approach to capacity, instead describing an approach that maximised the person's autonomy, indicating a relational view of autonomy.

Interactions in the socio-legal domain

The guardians are legal actors and producers of law. This section explores the dynamics of their activities within the plurality of codes and normative conventions that influence and constitute the socio-legal domain.

Legislation defines the guardians' role through tribunal appointment. In this way, guardians work 'before the law', and have statutory authority. When carrying out their decision-making duties, the guardians operate in the shadow of the law, advising people of the legal requirements of the legislation. Neglect, unresolved conflicts about care and other significant concerns about older persons with mental incapacity are able to be brought before the guardianship tribunal for a legally binding decision. In this way, formal law supports their activities. The guardians also work within the shadow of the law when applying the legislative principles in the Act, such as giving due consideration for the person's wishes and preferences and the least restrictive alternative .[40]

The conflicts experienced by the guardians who participated in the focus group presented as tensions between their interpretation and enactment of the law, and the interpretations of the law by others in everyday life. These tensions can represent a struggle for power in social relations, where parties have different priorities and sources of authority. The status of the guardians was ultimately greater than other parties as a result of the authority granted to them by law, but involved a struggle in enacting their interpretation of the law in some settings.

Working before the law can occur simultaneously to activities of innovation or resistance. In the case of the guardians, the strong integration of legal principles into their professional practice is indicative of the current 'rights' basis of the guardian agency to maximise autonomy (South Australian Office of the Public Advocate, 2012, 69). This approach extends beyond the general requirements of law. For instance, there is no legal doctrine or formal monitoring as to the interpretation and application of the legislative principles, and yet the guardians had developed innovative ways to enact these principles in practice. This unique implementation by the guardians represented 'new rules' to protect and promote personhood and autonomy, with the statutory role of the guardian giving strength to this rights approach.

---

[40] *Guardianship and Administration Act 1993* (SA) s5.

The guardians’ interpretation of law conflicted with the interpretation of guardianship law by some healthcare professionals and service providers, such as in attitudes to risk. Influenced by variations in legal consciousness, these interactions and tensions between these ‘actors’ in the legal domain were representative of law in the everyday.

In summary, the guardians, who are statutory substitute decision-makers, had an approach of valuing the individual for their uniqueness, and respecting their self-determination and wishes despite the cognitive impairment of the person. They spoke of building relationships with and seeking to understand the needs and preferences of the protected person, involving them in decision-making wherever possible.

The guardians described finding guidance in the legislative principles, but were challenged to uphold them in an environment of conflicting values and limited services of others. Guardians spoke of a lack of understanding about their role, and limited knowledge about legal substitute decision-making. The guardians described family conflicts and self-interest by family members. Strong expectations and manipulation by some service providers were challenges to guardians, though they also expressed appreciation at the support given by some service providers. The guardians talked of how resource limitations and inequities reduced choice for the protected person. Guardians spoke of having to confront the issue of risk, and taking time to think through the issues and decide what risks were tolerable, balanced in relation to the preferences of the person. While the guardians worked in the shadow of the law by applying the guardianship legislation, they also simultaneously worked as actors in the broader socio-legal domain, interpreting legislative principles to maximise personhood and autonomy, but often experiencing tensions and conflicts from varying values and everyday interpretation of law.

This chapter has described the individual perspectives and experiences of advocates and guardians in their work with vulnerable older persons. The next section explores similarities and differences of the two groups and gives a conclusion about the approaches to personhood and autonomy and the socio-legal domain.

III Advocates and guardians: commonalities and divergence

Both advocates and guardians worked with vulnerable older people in society. Some commonalities were their values towards personhood and decision-making. Some differences were in their described role, use of legality, and subsequent effectiveness in the broad legal domain. This section contrasts the two groups in the areas of role and client, principles and values, the prevailing culture and service structure, perceptions of capacity, and dynamics in the socio-legal domain.

Role and clients

There was a significant difference between the clients of the two groups. For advocates, involvement of clients was voluntary but dependent on the capacity of the person to give consent. In marked contrast, a tribunal appointed the guardians as substitute decision-makers, conferring the status of protected person compulsorily onto persons with mental incapacity.

Both advocates and guardians experienced satisfaction and challenges in their role. The advocates found rewards from empowering older people, and the guardians enjoyed strong job satisfaction from empowering people who were vulnerable from mental incapacity, and making decisions on their behalf that reflected their wishes and preferences. Both experienced frustration with the differing values and attitudes from family, health and community services. The advocates experienced limitations in achieving desired interventions on behalf of the older person, while the guardians faced challenges from conflict and resistance to the knowledge about and interpretation of their statutory role. Both considered there was a need for greater education of health care professionals and service providers, but with different knowledge priorities.

Principles and values

Both groups used principles that were supportive of autonomy, but each had a different basis. The advocates worked to charters and principles that reflected general legal, consumer and human rights, with some authority based in legislation such as the *Aged Care Act (1997)*, while the guardians had the duty to consider principles in the *Guardianship and Administration Act (1993)* when making substitute decisions. There was convergence of values in both groups, such as respect for personhood regardless of age and disability, and support for the person's self-determination. Both groups demonstrated person-centred approaches to decision-making with their clients, irrespective of cognitive impairment. They were respectful of the person's life choices, which they supported without judgement, and recognised psychological well-being when weighing up issues of risk.

Prevailing culture and service structure

Both groups shared similar experiences with the service system, such as the ageist and paternalistic attitudes of many service providers, who imposed their view of 'good'. They both talked of the elements of power and control, expediency, and suppression of the older person's voice in the service sector, and ageism and prejudice towards persons with cognitive changes, with assumptions of incapacity.

Service agencies were perceived as demonstrating strong risk avoidance behaviour, with duty of care often utilised in an over-protective way. Both groups experienced resistance to their interventions, with the guardians also reporting positive instances of collaborative care with service providers. The advocates and guardians both described service boundaries and limitations as restricting options for their clients. The guardians, however, exercised legal authority to make particular claims for services on behalf of their clients in some situations.

Advocates and guardians reported similar experiences in working with family members, who often held different values to their own regarding the personhood of older people. Both groups identified coercion, abuse and power and control issues in family dynamics, which affected their work with clients.

Perceptions of capacity

The concept of capacity had varied meaning to the advocates, with both global and decision-specific views of capacity in play, with uncertainty about thresholds of capacity. There was ambivalence expressed towards tests of capacity, but such tests still held authority for advocates, and they deferred the conduct of assessments to others. While the clients of the guardians had ‘mental incapacity’ arising from brain impairment, the guardian’s approach to capacity was specific to each decision, and the guardians discussed the importance of seeking the preferences and wishes of the protected person as part of any decision-making, maximising their autonomy.

Interactions in the socio-legal domain

The guardians operated in a formal statutory role, and this gave them authority when making substitute decisions for a protected person. In contrast, the advocates saw law as relevant but remote, and they were critical of its effectiveness in supporting the rights of older persons.

Both groups worked within the shadow of the law, the guardians in their statutory role, and the advocates because of the framing existence of guardianship and other legislation. Both groups were also legal ‘actors’ in the domain of everyday law. The guardians interpreted the legislative principles into strong and clear substitute decision-making approaches, beyond the minimalist basis in their guiding legislation, thereby innovating new rules within the legal domain. While they had limited statutory authority to enforce outcomes, they successfully utilised bluff (Galanter 1981) to insist that others comply with their instructions in relation to client plans, for example, in delaying discharge of the person. No-one chose to test this authority in the formal arena, inferring that the implied threat of the law was sufficient to ensure compliance in others. This activity appeared to be a mix of the extended interpretation of the legislation by the guardians, and the lack of specific knowledge of the law by other parties. The advocates utilised legal constructs such as decision-making capacity, undue influence and duty of care in their work with service providers to create agency policy, but appeared powerless when others ignored or resisted these concerns in relation to client situations. In these instances, bluff was not successful, presumably because the advocates did not consider it as their role to invoke, or threaten to invoke, the law formally on behalf of their clients. As a result, the other parties often maintained their own interpretation of law, and ignored the alternative view of the advocates.

A major difference between the groups was in their effectiveness to utilise law to achieve their purposes. Guardians had legal authority to assert some provisions and principles of the guardianship legislation, but also extended this authority in ways beyond this formal authority. In contrast, the advocates, while promoting their interpretations of law, did not invoke law to support these interpretations. There was a view expressed by both groups that education of the community and service providers about relevant law would facilitate the effectiveness of their roles. This represents their desire for others in the legal domain to share similar interpretations of law, and to give greater priority to these, rather than to other social codes or organisational priorities.

The two groups varied in their effectiveness to achieve justice for their clients. Guardians had more authority, backed by law, to enforce their decisions about the protected person, whereas the advocates spoke of relying on the ‘goodwill’ of others. Advocates were less effective in many situations where service providers wielded power over limited resources. One example of this was the ability of guardians to delay a person’s discharge from hospital, whereas the advocates, on behalf of ordinary but capable older citizens, were unable to achieve this. In this way, guardians were able to support the autonomy of a protected person more effectively than an ordinary older citizen could do so for her or himself. This aspect demonstrates the contradictory nature of guardianship, in both removing legal rights but protecting some citizenship rights.

IV Conclusion

The advocates and guardians presented as champions for vulnerable older persons in their support for autonomy and personhood, which included physical and psychological well-being. They took their legitimacy to function from legislative and rights charters, and while these codes are representative of a democratic society’s standards, they found them not to be reflected in general prevailing attitudes towards vulnerable older persons. They reported prevalent approaches to older persons of stereotyping and paternalism as indicative of deeply ingrained ageism. The presence of cognitive impairment and assumptions about reduced capacity caused further diminishment of personhood through the unnecessary exclusion from decision-making.

These experiences of advocates and guardians demonstrate that informal relations and structures are often inadequate to promote the relational autonomy of older people, especially for those with cognitive changes, with the structural limitations of service provision also restricting options. The effectiveness of the guardians and advocates differed in their role as actors in the broad legal domain. The guardians developed a congruent approach by applying the legal construct of decision-specific capacity, with a human rights philosophy in the interpretation of their statutory role, providing a model for enhancing relational autonomy. There is significant potential for the advocates to increase their effectiveness in supporting autonomy through enhanced legal consciousness.

To further the exploration of decision-making processes for older persons, the next chapter presents results from in-depth case studies incorporating a broad range of perspectives.

6 Case Studies: the person, context and intervention process

The previous chapter identified common themes arising from the perceptions of advocates and guardians in their work with older persons. There was a common view that societal attitudes and structures did not value the autonomy of older persons, with paternalism being prevalent towards vulnerable older persons. Guardians and advocates considered that cognitive impairment in an older person, perceived or actual, led to the exclusion of the person from decision-making by others.

The information gathered in focus groups did not permit the exploration of the nuances of individual situations. To aid in-depth study of personhood and decision-making from a range of different perspectives, case study methodology was utilised. Six case studies were recruited in a medical setting, an environment where decision-making is commonplace, and older persons are a dominant client group. The application of the doctrine of informed consent and the parallel issue of incapacity are both a part of the healthcare environment, making it a rich setting for study.

Data was gathered from observation of assessments, case file analysis, and interviews with assessors and family members. Together, these different sources of information produced an integrated story about the case participants not available in any of the sole perspectives. This data is analysed in this chapter and the next chapter, particularly with reference to the concepts explored in Chapters 1-3.

This chapter presents findings about the person, the context of their life and circumstances, and the hospitalisation intervention. The informal processes of decision-making that occurred during the hospital experience are presented, and the outcomes of this process. Attention is given to aspects of personhood, autonomy and disempowering practices and attitudes arising from the hospital intervention. To preserve anonymity pseudonyms are used, and are listed in Chapter 4.

I The cases

The six case participants are introduced in this section, drawing on their background, differing and shared characteristics, and the precipitating event leading to hospital admission. Common contextual aspects are grouped, consisting of issues of physical dependency, cognition, personality, family relationships and involvement with services.

The background

The participants in the cases studies consisted of four men and two women ranging in age from seventy-seven years to eighty-nine years. The first three cases came from three different wards in Hospital 1, and the second three cases from one unit in Hospital 2. Andrei (Case 1) and Kathleen (3) had been living alone at the time of their admission, while Reg (5) shared a house with his son, and Tom (4) with his partner. Lewis (2) lived in an aged residential care facility, and Daisy (6) in a supportive residential facility.[41]

Each case had some unique features. Andrei was born in Eastern Europe with English as a second language, and was blind. Lewis suffered from both long-term psychiatric and chronic illnesses. Tom suffered from chronic illness and impairment. Kathleen lived independently before her hospital admission, while Reg had a life-limiting illness as well as experiencing other recent medical emergencies. Daisy was physically fit, but had received mental health treatment in the past for a mood disorder.

The range of characteristics in age, mental and physical health status, living arrangements and history demonstrates broad diversity in the cases, representative of the natural heterogeneity of older persons' lives. The background story of each individual is outlined below.

---

[41] Supported residential facilities provide accommodation for persons who are usually physically independent but may require additional support due to issues of mental health.

Andrei

Andrei, aged 87, had been born in East Prussia, moving to Germany as a child with his refugee family, immigrating to Australia after marrying. He built the family home, and developed a successful cabinet making business. Andrei had lived alone since his wife's death from cancer three decades earlier. He experienced ill health from a heart attack and stroke in his 60s, and later the onset of glaucoma, which progressed to total blindness six months before the study, along with age related frailty. Andrei had been on a waiting list for home care services for the twelve months before the study. While Andrei had wanted his son Greg, and daughter-in-law Rose, to move in and care for him, they instead provided almost daily support, including culturally appropriate meals. The district nurse visited daily to supervise his medication, and provide weekly hygiene assistance.

Since experiencing total blindness, Andrei had become frustrated and irritable on a regular basis, with Rose finding Andrei to be increasingly demanding and unappreciative of her help. Andrei had lapsed at times into speaking German, a sign the family saw of changing cognition. Andrei also experienced vivid visual 'dreams' at times, which merged with his everyday reality. A few weeks prior to his hospital admission, Andrei had been experiencing discomfort from constipation, though an x-ray organised by the GP did not indicate any serious problem. On one visit, Rose found faeces on the doorframes and handles of the house. This occurred several more times, and Rose told Greg she would not provide care in those circumstances. The GP, when contacted, recommended that Andrei go to hospital.

Lewis

Lewis, aged 77, grew up in Tasmania, and lived in the bush with his father after the death of his mother. He later married and had a daughter and two sons. Lewis developed post-traumatic stress disorder after fighting in the Korean War, which was not diagnosed at the time. Lewis also developed a number of chronic illnesses over time, which included insulin-dependent diabetes, hypertension, chronic obstructive pulmonary disease, osteoporosis, gastro-oesophageal disease, cirrhosis of the liver, bladder cancer, urinary tract infections, vascular dementia and psychiatric 'adjustment difficulties' to his physical decline. Lewis had not been able to work regularly due to ill health, and his wife Jenny worked in order to support the family.

Lewis's physical and psychiatric conditions had affected the marriage. A few years prior to the study, Lewis experienced further deterioration from a stroke. Jenny struggled to manage his physical care at home, and experienced bullying from Lewis. Through a hospital application, a guardian was appointed to assist with accommodation decisions. Lewis went to a rehabilitation facility and later an aged care facility, with a second stroke causing him to become wheelchair dependent. Lewis did not like the environment of the residential care facility and was bored and depressed. His admission to hospital occurred following a reported fit of aggression at the aged care facility, with the aged care facility refusing to accept him back.

Kathleen

Kathleen, aged 88 years, had lived alone for three decades since the death of her husband. There were no children from the marriage, with her closest family members being her nephew and his wife, who lived in Sydney. Until retirement, Kathleen had run a successful business. Her nephew described Kathleen as strong willed and independent, honest, and with high expectations of herself and others. They kept in touch with her phone, and visited her when they could from interstate.

Kathleen lived independently, drove her own car, and employed a gardener to assist her with her garden, which was her major interest. She had also cared for a number of her friends during their ill health in the past, but was facing a shrinking of her social world. In the month before her hospital admission, Kathleen had been experiencing back pain, and had spent several days in bed. She fell while in the kitchen of her home, tripping on a step. The gardener was there to call an ambulance for her, and she was admitted to hospital.

Tom

Tom, aged 78 years, had been adopted as a child and grew up in Broken Hill. He moved to Adelaide in his early twenties and worked for a geological company, enjoying work in the outdoors. Tom had been in a homosexual relationship with Jay for some decades. Life changed significantly 19 years previously, when Tom's health deteriorated and he had a heart bypass. He did not return to work and Tom and Jay moved to the country several years later, with Jay providing the financial support for the couple. Several years ago, after the onset of diabetes, Tom had a benign brain tumour removed, which resulted in incontinence and right-sided weakness, and subsequent depression, poor sleeping and weight loss. Jay had also noticed signs of changing cognition in Tom.

Since this time, Jay had been finding Tom’s care demands stressful, and with Tom critical of his help, the relationship was under strain. Earlier in the year, suffering depression, Jay had left the home, returning after a recuperation period of six weeks. Tom had refused home rehabilitation and care services after an earlier hospital admission, which exacerbated the strain on Jay. One evening while Jay was out, having arranged for the neighbours to check on Tom, they found he had fallen. Several days later, when Tom was still unable to get out of bed, Jay insisted that Tom go to hospital, where he was admitted.

Reg

Reg, aged 87 years and widowed, lived in a beachside suburb with his son, who had mental health issues. Reg’s son had an interest in wild birds, which flew in and out of the house, and some health workers described the environment as close to ‘squalor’. Reg also had a daughter who had limited contact with Reg.

Reg was debilitated from the effects of chronic obstructive pulmonary disease. He had been admitted to hospital earlier in the year, followed by rehabilitation, but became acutely ill with an abdominal aortic aneurysm (bleeding from abdomen) and had urgent surgery. Reg had bowel complications from this surgery, acute renal failure, and contracted a resistant bacterial infection during the surgery, requiring a massive blood transfusion.

These medical issues and his chronic lung condition had seriously affected his physical health, but Reg recovered sufficiently five weeks later to leave hospital and spend three months in the residential transitional care program. Two days after being discharged home, Reg was found on the floor by a visiting occupational therapist, and readmitted to hospital.

Daisy

Daisy, aged 89 years, had lived in a supported residential facility for several years following the treatment of a mood disorder. With her husband dying some years earlier, Daisy had lived in her own unit, houseproud and enjoying her garden, until the onset of illness. Daisy was a cheerful person who had been the ‘life of the party’ in her early years. She had joined the RAAF in her teens and remained proud of her role as a driver for a Wing Commander. Daisy had lost her eldest son in a traumatic death when he was in his teens, and her main support was her remaining son Andrew, who resided in Queensland, with little contact with her two daughters.

Daisy enjoyed living in the supported residential facility with daily walks to the nearby beach. After some changes in Daisy’s behaviour, such as packing up her clothes and going in to other people’s rooms, the manager of the facility initiated an Aged Care Assessment Team (ACAT) assessment. Even though physically fit and mobile, and managing her own personal care, the ACAT assessment placed her needs as requiring high-level residential care, with concern raised about her frequent visits to the local jetty and the possibility of her getting lost. As the supported residential facility was ineligible to provide high-level care needs, Daisy was required to leave. Offered a bed in one facility, she and the son rejected this vacancy, as it was where her husband had died. The ACAT assessor suggested either having a social worker assist with accommodation or going to hospital, and the manager of the supportive facility took the latter option.

Precipitating aspects of admission

The admission of the six participants was preceded by either a physical event or a change in behaviour. For Kathleen and Reg, a fall directly precipitated the admission, while Tom had not recovered from an earlier fall. In Lewis and Daisy’s cases, their physical status was stable, but changes in their behaviour had led to hospital admission. Andrei had been experiencing slow physical decline but the issue of his hygiene was the precipitating factor to admission. These factors aligned with their home circumstances are summarised in the table below.

Table 8 Home circumstances and precipitating event to admission

Name	Age	Home circumstances	Precipitating event to admission
Andrei	87	Living alone	Family unable to manage hygiene/care issue
Lewis	77	Residing in a residential care facility	Outburst in residential care facility
Kathleen	88	Living alone	Fell and injured back
Tom	78	Living with partner	Not recovering following a fall, partner not managing
Reg	87	Sharing house with son	Fall at home following recent hospital discharge
Daisy	89	Living in a supported residential facility	Behaviour changes and accommodation inappropriate

While in each instance there was a clear precipitating factor that led to the person going to the emergency department, there was also interplay between the individual's personality characteristics, their physical health, relationships with family members, and the involvement of services. These contextual factors give a nuanced context for the admission of the person and subsequent events and are discussed below.

Physical decline/dependency

With the exception of Daisy, the case participants had all experienced physical decline. For instance, Andrei's general physical frailty and blindness was creating a care burden to his family, Lewis suffered from chronic illness, and Kathleen had been unwell with back pain. Reg was weak from acute and chronic ill health, and Tom had ongoing physical impairment and weakness due to surgery and chronic conditions. Their physical and mental ageing, in addition to chronic illness, had created greater vulnerability for them in their life circumstances.

Changes in cognition/behaviour/mood

Four of the individuals had demonstrated changes in behaviour: Lewis had been unhappy in the residential facility and had a significant behavioural outburst; and Daisy had been demonstrating behavioural changes in her supported facility, such as entering other people's rooms. Andrei's family reported changes in his cognition, and hallucinations. Tom was passive and dependent on his partner but also critical of his care.

Several of the individuals demonstrated resilience and determination: Kathleen was strongly independent in her approach to life, and Reg was determined to live at home despite his severe ill health and physical weakness. Daisy was cheerful and unaware of the effects of her behaviour on others.

Family dynamics and care limitations

Two of the participants did not have nearby family. Kathleen's closest family member, her nephew Brian, lived interstate. Daisy's son, Andrew, while supportive and in regular phone contact, was limited in his involvement by living interstate and caring for an intellectually disabled son. The family relationships of Kathleen and Daisy were marked by care and affection.

Reg saw himself as supporting his son, who had a mental illness, and there was no reciprocal assistance to Reg, despite his weakened physical state. In the other three cases, long term caring had altered the relationships between the person and their family. In the case of Andrei and Tom, long term caring by family members had led to stress and burnout, and Tom's partner had become emotionally disengaged. Lewis's wife Jenny demonstrated helplessness and fatigue from many years of caring for someone with personality changes and dependency.

The relationship between the older person and their family was a significant aspect in shaping the options available to them. For instance, Andrei's general lack of gratitude had reduced the motivation of his daughter in law to persevere as things became difficult, and Jay had become resentful and emotionally disengaged from Tom, and did not wish to continue in the caring role. Lewis's history and his long-term difficult moods had affected his wife's desire for close contact with him.

Community and residential services

While Kathleen had lived independently at home, the use and availability of service provision was significant to the context of all of the other cases. For instance, home support services were available for Tom but he did not want to use them, which affected his partner's motivation and future involvement. Carer support services may have assisted Jay in his stress and provided some other options earlier, but were not utilised.

Andrei was eligible for high care home services, and such a service would have reduced the burden on family members, but he was still on a waiting list one year later. In Reg's case, transitional services provided were limited in relation to his needs. Reg may have been eligible for a higher level of care, especially as he had a terminal illness.

There was no record of utilisation of either behaviour support services or mental health services for Lewis and Daisy, which may have led to alternative solutions to their problems than hospital admission. In Daisy's case, rigid funding guidelines following an ACAT assessment meant she was unable to stay in her accommodation, but community services were not utilised to help resolve the situation informally. Shortages of supply, lack of knowledge, or lack of thought about services are some of the possible reasons why services were not utilised more frequently.

The table below summarises these contextual factors in the categories of health, family and services.

Table 9 Comparison of aspects preceding admission

Case	**Health**	**Family**	**Services**
Andrei	General decline in physical function, blindness, hygiene issue	Close family support but fatigued/wishing to withdraw care	Inadequate services for what he was eligible for
Lewis	Physical dependency, mood and behaviour issues	Family no longer providing care and relationship affected	In a care facility; behavioural support services not utilised
Kathleen	Functioning had been affected by back pain and becoming 'run down'	Supportive family members interstate	Used private gardening services only
Tom	General decline from chronic ill health	Partner burnout in caring role/wishing to withdraw care	Had refused offered services.
Reg	General decline from chronic and acute illness	Family members not able to provide care	Limited home services had been utilised.
Daisy	Good physical health but behavioural changes	Supportive family member interstate	Community services not used to investigate behavioural changes

Once in hospital, each person became subject to the hospital processes. The next section gives the findings of different facets of the hospital intervention that emerged from data analysis. It describes the generalised process of events that was common for the six patients, and the communication dynamics of the cases.

II The hospital intervention

While the hospital was the place of intervention for the six people in the case studies, two of the individuals did not require the key medical services of the hospital. In the case of Daisy, there was no medical problem or psychiatric problem warranting hospital admission, and for Andrei, there was ‘a situational crisis’ in his daily care arrangements. In this way, the hospital became the generalised solution to investigate and resolve these varied situations, despite other community services being available to assist with solutions. The use of hospital services creates an institutional response to the crises and transitions in the lives of older people, rather than invoking informal responses or using less formal community based resources.

As each person entered the hospital, she or he made a transition from person to patient. The next section explores the processes of the hospital intervention, and preliminary information about the role of the patient.

The stages of the hospital intervention

The key events and dynamics in the case files were analysed and linked with the information from the assessment observations, and the interviews with family members. A general chronology emerged that gave shape to the hospital experience for the participants, which included admission, medical and allied assessment, the formulation of the case plan, communication with patient, issues for resolution in the case plan, and discharge. These stages are now discussed.

Admission

The first stage was at the emergency department, where the admitting doctor explored the presenting problem and determined whether the person was to be admitted or referred to the acute medical unit for further investigation. The reasons for the admission of the six case study participants included stress of family and the patient being unable to cope; behaviour disturbances and depressed mood; back pain and affected mobility from a fall; deterioration of patient and carer stress; a possible hip fracture; and decline of a patient who was resistive to placement. These are summarised in the table below.

Table 10 Case notes pertaining to patient admission

Case	***Key case file notes pertaining to admission***
1 Andrei	Stress of family, patient 'unable to cope' and not safe at home are noted
2 Lewis	Behaviour disturbances noted and low depressed mood
3 Kathleen	Back pain and mobility affected from fall. Social isolation and mild cognitive impairment
4 Tom	Deterioration of patient, stress of carer and need for alternative care is identified
5 Reg	Query of hip fracture, not orientated time/place on admission
6 Daisy	Decline and dementia noted, 'not suitable for accommodation', 'resistive' to placement.

Medical and allied assessment

Once admitted, the Resident Medical Officer (RMO) of the ward conducted a full medical assessment of the patient. Tests were ordered, and referrals made to other health professionals, such as social workers and physiotherapists. The social worker gathered further information from family and others as needed.

Case plan formulation

Once adequate medical and social information was assembled, the health care team developed the case plan, identifying any issues for resolution arising from that plan.

Communication with patient

Following the development of the case plan, communication occurred with the patient and family members about the treatment plan, and the patient's assent was sought.

Execution of case plan

As the plan was executed, issues that needed resolving, such as a capacity assessment or referral to services, took place. A capacity assessment was planned in each of the six cases and this process will be discussed fully in the next chapter.

The general chronology was extended in two of the cases. Reassessments, referrals to services and changes to the case plan occurred when Reg’s health fluctuated, prolonging his admission. In Daisy’s case, there was reassessment in response to her son’s concern regarding perceived inaccuracies in the ACAT report, and a referral to the psycho-geriatrician for assessment. These dynamics extended the length of stay for Reg and Daisy.

Discharge

Once the essential issues were resolved, the patient was discharged.

The following table outlines the general stages of the hospital intervention.

Table 11 Analysis of the stages during the hospital admission

Stages	***Description***
Admission	The admitting doctor assesses the person in the Emergency Department. The person may go first to the acute medical unit for further assessment, or directly to the ward.
General assessment	Medical and allied health assessments, such as physiotherapy and social work. Assessments are repeated if the situation changes.
Case plan and issues for resolution	A case plan is developed after information about the person’s medical and social situation becomes clear. Issues for resolution are clarified.
Communication with the patient	The patient is advised of the case plan and assent gained.
Execution of case plan	Action occurred on issues arising from the case plan, including capacity assessment, with the outcome recorded.
Discharge	The person is discharged from hospital.

A number of aspects about communication processes, which had an influence on the patient experience, emerged in the analysis of the hospital intervention, and are presented next.

The hospital communication processes

The chronology of stages emerged from the analysis of case notes, but also from the interviews with the assessor and family. It became evident in the study that knowledge about the case existed on a number of levels: the clinical notes, team meeting perspectives, verbal dialogue between the patient, family and health workers, individual health worker perceptions, and the patient's experience. With the exception of the direct patient experience, the study gathered many of these levels of information. Communication is a critical factor as it is how a person becomes known to those providing treatment, influencing their perceptions of the person, and indirectly, the outcomes for the person. From the study, knowledge of the patient was found to be influenced by the time available, the methods of communication, and stresses on the health care staff.

The case file

The case file was an important communication tool for the medical team to inform each other of relevant information, and as a record of accountability. However, not all events appeared to be reported in the case notes. For example, family members reported a meeting between Kathleen and a neuropsychologist, where Kathleen became indignant over her private affairs being scrutinised and walked out of the meeting, which was not recorded in the notes. In Tom's case, his distress regarding his need for residential care was not noted in the file, but emerged later in my interviews with the neuropsychologist.

There a number of possible interpretations for such events not being recorded, such as not being seen as relevant for the purpose of the case file, maintaining patient privacy, or that the health worker was uncomfortable with the event. While the files record the major events of treatment, they may not give the full story of a case, or neutralise some events, and therefore have limitations as the only tool of case review.

Information in the file was sometimes obscured, limiting its utilisation. In Daisy's case, the psycho-geriatrician may not have read notes about her previous mood disorder and current ward observations in her copious file. The finding of a mood disorder would have led to pharmaceutical treatment and potentially an outcome of capacity once Daisy was stable. This situation illustrates that reliance on case files as the major source of information for decision -making carries risk in that not all relevant information may be present.

Clinical team meetings

It was common practice for multi-disciplinary team meetings to be held twice a week in each ward, of approximately an hour's duration. They were comprised of the medical consultant, medical staff, allied health staff and the nurse consultant of the ward. Chaired by the consultant, up to 30 cases were discussed regarding progress towards discharge. Meetings were observed in two different units. From the observations, a number of aspects were identified. First, the major focus was on the barriers to discharge, not on the care of the person *per se*. Secondly, there was a sense of urgency in the meetings to cover all of the cases in the time available. Detailed discussion was rare unless there were particularly difficult or complex aspects to a case. Thirdly, there was an overall sense of pressure to achieve discharge as soon as possible. Lastly, the medical view was largely the 'official' case view. While there were individual differences of view, if not consensual, there appeared an unwritten expectation that team members would support the medical voice as final. This provides an indication of power relations in the medical setting.

Ad hoc meetings and discussion

Case notes and discharge meetings formed the formal structure of team decision-making. However, informal discussions and ad hoc meetings between staff, and contact with patients and family members constructed a hidden web of relationship dynamics and information exchange. This less obvious structure, which emerged in interviews with the assessor, recruiter and family, contributed to the culture of the ward. The allied health professionals and junior doctors of one unit met every morning for brief case updates, but this was an informal initiative.

Individual perceptions and team dynamics

Interviews with assessors, recruiters and allied health professionals showed a depth of individual views on the cases, sometimes with a wealth of knowledge about the patient and their context that was not utilised or given status. This failure to take into account all of the available information constrained fuller consideration of the patient as a person.

At times, individual health worker views were at variance with the ‘official’ view of the team or consultant. While not obvious in the notes, information about the team dynamics concerning Daisy’s mental status emerged in the interview with the assessor. The social worker and neuro-psychologist thought that Daisy’s inability to concentrate and process information might have indicated a resurgence of her previous mood disorder, and advocated for a psychiatric assessment. By doing so, they were utilising the medical paradigm to confirm their view of a mood disorder being present. If diagnosed, treatment would result and capacity assessment would be held off. The treating doctor made the referral, and the psycho-geriatrician visited Daisy, noting in the file that there was no psychiatric condition. The allied staff were not satisfied with this outcome, considering her current behaviour was still indicative of heightened mood. They requested a follow up consultation, which also occurred with the same result. There were significant tensions between the team over this matter, as a key factor affecting her future outcome. However, following the second psycho-geriatric consultation they had no choice but to resolve her case with placement.

There were similar team dynamics in the case of Reg, following the failure of the healthcare team to gain access to a rehabilitation or restoration service for him. The team considered that placement was the only option with his current health, but the social worker was aware of his ongoing wish to return home. She proactively engaged the family to consent to a trial at home awaiting placement, which the team supported ‘with reservations’, and Reg achieved his goal to return home, albeit briefly. Therefore, while the medical view was dominant within the team, the social worker resisted it in this instance, which is congruent with the social work role of advocating on behalf of client.

The team was also affected by time constraints. With the caseload in the medical and geriatric units large and constantly in flux, there was little time for professionals to reflect before the next cases demanded their attention. One example comes from Daisy's case. Several health professionals assessed Daisy as able to manage independently in her accommodation with some service support. This was at variance with the ACAT assessment, and yet this information appeared lost in the volume of notes in her file and other dynamics of the case. Such information could have been used to challenge the ACAT assessment in order to maintain her existing accommodation, or obtain external advocacy assistance, but time was not given to reflect on this aspect or pursue it, with a sense of fatalism over bureaucratic rigidity.

The 'churn' factor of cases could contribute to burn out and emotional detachment from patients. Health care staff can become mentally fatigued and may miss details. With up to twenty-five cases or more requiring attention at any one time, time to communicate, think creatively, reflect on practice or learn from particular cases is very limited. There is no structured time for case review or feedback, and therefore learning from cases, and different perspectives, appeared non-existent.

There is a question as to whether the structural issues of bed demand and funding models, generating a sense of pressure and urgency, which added to the lack of structured case review for learning and reflection on practice, may in the long run lead to inefficiencies and maintain professional habits and reliance on standard solutions. The next section explores findings of the informal decision-making process.

The clinical decision-making process

The overview of the cases earlier showed the patient's entity in the files as passive, through limited reference to their voice or preferences. The hospital processes were also generally suggestive of the idea of the patient as being 'done to'. Health care staff recorded observations, outcomes of assessments, medical tests, and professional views in the case file, which became the main conduit to formal communication and accountability. Expertise rested in the medical team, and this expertise extended to decisions about lifestyle and care. From the information gathered, the patient appeared to be advised of the plan, rather than being an active participant in the on-going decision-making process. This next section explores in more depth the findings of the clinical decision-making process around the patient and the outcome for the patient. Personhood implications are discussed in the final section.

An examination of the cases in-depth showed that the majority of decision-making is *about* the patient, and occurs informally as part of the hospital intervention. Analysis of the case file along with information from interviews with assessors, case recruiters and family, enabled the record of significant clinical decision-making to be placed within the chronology of the hospital process. This process showed that the decision can be made quite early in admission, such as in Tom's case, or occur in the general assessment phase or during the formulation of the case plan. The patient's involvement appears tokenistic and the health care team sought assent in most instances, rather than active engagement. The summary of the pertinent notes have been tabulated in a matrix, with the key decisions displayed in the stage it occurred, in bold font, as shown in the table below.

Table 12 Matrix of key decision-making in the hospital stages

Stage	***Admission***	***General assessment***	***Case plan/ issues for resolution***	***Communication with patient***
1 Andrei	Stress of family, patient, 'unable to cope' and not safe at home.	'Situational crisis', confusion noted and *insight queried.*	**Consultant notes awaiting ACAT assess/placement. SW notes family team agreement of placement.**	Hospital tells patient, family confirm news. Son concerned father may refuse care.
2 Lewis	Behaviour disturbances noted and low depressed mood.	Treatment for infection, Dementia noted, '*unrealistic expectations*, emotional lability'.	**Consultant** notes **placement will be required.**	Lewis was told by the consultant that he would need to go to another facility, and he agreed.
3 Kathleen	Back pain and mobility affected from fall. Social isolation and mild cognitive impairment	Team notes need for assistance, *confusion / cognition is a concern.*	Cognitive decline noted, team goals include **TCP and possible LC if no improvement.**	Not noted in file. Capacity assessment initiated re legal documents.

4 Tom	Deterioration of patient, stress of carer and need for **alternative care identified.**	Assessment by **team indicates placement is needed**. Pt expresses fear of placement and breakdown of relationship, is hopeful partner will change his mind.	Social worker notes likely **placement from hospital** Issue over decision-making of sale of property.	Dr asks Tom if willing to be placed in a nursing home, later notes 'is accepting of this'. ACAT assessment organised, placed on waiting list. Capacity assessment planned.
5 Reg	Query of hip fracture, *not orientated time/place* on admission	During assessment **concerns about Reg currently going home,** Health fluctuates with lung infection.	No restorative service options available; **team and family not supportive** of Reg going home. Team notes **pt qualifies for residential care**.	**Doctor** advises Reg of lack of services and **accepts plan** for placement reluctantly. Later, social worker responds to his desire to go home with family meeting for a **home trial.**
6 Daisy	*Decline and dementia noted*, accommodation not suitable, 'resistive to placement.	Confusion and *lack of insight noted*. Ability for personal care did not match ACAT report.	**Social worker indicates** Impasse of accommodation, **requires placement** in residential care.	Daisy **assents** to placement process but wants to return home.

The decision-making processes demonstrate that the health care team are active 'problem-solvers' to the case, whereas the patient provides the source of the problem. Information from the patient and family facilitates the available options to be offered to the patient, but the patient does not have any role to generate options or to make a decision, but rather to assent. Information of the contextual and individualised background for each case highlights the nuances of each case, with the cases of Andrei and Reg giving different contrasts to this process.

Case example: Andrei

From the earlier summary of Andrei's situation, it was noted that 'the patient was unable to cope' at home. Referrals were made to social work, physiotherapy and occupational therapy to assess functional status and investigate the social situation. The social worker queried Andrei's insight into the support needed to stay at home, noting that the 'family is not coping'. At this stage, the consultant noted that the patient was 'awaiting ACAT assess/placement', indicating that the team had settled on the case plan. The social worker organised a family meeting, and while Andrei was informed of the family meeting, it was implicit he was not invited to attend. Following the meeting, the social worker noted that the patient's 'responses are variable and [he] has a poor memory' and that Andrei needed high-level residential care. There were arrangements for paperwork to be completed, and for the patient to be referred for a capacity assessment. Andrei was absent from the meeting with no other representation, so his voice was not heard. There was no note in the file indicating that any other alternatives had been explored in the light of his preference to return home.

Case example: Reg

The earlier introduction to Reg's story was one of acute illness in hospital over an extended period of five months, with two days at home before a fall leading to the latest admission. After medical assessment, a referral was made to the ward physiotherapist, who noted 'intermediate to high risk of functional decline'. Reg developed a chest infection but once improved was adamant about returning home. After not gaining access to a rehabilitation program, the team did not consider Reg well enough to return home, and Reg was asked to assent to an ACAT assessment for a nursing home, which he agreed to 'just in case'. Tensions between the team were obvious in the notes, with the social worker noting that Reg understood that he could 'change his mind at any time', while the consultant was of the view that the 'pt (sic) does tend not to demonstrate insight into high risk level of return home', recommending a capacity assessment. The social worker made further notes in support of Reg's wishes:

> *Today he stated he wanted to go home but was convinced by Dr X to continue with placement. He had indicated that he feels somewhat under pressure and demoralised.*

After recovering from another chest infection from hospital-acquired pneumonia, which improved after treatment, the social worker noted that 'pt (sic) still of view would like to go home as first preference'. Following this, the social worker convened a subsequent family meeting, gaining family support for a home trial for Reg while waiting for a residential vacancy. The team had 'reservations' but supported the trial, with the social worker asserting the 'significant psycho-social benefits for the patient in respecting his consistently expressed wishes to return home for a period'. This is an example of the tension between the views by medical experts on the disease and respect for the psycho-social responses by the individual to their situation. Reg was finally discharged and spent two weeks at home, before being admitted to hospital with a chest infection. He died in hospital two months later.

Case comparison

These two cases, each in a different hospital, were similar in that both Andrei and Reg were physically frail, and their families considered residential care to be an appropriate outcome for them. However, there were marked differences, providing in-depth information as to the informal decision-making processes.

In Andrei's case, there were file notes as to issues of confusion and cognitive decline. Perhaps in relation to this view, his preferences were not given much weight, and he was not included in the family meeting about his future. In comparison, while Reg had some initial confusion resulting from the fall and the effects of medication, his voice was heard and the team aimed for rehabilitation so that he could return home.

When this option closed for Reg, there was a shift to the plan of residential care. While assenting to this 'in case it was needed', Reg continued to indicate his wish to return home, and the social worker worked proactively with Reg's family to gain their support for a return home while waiting for residential care, with Reg involved in the family meeting.

There was no such intervention by the social worker in Andrei's case. Rather, based on the stress of the family, the decision was made for residential care without consideration of any other alternative, even on a trial basis. Andrei's psycho-social needs were not considered. While Reg's assertion of wishes was part of the dynamic of his case, Andrei was passive and did not protest or insist on returning home. There was also a strategy of over-riding Andrei's views through Enduring Powers of Guardianship if he changed his mind and refused to enter residential care, indicating the use of social control to maintain the outcome. These actions were presumably based on assumptions and prejudices about Andrei and his capacity. The resulting processes excluded his voice, and led to a loss of recognition of him as a person with the attributes to participate in decisions about his life. This also reflected his reduced social personhood as perceived by others. The outcome did not change despite a finding of capacity by the assessing doctor.

Structural resource issues also featured in these cases. As Reg was a veteran, home services were able to be activated in a responsive way. However, in Andrei’s case, there may have been a significant wait for home care services in creating any alternative option to residential care, therefore constraining his options. The voice of the patient, individual health worker activity, and the availability of resources were all factors influencing the decision-making process. Underpinning the role of the person in this decision-making is the notion of personhood, where the person is understood in reference to their possession of specific attributes that are given status within a particular context. As explained in Chapter 3, ‘personhood’ in a social and legal sense is a term that signifies the status bestowed on the person by others socially, or formally by law, and is defined by particular capacities and attributes. The next section presents the findings on personhood and autonomy of the patient, with a further discussion of these matters in the following chapters.

III Personhood and the patient

Through the different stages of clinical assessment and decision-making, the patient appeared to be a passive entity, with assent for the decision sought rather than engaged in decision-making. The western bio-scientific approach of medicine relies on the expert, and through surveillance and assessment of the disease, has the effect of objectifying the patient, resulting in a loss of personhood. This section explores the notion of personhood that emerged from the files, with a focus on the language used to describe the person, the recorded preferences of the patient, assumptions about cognition and dementia, and attitudes and practices that affected personhood in the hospital intervention.

Language and personhood

One aspect of ascertaining personhood views came from the analysis of language in the files. Identifying words in the case file used to describe the patients showed that deficit words reduced the person’s status and identity. These words remain significant accounts in the written record, influencing other’s views of the person, possibly unconsciously. One example is from Andrei’s case file, where the deficit words outweighed the asset words, emphasising illness and dependency, and shaping his recorded identity. Some of the words are judgments rather than observations, such as ‘situational crisis’ and ‘failure to cope’:

> *Disoriented*
> *General decline*
> *Failure to cope*
> *Confusion; decline in ADL’s(activities of daily living)*
> *?early dementia*
> *Situational crisis*
> *Blind and poor hearing*
> *Hallucinating at night- sees things that aren’t there*
> *Pt agitated- confused, climbing out of bed- blind- risk.*
> *Pt’s memory has deteriorated*
> *Pt obsessed with bowel movements*
> *Pt’s responses are variable and poor memory*

There were also asset words in the case file, but these were less frequent in number and mostly occurred in the admission phase. Examples from Andrei’s file included were:

> *Conscious and orientated*
> *Lives alone in house he built 60+ years ago*
> *Very supportive family in d-i-l (daughter in law)*
> *Former cabinet maker, plays music by ear*
> *Alert*

The asset words command a sense of the person as master of their life, whereas the deficit words present the opposite picture. There is a limited description in the file as to the strengths of the person, and how he has managed with his disability, creating an unbalanced picture of dependency and deficit. Where behaviours of concern occurred such as agitation and confusion, there was no context provided in the file as to the cause of these behaviours, such as delirium resulting from medication. Without this information in context, these descriptions can create a particular impression of the patient and lead to assumptions about their cognitive state.

In Andrei's case, information was not available regarding hallucinations occurring with the sensory deprivation of blindness[42] and no notes about the difficulty of being in an unfamiliar environment. Language is therefore a tool that can create an inaccurate impression of the person's abilities that result in the loss of personhood status as conferred by others.

Analysis of the professional source of the asset and deficit words in the case files did not show any consistent pattern between the statements and the particular profession. For instance, in Andrei's case the deficit words came from the treating doctor, nurses and social worker, while the asset words came from the physiotherapist, geriatric consultant and liaison registrar. This may have reflected their roles, the prevailing culture or their individual values. In contrast, while deficit words only were written by the treating doctor and neuro-psychologist in Daisy's case, the nurses, social worker, occupational therapist and psycho-geriatric consultant all recorded both asset and deficit words**.**

Family use of asset and deficit words corresponded with the degree of carer stress. For instance, Andrei's daughter-in-law Rose, Lewis's wife Jenny, and Tom's partner Jay, who were all experiencing stress from caring, used a majority of deficit words. In comparison, Andrei's son, Greg, acknowledged both deficits and attributes about Andrei. Kathleen and Daisy's relatives also presented a balance of both. This finding is significant in that high levels of carer stress can potentially colour carer viewpoints and result in a biased description of the person and the home situation, which in turn can shape the perspective of professionals involved in case assessment.

Knowledge and respect for patient preferences

Another aspect of personhood concerns respect for the person's life meaning and of self-determination by others. The case files were examined for recorded preferences and priorities of the patient by health professionals. There was no clear consistency of such records in relation to professional background. One interesting contrast was that the social workers in the cases in the first hospital made no record of patient preferences, whereas the social worker in the second hospital recorded patient

---

[42] Discussion with an independent physician.

preferences in each of the three cases. As the profession of social work has a strong principle of respect for self-determination, this aspect suggests variables in professional values, culture or the role of the social worker. The table below illustrates a record of patient preferences in the case file and by which professional.

Table 13 Record of patient preferences by profession

Case	***Andrei***	***Lewis***	***Kathleen***	***Tom***	***Reg***	***Daisy***
Doctors	no	no	**yes**	**yes**	**once**	no
Nurses	**once**	**yes**	no	no	no	**yes**
Social worker	no	no	no	**yes**	**yes**	**yes**
Occupational therapist	**yes**	no	no	no	**yes**	**yes**
Geriatric liaison registrar	**yes**	no	**yes**	no	no	n/a
Consultant (assessment)	**yes**	**yes**	**yes**	no	no	n/a
Neuro-psychologist	no	no	no	**yes**	–	**yes**

Overall, the recording of patient preferences was limited. Patient preferences on the admission sheet or in the progress notes were not readily identifiable or given any particular status. As the file grew in size and information, such statements became obscured if the statements were not repeated elsewhere later in the file.

Greater awareness of patient preferences emerged from the interviews with assessors and recruiters, which had not been articulated fully in the file. Health professionals with strong patient relationships, such as the social worker with Reg and Daisy, were seen to respect and enhance their personhood within the available constraints.

The interviews with family members gave a rich picture of the person and the meaning that life gave them, including current preferences. For instance, Andrei’s son Greg had a strong understanding of his father’s meaningful life activities and his wish to be at home, and maintained his father’s engagement with the Masonic Lodge by taking his father to their events. In Lewis’ case, his wife Jenny understood Lewis’ wish to live at home and his boredom in the residential facility, but there was no active facilitation by her of activities that would relieve his boredom, such as taking him on outings. Kathleen’s nephew Brian, and his wife Joy, had a strong sense of Kathleen’s need for independence and understood the threat from her fall. In Tom’s case, Jay was aware of Tom’s desire to maintain their relationship in their home, but was no longer supportive of this continuing. Daisy’s son Andrew understood his mother’s preference to return to her accommodation, and was frustrated when it was not achievable due to the ACAT assessment.

This clear understanding of the person and their preferences and desires by family members was representative of their long-term relationship. Such a relationship is not possible in the health care sector, but family members remain a rich source of information about the person, which could be utilised more to enhance patient personhood. A clear and accessible record about the patient and their preferences, and a list of their assets and strengths, would possibly enhance understanding of the person and consideration of their needs in care planning.

Personhood in relation to cognitive changes and dementia

The status of the person can be affected by generalised views held by others as to the effects of dementia and the resulting inabilities of the person with dementia. The case files were examined for accuracy of description and assumptions about dementia. Notes about dementia made for some patients at admission were based on the observations of the admitting doctor and information from the family, and there was the possibility of assumptions about dementia. The records after admission indicated confusion for some of the case participants, possibly arising from shock, pain, infection and medications, but possible causes other than dementia were not noted in the files.

Kathleen’s case was an example of assumptions being made about cognitive changes. Her clinical case notes contained observations by nursing staff about Kathleen being confused at night in the ward. In a subsequent record, the social worker noted that Kathleen may not be able to return home if her confusion continued. There had been no medical diagnosis of dementia, and the family’s experience was that Kathleen was usually ‘as sharp as a tack’, suggesting that some short-term confusion was present. However, background information was not gathered from the family as to their knowledge about Kathleen's cognitive function to assist in diagnosing her confusion as a short-term condition. The observations in the hospital record did not link the influence of morphine for pain relief as an influence on cognition, even though this was the consultant's unrecorded view. Given this instance, the note by the social worker indicating that residential care may be necessary if Kathleen's state of confusion continued was premature. The social worker was not only making assumptions about Kathleen's' cognition but also assuming that these changes in cognition would necessitate a change in Kathleen's living arrangements. If Kathleen's confusion had continued due to continued use of morphine based pain relief, she may well have found her options limited by hospital perspectives, however inaccurate. Kathleen's situation gave a very clear indication of the assumptions that may be made about dementia, which could have serious implications for the person.

A second danger of an assumption of dementia is the linking of cognitive decline with decisional incapacity. Presumption of incapacity was found in case file comments such as 'insight queried'; 'unrealistic'; 'team concern with validity of legal appointments'; 'decline and dementia…lack of insight noted'. Either referring in a global sense to capacity or to specific decisions, these judgments, based on observations but without specialised assessment, imposed boundaries on the person's selfhood and decision-making.

In Reg's case, his confusion in the earlier part of his admission followed his fall, where there were thoughts that he may have had a seizure. Reg's cognition improved, but attitudes towards his cognitive status continued when the consultant queried his insight about returning home and recommended a capacity assessment. This is indicative of the imposition of the doctor's views about Reg's 'good' and her view that he was not making a rational or insightful decision.

The labelling of an ill person as 'cognitively impaired' without any exploration of pre morbid functioning or alternative reasons, can become a permanent label. There is power in the use of language in influencing others, and the specific dangers for a vulnerable person of assumptions of dementia and presumptions of incapacity, when cognitive changes are evident. This suggests that labels of dementia require extreme caution in use, along with other suggestive words indicating cognitive changes, due to their prejudicial effect.

Practices and attitudes that enhance or diminish personhood

The experience of personal empowerment and agency is part of autonomy, and can be enhanced or diminished by others' attitudes and the environment. This section explores how practices and attitudes towards the specific participants in the study enhanced or diminished their autonomy and personhood. Power relations are also identified when apparent.

Andrei

In Andrei's case, the unfamiliar hospital environment was not enhancing of his functioning, due to his blindness. In addition, it is likely that he was experiencing hallucinations linked to this sensory impairment, which were not identified as such. He also experienced delirium, which may have been due to medication. Some of the hospital practices were diminishing of Andrei's autonomy. The exclusion from the family meeting indicated an implicit presumption that these symptoms excluded him from being able to participate in decision-making about his future. Exclusion from the meeting modelled the values of reduced personhood to the family and others in the case meeting. Andrei was not given the opportunity to provide his own options or solution and in this way, the practices were paternalistic. The family's view of the care burden outweighed any view of Andrei's, further symbolic of the loss of his autonomy.

The assessment by the consultant was minimal in enhancing Andrei's personhood. The consultant was disinterested when Andrei gave some of his early history, and took a phone call during the interview. Further, while Andrei wanted to return home, the eventual outcome of the hospital intervention was that he was placed in residential care, and Andrei had permanent loss of his familiar environment. Power relations were evident from the intention that an application to the Guardianship Board would result in an order at the Tribunal supporting the hospital outcome, should Andrei change his mind about going to residential care.

While the hospital provided care for Andrei and negotiated a change in care arrangements, Andrei's personhood was diminished by exclusion from decision-making and lack of choice, along with disabling effects of the environment and medication.

Lewis

The hospital stay enhanced Lewis's physical and mental function. He was away from the residential facility that he disliked, and had relief from boredom. The hospital unit was familiar to him, and some of the medical staff knew him, which was affirming of his identity. His emotional and mental state was a major focus of treatment. Different activities were arranged, and the file indicated that he improved while in hospital. Lewis described to his wife that he felt that he was treated respectfully during his stay. He was also included in the family meeting to talk about his future. The doctor discussed his impairments and guardianship with him openly, indicating a respect for his personhood, and gaining his participation in events. The outcome of his hospital stay was relocation to a different facility.

However, the informal decision-making process of the doctor appeared to have paternalistic overtones. The doctor decided on the outcome for Lewis without any consultation with Lewis, his wife or his guardian, and then went through the processes of including Lewis and his wife towards this outcome, which is tokenistic and provides an example of the doctor assuming that they she knows best. In terms of power relations, the doctor took control of the case outcome from the outset. During the assessment, the doctor imposed value judgments of safety on the patient rather than ascertaining the meanings that Lewis held important in his life, thus imposing her own worldview onto Lewis.

Lewis gained benefit from the hospital environment, but it was uncertain whether he would receive similar benefit in his change of accommodation.

Kathleen

Kathleen received rehabilitation support in hospital for her fall, which was supportive of her long-term autonomy. However, the pain relief medication caused some delirium, with confusion at night. Kathleen was frightened by her illness, at one stage thinking she might die. She was anxious to organise her financial affairs, but this wish appeared to be unrecognised. She was also indignant at what she saw was the interference and questioning of her private legal affairs, walking out of a conversation with some health care professionals as a result.

In contrast, the consultant was respectful in her approach to the issue of Kathleen’s capacity to make legal appointments. She spent time building rapport with Kathleen and was reassuring to her regarding the personal concerns she raised regarding transitional care. She was respectful of Kathleen’s trust in her relatives. When Kathleen failed to provide precise information about advance directives, the assessor did not push for answers, but sought to ensure that she understood the legal implications of what she had signed and was satisfied in the arrangements she had made.

This approach contrasted with the paternalistic values apparent in the health care team. The imbalance of power relations was most apparent from their view that confusion may affect her returning home, when there had been little investigation of its causes.

After discharge, Kathleen spent time further recuperating in a restorative facility, and then returned home with services, achieving her goal. Overall, the hospital experience while assisting greatly in her physical recovery did not greatly support her psychological well-being.

Tom

The hospital admission gave respite to Tom’s situation. During his hospital stay, his physical functioning and walking improved, and in developing relationships with some of the staff, he experienced an increase in dignity and identity. Tom’s request to have Jay present at the different meetings was accommodated. Tom found the capacity assessment process a positive experience, with the neuro-psychologist sensitive to the grief issues he was expressing. In this way Tom was assisted therapeutically to make an emotional transition to his life circumstances.

Tom was involved in the discussion of his care needs with the doctor asking him if he was agreeable to residential care, acknowledging his residual autonomy.

However, he had little choice in the light of Jay’s wish to cease providing care. There were no other options developed for consideration, and Tom had very little power in this situation. Despite the loss of his previous lifestyle, overall the hospital intervention restored some physical functioning and emotional dignity to Tom.

Reg

The hospital intervention aided Reg during several events of infection and provided him with rehabilitation not available elsewhere. With ongoing ill health, the health care team then considered residential care as the main option, despite his ongoing stated wish to return home, and he experienced significant psychological pressure by the doctor to go to a nursing home.

Reg did not choose to discharge himself, which may have been indicative of his poor physical condition and his dependency on assistance to achieve his goal. The trial at home organised by the social worker supported his wish to return home, enhancing his autonomy. Reg experienced distrust of the hospital and he was apprehensive up to discharge home that this would be prevented. However he successfully returned home with assistance of services, albeit for a short time before another admission. While Reg received excellent physical care, and advocacy by the social worker, his psychological well-being was affected by his long extended periods in hospital and sense of powerlessness in the hospital system.

Daisy

Daisy experienced a loss of personal liberty during the nine weeks in hospital. With family interstate and rarely able to visit, she was not able to leave the ward unless staff took her for an occasional walk. Daisy was cognitively challenged to understand why she was in hospital, and wanted to return to her supported facility. Staff sought to involve her in ward activities where possible.

The neuro-psychologist conducting the capacity assessment was aware of what was at stake for Daisy in losing her freedom and familiar living environment, and was honest with her about the importance of the assessment. Her approach to Daisy was warm, respectful, and supportive, and remained so despite the tendency of Daisy to become distracted and divert the process continuously.

The focus of the team had been to support Daisy to return to her original accommodation, in support of her wishes, but this plan was thwarted by bureaucratic regulation, and they, along with Daisy, were disempowered by this regulatory system. In the last few weeks of her hospital stay, Daisy began to withdraw, and became belligerent, symptomatic of loss of control and depression. While the behaviour was recorded in the file, there was no identification of her mental state. Daisy was eventually transferred to a secure unit in a residential care facility, resulting in a permanent loss of liberty.

Overall, while Daisy remained physically fit, the hospital intervention was not conducive to her psychological well-being and she experienced physical and emotional disempowerment. There was no external scrutiny of her lack of liberty, such as by the Public Advocate, to examine whether the loss of her liberty was justified by the potential risks to her person.

The psychiatric unit was the only place identified in the case files where the emotional health of the patient was of clinical concern. In the other cases, the main focus was on the patient's physical status, and on resolving the social situation. This reflects the focus on the body and restoration of health and function, and social interventions were primarily given attention as affecting discharge, rather than a recognition of the psychological and social attributes of personhood, and the importance of integrated well-being. While the World Health Organisation considers health as holistic, being 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity',[43] it was not holistic in the environments under study. This lack of balance requires recalibrating if full well-being of the person is to be attained.

IV Conclusion

This chapter commenced with an introduction to the six participants of the case study and their context, with each person, while unique, sharing common factors such as the presence of physical or cognitive decline and increasing dependency on others. There has been an exploration of the process of the hospital intervention and a

---

[43] World Health Organisation definition of 'health' at *www.who.int/about/**definition**/en/print.html*

critique of the various factors that have shaped the patient identity and resulting decision-making, as examples of subsequent loss of social personhood. The official file record provided a scant history of the person, their life meaning, and the strengths and assets that they brought to the current life crisis or transition. The use of language in the files shaped views of the patient/person and their problem, and constructed the solution. There were assumptions about confusion and capacity as paired concepts, with led to exclusion of the person through a global view of capacity. The focus on deficits was representative of the bio-medical model of disease which focuses solely on the person, without recognition of their strengths and abilities and wider societal influences affecting independence, such as the distribution of resources.

Information sharing in the clinical setting was limited by prevailing values about what was pertinent, time constraints and communication processes, with the view of the medical staff having a dominant influence. The hospital intervention followed a common pattern, and examination of the decision-making process demonstrated that the majority of decisions were made *about* the patient, and were indicative of the role of medical experts in imposing 'moral judgements' in decision-making (Varcoe et al 2003, 957).

The hospital intervention varied in its effect of enhancing or diminishing physical and psychological well-being of the case study participants, with some experiences empowering, while others challenged the person's sense of self and autonomy. With some practices oppressive to the person, it can be argued that health care staff were themselves oppressed by the culture and constraints of the setting. In addition, resource constraints and family carer limitations were a significant barrier to maximising the person's autonomy.

The analysis of the cases in these domains occurred through scrutiny of individual interactions and events, gathering detailed information about different parts of the phenomenon of decision-making in this setting, and also through bringing the parts of the information together to give a picture of the 'whole'. This included finding patterns of behaviour that were consistent across the cases (Geertz in Schwandt 2000, 193).

The cases demonstrated that the hospital has a diverse role beyond the primary focus on treatment of medical problems: it is a place of respite, social investigation, and of negotiating and brokering personal life solutions for the individual and their family. The hospital by default becomes a ‘clearing house’, creating an institutional response to the crises and transitions in the lives of older people, rather than invoking informal responses or using less formal community based resources. This is an example of the elevation of medicine and subsequent medicalisation in our society, where medicine becomes the new authority in providing solutions, exceeding its scrutiny beyond disease in the body. The case studies as critiqued suggest that the bio-medical culture maintains its primary focus on the patient and not the person, and that the medical setting is not fully responsive to enhancing social personhood. Responses to these reductions in personhood will be discussed further in Chapter 8. The next chapter presents the findings on the socio-legal domain of the case studies.

Chapter 7 Case Studies: The socio-legal domain

The previous chapter presented the findings about the participants, the hospital interventions and the informal process of decision-making in the case studies. From the file analysis, a generalised chronology of assessment and planning emerged, as the six case study participants progressed through their hospital stay. Analysis of communication processes led to a conclusion about the time constraints of the members of the healthcare team in sharing available information for team decision-making. There was little opportunity for case reflection. The patient’s voice was minimal in the files and processes, with the healthcare team developing decisions about the patient without his or her active engagement. The team were active problem-solvers, and the patient the source of the ‘problem’ requiring resolution. In the study, the hospital role emerged as a ‘clearing house’ for those undergoing life transitions related to ageing, extending medicine’s role into brokering personal life solutions. In this process, there were limited accounts and acknowledgement of the attributes of full personhood.

This chapter is concerned with the socio-legal examination of the case studies. In the first part of the chapter, I analyse the process of the capacity determinations in relation to common law principles. I find a wide variation in the implementation of the legal principles and standards. I also analyse the procedural approach to the capacity assessments in the case studies. I set out the legal rules of procedural fairness and apply them to the facts of the case studies. I consider the accuracy of the contextual information used in the capacity assessments. I also evaluate the reasons or triggers for conducting the capacity assessments in the case studies and question whether the professional conducting the assessment considered alternative solutions to the problem. From this, I found the implementation of capacity assessments to demonstrate inherent limitations and weaknesses from a legal perspective.

In the second part of the chapter, I present the findings that result from a socio-legal analysis of the case studies, and identify different influences on the interpretation of law in the everyday. The case studies showed limited legal consciousness of law evidenced by distorted facts, diverse interpretations, and localised myths. Law was proved to be malleable; enabling adaptations that maintained the practices of the dominant medical culture, but, in some instances, resisted the intrusions of medicine on patient autonomy, reflecting the impact of values on the interpretation of law.

I Capacity determinations: a legal analysis

In this section, I analyse the capacity assessments in the case studies against these common law principles, utilising the perspective 'of the internal logical structure' of law (Cotterrell 1992, 2). I conclude that there was a significant gap between the 'law in books' and the 'law in action' (Harding 2011, 17; Pound 1959). The case studies identified the areas of 'gaps' in this context. For example, while common law principles require evidence of brain impairment, there were presumptions of incapacity in the cases where a diagnosis did not occur. In addition, there was a lack of comprehensive assessment of functional understanding of the decision, despite this being the fundamental basis of capacity in common law, with the reasons for the determinations not always reflecting the common law standard in several instances.

The common law standard for capacity determinations

As discussed in Chapter 2, the concept of incapacity arises from the doctrine of consent. It has a basis in tort law, which protects the individual's civil liberties, including the idea of bodily inviolability. Physical intervention without consent is unlawful and constitutes trespass in common law.[44] In circumstances when a person's inability to consent is evident, another person, such as a family member, will make the decision unless there is an appointed substitute decision-maker.[45]

Capacity determinations to resolve decision-making impasses have extended beyond consent for medical treatment, to include domains as diverse as care and accommodation, and the ability to manage finances (Darzins, Molloy and Strang 2000; NSW Attorney General's Department 2008). Capacity is also an important

---

[44] Dept of Health and Community Services (NT) v JWB (Marion's case (1992) 175 CLR 218

[45] *Advance Care Directives Act 2013* (SA) s 23 outlines the powers of the substitute decision-maker for health care decisions; the *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 14 gives provision for substitute decision-making if the person requiring medical intervention has mental impairment and cannot give consent.

concept in contract law, where law requires that the parties understand the effect of the particular contract (Caffrey, 1991). Capacity assessments are an applied process with the aim to meet these evidentiary requirements of common law.

Law presumes the adult person to be autonomous in determining their life course and managing their affairs. Where capacity may be in doubt for an individual, common law provides the legal principles that together set out the primary obligation to prove or disprove incompetence. These principles, listed in Chapter 2, and in addition to the presumption of competence, include a requirement for the presence of brain impairment related to decision-making, and evidence of the ability to understand the specific decision in hand. Additional principles are concerned with the threshold level of capacity in relation to the complexity of the decision to be made and the seriousness of the risk involved, with a requirement for commensurate proof of understanding (see Appendix 2).

Though derived from English cases, these principles have been accepted into Australian law (Kerridge, Lowe and Stewart 2009). Using these principles, I analyse the language and meaning of the capacity determinations from the case studies, against the common law standard. I found there to be presumptions of incapacity with a lack of diagnosis of brain impairment. I found that some assessments did not appear to assess functional understanding in a comprehensive manner. I noted that those undertaking the assessments did not give attention to the relationship between the level of understanding and the gravity of the situation, and there was an absence of qualification of risk associated with the nature of the choice. The reasons given for the outcome were not always commensurable with the key aspect of understanding required in common law, in all of the cases. The findings are presented below in relation to each principle.

Presumption of capacity

The law treats individuals as having capacity until proven otherwise,[46] but the opposite was evident in two cases. For instance, case notes inferred that Andrei had incapacity before the assessment, and this led to his exclusion from conversations

---

[46] *Re T (Adult: Refusal of Treatment)* [1993] Fam 95; see Appendix 1.

about his future. Kathleen's confusion led to staff presuming her incapacity and instigating an investigation into the validity of her legal appointments:

> *Researcher:* *Why do you think ward staff queried her capacity?*
> *Consultant:* *I don't know, I don't get a clear picture from the notes...I think they were just worried that she was doing it [legal appointments] in hospital and I especially think she wasn't quite as good when she did that as she is now.*

In both of these cases, there was a lack of distinction between the presence of mental confusion and the person's legal capacity.

Evidence of brain impairment

For a determination of incapacity, common law requires evidence of brain impairment that has an effect on decision-making.[47] Case records in the study showed that mental confusion, which triggered concerns about capacity, abated during admission for some case participants. This suggested short-term acute causes such as infection or side effects of treatment, but there was an absence of diagnosis or differentiation between acute and chronic conditions affecting cognition, in the case records of four of the cases. Assessment of capacity is not appropriate where mental changes are associated with acute illness and treatment, as the person is disadvantaged, and an assessment in these circumstances may lead to a false conclusion. In one example, Kathleen had been confused earlier in her admission, which was the reason for the capacity assessment, even though a diagnosis was not recorded in Kathleen's file. The consultant undertaking the assessment thought delirium[48] may have been the cause, but did not make a formal diagnosis:

> *...she did have some cognitive impairment when she came in, and ... was in a lot of pain, and ... on some medications that may have affected her cognition…so my feeling was that she probably had some type of delirium, which seems to be improving.*

From my analysis of case files, four cases did not record a diagnosis of a brain impairment related to decision-making during the admission, therefore appearing to lack sufficient evidence of this common law standard. Two cases recorded a formal diagnosis of permanent brain impairment: Lewis, who had a prior diagnosis of vascular dementia; and Daisy, who had a diagnosis of dementia.

---

[47] *Re T (Adult: Refusal of Treatment)* [1993] Fam 95.

[48] Delirium is a short-term disorder that is described in Chapter 5.

This information is summarised in the following table.

Table 14 Evidence of brain impairment for legislative threshold

Case	***Evidence of brain impairment***	***Sufficiency for common law standard***
Andrei	Confusion and hallucinations present, but no clinical assessment of dementia.	**Not sufficient**: no diagnostic process to determine if dementia was present and related to decision-making.
Lewis	There had been a diagnosis of vascular dementia at an earlier admission.	**Sufficient:** Previous diagnosis of vascular dementia
Kathleen	Confusion during admission was documented, but there was no clinical assessment or identification of cause.	**Not sufficient**: no clinical assessment made.
Tom	Confusion when admitted and a low mini mental score indicative of impairment in functioning.	**Not sufficient**: earlier brain injury but no diagnosis of current cognitive status
Reg	Early confusion with the cause queried as infection or delirium.	**Not sufficient**: there had been no diagnosis or evidence of brain damage or disorder.
Daisy	There was ongoing confusion assessed as 'progressive dementia with likely frontal lobe damage'.	**Sufficient**: there had been a clinical diagnosis made, and evidence on assessment of an acute mood disorder.

Understanding of the specific decision

This principle is based on the recognition in law that competence is specific to the agreement in question.[49] When extended to decision-making, at the same time the person may be considered competent for one type of decision but not for another, with the implication that capacity is a variable construct to the specific decision only and is not a fixed state (Kerridge, Lowe and Stewart 2009; Charland 2008). In recognising that abilities vary according to the task, each decision therefore requires individual assessment. There have been various approaches to translating the common law principle of 'understanding'[50] into an assessment process, resulting in a wide range of tests and tools (see Appendix 2). I have utilised the Darzins model described in Chapter 2, to examine the assessment of understanding in the capacity determinations. In this model, for each specific decision to be made, Darzins and co-

---

[49] *Gibbons v Wright* (1954) 91 CLR 423, 437-8; see Kerridge et al 2009; Charland 2008.

[50] *Re C (Adult Refusal of Medical Treatment* [1994] 2 AC 1.

authors describe functional *understanding* as comprehension of the current issues of concern, the choices the person has available, and their consequences (2000).

In the analysis of the study data, I found that the professionals making the assessments did not comprehensively explore the different aspects of understanding. For example, during his assessment, Andrei did not have the opportunity to demonstrate his comprehension of the hygiene problem that led to his admission, or the stress experienced by his family in his care. In relation to understanding the choices available, the professionals in three of the assessments included discussion of different choices. In two of these cases I identified an observable bias by the assessor to some choices with other choices excluded or minimised. With the exception of the comprehensive nature of the neuro-psychologist's interview of Daisy, the examination of the understanding of consequences of choices appeared limited in the other assessments.

The table below summarises the areas of understanding of context, choices and consequences addressed in the interviews of the four capacity assessments where transcripts were available.

Table 15 Analysis of content of observed capacity assessments

Case	***Context/issues***	***Choices***	***Consequences***
1 Andrei	Current care needs discussed only and not reason for admission	'Going home' raised by the patient, while the doctor raised nursing home care	Only a positive consequence of nursing home was raised and a negative consequence of going home
2 Lewis	Understanding of contextual problems that led to hospital admission were not discussed	Some choices raised by the assessor had judgments imposed with understanding of Lewis not gained	The assessor raised some consequences of home care and nursing home care but gave own opinions.
3 Kathleen	Explored Kathleen's understanding of legal documents but did not raise previous confusion.	Checked understanding of her choice to appoint her relatives but did not investigate other choices.	Consequences of legal delegations given by the assessor but the patient's ability to explain them was limited
6 Daisy	Tests; seeks to gain understanding of patient's insight into her current situation and others' concerns.	Patient's choices are returning to her unit or the supported facility. The assessor raises option of residential care.	Patient unable to give any consequences of her option to returning home, or going to a nursing home.

Degree and evidence of incapacity commensurate with the decision

Daisy’s assessment was an example of a thorough examination of her understanding of all aspects of her choices and consequences. The neuro-psychologist was of the view that it would be unsafe for Daisy to live alone. However, she was aware that a finding of incapacity would have had a significant negative outcome for Daisy, by having residential care imposed on her. There was not a similar level of comprehensive assessment for the other case study participants, even though each finding of incapacity was significant in shaping the future for each individual.

Consideration of the merit of the choice

Common law principles imply a relationship between the seriousness of risk resulting from the choice and the level of understanding.[51] This is contentious as it may allow judgement of the rationality of the decision (Kerridge, Lowe and Stewart 2009). If applied, it would require some qualification of risk associated with ‘the nature’ of the choice.[52] In relation to the capacity determinations in the case studies, there was an apparent absence of recognition of this relationship. There was no description of specific risk or consequences in the case files, nor was one developed during the assessment process. In two assessment interviews, those conducting the assessment raised concepts such as ‘safety’ and ‘better care’. This implies a concern with risk to physical safety, but does not provide clarification. For example, there was no objective assessment of the potential risks of harm for Andrei if he returned home, or an assessment of these risks in relation to the benefits of going home. Lewis was told by the assessing doctor that home residential care was ‘safer’, even though the doctor did not compare the risks of residential care with alternative choices.

Overall, the findings of the practices of capacity determination in the cases in relation to common law principles show clear gaps between the law in theory and the law in action, and are indicative of the complex challenge in applying common law principles in capacity assessment in practice. In the final part of this section, I

---

[51] *Re T (Adult: Refusal of Treatment)* [1993] Fam 95; *Fitzpatrick v K* [2008] IEHC 104; see Appendix 2.

[52] *Re T (Adult: Refusal of Treatment)* [1993] Fam 95, 113 per Lord Donaldson.

analyse the language used in the capacity determinations as an indication of the alignment with common law language and doctrine.

The language and reasons of the determination

Those conducting the capacity assessments in hospital subsequently made a capacity determination for each patient. Andrei and Kathleen were found to have capacity, while Lewis and Daisy were found to be incapable of making decisions about care, and Tom was found to be incapable of making his financial decisions. I analysed the language used in the determinations in the case studies for their commensurability to the central concept of ‘understanding’ in the common law principles. I found that in two of the determinations, the language used by the professional conducting the assessment demonstrated a divergence from the common law standards.

The language and reasons for the determination varied. In Andrei’s case, the consultant considered Andrei to be ‘as competent as any I have met’, as he *recognised* his disabilities and *agreed* with the need for care. However, Andrei’s ‘agreement’ with the decision for a nursing home could equate with passivity and compliance, and not understanding on the part of the patient, indicating a tendency for doctors to equate capacity with agreement to the treatment proposed (Ganzini et al 2003).

In Lewis’s case, the consultant determined that Lewis did not have capacity due to his *ambivalence* and *contradiction* in the reasons he gave for his choice. These assessments are not, however, necessarily indicative of a lack of understanding. In the determination for Kathleen, while using the language of ‘understanding’, the consultant did not rely on a black and white concept of capacity as in common law. While the consultant found that Kathleen had only a *general understanding* of the effect of making an Enduring Power, the consultant determined that Kathleen’s trust in her relatives for decision-making on her behalf was of greater importance than her limited ability to understand the documents. On this basis, the consultant recorded a finding of capacity for Kathleen in relation to making the legal appointments. The consultant referred to a principle in the guardianship legislation for supporting informal arrangements,[53] and considered that this situation came within that gamut, even if Kathleen did not fully meet capacity criteria. This can be construed as indicative of confusion between approaches, that is, Kathleen is competent (common law) as there is strong trust in her relatives and they can maintain existing arrangements (guardianship law). This response appears to confuse or merge the tests for capacity in the two different types of law. If an application for guardianship was made, then the guardianship principles would apply, however this was not the case here, and these principles do not constitute a capacity assessment approach.

The neuro-psychologist based her determination of finding Tom to have incapacity for financial decision-making on observation of his lack of ‘realistic’ understanding of finances, linked to the common law concept of understanding. However, the reason for his response may have been a result of lack of knowledge, not cognition, and I explore this aspect in a later section.

The neuropsychologist based the determination of incapacity on Daisy’s *inability* to comprehend her living situation and others’ concerns for her well-being. Her lack of awareness of the effect of her mental health condition on her everyday life, and her inability to identify risks in her situation and to generate solutions to problems, aligns with common law criteria. The assessment, including interview and neuro-psychological tests, had a broader focus than Daisy’s specific ability to decide on her future accommodation. As capacity assessments challenge the person’s legal personhood, they can be a threat to their sense of identity and worth, and therefore should only occur when necessary, and to the extent required. Neuropsychological tests, while they can confirm the presence of cognitive impairment in different parts of the brain and infer the relationship to decision-making, they are not tests of capacity (Wood 2007), making this approach unnecessarily intrusive, and blurring the medical approach with the specific legal task.

Overall, there was not always congruence between the common law principle of understanding and the actual determinations. At times, the assessment intruded into areas not required by common law.

---

[53] *Guardianship and Administration Act 1995* (SA) s 7(1).

In this section, I have analysed the process of capacity assessment in the case studies against the common law principles of capacity determination. I have found that there appeared to be a presumption of incapacity in two cases without an objective basis provided by a diagnosis rather than perceptions. In four of the five cases, as there was no underlying diagnosis of brain impairment, the assessment did not meet the common law standard at the outset. The assessment of the person's understanding of the capacity assessment process and its outcomes was not comprehensive in all of the assessment interviews. Only one assessment, with Daisy, demonstrated the relationship between the evidence gathered about the level of understanding and the gravity of the decision. There was a lack of recognition of this relationship in the remaining cases. While there were inferences about the individual's personal safety as paramount in any outcome, those making the assessments did not explain, describe or quantify risk to the person assessed. The analysis also demonstrated that the reasons for the determination were not always representative of common law language and principles.

This section has evaluated the capacity determinations strictly in relation to common law principles. The findings confirm the variability of capacity assessment in its implementation. This variation has been described in the literature (see Vellinga et al 2004; Sullivan 2005) and supports Kapp's view that professionals largely 'bumble through' capacity determinations (2002, 413). The variability also challenges the legal requirement of fairness for individuals under the law. The next section explores these procedural requirements of capacity assessment and determinations.

Procedural considerations

Capacity determinations utilise an assessment process with a focus on reasoning and understanding, but also incorporate contextual information, such as the circumstances and values of the person, as an aspect of their understanding (see Chapter 2; Darzins, Molloy and Strang 2000; Freedman 1981). Such considerations can cross the boundary of neutrality into value judgments about the outcome (Charland 2001). This section addresses the procedural aspects of the assessment process, the legal standards of procedural fairness; the evaluation of a valid trigger for the determination; and the accuracy of the contextual information applied and considered.

Procedural fairness

In Chapter 2, ‘the hearing rule’ and ‘the rule against bias’ were presented as key components of the doctrine of procedural fairness in law (Katzen and Douglas 1999). These standards provide a measure with which to review the capacity determinations that occurred in the case studies. The hearing rule ensures fair proceedings for the person and requires a person to be notified of the reason and time of the capacity assessment interview. The person must be provided with the opportunity to present any of their own information about the issue for consideration by the decision-maker. After the determination is completed the person should also be advised of the outcome and given reasons for the determination. All of the case study participants were informed of the assessment beforehand and the reason for the interview was explained at the beginning of the assessment. The explanations given were moderately benign without the full implications given, which could have been highly anxiety-provoking to the person being assessed. For example, the consultant informed Kathleen:

> *I have been asked to see you today for a capacity assessment of giving Enduring Power of Attorney... to see if you understand it.*

The case study files showed that two of the participants were informed about the findings and outcome of their capacity determination. This was not documented for the remaining three participants, suggesting that the professional in these cases did not appreciate this aspect of procedural fairness as significant to the outcome. All interviews took place in a private room, except for the interview with Andrei. The interview with Andrei took place in a shared room, which was disruptive due to the nursing requirements of the other patient, potentially affecting Andrei’s concentration during his assessment.

Two of the interviews incorporated an educative approach, that is, the person being assessed was given the opportunity to hear and utilise all the information relating to the determination, ensuring that an assessment of capacity was not affected by a lack of knowledge on the part of the patient (see Darzins, Molloy and Strang 2000). One example is the interview with Kathleen, where the consultant explained and explored the consequences of delegated powers by using an educative approach, rechecking Kathleen’s understanding of the information given. In Tom’s case, where he was found by the professional to have an ‘unrealistic’ financial understanding of the worth of property, no such discussion occurred. Tom therefore did not have the opportunity to incorporate this information and learning in his responses in the interview.

Another key component of procedural fairness is ‘the rule against bias’. This rule requires a decision-maker to be neutral towards the outcome of the decision being made. Bias may occur where assessing professionals impose their own view as to the preferred outcome of an assessment. This suggests that the decision-maker has ‘pre-judged the case’ rather than being open to a change of mind from the evidence arising in the interview (Katzen and Douglas 1999, 208).

I found the presence of bias in two cases by the professional conducting the assessment. For example, in Andrei’s case, the consultant ignored Andrei’s stated wish to return home and instead told Andrei that his family were looking at a residential care facility where he would get more help compared to ‘struggling at home’. The language directed attention to the desirability of a particular choice and was evidence of a value judgement about the outcome.

In Lewis’s case, the psycho-geriatric consultant indicated that the purpose of the assessment was to ascertain whether Lewis knew what was best for himself:

> *We will talk about your accommodation again... to see in this discussion … the conclusion you come to, if this is in your best interests. It’s called capacity assessment.*

This choice of language focuses on an evaluation of the outcome of the choice, and not Lewis’ capacity to make such choices. It may also be indicative of the consultant confusing traditional approaches to guardianship, which has a focus on protection, with the value-neutral approaches of capacity determination in common law. While the assessment was ostensibly to determine if Lewis had a sufficient understanding of the implications of a choice of future accommodation, the consultant had her own view that safety was a priority in any choice, and imposed this onto Lewis. This undermined the neutrality of the assessment:

> *Psycho-geriatric consultant: What about the option of going home- using supports at home- help, staying with you?*
> *Lewis: That would be good.*
> *Psycho-geriatric consultant: My opinion is that safety is important, and [you will be]safest at [the]nursing home.*

While the consultants undertaking the capacity assessment were not those providing ongoing medical treatment to the participant, they were employed by the same health service. They are therefore subject to the same patient management requirements and are colleagues in regular contact with the treating professionals. The influence of possible value judgments and conflicts of interest in such settings, have been raised as reasons to recommend independent assessors be involved in capacity assessments, rather than using the staff from the treating health service (Darzins, Molloy and Strang 2000).

Overall, the legal standards of procedural fairness were upheld in the majority of the case studies. The location in which the interview took place in one case and evidence of bias in two cases however did not adhere to these requirements. These results are summarised in the table below.

Table 16 Aspects of Procedural Fairness

Aspect of procedural fairness	***Outcome***
The hearing rule	
Was the person informed about the assessment occurring, and a time made?	All patients were informed of the assessment
Was the person informed about the reasons for the assessment?	Either prior or at the start of the assessment.
Did the interview happen in a private space?	In all but one case
Was the person informed as to the outcome of the assessment?	Two of the patients were informed but this was not documented in three of the cases

The rule against bias	***Outcome***
Was the evidence heard free of bias?	Two cases indicated assessor bias

Evaluation of the reason for the assessment

As capacity tests are invasive, evaluation of the validity of the ‘trigger’ ensures that any capacity determination that occurs is appropriate (Darzins, Molloy and Strang 2000, 13). This notion of the ‘trigger’ is the same as identifying an administrative decision to be made in administrative law, which includes whether there is appropriate jurisdiction to proceed. Darzins and co-authors suggest that valid triggers consist of ‘events that put individuals being assessed, or others, at risk due to apparent incapacity’ (2000, 13).[54] In the case studies, two assessments were initiated in response to concerns expressed by family members, whereas concerns within the healthcare team about the person’s future care and accommodation, or the making of legal appointments, led to the other four assessments. The following section examines whether the professional initiating or undertaking the capacity test clarified or evaluated the particular triggering event. It also questions whether the professional considered or explored any other appropriate alternatives to a capacity assessment. It concludes that a process of testing the validity of the trigger did not occur in the cases under study.

In Andrei’s case, the hospital consultant only queried the reasons behind the capacity assessment on his way to visit Andrei to conduct the interview. Raising questions at this late stage meant that his inquiries did not avert the capacity assessment. While Andrei had agreed to enter a residential care facility, the trigger to his capacity assessment was his son’s concern that Andrei may change his mind before entering the accommodation. This is not a valid basis for a capacity assessment as it was still a hypothetical event and such an assessment needed only to occur if Andrei did indeed refuse in the future.

---

[54] Valid triggers include demonstrated behaviour placing persons at risk of considerable harm; suspected or known impaired decision-making; choices that are not consistent with previously held values; and where other attempts to solve the problem have failed; and the appropriate appointment of a decision-maker will solve the problem (Darzins, Molloy and Strang 2000).

In Lewis's case, the psycho-geriatric consultant indicated that the reason for undertaking Lewis' assessment was to ascertain if he was able to participate in the decision about his future accommodation. She did not evaluate this reason or alternative approaches. As Lewis had a guardian to make his accommodation decisions, the current assessment appeared obsolete and imposed the process on Lewis unnecessarily. The guardian's role includes consideration of Lewis' preferences in any accommodation decision, and it would have been an appropriate action for the consultant to involve the guardian at this point as the alternative to assessment.

Kathleen's capacity assessment was ostensibly triggered by a perception that she was as unable to understand the effect of changing her Enduring Powers of Attorney and Guardianship. While in hospital, Kathleen, with her lawyer, had undertaken the process of changing these documents prior to the capacity assessment. It was the lawyer's responsibility to raise questions of her competence not the hospital staff. The hospital did not have a duty of care in this instance to question her capacity in these circumstances and this suggests that the healthcare team did not understand the lawyer's role.[55] In addition, a capacity assessment does not give any retrospective clarification as to Kathleen's abilities at the time she signed the documents, so cannot take into account the recognition at common law of variable capacity. The consultant did not evaluate the validity of the trigger in Kathleen's case or appear to have the necessary understanding of these issues when accepting the referral to conduct Kathleen's capacity assessment.

Tom's assessment arose from his partner Jay's concern that Tom might have rejected his financial decision-making power in the future; however, as Tom had not expressed any concerns, this assessment had a hypothetical basis. The consultant proposed the capacity assessment of Reg due to a concern that he might decide to leave hospital or refuse a residential care place when one became available, which

---

[55] The lawyer had the professional duty to ascertain Kathleen's capacity before she signed any documents. While a lawyer in these circumstances might make some enquiries of the hospital staff or doctor, there may have been valid reasons for the lawyer not to do so. This could include having a longstanding relationship with the client, a view as to whether the client's new instructions were consistent to her previous wishes, and an absence of any presenting factors that might suggest a lack of capacity of the client to create these particular documents.

was, again, hypothetical. Both of these capacity assessments were anticipatory, focused on potential future decisions, rather than any current decision. As neither of these situations had occurred at the time of the assessment, the determination was not required.

The assessment of Daisy's capacity was in response to her refusal to accept residential care, and an absence of other alternatives. In this regard, given the lack of consent or assent, the assessment was necessary.

Tom, Reg and Daisy were inpatients of the same unit within the second hospital. The trigger for their capacity assessments came from either the social worker or consultant, who presented their concerns to the clinical team meeting. The hospital team, in supporting these concerns, arguably had a conflict of interest towards the outcome of discharging the patient easily and against the patient refusing their advice as to future accommodation and care. It is also noted that the neuro-psychologist, who conducted the assessments, was not in a position within the hospital hierarchy to reject a medical referral for capacity assessment. The trigger for the capacity assessment therefore lacked any independent evaluation in this hospital setting.

The evaluation of the trigger for a capacity determination was not a defined process in any of the case studies. In every case, the person conducting the capacity assessment did not explore alternative ways to resolve the issue that prompted the assessment. There was an implicit assumption that the capacity determinations were the only way to advance the issue of concern.

From this analysis, I found that the triggers for the capacity determinations were non-existent in one case (Lewis), anticipatory or hypothetical in two cases (Andrei and Reg), and unnecessary in two cases (Kathleen and Tom). Only the capacity determination of Daisy was necessary and appropriate (see Table 17). Greater rigour is required in evaluation of the trigger to avoid unnecessary or inappropriate challenges to a person's capacity.

Table 17 The trigger for the assessment and professional involved

Case	***Professional initiating***	***Trigger***	***Assessment of trigger***
1 Andrei	Social worker	Family concerns: son was concerned about Andrei changing his mind about care; Barrier to discharge: this would affect discharge plan	Anticipatory
2 Lewis	Psycho-geriatric consultant	No valid trigger as a guardian already appointed	Non-existent
3 Kathleen	Social worker	Duty of care: Kathleen's ability to sign the documents occurred in hospital	Unnecessary
4 Tom	Social worker	Family concerns: partner's concern about acceptance of EPA decision-making by Tom	Unnecessary
5 Reg	Geriatric consultant	Duty of care: concern the patient may discharge himself ; Barrier to discharge: Reg may refuse placement and affect discharge option	Anticipatory
6 Daisy	Social worker	Barrier to discharge: Refusal of option of aged residential care	Necessary and appropriate

Accuracy of information

Gathering contextual information about a person's case history is an important aspect of a capacity assessment to ensure accuracy and fairness (Darzins, Molloy and Strang 2000). I found a variety of approaches to information collection by professionals, ranging from reliance on long-term knowledge of the case, to varying degrees of effort by staff in gathering relevant information. For instance, one consultant sought key information verbally on the way to the assessment, without examining the case file. Others gathered information about the social context and the medical history before the capacity assessment. In Kathleen's case, for instance, the consultant undertook significant preparation for the assessment by reading the file, speaking to the geriatric liaison registrar and ringing family members for information. These variations in preparation for the assessments are summarised in the table below.

Table 18 Information gathering about case by assessor

Case	**1 Andrei**	**2 Lewis**	**3 Kathleen**	**4 Tom**	**6 Daisy**
Information about case by person assessing	*Limited-gathered on way to assessment*	*Known from past treatment*	*Obtained information from file, and spoke to family members*	*Obtained from file and briefing from social worker*	*Obtained from file and briefing, rang family and manager*

The quality of the contextual information gathered about the person affects the outcome of the capacity determination. The professional making the assessment bases their determination on the 'evidence' available, therefore inaccurate information can lead to an unsound outcome (see Katzen and Douglas 1999, 202). In two cases, I found the conclusions drawn had a link to inaccurate information. For instance, in Tom's capacity assessment, the neuro-psychologist based the finding of incapacity to make financial decisions on Tom's lack of 'realistic' understanding of finances. In his interview, Tom provided a very low estimate for the worth of the property where he had been living with Jay. The neuro-psychologist had only partial information about Tom's previous and lifelong abilities, and failed to take into account that Tom had always displayed limited skills in managing his financial affairs throughout his life. Tom's partner Jay reported:

> *I had to take the assessment to the doctor …to say he was no longer capable of handling finances. But he never was! But I didn't say that and I just said OK so I just signed…*

Despite Jay recognising the incongruence of this assessment, Jay supported the outcome as it secured his authority as EPA. In this case, however, lack of experience, confidence or knowledge by Tom about financial matters does not necessarily indicate cognitive incapacity. If Tom had been provided with some information as to the current monetary value of his property during the interview, this may have led to Tom revising his view on which the finding was based (see Darzins, Molloy and Strang 2000), and instead be found capable of participating in his financial decisions.

In Daisy's case, despite extensive information gathering by the neuro-psychologist, two areas of information affecting the determination appeared inaccurate. For instance, one of the reasons used by the neuropsychologist to support the finding of incapacity was that Daisy could not always remember where she lived:

> *She gave inconsistent responses about where she lived- for the most part she said she had come from her unit…*

Daisy’s son later indicated that she often referred to the supported residential facility as her ‘unit’. The neuro-psychologist did not know of Daisy’s preferred terminology but inferred from the interview that Daisy did not know where she lived. This finding led to a conclusion of impairment that was possibly greater than her actual cognition. In Daisy’s case the misapprehension about the words used to describe where she lived was significant, as it contributed to a finding of incapacity and the subsequent decision supporting residential care, against her wishes.

A second area of inaccuracy in this case was the neuro-psychologist’s view that Daisy was unable to manage daily living independently, and had limited insight for decision-making in this area:

> *She …believed she could manage independently in her own unit, so she didn’t have realistic understanding about what her functional limitations were, and therefore reduced insight into her care needs.*

The occupational therapist had assessed Daisy as having adequate skills to manage everyday activities in independent living. Based on this assessment, Daisy could have lived semi-independently in the community with support from home care services.

These examples demonstrate how inaccurate information can lead to flawed conclusions, and do not meet the evidentiary requirements for procedural fairness. The importance of adequate and accurate information suggests that healthcare professionals, who are often limited in available time, are less suitable to carry out this role than an independent assessor (see Darzins, Molloy and Strang 2000). Even with a significant input of time, the person assessing capacity can miss important information, leading to significant consequences for the person. This indicates some of the inherent risks of capacity assessment, supporting the notion that such assessments should only be conducted when the necessity is apparent.

Overall, in this review of procedural aspects, I conclude the assessment processes did not meet some aspects of the hearing rule, there was bias in several cases, and inaccuracy of information influenced some determinations. A lack of rigour in the evaluation of the trigger for a capacity assessment potentially resulted in several unnecessary assessments in the case studies. Consideration of alternative resolution processes were lacking and capacity assessments did not occur as the last resort.

In summary, the first part of this chapter has looked in detail at the practice of capacity determinations in the case studies in relation to the common law principles of capacity. This focus highlights how the law would approach these cases in a formal legal adjudication. In this analysis, I found there to be presumptions of incapacity in some of the cases, and a lack of diagnosis of brain impairment in four cases, which do not meet the common law standard. I found that the approach to the different components of functional understanding was not always comprehensive. The language and the meaning of the reasons for the determinations did not always align with common law standards, and there was an absence of risk assessment in considering the merits of the person's choice. There was a lack of neutrality in some of the assessments, influencing the capacity determinations. There was limited evaluation of the trigger for assessment, which resulted in several unnecessary capacity assessments taking place. Inaccurate information also led to some unsound conclusions.

The findings demonstrate that the legal construct of capacity is difficult to implement in practice, with those conducting assessments 'bumbling through' in everyday practice (Kapp 2002, 413). In part, this difficulty comes from an assumption that the legal rules from the artificially constructed world of law have a logic that can apply in the real world, but that is not always reality, as 'only in law books can legal rules have a life of their own' (Cotterrell 1992, vii; Naffine 2009).

The varied interpretation of the legal construct of capacity, and its implementation in the everyday world as found in the case studies, demonstrates the gap between the law in books and law in action (Galanter 1981; Harding 2011); the 'legal impact' of decision-making law on 'behaviour and attitudes' (Cotterrell 1992, 34). In this second part of the chapter, I undertake a socio-legal analysis of the interpretation and production of law in everyday activities. It explores the 'innovation and interpretation' of law in the study setting (Galanter, 1981, 34) and offers further insights about law and society in the everyday.

II Law in the everyday: a socio-legal analysis

The previous section of the chapter provided an analysis of capacity assessment according to the internal logic and rules of law. Cotterrell suggests that such pure legal analysis belongs mainly in law books, and is often not realistic in everyday application, with even judicial decision-making influenced by 'assumed social purposes of law' (1992, 2). He suggests that the character of law is both 'abstract logic'(Cotterrell 1992, vii) and 'a social phenomenon which only 'exists' if the prescriptions of conduct actually have some effect on the way people think and behave' (Cotterrell 1992, 8). This conveys the idea of 'living law' (Cotterrell 1992, 28) where citizens apply law in the everyday 'in terms of the subjective meaning of those ideas…within a social order' (Cotterrell 1992, 12).

The study of the law in the everyday, introduced in Chapter 2, highlights that different levels of legal consciousness, cultural norms and power structures can result in variable levels of engagement with and interpretation of law (Galanter, 1981). Cotterrell suggests that 'the factors that determine how rules are interpreted in particular contexts are at least as significant as the content of the rules themselves' (1992, 42). Law can be used and adapted in practice to substantiate different versions of truth, or can be ignored and discounted in order to maintain prevailing power structures and practices. These dynamic interactions create unique forms of legality in different contexts.

One way to interpret the study data is through the phenomenon of legal pluralism, where a 'variety of different legal or normative systems exist, all of which can be described as law', including 'unofficial forms of ordering located in social networks or institutions' (Harding 2011, 29; Merry 1988). The earlier look at the different contexts and values can be seen as a form of legal pluralism as they show 'semi-autonomous social fields' (Moore 1973, 719) operating in a quasi-legal fashion. However, my focus here is on the everyday context generating different practices in the shadow of the law.

Narratives are one way to expose these subjective interactions, as they express different meanings of law, identified by how people think about law, talk about law and implement law (Ewick and Silbey 1998; Marshall and Barclay 2003), with ‘law’ being ‘anything that people, in their social practices, treat as law’ (Harding 2011, 31). The case studies enabled exploration of this dimension within the bounded domain of the hospital. The next section describes the environmental and cultural context for the case studies followed by an analysis of the production of legality in this setting.

The context for law in the everyday

The bounded hospital community of the case studies is a complex cultural mix of codes, values, conventions and processes, defined by time, place and physical structure. This setting contains actors whose identity and role are determined by this culture (see Engel, 1995). The following section describes the actors and their roles, and the cultural aspects of the setting that influence the production of legality.

Roles and identity

The main actors consist of staff and patients, with role and power differentials clearly delineated within the institutional nature of the hospital. The staff group is diverse, consisting of roles such as administrative staff, medical technologists, nurses, occupational therapists, physiotherapists, psychologists, social workers and doctors. Staff have a separate status from patients, signified by identity tags and passes, with the right to access areas of the hospital locked to patients, and with private spaces of offices, staff tearooms and meeting rooms. A hierarchy exists between and within these groups, with clinicians having the greatest authority, reflecting the key purpose of the organisation.

Patients as residents in the hospital have a different social experience. An admission ritual creates the identity of patient, which is signified by a wristband (Cheek and Rudge 1994). Patients have the semi-private space of a bed, which is the place for treatment, meals, medical discussion, and conversation with visitors. Privacy is limited. Clinical notes from medical observations and surveillance of the patient are the province of the treating medical team. Set procedures and practices such as meals, ablutions, medication rounds, medical observations, ward rounds, and interviews by doctors and allied professionals, define the daily routine. There is no guide, flow chart or orientation which might enable the patient to understand the processes of the ‘system’ (Huby et al 2004, 130), which has its own life, engendering a sense of passivity and relinquishment of control to the experts, and unspoken codes of compliance (Cheek and Rudge 1994). The patient undergoes a process of having their identity removed, described by Goffman as ‘disculturation’ (1961, 13). Through losing control of her or his life and subject to others dominion, the patient can ‘effectively be reduced to something akin to the property of another’ (Davies and Naffine, 2001, 2).

The organisational sphere

The structural frame of an organisation shapes the actors through roles, hierarchies and work teams, which are designed to achieve organisational tasks and goals. Complex organisations such as hospitals have political and symbolic attributes, concerned with diversity and scarcity, which underpin power dynamics (Bolman and Deal 1991; Foucault 1982). The hospital’s daily functioning is orderly within the hospital, reflecting the idea that the hospital is a self-governing institution (Foucault 1991).

There is a social world within the hospital, with dynamic relationships between staff and patients. The hospital is also a place of pain, anxiety, and grief, with challenges to privacy and dignity. It is also a place of healing and repair, where hope and dignity are restored, and life is improved and extended. It is a place of the major life transitions of birth and death. Emotions in response to these immense life events in the hospital are generally contained and private, and not consequential to medical activity. Focus is on the body, not the psychological experience. At times of patient distress or anxiety, observations by the author are that pharmaceutical solutions, or a referral to a social worker or chaplain, are offered.

Medicine, with its social and scientific authority, is dominant in this setting, and doctors’ ‘powerful sociological status’ has an effect on doctors’ behaviour and others’ responses (Gillon 1985, 160). Evidence based treatments shape behaviours and practice, with associated medical technologies and pharmacology. There is high demand for medical services and pressure on resources, affecting services and the human experience. Such aspects contribute to the hospital having a complex social order. The next section explores how the legal frame interacts with this organisational structure.

The legal interface and the everyday

Within the complexity of the hospital, with its overriding focus on medical and social problem solving, the world of law and its artificial framework appears distant or invisible. However, the law shapes healthcare practices. For instance, processes of patient consent for heath interventions are in response to common law and the avoidance of criminal and civil actions in battery and negligence. Legislation sets perimeters for the cessation of treatment and provision of palliative care[56] and patient rights and responsibilities are enshrined in legislation.[57] In addition, hospital policies and regulations may be a response to law as a 'set of operative controls' on this 'partially self-regulating sphere' (Galanter 1981, 13; 19). The interactions in response to this broad legal frame create legality in the everyday world.

From an analysis of interviews and practices occurring in the case studies, a number of themes can be identified which contribute to the everyday production of legality. These themes were the knowledge about the law and its concepts; the alternative authority of medicine; and the role of values about personhood. From these dynamics, there were occasions of invoking the law, innovations in law, avoidance of law, and resistance to law.[58] These approaches had an influence on both the outcomes for the patient and the understanding of family members about decisions made. Their limited consciousness of law led to dependency on the health professionals for guidance. The following section describes these aspects with reference to the case analysis.

---

[56] *Consent to Medical Treatment and Palliative Care Act 1995* (SA).

[57] *Health and Community Services Complaint Act 2004* (SA) s 22.

[58] Ewick and Silbey describe three types of 'legality', described in Chapter 2 as being 'conformity *before* the law', engagement *with* the law, and resistance *against* the law' (Ewick and Silbey, 1998,45). Using this schema as a base, additional terms have been used to show nuances and are described later in the chapter.

The knowledge of law

Several cases illustrated a variable knowledge about the 'law in books' (Pound 1959), in relation to decision-making capacity and related legal concepts. For example, the consultant in Andrei's case was able to articulate the risks and benefits of capacity assessment, indicating recognition of the concept of autonomy:

> *…I think the benefit is to protect the individual from a number of issues, such as safety, self-harm…some financial protection… I think the disadvantages occur when the capacity assessment is wrong… to say that someone does not have capacity when they do, and that I think is the biggest mistake that can be made…removing that individual's right to determine his future.* *Dr Harris*

However, the consultant did not acknowledge capacity determinations as a legal construct:

> *Researcher: About your understanding of law in the area of capacity assessment- have you any information about what the law says?*
>
> *Dr Harris: I really don't know much about the law.*

Dr Harris described his approach to capacity assessment as including information from cognitive tests and assessments of daily living abilities, as well as the assessment of the patient's insight into his problems and the intervention required. Dr Harris described his approach as primarily formulated through discussion with his peers, where he stated that there was no agreed professional standard. Dr Harris had a limited consciousness of legality, or his role in producing law, though his articulated responsibility of the rights of the capable person demonstrated the permeation of the frame of law into the everyday.

In the same case, the social worker revealed limited understanding about the legal provisions of Enduring Powers of Guardianship (EPG).[59] This is an example of how myths about law can be perpetuated in a bounded community, leading to inaccurate and altered reproductions of law (Galanter 1981). The social worker's interpretation of law in this area exacerbated the confusion already present for Andrei's son Greg, who had received information from friends that the Guardianship Board would 'take over' his father's affairs. This variable knowledge about law in the community, in

---

[59] The social worker considered that an application would need to be made to the Guardianship Board for an EPG, however, the Board can only revoke EPG's and appoint guardians. The social worker also thought that an EPG had to be made two years before the person became incapable, whereas there is no time restriction in the legislation.

combination with the social worker’s mixed understanding, contributed to the case confusion.

In Lewis’s case, Dr Royal presented as confident and knowledgeable in her approach to capacity assessment with a focus on the process of decision-making and of the role of understanding of the different options, to:

> *see if their decision is consistent…the way they use arguments to make the decision…so really the process of thinking through, not the outcome necessarily.*[60]

While Dr Royal’s approach reflected common law in relation to exploring options, the focus on consistency rather than understanding is not an accurate description of common law principles. Dr Royal had described the capacity assessment as determining the patient’s insight of his or her best interests, which may suggest giving too much attention to the outcome compared to the common law focus on the process of reasoning and neutrality to the outcome.

In Daisy’s case, the health professionals created a logic about the capacity determination, in that if Daisy did not pass the capacity threshold, she could not make the choice to return home, and would need to go to a nursing home. Lost in this interpretation was the legal role of the capacity determination, which was to ascertain if a substitute decision-maker was needed. This substitute decision-maker could make the decision and accept risks on Daisy’s behalf. While this confusion can be interpreted as a knowledge issue, it could equally reflect a view of law adapted in medicine that a lack of patient capacity removes patient’s rights for decision-making, giving power and permission for the hospital to pursue its own goals for the patient.

Other rights were also ignored. Daisy had an extended stay in hospital without detention, despite her repeated requests to return to her place of residence. In this instance, the hospital may have been operating in the shadow of the law, with assumptions that her stay in hospital would be supported if any formal legal process

---

[60] This description of approach was not fully evidenced in the observed assessment, where there was strong influence by the consultant to favour the outcome of residential care. This suggests the influence of personal values to which the consultant may be unaware. The focus on consistency but not on understanding is not part of the common law principles, though is prevalent in medical ethics literature as ‘authenticity’.

was invoked. However, the lack of a clear policy regarding keeping patients in a secure setting without detention[61] and no audit or scrutiny of patient rights in this situation, suggests ignorance or disregard for the law in relation to a patient's loss of liberty and overriding paternalism.

In Kathleen's case, Dr Windsor had accepted the need for a capacity assessment as identified by the health care team. This approach was suggested earlier to be indicative of a lack of knowledge or clarity about duty of care, or the lawyers' obligations. At the same time, Dr Windsor demonstrated her understanding of other forms of law, in that she had spoken to the relatives and was satisfied that there was absence of 'undue influence', reflecting the integration of a legal responsibility. The consultant also referred to the guardianship legislation principles as a guide to Kathleen's situation:[62]

> *I don't think she had full understanding, but I think she believed that these were her people she trusted…and that they would do the right thing by her…and my understanding of the Guardianship Board Act is that they want informal arrangements, if they are working, to continue…*

The determination was an activity within the shadow of the law, with Dr Windsor anticipating the Guardianship Board outcome as supporting the status quo. In this way, the consultant justified her support for non-interference. Dr Windsor was also creating an innovation of law through adapting a principle of one form of law (guardianship), to justify an outcome framed within common law (capacity).[63] The finding that Kathleen had decision-making capacity through this reasoning avoided the need to invoke formal law and challenge Kathleen's delegations. The doctor used law to justify the outcome, though the interpretation indicated limited legal knowledge about the different purposes and distinctions of these laws.

---

[61] Interview with the social worker of the hospital unit.

[62] The Principles in the *Guardianship and Administration Act 1993* (SA) s 5 are
(c)consideration must, in the case of the making or affirming of a guardianship or administration order, be given to the adequacy of existing informal arrangements for the care of the person or the management of his or her financial affairs and to the desirability of not disturbing those arrangements; and
(d) the decision or order made must be the one that is the least restrictive of the person's rights and personal autonomy as is consistent with his or her proper care and protection.

[63] The *Guardianship and Administration Act 1993 (SA)* does not require an assessment of incapacity but evidence of brain impairment and inability of the person to manage their health or affairs.

The neuropsychologist, Tanya, assessed Tom on the understanding that activation of the EPA would be required for the division of assets between Tom and Jay. While the clinical team may have considered they were acting in the shadow of the law by activating the EPA, this response indicated their lack of understanding of the role of law in also supporting the informal relations that had been operating in the financial affairs up to that time. This included the importance of maintaining informal arrangements, which is a recognised principle in the guardianship legislation of their jurisdiction.[64]

This section has provided a number of examples of how variable knowledge of law becomes a dynamic in the interpretation of law in the everyday. In this instance, I am using the traditional view of legal consciousness as an understanding of law as a discrete set of activities relying on the knowledge of legal conventions (McCann and March 1996). With inadequate or patchy knowledge of these conventions, law becomes further vulnerable to unconscious distortions. The next section discusses the influence of medicine on law in this space.

Medicine as the dominant authority

The case studies were indicative of activities where law was subservient to the stronger codes and values of medicine. For instance, in Kathleen's case, the health care team disregarded the lawyer's duty of care to his client, believing that they had this duty of care. However, while intervening in Kathleen's private arrangements with her lawyer can be viewed as concern for her vulnerability, it can also be seen as indicative of the health care team's sense of authority in regard to their patients, and related to the dominant medical mores of control and oversight of the person's life while in hospital.

The use of neuro-psychological tests in capacity assessment was a demonstration of the medical goal of objective evidence and certainty. The neuropsychologist used these tests to assist in the assessment of capacity, rather than relying on the interview to assess functional understanding. However, the neuro-psychological assessment

---

[64] *Guardianship and Administration Act 1993 (SA)* s 5(c).

exceeded the common law requirement, and was indicative of the assessment practices prevalent in this medical domain.

The earlier example of Dr Harris using cognitive and physical assessments as part of a capacity determination demonstrates the overlay of the medical model of assessment. Medicine has modified capacity determinations to fit the medical approach. Medicine's focus extended beyond an assessment of 'understanding' to include substantive factors such as the social relationships of the patient, clinical assessments and the clinician's opinion. This is demonstrated by the social worker's description of the capacity assessment approach:

> *When we do a proper capacity assessment ... we need to look at different domains… what the geriatricians are looking at, what are his life decisions like, what does his house look like…what are his relationships like…how does he communicate with us…its multi-factorial…demonstrating he understands the seriousness of his illness…that he understands the risk factors…*

Clinical views about health, safety and best interests were influential in some of the case studies. Reg's social worker, Jane, found that the medical view about his physical needs superseded any views of his legal capacity. Her description of this gave an indication that medical norms were dominant in his assessment:

> *They were labelling him…people see physical frailness as the reason for people to go into residential care irrespective of their mental status…*

Jane also thought that doctors were making assumptions about Reg's capacity because he wished to return home in a poor state of health:

> *The old chestnut…if he had capacity he'd know he can't go home because he is too sick…that's the one that is always brought up…*

The priority given to the patient's physical status, and the imposition of value judgments about the patient's rationality, was an adaptation of the concept of capacity to suit the medical model. There was a lack of recognition of the patient's subjective views of their own 'good', and a substitution of the doctor's views of 'good'. In Lewis's assessment, the approach by Dr Royal towards capacity as requiring an understanding of Lewis of his 'best interests', also reflected traditional medical values. During the interview, Dr Royal also made value judgments about Lewis's stated preferences, particularly about ideas of safety, further demonstrating the power given to medical values. This traditional beneficence approach compels the patient to 'adopt the physician's values, levels of risk aversion, and professional preferences (Moulton and King, 2010, 86).

The dominance of the medical paradigm affected non-medical professionals within the hospital setting in different ways. For instance, the social workers in Andrei and Kathleen's cases collaborated with the heath care team in their focus on physical safety and the exclusion of the patient's voice. In doing so, they adopt the dominant medical discourse (Cheek and Rudge 1994; Sherwin 1992). The social worker in the second hospital, Jane, took a different approach, aiming for Reg's voice to be heard in order to counter the assumptions being made about him by the medical team:

> *What I did was get the team to listen and remind them of their legal responsibilities, motivate the team…to see changes enough to see him home…*

Despite some integration of medical values in her practice, Jane saw her professional social work role in the hospital as different to those using the dominant medical model. Therefore, to have some professional influence about her clients in the healthcare team, she worked strategically to 'insinuate' herself 'into the team, to build relationships there'.

Jane was aware of the hierarchies of power in the hospital in which she sought to exercise her own professional contribution:

> *In this particular environment…you identify the power differentials…even though I feel at the bottom of the ladder in terms of the medical model, I am quite a powerful person here, I know how it works…there's lots of barriers here to people being able to achieve what they can achieve…and [I am] working to overcome those barriers…*

The interpretation of law by the social worker in this context was one that supported her professional values, while at the same time avoided conflict with the medical team. While using law to support autonomy and choice for the capable person, Jane also recognised the intrinsic benefit of maximising the autonomy of patients with diminished cognition (Deci 1980).

Jane viewed that identifying the ‘legal situation’ for each client, such as their status in decision-making rights, was of value to the organisation: instead of prolonged case debates it clarified the (competent) patient’s right to pursue their preferences:

> *...pragmatically it gets people through the (hospital) machine quicker, with less mishaps, with better outcomes, less complaints…*

However, she observed the hospital to be ‘reluctant’ to incorporate a legal focus in their case management, with this indicating a resistance to law as having authority in medical processes.

While Jane interpreted respect for autonomy of the person as part of her social work role in the medical setting, some of the case studies indicated that this was not a standard approach by other social workers. This indicates the role personal values play in one’s professional identity. Such values also influence the interpretation of law, and this next section gives examples of different values about personhood influencing outcomes.

Attitudes and values about the person

In this thesis attention has been given to the concepts of personhood, which refer to the social and legal status conferred on the person. As described in Chapter 3, these vary according to different worldviews. The legal understanding is that the person has rights and duties. Law also, less consistently, views the person as having metaphysical attributes, such as rationality, sacredness, and as being an embodied or social being (Naffine 2009). While emphasis of the multi-dimensional person seems more representative of humanity, there are diverse worldviews about the attributes of the person that are given status, which influence the attitudes and behaviours towards persons (Naffine 2009). This section explores the different attitudes towards the person detected in the case studies.

Several of the case studies raised examples of minimal recognition for respect for the person’s views, such as in the case of Andrei. His exclusion from participation in the family discussion about his future was indicative of the low regard for the intrinsic value to the person of self-determination. Potential prejudices about cognitive changes can affect the perceived status of the person, which seemed active in this case.

In contrast, the social worker in the second hospital, Jane, held different views about the status of the patient in having insight to make choices, from both her social work and medical colleagues. She gave priority to maximising autonomy and supporting choice in ways that recognised their social right to self-determination and that enhanced the psychological well-being of the person, implying this was not always possible in the legal consideration of capacity:

> *…whether people have capacity or not is a legal question, and what ultimately guides us, but it's not necessarily the only professional path I take…we might need to look at what the person is saying… if we can give somebody without capacity that sense of autonomy, if we can involve families…in that process, we can still make the decisions…apart from it being a more humanitarian approach.*

The social worker considered that the authoritative medical environment created passivity in patients, and this led to neglect of their voice, which was heightened in the case of older patients. In response, she viewed her role as enabling the person to be heard:

> *…making overt the person's voice… creating a space in which the person feels safe to talk about themselves…It becomes problematic with older people because they've often learnt these behaviours and don't speak up...the doctor's always right, do what you're told. They become very vulnerable…*

While recognising the legal construct of capacity, Jane was affirming of social personhood. Her personal and professional values were person-centred, and in support of autonomy:

> *…one of the things I can do for people is not to do for, not to take over, not to make their decisions…it's what the person seems to want…the world from their point of view... I come alongside and help them.*

Jane went on to comment that while she strove to look at the world from the patient's view this was not possible all of the time, implying that hospital mechanisms claimed priority over patient-centredness:

> *I mean it sounds idealistic; I don't do this all of the time, sometimes its business as usual…*

While a number of the cases revealed medical practices that reduced the social status of the person, two of the clinicians, Dr Thomas and Dr Windsor, demonstrated attitudes and practices that were respectful of the person and their preferences. The geriatric liaison registrar, Dr Thomas, was responsible for the initial assessment following a capacity assessment referral. She described capacity assessments as a difficult area of her work, due to their impact on the psychological well-being of the person:

> *I think I feel less competent now that when I started- I find it quite an overwhelming area. The more one looks at it the more complicated it is, and to tell you the truth, if I can find a way around doing the capacity assessments I will, as it is so confronting for the person.*

While the task of capacity assessment was a part of medical conventions, Dr Thomas found the black and white approach to capacity and the effect on the person's choices and freedom problematic:

> *…if they are assessed and found to have capacity…it affirms their ability to make their own decisions. ..if incapacity is found, then that can be for the psyche of the individual a very destructive thing if they have any insight into the process…*

Dr Thomas described her concern about a case where the determination of incapacity was going to lead to an outcome that would reduce the patient's well-being:

> *I do feel very sad about the fact that she has been found not to have capacity to make decisions about going home, she will probably end up in an institution in which she will not thrive…that there was not a way that could have been found to have her managed and supported in the community.*

This comment by Dr Thomas indicated her concern for the person and the constraints on the patient's choice, and the issue of resource use, discussed as a structural constraint to autonomy in Chapter 3.

Dr Thomas' respect for social personhood extended to conversations with family members. She recognised that individual values and stressors on the family impacted on their decision-making choices for the older person. She introduced family members to the importance of self-determination, and influenced the family's decision-making, particularly when residential care had been mooted for the older person:

> *…so I have that sort of discussion with the family and talk to them about the seriousness of taking away somebody's right to make decisions and really present that as the last resort option…*

Concern for personhood was also evident in the involvement of Dr Windsor in Kathleen's case. The capacity assessment was enhancing of autonomy and person-centred. Dr Windsor gave attention to Kathleen's life meaning, preferences, and relationships, and validated her concerns. While Kathleen had difficulty explaining her delegation of substitute financial decision-making management, Dr Windsor gave a determination of capacity, in response to Kathleen's statement of trust in her family to manage her affairs:

> *I trust Brian and Joy, they are the people to do everything.*

In this approach, the consultant used a substantive approach, giving priority to Kathleen's trust in her personal relationships rather than relying on her generalised understanding of the documents.

The case examples demonstrate the pluralism of values held by clinicians and social workers in relation to the personhood of the patient. This pluralism is probably representative of wider society. Values towards personhood, both reductionist and enhancing, were highly influential in the approaches taken towards the patient and ultimately affected the outcome of the hospital intervention for the patient. Significantly, values about autonomy and personhood influenced the professionals in their interpretation and use of law. Family members had limited information about legal concepts and processes, making them vulnerable to the approach and authority of the healthcare professionals.

Another related aspect to personhood is that of respect for the person, as revealed in the interactions between the professional conducting the assessment and the person being assessed. This included the way the professional communicated to the vulnerable person in language and tone. An analysis of the interview transcripts revealed three different interview styles, the 'interrogative approach', the 'conversational' style, and the 'assessment' approach, with each approach having different effects on the person. I consider these styles to be suggestive of attitudes of the professional towards the person. For instance, the interrogative approach heightens the power differential, with the patient subservient, whereas the conversational style is sensitive to the person's sense of ease and indicates support for personhood. The assessment process shows that the professional has power associated with their expertise, but is respectful to the person.

The capacity assessment interviews varied in duration, with additional neuro-psychological tests in two cases. In the interrogative style, the interviewer asked a series of questions. In both of these interviews,[65] the interviewer tended to shape the questions towards a focus on care needs, and to the care solution considered appropriate by the healthcare team. The language used gave weight to the desirability of the outcome and the inappropriateness of the alternative. This style was also linked to a suppression of the patient's voice, as in the interview with Andrei, where the consultant ignored Andrei's expressed wish to return home.[66] The interrogative style also featured in Lewis' interview, which was long and at times confronting. He later told his wife Jenny that 'Dr Royal was there and she was really grilling me'. The interviewer using this style has a business-like and distant stance, which could be confronting to the person.

In contrast, the conversational style used in Kathleen's interview was relaxed and informal. The consultant spent time at the beginning of the discussion 'establishing rapport' with Kathleen, who responded positively. The consultant empathised with Kathleen's concerns about the uncertainty of her discharge plans, and gave her information about Enduring Powers of Attorney. Kathleen appeared at ease in the assessment and was positive about the interview, reporting to her relatives that the consultant was 'a nice lady', in marked contrast to the previous interview about her affairs that had caused her distress.

The assessment style of the neuro-psychologist who interviewed Tom was friendly, but the interview was long and methodical. Tom gave his view of the assessment to the social worker:

> *Marta (neuropsychologist) spoke very clearly and left huge gaps for me to reply so I could not fault her. Wasn't laughing but I got very emotional at one stage because Jay and I have been together nearly 50 years…*

Daisy found the long neuro-psychological tests tiring, but persevered. She joked during the interview and when reminded how important the assessment was by the neuropsychologist, said to herself:

---

[65] The interrogative style was identified in the interviews with Andrei and Lewis.

[66] The interviewer did not respond to Andrei's comment of his situation being 'the beginning of the end'.

> *Be serious Daisy, this is important for what happens to me …on the ball…*

When asked if she was finding it difficult or needing a break, indicated her general comfort with the interview style:

> *Happy to have you ask questions- you're interested in me…'*

This approach had the interviewer giving information to the person being assessed about the concerns of others, which can be confronting. Daisy, when told of some of the concerns others had of her, became suspicious*:*

> *Tanya: ACAT was concerned about you…*
> *Daisy: (crosses arms) what were they worried about?*
> *Tanya: that your memory…*
> *Daisy: you're building up to something. What do you want me to do?*

There was a marked difference in the style used by the professional assessing, with the reactions from the case study participants demonstrating their greater comfort in the conversational and assessment styles. The two professionals using the interrogative style also demonstrated overt bias in the interview, as discussed in an earlier section.

The qualitative information about the process of the capacity interviews, and the earlier procedural analysis, aids in understanding more about the 'personal nature of encounter between the assessor and the person assessed' (Donnelly 2010, 173).

This section has reviewed attitudes and values towards the person and their self-determination, as indicative of respect and conferred social status. Overall, there was a diversity of values and attitudes found from the analysis, with numerous instances where social personhood was both enhanced and diminished. These values about the person, especially where cognitive changes are present, influence the view of legal personhood and accompanying rights.

The case studies highlighted the nuances of law in the everyday. The interpretation of law was contextual and affected by knowledge and experience, personal and professional values, medical codes and conventions, and roles and power differentials. This interplay of factors resulted in different interpretations of law in relation to the patient's autonomy and capacity, and in the production of legality unique to that setting, made transparent the 'real location of the decision-making powers' (Donnelly 2010, 278). The final section explores the different forms of legality produced.

The law in action

Different forms of legality that are produced in societal interactions were described in Chapter 2 as being 'conformity *before* the law', engagement *with* the law, and resistance *against* the law' (Ewick and Silbey, 1998,45). Using this schema as a base, some additional classifications were created to demonstrate some nuances between the different observed expressions of legality.[67] The categories used here are *invoking* the law, *avoiding* the law, *adapting* the law, and *resisting* the law.

Invoking the law

Capacity assessments are an activity operating within the shadow of the law. They are used to solve a problem relating to decision-making, recognising law as a final arbiter. Their alignment with the law in books and courts is variable, due to the many factors involved in the way law unfolds in everyday life.

In a number of the cases, there was consideration of invoking formal law, such as in the option of making application to the Guardianship Board. Law was also invoked as a set of 'operative controls…communicating symbols of threats, promises, models, persuasion, legitimacy…' (Galanter 1981, 13), illustrated by the social worker using mention of 'the law' in order to support the autonomy of the patient:

> *I always had the trump card- 'I'm sorry but he has capacity and this is what he wants to do… it's not for me, but (what) the law says'. I do tend to take a legal approach because I find that is a shared language…*

In this instance, invoking the law verbally was highly effective with the clinical team, and indicated the effectiveness of law's symbolic nature.

Avoiding the law

The approach of the healthcare team reflected the systemic and cultural focus on medical and social problem solving, with avoidance of law until a barrier was

---

[67] For instance, the case analysis identified practices of 'invoking the law' and resulting specific 'innovations' which can both be seen as part of 'engagement with' the law, and avoidance behaviours which can be understood as a sub-grouping of 'against the law'.

reached to their practice where law offered a resolution. In many cases, this use of law enhanced the social control of medicine, especially for patients who did not meet the threshold of capacity. This supports the idea that many practices applied in the everyday world are ‘not always the expression of harmonious egalitarianism’ but ‘often based on relations of domination’ (Galanter 1981, 25).

Law was also avoided in some of the cases in order to enhance the autonomy and personhood of the patient. Dr Thomas viewed capacity assessments as restrictive and, with each patient referred, investigated the contextual situation for other solutions to the problem, leaving capacity determinations as a last resort:

> *…it is not uncommon when you dig into the issues to find that it is not the issue and you do not need to go down that path…*

In one case described by Dr Thomas, the healthcare staff had made a referral for a capacity assessment, as the patient was uncooperative with her rehabilitation. In talking the situation through with the patient, Dr Thomas found she was able to resolve the problem informally:

> *...so we are not going to go through the process and I see that as a success.*

Dr Windsor’s approach in Kathleen’s assessment avoided invoking the formal legal processes of the Guardianship Board, through a decision to support informal arrangements that were preferred by the patient. Therefore, avoidance of the law had both the goal of maintaining medical power, but also in another instance to provide greater autonomy to the patient, indicating the suppleness of these problem-solving strategies.

Adapting the law

Capacity assessments, while aligning ‘with the law’ are also an innovation of law. They represent the medical endeavour to implement the law regarding consent into a process that is congruent with the medical approach of objective evidence-based assessment. This has led to the development of tools and tests that in some cases have diverged from the simple test of understanding, and in some cases are complex. The use of neuro-psychological tests, with their objective value, has become adapted into this process, even though their role is to assess brain function and not capacity (see Wood 2007). The debates in this area of literature are representative of the reactions and tensions to these innovations, with some commentators challenging the ability of assessors to implement the artificial construct of ‘capacity’ (Welie 2001; Sabatino and Basinger 2000).

The use of capacity assessments to solve a future problem, as anticipatory insurance for case management, such as in Andrei and Tom’s case, was an adaptation of the law. Another innovative use of law occurred when the social worker in Daisy’s case sought a finding of capacity, which would allow her to challenge the ACAT assessment of Daisy’s ability to manage her daily activities. The use by Dr Windsor of principles from guardianship legislation to justify maintaining the status quo, when Kathleen did not reach the capacity threshold, was an example of adapting law to the particular context.

These examples show how the application of law can be adapted to achieve particular ends.

Resisting the law

The case example of Reg was indicative of the priority given to a paternalistic view of Reg’s best interests, with law’s support for autonomy having minimal status or recognition. This example illustrates the ethical debates in health law and practice regarding principles of beneficence and autonomy, and can be seen as symbolic of medicine’s resistance to law’s support for non-interference.

In the exploration of these cases, medicine appeared to give law minimal conscious attention. More broadly, there are tensions between the disciplines of law and medicine. In particular, the law of torts, based on a principle of non-interference, is challenging to medicine, being non-commensurable with medicine’s interventionist approach. While the doctrine of consent and capacity provides the legal framework for health law, the case studies demonstrate how medicine can resist and subvert law, creating itself as a ‘viable substitute’ in the maintenance of its power relations and *modus operandi*, which includes a reductionist approach to autonomy (Marshall and Barclay 2003, 625). In this way, law and medicine are in opposition.

In summary, this section has described the production of legality in the everyday world, through the window of the case narratives. The everyday world was the bounded domain of the hospital, which is a complex mix of conventions, policies, practices and processes. Law, in this primary setting of medicine, was of secondary concern to the actors, with knowledge of the law not a high priority. The medical culture was powerful in shaping the roles, interactions and hierarchies in this setting, creating its own law.

The unique interplay of contextual and cultural influences in the interpretation of law in everyday practice led to varying outcomes for the person who was the subject of law. The focus on physical outcomes, being a priority of medicine, imposed these values onto the patient's decision-making processes. The interactions in the everyday within this complex and pluralistic environment produced different forms of legality, which co-existed (Ewick and Silbey 1998). There was avoidance and resistance to law, but where necessary, law was utilised and manipulated in diverse ways, consciously or unconsciously, to achieve desired outcomes. Such ends included the enhancement or diminishment of autonomy of the patient/person, and the maintenance of clinical power relations and order in the setting.

III Conclusion

This chapter has focused on the analysis of the legal and socio-legal domain of the case studies. Using the lens of the artificially constructed and internally rational world of law, the practices of capacity determination were compared with the messages from the courts. While they took place in the shadow of the law, the capacity determinations in the case studies did not accurately represent how the law may approach these cases in any formal adjudication. With the majority of the capacity determinations not meeting the common law standard, these case examples identified in detail where practice departs from law. These findings confirm the diversity of approaches towards capacity assessment, and provide valuable information about the application of the legal construct of capacity in a healthcare setting.

While contemporary law offers a prescription for behaviour to society, based on societal mores, it has become complex with its internal rules, language, and meaning, and more removed from folk law consciousness (Cotterrell 1992). The translation of contemporary law seems an unrealistic task for those outside of this legal world, suggesting the need for interpreters, with a foot in both worlds, who can assist to bridge this gap.

The second part of the chapter analysed the interactions of law with society through the hospital setting. While law shapes many of the practices in health care, the case studies demonstrated variable and often limited legal consciousness of law, with a distortion of facts, diverse interpretation, and the development of local myths. The study demonstrated the adaptations of legal constructs by medicine to suit the clinical approach and achieve desired outcomes. Law's value of non-interference, and support of autonomy, being non-commensurable with traditional medical values, was resisted in some cases. Law was therefore found to be highly 'malleable' (Galanter 1981) in the production of legality to achieve certain ends (Ewick and Silbey 1998, 17).

The pluralism of values in the health care setting led to activities that were in accordance with the dominant collective medical culture, but there were also acts of individual resistance to practices that were oppressive to personhood and autonomy. This included activities of avoiding or invoking the law, indicating that relationships are instrumental in the expression of autonomy (Nedelsky 2011).

These activities lend themselves to the view that 'law is whatever people identify and treat through their social practices as "law"' (Tamanaha 2000 in Harding 2011, 31). Law in the everyday is not only the subjective interpretation of formal legal concepts in practice, but extends to those rules developed within groups that reflect their social values (Cotterrell 1992). In creating its own law, medicine holds some values that are in conflict with that of formal law, but also with those groups who resist the paternalism that prevails in medicine's internal rules.

Values, as ‘conceptions of the desirable society…held in common by its members’ Parsons 1967, 8), become central to the operation of society and law (Cotterrell 1992, 30). Values ‘imbedded in social institutions’ offer legitimacy to the social system and shape social roles (Cotterrall 1992, 83). While there are different views as to the influence of law on values (Cotterrall 1992, 50; Nedelsky 2011), the socio-legal analysis of the case studies has confirmed the central importance of values in the expression of law and of understanding of personhood.

Chapter 8 Reclaiming personhood and autonomy in decision-making

At the start of this thesis, I set out to explore the interface of decision-making and personhood for vulnerable older persons, through the lens of law. My aim was to investigate the moral and legal personhood of older persons with cognitive changes, and how and when autonomy becomes diminished or 'lost' by such individuals.

The fictional story of Faith illustrated some common changes to autonomy resulting from the cognitive and social effects of dementia. Overarching this story was the frame of law, providing a structure for self-government and relations with others. Individuals and organisations interacted dynamically within this socio-legal domain, further influencing Faith's expression of autonomy.

In Faith's story, brain changes were characterised by her diminished abilities and limited insight. However, the essence of her personality and sense of self was apparent in her character. The story conveyed her strong desire to continue living in her home, and in this context, the decision by others to impose an intervention of residential care represented a violation of her intrinsic sense of self. This intervention represents the complex mix of attitudes towards ageing, mental impairment and physical safety and dignity, which can be at play in this type of scenario. It is characterised by limited recognition of the person's psychological needs and of life meaning as important to well-being. In this example, protection was given priority over autonomy. This story conveyed the gamut of factors that are influential in understanding the interface between decision-making, personhood and the law, and provided a framework for this study.

A discussion of the intrinsic relationship between autonomy, selfhood and law (Nedelsky 2011) framed the cross-disciplinary exploration of literature in the initial chapters. The first chapter identified the salient characteristics of autonomy from the liberal tradition, and identified non-intervention as its main mechanism to support autonomy. The account of various affronts to autonomy illustrated the power dynamics that can occur in social relations, which do not respect the person, and where the mechanism of non-intervention is therefore ineffective.

The second chapter explored the legal framework of decision-making capacity in common law, its relationship to the liberal notion of autonomy, and the controversies and limitations of this approach. Relevant pieces of legislation were analysed for the ways in which they construct the inherent attributes of autonomy, demonstrating that over time, the law has adopted a broader concept of autonomy in recognising fluctuations in capacity, and enabling support in decision-making. I outlined the idea of law as existing in, and through, the activities of the everyday world, and the resultant adaptations of law's message to particular contexts and relationships.

The third chapter explored notions of personhood and their contextual permutations, such as the approach to personhood to be found in medical discourse. A fuller multi-dimensional understanding of the person, contextualised in relation to approaches to the person with dementia, gave a richer understanding of the concept of personhood. From this personhood basis, I identified some decision-making approaches as alternatives to the prevailing rational/cognitive model, suggesting that these have validity within the freedom provided by law for the informal resolution of human problems. These alternatives include approaches that incorporate contextual considerations into procedural assessment, but also approaches that support self-determination without the requirement of capacity, instead facilitating the person's life meaning and values to take expression.

To research different perspectives of the phenomenon of decision-making and law in relation to vulnerable older persons in the everyday, in Chapter 4 I outlined a methodology based on social constructivism. The subsequent perceptions of advocates and guardians from the focus groups, and in-depth data from the case studies in two hospitals, allowed comprehensive data analysis, with the findings presented in the following three chapters.

Chapter 5 provided an analysis of the perspectives of advocates and guardians in their championing of autonomy and personhood for older persons, both those with intact cognition and those with changing cognition, and highlighted some prevailing social attitudes and practices that altered the autonomy of this group.

In Chapter 6 I presented the background stories of the six case study participants and the stages of their hospital intervention. The informal decision-making processes revealed by this study gave a general picture of depersonalisation, disempowerment and the imposition of others' solutions to the non-medical issues confronting the older 'person as patient'. Language, attitudes to cognitive changes, and differing values characterised the influences on the expression of autonomy in this context.

In Chapter 7 I analysed the processes of capacity determinations by reference to common law principles, finding significant variation from law, and adaptation to particular circumstances. I found that the expression of law in everyday activities was shaped by factors such as knowledge of the law, personal and professional values, and the norms of the prevailing medical culture.

In this final chapter, I discuss the implications of these findings for the ideas, knowledge, and debates about decision-making. I also review the concepts of autonomy and personhood from the information gained about those vulnerable from physical, cognitive or social ageing. I review the implications arising from the gap between the law and the practice of capacity determinations, and the effect of alternative sources of authority, such as medical authority, on decision-making. I revisit the notion of autonomy and re-imagine Faith's story, from the perspective of respect for her full personhood.

Giving weight to the relational understanding of autonomy, I propose a person-centred model for decision-making that is respectful of the person and their well-being. I comment on the interface between the person-centred approach and law within the broad socio-legal domain, and the default role of capacity determinations. Lastly, I discuss future directions for integrating the approach of relational autonomy, as expressed in person-centred decision-making, into law, policy and practice.

As the concepts of autonomy, personhood and law intertwine conceptually and in everyday life, any discussion cannot fit in neatly bordered categories. However, I will commence with an exploration of autonomy and its relationship with societal norms of ageing, the assumptions and prejudice about cognitive decline, and the relationship of autonomy and personhood, as informed by the study findings.

I Autonomy in theory and practice

Although it is often strongly critiqued, the liberal notion of autonomy remains a significant societal ideal that pervades the current social order, including the law (Christman 2003). As discussed in Chapter 1, it takes the form of protecting individual freedom, asserting confidence in the competent individual to shape their life and pursue their own idea of good, without judgement or intrusion by others (Mill 1906; Christman 2003). However, a broader understanding of autonomy is emerging that recognises its socially constituted nature, and expands the notion of personhood.

In this section, I explore the expression of autonomy in the everyday activities made transparent by the study findings, commencing with attitudes to ageing.

The impact of ageism

The case studies indicated that the liberal ideal of respect for autonomy was not evident for some older persons in the study who might lay claim to this right. For instance, the advocates gave accounts of older persons with intact cognition as subject to subtle but recognisable forms of ageism and discrimination. This took particular forms in institutional and organisational practices, where those providing services often did not listen to the older person’s voice, giving prominence instead to what they thought was ‘good’ for the older person. The resulting paternalistic practices observed by the advocates reduced the person’s freedom and was demoralising to the individuals concerned. There was little apparent or intentional recognition of the psychological needs and well-being of the older person, including the intrinsic benefits of self-determination, and its link to motivation and life meaning. Moreover, there was interference in the chosen life course or experience of some older persons by family members and care organisations.

The findings from the focus groups and case studies about attitudes towards older persons can be understood to be indicative of broader societal discomfort with ageing, and its associated disability, dependency and mortality (see Cuddy and Fiske 2004; Nelson 2005; Kite and Wagner 2004); Sherwin 1992). Paternalistic behaviours that depreciate personhood can be projections of these attitudes (Nelson 2005; Kite and Wagner 2004).

This phenomenon indicates that societal norms are not keeping pace with key demographic and social changes. For example, societal investment in medical technologies has come from the collective desire to conquer illness and extend life, but the increase in longevity has also resulted in a longer period of unwanted disability in later life (Access Economics 2003). Longevity appears desirable, but this is conditional on an accompanying quality of life. By extension, older persons, as the recipients of the societal goal of longevity, become victims of this societal ambivalence when they become frail (Becker 1994; Lovitt and Wilkinson 2010), leading to subtle social denigration.

From the findings, ageism and the paternalism that results from stereotypes contributes to the ongoing diminution of autonomy of this group. Critically, society has had to develop specific advocacy services to intervene against such impositions towards older persons due to limited natural protection occurring within the social order.[68] These societal attitudes remain a barrier to respect for autonomy for older persons.

Cognitive status and autonomy

In addition to the influence of ageism on autonomy, the cases also gave evidence of behaviours leading to the diminishment of autonomy for persons with perceived cognitive impairment. For example, assumptions of cognitive changes led to service providers excluding the person from decision-making, without any clear evidence for doing so. This finding implies that cognitive impairment *per se* (rather than legal incapacity) is sometimes a cause for a denial of the freedoms that usually come with

---

[68] Advocacy services for older persons, with a focus on rights, exist in every state in Australia, funded by the federal government.

full autonomy. For instance, advocates reported that service providers assume that the presence of confusion or memory loss equated to the global loss of decision-making ability in older persons, consequently by-passing their views and preferences. The presumptions became an acceptable justification for suppressing the person's voice and seeking an alternative authority, or giving priority to their own view of the person's best interests. There was little recognition of the residual autonomy of those with mental impairment.

The social exclusion of persons based on cognitive disability alone, rather than the legal standard of incapacity, is discriminatory, and weakens the liberal tradition of protecting those who meet the autonomy threshold. However, this legal threshold appeared to have little traction in the cases, with any presence of cognitive impairment appearing to lead to the social and legal exclusion of persons. This finding supports the view that the cognitive-rational ideal remains prevalent (Post 1995), with social norms reinforcing the narrow view of the person's status as dependent on being a ‘cognizer’ (Charland 1998, 70), regardless of any legal threshold. The presence of cognitive frailty in the case study participants appeared to be perceived as a social weakness that diminished the worth of the person and exacerbated the diminishment of their autonomy. In these instances, there is high dependency on others for the expression of their autonomy.

Autonomy and personhood

The idea of the multi-dimensional person, with embodied, cognitive, affective and relational attributes (Naffine 2009), is intertwined with a relational concept of autonomy. Both of these concepts recognise the value of the individual and of each life as unique. They also recognise the interdependence of humanity and understand persons as gaining identity and support for autonomy from their social roles and relationships (Naffine 2009; Kitwood 1997; Nedelsky 2011).

However, the findings indicated that this range of personhood attributes as recognised by law received little recognition. For instance, guardians reported that family members and care personnel frequently resisted their support for the autonomy and inclusive decision-making of their clients, disregarding the essential value of self-determination of the person, and conferring minimal social status for decision-making. Similar attitudes and behaviours about social personhood were also apparent in the case studies. The informal decision-making process for non-medical decisions in the hospital showed that ‘solutions’ to the patient’s ‘problem’ were developed externally to the patient, often without the patient’s inclusion or acknowledgement of their wishes or preferences. The health care team constructed the solution from their viewpoint, and negotiated its acceptance with the patient, family members and care services. The health professionals treated compliance of the patient to the proposed solution as a sign of insight and capacity, but there was further erosion of social personhood for those who were viewed as lacking insight about their own good.

These practices exacerbated the loss of social identity and the sense of self in the vulnerable older person, resulting in a weakened ability to resist the covert and overt imposition of values, and to protect one’s interests (see Cohen 1990; Benson 2005; Stoljar 2013; Mackenzie and Rogers 2013).

Despite such disempowerment, the person’s character, history, life meaning and authenticity of preferences clearly emerged in the narratives about each case participant (see Tetley, Grant and Davies 2009), reflecting the multi-dimensional aspects of their humanity. There were instances where health professionals acknowledged the person beyond the medical focus, and acknowledged their preferences and needs. ‘Respect for people’s choices, autonomy and well-being [is]often summed up as person-centredness’ (O’Connor and Purves 2009, 95).

Several health professionals reported a sense of powerlessness in relation to some of the negative outcomes for the vulnerable older person from the broader medical system, which they were unable to counter. These individuals were female, perhaps therefore having greater social permission to express empathy. However, gender and empathy may not be strongly associated: a female clinician imposed her values on the patient, and a female social worker collaborated in disempowering practices. The values held about personhood appear to be of greater significance than the influence of gender *per se*, though greater numbers of female clinicians may assist in modelling practices that enhance personhood (Boulis and Jacobs, 2010; Roter and Hall 2004). Such health professionals require the ability to resist full conformity to the prevailing culture, and broader medical education about person-centred approaches could further support these practices.

Overall, the intertwined nature of autonomy and personhood was evident from the findings of the study, where particular attributes reflected the social worth of the person and were influential their expression of autonomy. Predominantly, older persons with physical and mental frailties experienced a reduction in both their personhood and autonomy, resulting in the imposition of values and constrained choices. Where there was respect for the person’s unique life meaning and values, autonomy was an expression of the deeply held authentic values of the person, implying recognition of their ability to value, and not just reason (Jawoska 1999).

The study showed that, in general, autonomy was afforded little respect both on the traditional basis of the cognitive rational threshold, or on an expanded understanding of personhood. In both instances, autonomy and personhood reflect each other, as self-determination gives expression to the attributes and values of the person, with their values reflected in choices made. Therefore, both are vulnerable to overt and covert erosion at the personal, organisational, disciplinary and societal level in everyday interactions (Sherwin 2012, Nedelsky 2011).

II Decision-making law in theory and practice

The previous section has considered the relationship between autonomy and personhood. In this section, I consider the findings in relation to law and decision-making.

In Chapter 2 law was described as providing formal rules for the social ordering of society and the resolution of human problems. Relatively few human conflicts actually result in cases before the courts, with the majority of human conflicts and problems resolved informally (Cotterrell 2006). Law is effective in casting a shadow over these informal relations, achieving social order through threats and promises

(Galanter 1981). Systems of formal law are available in those instances where significant human conflicts remain resistant to informal resolution in everyday life. I now focus on the findings from the case studies in relation to the everyday implementation of the legal construct of capacity, and the effect of other sources of authority to law, such as medicine, in adapting this legal construct.

Capacity determinations in practice

The construct of capacity is a source of controversy, as outlined in Chapter 2. Perspectives from disciplines such as philosophy, psychology, medicine and neuroscience challenge the concept and its implementation. Such contentions include the artifice of the ‘bright line’ of capacity (Donnelly 2009, 475; Sabatino and Basinger 2000); the limits of the cognitive rational basis and new evidence about intuitive thinking (Kahneman 2012); the role of values in decision-making (Charland 2001); and of decision-making as a shared rather than singular activity (Nuffield Council of Bioethics 2009). Despite the view that the construct of capacity is unable to solve all ‘decisional dilemmas in health care’ (Welie 2001, 147), there remains an expectation by many that the use of this legal construct is appropriate and effective (Marson et al 1996).

The study I undertook showed a gap between the theory and practice of capacity determinations. This was evident through the variability in approach to the determinations, the lack of clarity as to the actual purpose of the assessment, and because the determination finding did not consistently reflect the common law basis for deciding capacity. Legal principles, such as those that provide for the least restrictive alternative for the person and of maintaining familiar arrangements where possible, appeared unknown and under-utilised, and capacity assessments were not treated as a last resort. From a legal perspective, the study supported the view that those undertaking the process of capacity determinations, largely ‘bumble through’ (Kapp 2002, 413).

The findings identified that there was limited knowledge of the law by those undertaking capacity determinations. Donnelly suggests that the ‘full meaning’ of the legal standard of capacity ‘can only be appreciated in the light of the body of case law’ (2010, 173), and Cotterrell suggests that the complexity of law relies increasingly on those with legal knowledge, such as lawyers, for translation (2006). Without sufficient legal literacy, or ready access to legal consultancy in the medical arena, distortions are an obvious outcome.

Education in itself is not a guarantee that capacity determinations, undertaken in the socio-legal domain, will align with law. Adaptations of the law can also result from the projection of personal values onto the decision-making process, and from conformity to the expectations arising from the professional role and its cultural environment. For example, medicine’s codes and conventions, such as strong risk avoidance, along with pressure to support medical recommendations, can insidiously constrain the options that then frame the approach in the capacity assessment. In one case study, the incapacity determination was perceived as support for the authority of the healthcare service to proceed with the outcome as medically constructed, despite resistance from the patient. In this and similar instances, the capacity assessments were adapted to serve the discipline and its institution, and thus became a form of social control.

Capacity determinations carried out in the shadow of the law may lead to more restrictive outcomes than would be the case if the same judgments were made in the courts (Galanter 1981). There appeared few informal safeguards in the case studies, as might occur when family members have sufficient confidence to challenge the medical authority. There was also the lack of a formal safety net for these instances, such as independent audits or the use of independent second opinions.

Cotterrell suggests that the study of law in interaction with society gives an indication of society’s prevailing character: ‘society’s nature is expressed in and through law’ (2006, 29). The findings from the case studies indicate that medicine can exert subtle forces of control through the legal construct of capacity, indicating some of medicine’s predominant values.

Medicine as an alternative source of authority

As capacity assessments occur predominantly in health settings, the study findings about the relationship of medicine and law are significant. In Chapter 3 I discussed the concept of medicalisation and the adoption of scientific positivism that creates an ideology and ‘truth’ from this knowledge base (Cheek and Rudge 1994, 41; Waitzkin 1989) and the extension of this discourse into broader society and its values (Robertson, 1990). In the analysis of the case studies I examined some of the ways in which medicine gives priority to its own source of authority and truth above that of law. I found this to be particularly the case with patient autonomy, which is a vexed and unresolved issue in the practice of medicine (Beauchamp and Childress 1994; Veatch 2009; Gillon 2003). While medicine is protective of its own sovereignty, connected to the view of the doctor as the expert, it does not have a similar respect for patient autonomy, which challenges this power basis.

Philosophically, in relation to their dominant goals, it appears that medicine and law have non-commensurable approaches. Donnelly suggests that these differences have ‘normative contexts’: medicine’s focus is on healing, while law has a focus on protecting the rights and status of individuals (2010, 165). There are also normative differences when viewed from the perspective of autonomy as in this study: medicine is interventionist, with its *modus operandi* of diagnosis and physical treatment of bodily ills, while in contrast, law supports the liberty of the person, which takes the form of freedom from interference (unless consent is given).

From the study, I conclude that medicine responds to law with activities that resist or adapt law to meet its own ends, and law, which can be an intrusion, becomes instead a tool of medicine (see Ewick and Silbey 1998). The disconnection between capacity tests and the constructs of law, illustrated in the study, was a result of the medicalisation of capacity assessments, and is an example of an innovation that aids medicine to maintain its *modus operandi*, and achieve its desired outcomes. This is congruent with the view that ‘[l]aw may be withheld or excluded from domains that have their distinctive norms and norm enforcement’ (Engel 1995, 134). Engel suggests that law may be ‘“domesticated” in ways that assimilate it to the values and perspectives of the social order… [contributing] to a sense of stability, at least among those who benefit from the preservation of the status quo' (1995, 168).

The approach of medicine is significant due to its expanding 'gaze' (Foucault 2000, 129), leading to greater scrutiny of persons as patients in healthcare institutions than when they are living in the everyday world. As older persons constitute a larger proportion of hospital patients and enter health institutions more frequently than other age groups,[69] they are subject to more detailed observations and examinations, including of their cognitive status, than would otherwise occur, and are therefore more vulnerable to direct social control (Waitzkin 1989).

In relation to decision-making, the medical scrutiny of patient capacity has also extended from that of healthcare treatment to non-medical areas such as managing finances, driving and accommodation (Darzins, Molloy and Strang 2000). While the concepts of consent and capacity have their basis in the doctrine of consent, the extension of these assessments into lifestyle decisions, 'medicalise' normal social conditions and lifestyle transitions (Bond 1992). This evolution in medical practice was confirmed in the study and deserves further scrutiny. There is already a foundation for challenging the appropriateness of clinicians to undertake capacity assessments due to their own socialisation within medicine's paradigm, but specific attention is required of medicine in undertaking capacity determinations outside of its direct medical expertise.

The study demonstrated that assessing capacity for social and personal decisions extends beyond the uncontested knowledge base and authority of medicine in relation to disease. Doctors have expertise in assessing and diagnosing mental impairment, as part of treatment and management strategies, and as information to aid a capacity determination. However, I view that assuming expertise in assessing capacity for decisions related to lifestyle may extend this authority too far. While social work members of the multi-disciplinary care team may have this expertise, as seen from the findings, they can also be constrained by the medical discourse.

---

[69] People aged between 65-75 years are twice as likely to be admitted to hospitals as the rest of the population and those aged over 85 years are more than five times likely to be admitted to hospitals (Report-SA Health, Health Service Framework for Older People 2009-2016, 6).

I conclude that it is appropriate to consider an alternative arrangement for capacity assessments in the medical environment, where the decision is not of a medical nature but concerns a social matter. The provision of independent assessors, who are outside of and therefore not constrained by the medical paradigm, would offer a greater neutrality and expansiveness towards options. Such assessors would require knowledge of legal principles, but also be able to incorporate person-centred approaches to the process, similar to guardians. Purser suggests that such a development would meet the need for a 'neutral fact finder' in capacity assessments who would give necessary attention to issues of 'bias, honesty and expertise' in the assessment process, and check the actual facts (Purser et al 2015, 10).

An alternative to independent assessors is to have independent scrutiny of capacity determinations, particularly if the determination will result in unwanted, restrictive or irreversible outcomes for the person. Such scrutiny would ideally take the form of an interview with the vulnerable person, due to the need to identify subtle disempowering processes that would not be transparent in case files. With ongoing awareness and education, healthcare staff could develop a protocol on decision-making, with a form that outlines the actions taken to expand choices for the person and seek least restrictive options, which could have an independent audit. While the incorporation of person-centred approaches in healthcare in the future may make such interventions unnecessary, they appear justified in the short-term to protect the autonomy of vulnerable persons.

In this section I have discussed the implications of the study findings in relation to medicine's adaptations of capacity determinations, and the constraints of this on the autonomy of vulnerable persons. To ensure greater support for autonomy in decision-making, and to safeguard against oppressive outcomes, I conclude that independent assessment, or additional scrutiny, is warranted.

III Toward an alternative model of decision-making

The previous section discussed the findings in relation to how law was utilised by medicine to maintain its disciplinary authority. In this section, I review the evolving concept of relational autonomy and re-imagine Faith's story from the perspective of enhancing her autonomy as an expression of selfhood. Giving weight to a relational understanding of autonomy, I propose a person-centred model for decision-making that is respectful of the person and their well-being. This model recognises that autonomy is essentially socially constituted, and seeks to enhance rather than test capacity, as a means to achieving a meaningful, authentic and just outcome for the older person. I then consider future directions for promoting and integrating person centred decision-making.

Autonomy revisited

The study findings give substance to the idea that the traditional view of autonomy does not adequately encompass the nature of personhood. While freedom from non-interference in the exercise of autonomy is an important value of liberalism, it neglects the social, political and legal norms that operate to structure relationships and practices (Downie and Llewellyn 2012). The concept of relational autonomy provides the lens for identifying social relations, structures, and activities, at the micro and macro level, that reduce autonomy (Nedelsky 2011; Harding 2014). As such, the traditional liberal model of autonomy, with its static character and narrow boundaries of cognition, is inadequate in consistently supporting the emerging understanding of personhood and autonomy. Instead, autonomy is increasingly understood as socially constituted, and the person is 'encouraged to retain and express their sense of self, rather than simply be protected from harm or interference' (Nuffield Council of Bioethics 2009, 21).

The case studies provided nuanced examples as to how the dynamics of social relationships, power differentials, and prevailing values, diminished or enhanced autonomy. The findings reinforce the idea that autonomy is socially constituted, and support the relational view of autonomy as a valuable construct in understanding the dynamic influences on the older persons' selfhood as shaping their ability and expression of self-determination (Nedelsky 2011).

This emerging concept of autonomy does not aim to meet the philosophical threshold requirements of self-government (Mackenzie and Rogers 2013). Instead, it embraces full personhood beyond the cognitive divide, where the person's humanity is expressed through their activities of self-determination:

> *A loss of capacity does not necessarily mandate a commensurable loss of autonomy… Capacity deals with the issue of whether or not the relevant legal system recognizes an individual's right to make particular decisions. Autonomy is more fundamental. It is generally concerned with the right to make and implement our choices…Whatever the precise content of autonomy, our claim to it is based on our humanity (Surtees 2014, 450).*

The resulting 'personhood' (Kitwood 1997) or 'empowerment' (Donnelly 2010) approach to autonomy incorporates the traditional liberal values of the intrinsic right of determination, but is situated within a social and relational context, recognising the interdependence of humanity and the role of social relationships in constituting and supporting autonomy. This approach understands autonomy's responsive nature, and seeks to identify opportunities to enhance autonomy. Its relational basis 'rehabilitates liberal autonomy by recognition of factors that inhibit it' (Downie and Llewellyn 2012, 6).

Relational approaches can improve the well-being of those vulnerable to societal effects on autonomy, through validating identity and selfhood, and providing support for self-determination. This was illustrated in the self-reported actions of the guardians, who stated that they sought opportunities to enhance their client's well-being and autonomy, demonstrating that changes in cognitive function do not need to result in further disempowerment. Their approach included features of the model of 'presuming capacity' (Dubler 1985) through a focus on consistent wishes and preferences, and of 'supportive decision-making' (Flynn and Arnstein- Kerslake 2014) through including the person in decision-making and responding to their choices, as described in Chapter 3.

However, the guardians experienced resistance by some health professionals and service providers to this type of approach, indicating limited acceptance of its value base. There is a significant social challenge in integrating the concept and values of relational autonomy into social norms and practice, including decision-making practices (Nedelsky 2011; O'Connor and Purves 2009), with Flegal and Macdonald suggesting that:

> *Exercising control…may be the last remnant of our ability to retain our humanity'(2008, 127)*

At the beginning of the thesis, I gave an account of Faith and the responses to her autonomy as her dementia advanced. Before describing the details of a decision-making approach congruent with a relational approach, I firstly imagine how the person-centred values, applied to Faith's story, may have led to outcomes that were enhancing of her autonomy and personhood.

Faith's story re-imagined

Could Faith's story have unfolded in a way that recognised some essence of her autonomy and personhood, and responded to maintain her well-being while respectfully seeking to meet some of her unmet care needs? I have rewritten the last part of Faith's story, from the time when the doctor and nephew visit and propose that Faith requires residential care.

The GP and nephew visit Faith and express concern for her well-being. They propose to Faith that it would be beneficial for her to go into respite for a few weeks, but Faith reacts strongly against this idea. Recognising Faith's instinctive desire to stay in her familiar environment, the doctor suggests to Faith's nephew that dementia home supports are tried first. The GP makes a referral for dementia support services for Faith. The social worker from the service visits Faith again, who is still quite adamant that she does not need any help. The social worker, understanding that there is limited tolerance to Faith's current situation by family members, perseveres. She asks a worker to visit daily to initially chat to Faith and gain her trust, and they involve Sarah the neighbour to assist with this. Sarah visits Faith at the time of the worker's visit, introducing Jenny to Faith over a cup of tea, and builds some rapport with her. Jenny decides to visit each lunchtime to ensure Faith eats when her meals are delivered.

After a week of visits, Faith allows Jenny to provide help in the kitchen with the dishes, and then to assist with laundry. Faith has poor hygiene but refuses showering assistance and Graham suggests that home care is not sufficient for his aunt's needs. The service asks for more time to build trust, and Jenny, in suggesting taking Faith out to lunch and the hairdresser, has Faith agree to have a shower beforehand, and put on clean clothes. Over the next month a routine develops that maintains hygiene. The District Nurse continues with daily medication supervision, and on weekends a care-worker visits to ensure that Faith remembers to have a meal, and to buy Faith her favourite meal of roast chicken on Sundays. Faith's neighbours are visited by the service and are encouraged to maintain visits and meal invitations on weekends.

As Faith's dementia progresses she is taken to a day care centre several days a week. Care visits increase and workers visit Faith each morning to assist with showering and breakfast, and each evening to check she has eaten and is orientated for bed. The service liaises with Graham over essential purchases to assist Faith.

Over the next six months, Faith begins to lose recognition of her home environment and of objects and needs constant orientation. She has responded well to the day respite, and it is decided to have her stay overnight in preparation for long-term care. Faith does not raise objections and participates in the activities. Her short-term memory is poor and she does not ask about returning home, and is cheerful with the company and routine. The service suggests to Graham that residential care is now appropriate, and with his agreement, an appropriate residential care setting is located. Faith is linked with a care worker who works as a 'buddy' to ease her transition to the new environment, which occurs seamlessly.

There are many possible stories for Faith, each contingent on the particular situation, the attitude and values of the players, the interpretation of their particular duties, and the resources available. In this alternative story, I have given attention to the way that values in support of Faith's psychological well-being and self-determination had priority. Apart from knowledge of the options available, and access to appropriate and flexible services at the time needed, it also requires others in the story to place the worldview of the person first, and avoid imposing restrictive solutions based on their own views of best interests.

This is an idealised, but not impossible outcome, as seen by the approach of the guardians, and as can occur through family support and the work of community based services.[70] However, the experiences of guardians suggest that there is a prevailing tendency of the community to view such persons as requiring the protection of institutional care. Even where there is motivation to pursue person-centred outcomes, life and relationships are messy, and it may not be possible to achieve the seamless care and attention to Faith’s psychological, as well as her physical needs, described in this revised story. The caring burden for family (Donaldson and Burns 1999; Chappell and Reid 2002), coupled with limited services, are common and real limitations, even when there is a desire for person-centred outcomes.

The person-centred approach can be applied to the case study of Daisy. Recognition of her wishes and lifestyle suggested that the option of institutionalisation was not supportive of her holistic well-being. Re-constituting Daisy’s previous lifestyle would have required strong advocacy and investigation regarding the bureaucratic barriers. If this was not possible, an alternative residential arrangement, which was responsive to her need for a sense of independence but with some care supports, deserved exploration. Working across service systems of mental health and aged care may have offered synergies between resources. Most particularly, it required those in the healthcare setting to give greater priority to her personhood, and to thinking beyond constrained options.

The idea of a person-centred relational approach to decision-making for vulnerable persons has been emerging in the literature (O’Connor and Purves 2009; Harding 2012). This requires a nuanced decision-making process that integrates key understandings of personhood and their expressions in practice, with the goal of

---

[70] I was a social worker in a community geriatric service in an earlier career, where people with dementia were supported to live at home, despite advanced cognitive impairment, through the support of care workers, day centres, nursing and meal services.

maximising autonomy. Using the results from this case study research, and with reference to some of the different approaches outlined in Chapter 3, I describe an ‘ideal’ schema for application in the everyday. In contrast to paternalistic approaches, where the ends of protection justify the means of intervention, this approach seeks to have both the ends and the means of decision-making enhance autonomy and personhood.

A person-centred decision-making schema

A person centred approach to decision-making draws deeply on the person’s life meaning and the contextual aspects of their life. It is affirming of individual worth and respectful of the person’s life values (McCullough et al 1993), recognising the intrinsic value of self-determination. It also understands the harm that can result from exclusion from decision-making and imposed solutions to life’s challenges.

The approach supports autonomy and freedom beyond the current cognitive divide, with life-long held values of the person equal to or more significant than reasoning ability, recognising the person as a ‘valuer’ (Jaworska 1999, 130). The person is socially situated, with their autonomy influenced by the quality of their relationships, such as the presence of empathy and trust.

The approach seeks to take into account the knowledge and concerns of others, but also aims to identify where value judgments and competing conflicts of interest may result in unnecessary restrictions, manipulation or control. In addition, it seeks to enhance autonomy through expanding options, and supporting the person in their decision-making, and in activating that choice. In this way, the model connects to the negative and positive rights of liberal philosophy, through both respect for freedom to be self-determining, and the provision of supports to empower those who have limited personal and social assets. Lastly, where significant barriers to the person-centred approach prevent resolution, the model connects to the legal capacity model, guided by common law, as a default mechanism.

Chapter 3 considered a number of approaches to decision-making that offered an alternative to the capacity approach. These included the combined substantive/procedural approach (Breden and Vollman 2004; Darzins, Molloy and Strang 2000); the partnership approach (Glass 1997; Flynn and Arnstein-Kerslake 2014); the presumption of capacity approach (Dubler 1985; Herring 2009); and the hermeneutic/narrative approach (Benaroyo and Widdershoven 2004; Hughes, Louw and Sabat 2006). While giving different emphases, the essential element of the last three of these approaches is of empowering the person to be self-determining, and of respect for the life meaning and purpose of the person. In utilising these themes, and combining them with learnings from the case studies, such as the need for awareness of bias from professional values and of conflicts of interest, I have devised a schema that can be utilised as an alternative guide to the capacity approach in medical and community service settings.

While aspirational, this approach also provides a practical evaluative approach to the 'problem' and creates a suitably high threshold for resolution before resorting to the capacity approach. There are many varying approaches proposed in literature, with some discussed in Chapter 3. Ethical decision-making approaches are also well established (Kerridge, Lowe and McPhee 1998, 84). I therefore hesitate to add to this proliferation, but do so to demonstrate the lessons learned from this study. It is, as such, 'a work in progress' within this emerging domain of new approaches to person-centred and relational decision-making (Berghmans, Dickenson and Rudd 2004, 261).

There are four stages to the schema: assuming capacity; knowing the person and their context; creating and expanding congruent choices; and supporting the person in the decision-making process. Where a default capacity approach is required as a last resort, and the person does not attain the capacity threshold of understanding, the focus is on substitute decision-making that takes the preferences and life meaning of the person into account.

Assuming capacity

In this stage, the service provider starts with the assumption that the older person has capacity. This assumption is based on the idea that the older person has resilience, experience, wisdom, and knows what is important to them, despite cognitive impairment (Dubler 1985). There is recognition that emotion and values remain intact long after cognitive abilities have diminished, with intuitive responses predominating. In this stage, cognition is not the basis of decision-making capacity. Responses by the person that are congruent with life-long values confirm the presumption. While incongruent responses could be a challenge to this presumption, this stage requires service providers to consider respectfully the current preferences of the person. This approach recognises that as humans, while we change over time, including cognitively, we 'exercise our autonomy on who we are now' (Surtees 2014, 450).

Where there is dissonance between previously held values and the current expressed wishes, present preferences have priority unless advance care directives, indicating different wishes, are in place.[71]

Knowing the person

An understanding of the life story of the person, their significant values, their view of their current situation, and the significant persons in their life, is crucial. One study has shown that the gathering of the person's life story in a clinical setting 'helped practitioners to see patients as people' and also forged closer family relationships (Clarke, Hanson and Ross 2003, 695). There is emphasis on building rapport and trust with the person. Those in close relationships can contribute to the story of the person, and give their perspectives and concerns. This is in recognition that people involve those close to them in shared decision-making (Roberto 1999). In addition, there is the opportunity for family members to understand the values and preferences of the person, and by bringing both parties together to discuss 'potential care needs' of the person, reduce the knowledge gap that can contribute to conflict (Whitlatch, Piiparinen, and Feinberg 2009, 226). This conversation can be aided by the use of 'Values and Preferences Scales' (Whitlach Piiparinen, and Feinberg 2009, 226) or by creating a 'values map' (McCullough et al 1993). A list of strengths of the person is compiled as a reminder of their full personhood and resilience. There is also a reframing from the 'problem' approach to recognising the current challenge as part of life.

---

[71] These vary between jurisdictions, but can include verbal and written instructions. For instance, the *Advance Care Directive Act 2013* (SA) s 9(e) 'ensures that the directions, wishes and values of a person who has given an advance care directive are considered'.

These activities are opposite to automatic stereotyping, requiring energy, effort, attention, and openness (Cuddy, Norton and Fiske 2005).This stage aligns with the information-gathering step and the evaluation of the trigger step in the Darzins model (2000). Communication and transparency of the issues at this stage may provide resolution (Darzins, Molloy and Strang 2000).

Creating choices

This stage requires exploring, creating, maximising and facilitating choices for the person that is as congruent as possible to their personal priorities and values, as applied in the current situation. It may require imaginative identification of resource options and services (Higgs 2004), with an understanding that ‘respect for justice …require[s] a range of options’ (Donnelly 2010, 4). This stage also includes identifying potential conflicts of interest, value judgments, attitudinal restraints, oppressive practices, and resource constraints that are potential barriers to the person’s choice, bringing the different arguments together as elements of the narrative, subjecting them to analysis and opportunities for consensual resolution (Higgs 2004).

This stage explores where the choices of the person may result in potential harm to the person, or affect others. The goal is to ensure that risk aversion per se does not result in the imposition of unnecessary restrictions, but takes a contextual and individual approach, with strategies developed to minimise potential harm where possible. Any potential risks from the choice need to be balanced with the benefits to the person, including psychological risks and benefits (Nuffield Council of Bioethics 2009; Denson 2006).

Supporting decision-making

This process focuses on assisting the person to understand the relevant information, and requires spending time listening, offering information, repeating information in several sessions as necessary. In addition to natural intuitive thinking processes, this process facilitates reflective thinking depending on the person’s capabilities, to ensure the person understands as much of the choices and consequences as possible. This requires time for the person to reflect and ‘let ideas mature’ (Tyrrell, Genin and Myslinski 2006, 490). From this process, a collaborative plan involving significant others is formulated, and assistance given in linking to resources and services to aid its achievement. This may include some negotiation with others about managing risk (Huby et al 2004).

The default capacity approach

After all efforts to enhance autonomy and support the goals of the person have occurred in this person-centred approach, the issue may be unresolved. There may be strong concerns regarding the practicality or potential harm for the person, or resistance by those in significant relationships with the person, creating an impasse in finding a way forward. There may also be a lack of resources to enable the preferred choice to be enabled practically. Capacity determinations, using procedural approaches such as in Darzin's model, are the default process. This requires the assessor to ensure that there is a brain impairment related to decision-making, to suspend value judgments and measure the rational-cognitive ability of the person to understand the choices and consequences (Darzins, Molloy and Strang 2000).

If achieving the legal capacity threshold, the person receives assistance to follow the choice through, but, if not, a substitute decision-maker makes the decision, using a person-centred approach based on the preferences and well-being of the person. Where autonomy, and consequently participation and supported decision-making, is particularly limited due to advanced cognitive impairment, the task of the substitute decision-maker is to continue the person's life story as it is understood that they would write it (Blustein 1999). The decision-maker views the decision from the position of the person's values and life view, known in ethics as 'substituted judgment' (Kerridge, Lowe and Stewart 2009, 251).

This section has described a process of decision- making that incorporates the values of personhood. This process will have the greatest success within an environment that values personhood and human flourishing. The approach gives the ideal process, understanding that humans facilitating this process vary in their skills, emotions and beliefs. However, the process uses the relational lens to aid dynamics that affect the expression of autonomy to be transparent, and provides guidance to navigate these complexities. A full description is in Appendix 8.

Table 19 The stages of the person centred decision-making schema

Stage	Tasks
Assuming capacity	Involves a focused attitude on the person as a adult with preferences developed over a long period of time
Knowing the person	Involves gaining an understanding of the person's life, its meaning, and the role of significant others. A list of strengths are compiled, and the values of the person and family in relation to the current situation identified in dialogue, along with barriers.
Creating choices	Involves exploring, creating, maximising and facilitating choices for the person in relation to their situation and preferences, and clarifying risks and identifying resources that could assist with the preferred outcome.
Supporting decision-making	Time is spent with the person discussing the relevant information, choices and concerns of others, leading to the development of a collaborative plan.
Default legal capacity approach	If the issue remains unresolved, or unsurmountable barriers restrict the person's choice, legal capacity is assessed using a value-neutral procedural approach. Support is given to the substitute decision-maker in making any decision.

This schema can appear to be a combined substantive/procedural approach, utilising the capacity approach as a second stage, such as in the Darzin's model (2000). In many ways, this schema can be seen as an elaboration of Darzins model. To an extent, this is true; however, the significant difference is that the person-centred schema, conducted in a sympathetic setting, can stand alone as the process for supporting decision-making. The second major difference is that the vulnerable person's perspective takes priority, rather than the viewpoints of others in the setting. Lastly, this schema provides an evaluation of the reasons prompting the assessment, by questioning who has the problem, and identifying the prevailing norms and other interests that led to the construction of the problem.

In the next section, I discuss the relationship of this model with the legal approach of capacity determination in common law.

The interface with law

In Chapter 2 I described the distinction made between 'law' as the formal realm of legal institutions and actors, and 'legality' as activities that respond to the law in the informal domain (Ewick and Silbey 1998, 22). In this section, I distinguish the interface of decision-making within these two realms.

Law encapsulates the liberal ideal of autonomy. It utilises the legal fiction of decision-making capacity (Sabatino and Basinger 2000) to achieve a binary outcome in relation to decision-making (Donnelly 2010). This legal construct provides the function of clarifying when the state ‘legitimately may take action to limit an individual’s right to make decisions’ (Sabatino and Basinger 2000, 120) with law providing in these instances the appointment of a substitute decision-maker (Kerridge et al 2009). Donnelly, in exploring alternatives in response to the limitations of this construct, concludes that ‘a standard based on capacity would still seem to offer the best option in respect to sorting healthcare decisions’ (2010, 130). In the formal arena of law, such as the courts, the capacity approach, with its basis in common law, is the recognised legal standard.

This legal standard has extended into the informal domain. Operating within the shadow of the law, this construct is utilised in health care settings, by non-legal actors, to resolve everyday problems. This is a practical application of law in the everyday, says Skene, as the alternative requirement of using formal legal processes to appoint substitute decision-makers would be ‘burdensome’ (1998, 134). However, as seen in the case studies, this construct alters during its application due to a dynamic interplay of factors within this informal domain. As a result, instead of value neutral approaches towards the determination and minimal restrictions to the autonomy of the person, other interests are served. This outcome, combined with the exclusions resulting from the capacity approach, has led to my conclusion that capacity determinations should be a last resort in the informal domain. Instead, a person centred approach, which aims to enhance rather than test autonomy, is warranted. Such an ‘empowerment’ model is not a legal model, suggests Donnelly (2010, 7), and as ‘this view of autonomy blurs the boundaries between capable and incapable, it still does not provide a foundation for a legal and ethical framework within which to deal with decisions made by people who fall outside of the autonomy “norm”’ (2010, 47).

However, from the perspective of everyday law, it can be argued that this approach has equal status to the innovations of the capacity approach in the informal realm. Within law’s value-neutral domain, there is space for a range of normative responses.

In its broadest sense, law provides a space for activities that may be enhancing or reducing of autonomy. The person-centred decision-making process of enhancing capacity is free to operate in this domain. It offers an approach based on the value of respect for all persons, in contrast to capacity approaches that narrowly define personhood and can result in diminished autonomy and oppressive outcomes. The underlying legal frame to person-centred approaches can be considered as closer to human rights conventions than to the constructs of healthcare law, with the human rights framework offering a model for participative decision-making (Donnelly 2010; South Australian Office of the Public Advocate 2009; UNCRPD 2006).

In an understanding of law supporting principles of autonomy and justice, the evolving social constructionist understanding of relational autonomy allows the creation of 'new' expressions of law in the everyday. In this way, it has both a moral and legal validity. However, there are also calls to legally incorporate person-centred approaches; the disability and human rights advocates seek to have supported decision-making approaches recognised in law, so that the individual maintains 'legal capacity' as enshrined in the UN Convention for the Rights of Persons with Disabilities (2006 s 12). Co-decision-making laws enshrined in some Canadian jurisdictions are seen as early adopters of this principle (see Schindler and Waksman 2014; Browning, Bigby and Douglas 2014). This extends the current legal approach of supporting decision-making through the provision of advance care directives, and limiting restrictive guardianship, through proposed new provisions in Victoria of appointments of 'supportive guardian', in addition to the traditional guardian role.[72]

Restoring liberty by providing legal decision-making status to those with significant impairment through co-decision-making has some way yet to travel. However, as 'changes in law come from society itself' (Cotterrell 1992, 29), the resulting synergy from these emerging directions may reshape law in the future. Such changes link to the idea of law being 'therapeutic' (Winick 1996), with a goal to 'enhance the potential' of persons (Perlin 2000, 1047-8), and completing the circle back to the

---

[72] The Victorian *Guardianship and Administration Bill 2014* s 6(6) contains provisions for a 'supportive guardian to give assistance with decision-making rather than substitute decision-making.

relational view of law (Nedelsky 2011). Such changes occur in response to changing societal values:

> *...the nature of law shows that legal reforms usually take place only when new methods have been accepted by the field (Berghmans, Dickenson and Rudd 2004, 261).*

Whether approaches to enhance autonomy eventually lead to changes in law, they commence with expanding use in the everyday world. This relies on domains and actors where priority is given to social personhood and this will require change in prevailing societal values, which I address in the next section. Even in environments where the person-centred approach is utilised, barriers to successful resolution may require default to the legal safety net of the capacity approach. As discussed, these capacity determinations require closer adherence to common law principles, and a value-neutral procedural approach (see Purser, Magner and Madison 2015). Where there is dissatisfaction with the outcome of a capacity determination, formal legal systems, such administrative or guardianship tribunals, can be invoked.

While advocating for the precedence of the person-centred approach to decision-making in the informal domain, I recognise some situations where the person-centred approach is not applicable. For instance, law requires certainty in its commercial and legal transactions, and competence of the parties is an essential requirement of any legal contract (Caffrey 1991). Secondly, a person-centred approach has limits where supporting someone’s preferences may lead to a criminal activity, or may render the supporting person liable for negligence or open to prosecution (Flynn and Arnstein-Kerslake 2014). Thirdly, there are instances where the legislative requirements override informal activities, such as the capacity threshold in advance care directives.[73]

In summary, this section has explored the interface between law, capacity and person-centred approaches to decision-making. There is recognition of the informal socio-legal domain, where there is freedom to use the person-centred approaches in the navigation of human problems, with recourse to the legal construct of capacity when necessary. There are emerging new directions in enhancing autonomy through

---

[73] *Advance Care Directives Act 2013* (SA) s 7(1).

supportive decision-making, and restricting guardianship, which may shape law in the future. At times, the activities in the everyday will lead to an invoking of formal legal processes, using systems such as tribunals and courts, where concerns persist. Requirements of some legal transactions exclude person-centred approaches and rely on the capacity approach for legal certainty.

In the final section, I outline some of the strategies that can be utilised to facilitate understanding and use of the person-centred approach to decision-making in everyday life.

Future directions

This thesis has indicated some of the ways that the legal and social personhood of vulnerable older persons is eroded in decision-making processes. Reclaiming this personhood requires a change in prevailing societal values that affects personal, social, legal and political domains. Ageism, paternalism and prejudice towards persons with physical and mental ageing, present as the predominant causes of this diminishment of personhood, and influence the expression of autonomy.

There are recognised social mechanisms that have an influence on social values, attitudes and behaviour in society. These include strategies of social awareness, knowledge transfer, social policy, services, law, and research. An example of the use of such mechanisms to shift social attitudes and shape behaviour is that of the campaign to reduce smoking. This has been achieved through the sustained use of media to promote anti-smoking messages, price disincentives, changes in cigarette packaging to remove status symbols, and regulations regarding restrictions in smoking in public places. As a result, smoking is perceived as ‘no longer cool’ (Killoran 2011). This campaign demonstrates the success of such social strategies, but these require significant social and political investment. The very existence of ageism is one reason why social investment in changing attitudes to ageing may be low. Nevertheless, I outline some of the ways these strategies can be utilised to work towards the goal of valuing personhood and integrating person-centred approaches to decision-making, to benefit this group of vulnerable citizens.

Social awareness

Citizens are socialised with messages over their lifetime that serve to shape their behaviour, contributing to an ordered society. This mechanism can be used for social purposes. For instance, there are organisations that advocate for improved attitudes towards ageing through transmitting key messages in annual campaigns (COTA 2015). The Alzheimer's societies have also recognised the issue of the stigma of dementia, with resultant media campaigns, resulting in a large shift in public awareness towards dementia in the last two decades. Increasing societal acceptance of dementia is represented through such activities as the portrayal of persons with dementia and with other disabilities in movies and books.[74] These events, and other types of social media, influence the values of persons, but with the insidious prevalence of negative attitudes, building greater respect for marginalised persons in society is a slow process of social evolution.

As well as positive community education strategies, it may be necessary to expose prejudice and discrimination through a 'naming and shaming' approach, such as occurs in drink driving campaigns. As people respond well to positive incentives, the development of an annual award to reward and celebrate the integration of person-centred decision-making models is a possibility, giving public recognition to effective individuals and organisations.

Knowledge transfer

The knowledge for this study of the gap between theory and practice in capacity determinations can be transmitted. This can raise awareness of the risks of misusing capacity assessments, and knowledge on how to ensure that such processes are fair. Dissemination of this knowledge can occur through journals, seminars, conferences and formal in-service education of health and community professionals. There is a need for greater awareness and dialogue about practices that currently reduce personhood in healthcare. Potentially, strategies can be developed through collaboration between consumer organisations and the government sector concerned with safety and quality in healthcare. The promotion of alternative person-centred practices may provide support to sympathetic health professionals and aid in shaping

---

[74] Recent movies include *Still Alice*, about a college professor with Alzheimer's, and *The Theory of Everything,* about Stephen Hawking).

medical and organisational culture. These include education seminars with doctors, social workers, patient advocates and patient consumer groups, and a broadening of education opportunities on decision-making during and after medical training.

Greater dissemination of information about alternative decision-making models is necessary. For example, documentation of the person centred decision-making approach by the guardians, and its promotion to those involved in the care of vulnerable persons, can support alternative practices.

Social Policy

The case studies gave evidence that the legal construct of capacity determinations became distorted in application, highlighting the various influences at play in the medical setting. Healthcare policies are required that render capacity determinations as a last resort, and encourage person-centred responses. Recent successful examples in policy development are health care policies in end-of life care, and of advance care directives, designed to integrate these approaches into clinical practice.[75]

A policy about safeguards of decision-making requires development, considering options of independent assessors for social decisions in healthcare, or for a system of scrutiny of capacity determinations that occur in hospitals. The development of a protocol on decision-making, that outlines the efforts made to expand choices for the person and seek least restrictive options, for independent audit, is one possible safeguard. The approach, structure, implementation and costs of such safeguards require study. Such a role fits the mandate of the Office of the Public Advocate,[76] but would require government resources to implement.

Policy attention to resource inadequacies and inequity that constrained choices is another area requiring greater policy attention, particularly in examining the consequences of these limitations on the person’s life and outcomes.

---

[75] The South Australian Department of Health and Ageing has implemented clinical policies for staff in these areas.

[76] The Public Advocate’s duties include ‘to promote the rights and interests of any class of mentally incapacitated persons’ in the *Guardianship and Administration Act 1993* (SA) s 21(1)(c).

Services

Funding agreements and organisational policies of services can reflect values related to respect for autonomy and its maximisation, as well as system fluctuations in service quantity (Lovitt and Wilkinson 2010). An example is the recent shift to ‘consumer directed care’[77] in the delivery of federally funded consumer services, which gives greater choice and control to the consumer. An extension of this approach is appropriate for the residential care sector, and for state-funded community services.

Education of healthcare and community service personnel about the law appears necessary, especially in relation to risk avoidance practices and duty of care concerns. It is also valuable for a greater understanding of the freedom to utilise person-centred approaches, and its contra-indications for use, to avoid unnecessary legalism and resulting restrictions.

Law

Knowledge arising from the study of law and society indicates that while law provides a structure to order society, there is wide variation in the success of law in achieving compliance in its citizens. As seen in this thesis, law can be misconstrued, or adapted to meet other ends. However, law can be utilised and adapted for the enhancement of autonomy. For example, in the study, the guardians used legislation to enhance their authority to maximise the autonomy of those with mental impairment.

Law maintains structures that organise relations, ‘which in turn, promote or undermine core values’ such as equality, justice and respect for autonomy (Nedelsky (2011, 65). As law shapes relations, Nedelsky suggests that attention to the relational aspects of law is important (2011). The analysis of legislation in Chapter 2 indicated some evolution of guardianship law in relation to a broader understanding of the person and reductions in restrictive responses to vulnerable persons. Where jurisdictions have guardianship legislation with dated global concepts of incapacity,

---

[77] The Australian government has introduced consumer directed care into the Home Care packages programme, see <https://www.dss.gov.au/sites/default/files/documents/ 08_2014/ home_ care_ packages_guidelines_2014.pdf>.

reforms are appropriate to incorporate contemporary approaches to maximising capacity and supportive decision-making. For instance, the *Mental Capacity Act 2005* (UK) has incorporated principles such as providing practical support for decision-making.[78] While South Australian guardianship legislation, for instance, has principles of value to autonomy, such as considering preferences and seeking the least restrictive alternative[79], these principles only apply to appointed guardians, but could extend to include health and community service personnel. Advance care directives are also legal provisions that promote the autonomy of persons (Donnelly 2010), and it is appropriate for each jurisdiction to update these provisions to reflect contemporary understanding.[80]

Therefore, while law cannot ensure changes in social values, it can provide legal frameworks that can support the expression of autonomy by vulnerable persons.

Ongoing research

Lastly, there is the opportunity for further research to test these findings more broadly, especially in the areas of healthcare and community care. This study involved broad perspectives from focus group participants, and six in-depth case studies. While the findings of the studies confirmed prevailing themes in literature, and offer valuable lessons for learning from each case, the small case study set does not allow generalisations to other settings and cases. Duplication of the case study approach in other settings can test the findings arising from this study.
‘Few studies have investigated the nature, determinants or consequences of respectful treatment’ (Joffe et al 2003, 106), and further research can also occur into models of decision-making in practice that recognise relational autonomy (Nedelsky 2011) and promote well-being (Tyrrell 2006), and the model described in this thesis can be evaluated and refined in practice.

This section has reviewed a range of mechanisms that can be utilised to shape society’s values in support of enhancing the autonomy of vulnerable older persons. Effectiveness may increase where synergies between these methods are achieved.

---

[78] *Mental Capacity Act 2005* (UK) s 1(3).
[79] *Guardianship and Administration Act 1993* (SA) s 5.
[80] AHMAC National Framework for Advance Care Directives 2014.

IV Conclusion

This chapter has discussed the implications of the findings from the study.
The findings indicate that respect for the autonomy of the older vulnerable person is eroded by negative attitudes towards ageing. This ageism is at odds with the reality of current and projected demographics in relation to longevity, but remains a current and powerful barrier to the expression of autonomy of this group. Prejudice about those with cognitive changes, despite the presence of legal capacity, leads to the person’s voice being excluded and restrictions to their activities of self-determination. Where cognition is significantly impaired, residual autonomy is rarely acknowledged. Overall, there is a personal and societal resistance to accepting frailty and subsequent dependence as part of the human life cycle.

In relation to capacity determinations, the gap between theory and practice has a link with a lack of legal knowledge, which causes distortion of law. However, capacity determinations are also shaped by prevailing values in the setting. These adaptations constrain choice and self-determination, and can lead to the imposition of solutions, thereby being autonomy reducing. There was limited recognition of the intrinsic value of self-determination and the effect on well-being of the person. Such activities appear particularly prevalent in medical settings, where the authority of medicine predominates. Further, capacity assessments of personal and social decisions, rather than those concerned with medical treatment, do not fit with the available medical expertise and culture. I propose that independent assessors would provide a safeguard. Alternatively, there needs to be scrutiny of determinations where restrictive outcomes for the person may result.

I consider that that the use of the legal frame of capacity should be a last resort. Instead, approaches to decision-making that incorporate a fuller conception of autonomy than the traditional liberal concept are required, reflecting the essence of the person and their life meaning, as expressed through self-determination. With the understanding of autonomy as socially constituted, societal structures and relationships are recognised as enhancing or diminishing of autonomy. From this position, person centred approaches to decision-making, which aim to enhance rather than test autonomy, deserve priority. Respect for the person is of primary value in this approach, with the recognition of a range of attributes of personhood. In support of this approach, I propose a person centred schema for decision-making, and claim that such a model has equal legitimacy to the capacity approach in the space provided by law for the informal resolution of human affairs.

There is an overview of potential future directions in community education, knowledge transfer, social policy, services, law, and research in response to these findings.

Overall, the increasing demographic of older people with changing cognitive abilities, and the associated prejudices, gives an imperative to ensure fair and just approaches towards this group. Society requires new responses to a population where the increased prevalence to cognitive impairment becomes the new ‘normal’, and where current practices indicate a diminishment of freedom and respect for autonomy in this domain.

Conclusion

This thesis has explored the character of autonomy and the well-being of vulnerable older people as symbolised by, and given effect through, decision-making. This has incorporated an understanding that the freedom to make one's own decisions is a basic attribute of liberty in western democracies, with law creating and maintaining the space within which citizens are free to direct their own lives.

However, the traditional liberal view of autonomy, based on freedom from non-intervention, fails to achieve this ideal of freedom for many older people in the everyday world. Negative attitudes, linked to a wish to avoid the rigours and losses of old age, restrictive stereotypes, and power imbalances, diminish the personhood, self-identity and autonomy of many vulnerable frail people. Society is not, in general, age-friendly.

While older people may be classed as vulnerable due to their biological aging and increased dependency, the greatest threat to their overall well-being comes from other people. Many of the ageist and paternalistic behaviours detrimental to well-being may well be unconscious or thoughtless, but tend to expose a lack of empathy by persons and an arrogance in imposing one's view of good onto another. This is to some extent a consequence of the liberal paradigm, in that people have the freedom to be egocentric. At the same time, this freedom to develop and express an individual worldview is not matched by a reciprocal respect for another's freedom to also shape their lives in the way they wish. Mutual respect appears minimal, and becomes particularly obvious in the relationship dynamics of later age.

Cognitive changes are a natural part of ageing, but feared by many people, which exacerbates the low social status of older persons in society. The pity and patronising of persons experiencing these changes has a link with the liberal threshold of exclusion, which is based on mental acuity and reasoning. Developing into prejudices, there can be further diminishment of social personhood and accompanying social and legal constraints. Ironically, such reactions continue to entrench social values that may well be active and adverse to the current younger cohort in later life. Just as our society is uncomfortable with death, there is also an inadequacy in integrating an understanding of ourselves in the entirety of the life span, including our inter-dependency.

The socio-legal domain of decision-making has been explored in in this thesis using a unique approach that integrated cross-disciplinary knowledge and perspectives in an analysis of the phenomenon of decision-making. The contrived and contentious legal construct of incapacity, with its basis in the liberal model of autonomy, has been shown to be difficult to apply in practice, as well as being disenfranchising to some. Law is reliant on utilising a contrived construct that does not reflect the reality of decision-making. The construct of capacity, creating exclusion for some, generates a space where lesser legal citizens become vulnerable to the value impositions and expedient actions of others. The story of Faith illustrates this, where the conclusion to her life story was diminishing of her personhood and quality of life.

While law, with its principles of procedural fairness and equality, can protect the rights of decision-making for some, it is not well understood or accurately applied in the everyday. The study showed a significant gap between the law in books and the law in practice, which is not just from lack of knowledge, but also distorted by other interests that can lead to law being ignored or adapted. Contextual attitudes and practices significantly influenced the shaping of personhood, the construction of the problem, and the implementation of the capacity construct. The in-depth case study research provided valuable insights as to how norms and structures contribute to the variable interpretations of law. This confirms that law is socially constructed, that law and society exist in dynamic interaction, and that law is malleable in the everyday. Procedural principles in law, which seek to ensure fairness, were undermined by the predominant values of the medical setting.

Medicine has strong interests in maintaining its own authority. Medicine enjoys high status and power in society, and presides over a large and institutional structure, with highly commercial and lucrative offshoots, positioning science as its truth. The objectivity of the scientific approach tends to predominate against any holistic view of humanity and well-being. The study demonstrated that decision-making in the medical domain, a common setting for older persons, was constructed in response to this cultural paradigm, and that law was adapted to suit the purposes of medicine. The case studies identified a reductionist approach to the autonomy and decision-making involvement of the older person. As an older person, one is more likely to require medical services, but is also extremely vulnerable to an even greater loss of autonomy in these settings, where oppressive activities are justified by the expanded medical approach of judgements into the personal combine with paternalism towards frail age.

From the perspective of law's role in society, there is often freedom to resolve issues informally without invoking the use of formal law. I extend this to include the avoidance of invoking the legal construct of capacity unless absolutely necessary. This would require a higher threshold than was observed in the case studies presented. While the capacity construct has a role to serve law and therefore society's interests, care must be taken that it is not misused as a tool of social control in order to serve specific interests, at the expense of the older person's selfhood. Adapted as capacity assessments were in the study, they serve neither law nor the person. Where they meet this threshold, and the decision is in the personal or social domain, independent assessment is desirable. Such decisions, already complex, require a different value set to that of medicine. If this is not possible, independent scrutiny is required as a safeguard where the outcome of a determination leads to lifestyle restrictions for the person.

These medical adaptations of the capacity construct are based on the validity of law, however loosely. This leads to the irony that personhood may be better protected by disregarding law, (or adapting law), if informal alternatives that support personhood can be assured. However, such assurance is limited, given society's prevailing values, but transparency regarding the subtle imposition of control and its ill effects on persons will continue to add weight to the necessity of a societal shift in approach to what has remained relatively acceptable in society:

> *…when you grow old, you will stretch out your hands, and someone else will gird you, and bring you where you do not wish to go. John 21:18*[81]

---

[81] With acknowledgement to Flegal and MacDonald 2008.

This leads to the review of autonomy, and the emerging understanding of the person as socially constructed and shaped within a network of relationships as recognising the dynamic relational nature of autonomy. This concept offers a richer perspective on personhood and well-being, and there is a slowly growing acknowledgement in commentary towards this expanded understanding of autonomy. Emerging views are also assisting in reclaiming autonomy and personhood for persons with cognitive impairments such as dementia, based on a worldview where identity is socially constructed and based within culture and relationships.

With the appreciation that the social environment shapes the attributes and abilities of persons, and can diminish or enhance autonomy, an optimal environment supporting identity and meaning within a network of relationships becomes desirable for well-being. This does require, as Nedelsky (2011) suggests, greater attention to societal structures and relationships that can enhance or diminish autonomy. Greater scrutiny and safeguards, with associated awareness raising of activities that undermine personhood through oppression and control, is an urgent and basic requirement.

Both the ends and the means of the decision-making process can enhance autonomy. Using decision-making approaches advanced by recent literature, and combined with learning from this research, the proposed person-centred model of decision-making is respectful to each unique person. This schema aims to increase the transparency of socially constituted constraints to autonomy, seeking outcomes as congruent as possible to the person's personal priorities and values, as is practicable. It recognises the interconnectedness of the person as situated within a fuller network of relationships and societal structures, with its constraining power differentials, resource constraints and human limitations.

Law provides a space for diverse responses and I view such an approach as having equal legitimacy in the informal socio-legal domain as existing approaches to decision-making, in reclaiming moral personhood. In this model of personhood, autonomy is not fully dependent on cognitive ability, but on the contextual social factors that allow and support autonomy to be maximised and extended. In reality, as a tool to give attention to the process of decision-making, and while idealistic and aspirational, the process itself may serve to make transparent potential threats of imposition, control and socially constituted constraints, and raise awareness about the effects of values.

Personhood values are pertinent to medicine, which, in its pursuit of expertise and objectivity in increasing extension into everyday life, fails to create structures and processes that recognise medicine as a means to an end, being that of enhancing the full personhood of patients and their well-being. The effect of being a patient, old, and frail, is a triple jeopardy to the sense of self, in this increasing group of clientele in the hospital setting. The pursuit of person-centred medicine, along with decision-making, is a needed societal goal.

Law not only provides a space for diverse responses, but also shapes and is shaped by societal values over time. I conclude that there is a need for greater focus on enhancing decision-making capability and maximising options within the space provided by law. The fostering of social practices that recognise relational autonomy, and the use of different mechanisms to shape societal values, may contribute over time in reclaiming the legal and moral personhood of vulnerable older persons. Emerging directions in law, such as supportive decision-making and advance care directives, give evidence of law evolving with an expanding understanding of autonomy. Overall, greater attention to law’s transcendent principles of justice, equality, dignity, autonomy and respect for persons, may be an effective way to reduce the damaging effects of ageism, paternalism and prejudice as current contributors to social ageing and diminished personhood.

Appendices

Appendix 1 The common law basis of decision-making incapacity

Four court cases in particular have contributed to common law understanding of competent decision-making and therefore the legal guidance for the inverse state of incapacity:

- *Re T (Adult: Refusal of Treatment)*[1993] Fam 95
- *Gibbons v Wright* (1954) 91 CLR 423
- *Re C (Adult Refusal of Medical Treatment)* [1994] 2 AC 1
- *Fitzpatrick v K* [2008] IEHC 104 (2009)

These key cases have provided the legal principles that together satisfy the primary obligation to prove or disprove incompetence (Kerridge, Lowe and Stewart 2009). Though derived from English cases, these principles have been accepted into Australian law:

- Capacity is presumed;
- Incapacity is to be proven;
- Incapacity has a basis in brain impairment or damage;
- Capable decisions are not dependent on rational outcomes;
- Capacity is based on 'understanding';
- Capacity is in relation to the specific decision to be made;
- Capacity is a construct that varies with each specific decision;
- Capacity is commensurate with the gravity of the decision;
- Evidence of incapacity is commensurate with the gravity of the decision; and
- Capacity includes consideration of merits of choice.

Capacity is presumed

The case of *Re T (Adult: Refusal of Treatment)*[82] indicates that the courts will make a presumption that capacity is present unless it is rebutted (Kerridge et al 2009, 259), as outlined by Lord Donaldson in his judgement:

> *The right to decide one's own fate presupposes a capacity to do so. Every adult is presumed to have that capacity, but it is a presumption that can be rebutted. This is not a question of the degree of intelligence or education of the adult concerned... a small minority of the population lack the necessary*

---

[82] [1993] Fam 95.

> *capacity due to mental illness or retarded development…Others may be deprived of it or have it reduced by reason of temporary factors.*[83]

This principle is based on the assumption of autonomy of the person in law and reflects the liberal principle of freedom for self-government.

Incapacity to be proven

Re T (Adult: Refusal of Treatment)[84] provides the basis that for a person to be accepted as not having capacity, evidence needs to be provided to counter this presumption (Kerridge et al, 2009) with the onus on proving incapacity, not capacity. Therefore, if members of a liberal society are self-governing, interference to remove this right requires justification.

Incapacity has a basis in brain impairment or damage

The court in *Re T (Adult: Refusal of Treatment)*[85] also posits incapacity as dependent on the presence of organic changes or damage to mental functioning, and confirms that incapacity is not based on variations of intelligence or education. This principle relates to requiring adequate justification for questioning the ability for self-government, and evidence of brain impairment or damage provides an impartial basis, rather than a normative judgement.

Capable decisions are not dependent on rational outcomes

Kerridge draws on this same case as indicating that the decision of a person is not required by law to be a rational one, with Lord Donaldson stating:

> *…the patient's right of choice exists whether the reasons for making that choice are rational, irrational, unknown or non-existent…That his choice is contrary to what is to be expected of the vast majority of adults is only relevant if there are other reasons for doubting his capacity to decide.' (Re T (Adult: Refusal of Treatment)*[86] *in Kerridge et al 2009, 261).*

In the same case, the statement by Butler-Sloss LJ confirms this aspect by stating:

---

[83] Ibid 112-13.

[84] Ibid

[85] [1993] Fam 95.

[86] [1993] Fam 95, 113.

> *'[a] decision to refuse medical treatment by a patient capable of making the decision does not have to be sensible, rational or well-considered' (of Re T (Adult: Refusal of Treatment).*[87]

This draws on the legal distinction between the *process* of decision-making and any *evaluation* of the merits of the decision made. Even though rationality is favoured in the liberal ideal, this principle indicates the primary respect of law for neutrality in regards to the autonomous choices of individuals, without imposing moral judgments.

Capacity is based on 'understanding'

The English case of *Re C (Adult Refusal of Medical Treatment)*[88] provides the basis for criteria for 'understanding' in common law. In this case, a patient with schizophrenia refused amputation of a gangrenous leg, and the court considered there was no evidence tendered to support the view of the patient being incapable of understand the decision to be made (Kerridge et al 2009). The court upheld the patient's ability to refuse and suggested using three stages of decision-making as criteria, which Kerridge quotes as:

> *'The comprehension and retention of the information about the treatment*
> *believing that information; and*
> *weighing up that information in the balance so as to arrive at a choice.'*
> *(Kerridge et al 2009, 260).*

Devereaux confirms that 'actual understanding' is the test that has been adopted in Australian law but that there are challenges resulting from the potential range of meanings particularly in relation to information provision, with contention in literature (1999, 79; Berg, Appelbaum and Grisso 1996; Stewart and Biegler 2004). Disagreement about this aspect indicates that while common law provides some guidance, its general nature has led to substantial variations in interpretation (Devereaux 1999; Kerridge et al 2009) and consequently in practice.

The requirement of 'believing the information' is considered only relevant in cases of delusion, where the delusional thought interferes with an acceptance of the facts, and therefore renders the person incapable (Kerridge et al 2009, 261; Darzins,

---

[87] [1993] Fam 95, 116.
[88] [1994] 2 AC 1.

Molloy and Strang 2000). The requirement of 'weighing up' the information relates to the process of decision-making and not to value judgments on the outcome, with this issue remaining a source of contention (Stewart and Bieglar 2004; Kerridge 2009; Darzins, Molloy and Strang 2000).

Capacity is in relation to the specific decision to be made

There is recognition in law that competence is specific to the contract or decision in question, says Kerridge (2009), who refers to the following High Court finding as providing the basis for this principle:

> *The law…requires, in relation to each particular matter or piece of business transacted, that each party shall have such soundness of mind as to be capable of understanding the general nature of what he is doing by his participation….the mental capacity required by the law in respect to any instrument is relative to the particular transaction that as being affected by means of the instrument, and may be described as the capacity to understand the nature of that transaction when it is explained…(Gibbons v Wright).*[89]

This statement conveys a principle dominant in contract law of understanding specific to the particular contract. In extension to decision-making, Charland (2008) refers to Buchanan and Brock (1989) in extrapolating this principle as to each decision being specific to the time and context .

Capacity is a construct that varies with each specific decision

The previous case indicates that capacity can be variable depending on the matter at hand and the particular understanding required for the agreement or transaction. This means that a person may be considered competent for one type of decision but not for another, at the same time, with the implication that capacity is a variable construct to the specific decision only and not a fixed state.

Areas of contention

The previous principles are generally accepted without significant debate in the literature. One exception is the issue of 'understanding' in relation to the 'comprehension and retention' of information. Three further principles arising from these cases deserve discussion to assist in understanding issues of contemporary practice, and are outlined below.

---

[89] (1954) 91 CLR 423, at 437-8.

Understanding of information

The case *Re C (Adult Refusal of Medical Treatment)*[90] outlined criteria of stages in decision-making, of which the first was the ‘comprehension and retention of the information’ (Kerridge et al 2009, 259). Subsequent debates range about how much information the patient needs to be given, or to know and understand, particularly regarding the technical nature of medicine and variations in an individual’s ability to understand.

Kerridge et al 2009 supports the criteria for capacity as the person understanding ‘the broad nature and purpose of the proposed treatment’ but outlines the difficulty in interpreting this first requirement, particularly as it relates to the amount and type of information given to the person (2009, 259). Devereaux and Parker consider that the provision of general information to avoid a charge of battery is sufficient (1999), which is a minimal approach. Other writers consider that material risks should be explained (Stewart and Biegler 2004). Australian law has contributed to clarification about disclosure through the High Court case of *Rogers v Whitaker*[91] requiring the provision of information about risks that may be considered significant to the patient (Skene, 1998, 39). This infers a requirement of the clinician to have some knowledge of the patient, and of what is important to them.

Overall, this debate is indicative of the limitations of current case law in providing specificity for the everyday application with the nuances of each situation, and the lack of consensus on how to apply the law, thus explaining some of the confusion and variables in current practice.

Degree of capacity to be commensurate with the decision

The case of *Re T (Adult: Refusal of treatment)*[92] raises the idea of capacity being of ‘degree’ in relation to the decision to be made (Kerridge et al 2009) based on Lord Donaldson’s additional comments in the case:

> *…[w]hat matters is that the doctors should consider whether at that time [the patient] had a capacity which was commensurate with the gravity of the decision which he purported to make. The more serious the decision, the greater the capacity required.*[93]

---

[90] [1994] 2 AC 1.

[91] [1992] 175 CLR 479.

[92] [1993] Fam 95.

[93] Ibid (at 113).

This aspect is contentious in literature, as it provides a qualification based on the seriousness of the decision, whereas the previous principle was reliant on understanding *regardless* of the decision. Stewart and Biegler (2004) consider that it could undermine the absolute nature of capacity being present or not, but find it acceptable if it means that scrutiny and evidence should be greater with life threatening examples (in Kerridge et al 2009).

Evidence of incapacity to be commensurate with the decision

Kerridge considers that this aspect of degree of capacity was clarified in a later case in Ireland, in terms of evidence required dependent on the seriousness of the situation (2009). In *Fitzpatrick v K*[94] Laffoy J supported Lord Donaldson's view regarding the complexity of the decision requiring a higher threshold of understanding, stating the requirement for the level of evidence in life threatening situations:

> *[T]he principle enjoins the doctor to view the issue by reference to the gravity of the outcome…Clear and convincing proof is required.*

This statement has led to debates on the threshold level of capacity, the level of risk involved, and the complexity of the decision to be made. For instance, Charland suggests that the threshold concept or 'risk standard' proposed by Buchanan and Brock (1989) refers to the view that a higher level of competence is required for those decisions where the risk of refusing treatment has life threatening consequences (2008). This aspect typifies the tensions and inherent contradictions within law, with different emphases in court cases given to both the procedural standard, where the nature of the situation should not cloud the assessment of mental capacity, and of taking the gravity of the situation into account, adding to conceptual confusions (Devereaux and Parker (2006).

Capacity includes consideration of merits of choice

A third issue in literature arising from case law has been one that infers an evaluation of the decision as a possible indicator of incapacity. Arising from the case *Re T (Adult: Refusal of Treatment),*[95] was the statement that the merits of the choice can be considered in determining incapacity where doubts are present about capacity:

---

[94] [2008] IEHC 104.

[95] [1993] Fam 95

> *[t]he nature of his choice or the terms in which it is expressed may then tip the balance (Lord Donaldson, at 113).*

This latter statement by Lord Donaldson provides shades of grey regarding considering the outcome of the decision in the determination of incapacity. There has been robust discussion in the literature on this aspect, particularly in philosophical discussions on autonomy outlined in Chapter 1, and this adds a significant nuance to determining capacity for decision-making. Analysis of the choice and how it is communicated has a potential vulnerability to subjectivity and the personal bias of the assessor, including value judgments, with no guarantee of self-insight. This aspect can potentially conflict with the principle of capacity not reliant on rationality, as it may be a seemingly irrational decision that creates doubt, and may be used to justify a determination of incapacity. Thus the guidance of the law in this instance becomes susceptible to varying and subjective interpretation by others in assessment.

Appendix 2 Common tests and tools used in capacity assessment

Tools, tests, and guides are different approaches to evaluating of decision-making capacity, which has the goal of achieving a yes/no judgement. The main tools are in the form of an interview, with semi structured or structured questions, or as vignettes where the patient is asked questions based on a 'hypothetical situation and treatment choices' (Moye and Braun, 2007 p 213; Glass, 1997). Examples of instruments in general use are:

- The ACE (Aid of Capacity Evaluation) tool for medical decision-making where the person understands the medical problem, the treatment and alternatives and consequences of accepting or refusing is assessed (Etchells 1999; Moye and Braun, 2007)
- Hopkins Capacity Assessment Test (HCAT) is considered an aid to assessment but not the actual determination of competency, and offers an essay and questions for the patient (Janofsky, McCarthy and Folstein, 1992; Sullivan, 2000)
- Mac-CAT-T (Moye and Braun p 216) designed for psychiatric patients to provide 'empirical evidence' on understanding of treatment decisions and includes both vignette and contextual questions (Glass 1997, p 17; Applebaum and Grisso, 1995)
- A 'legal standards' instrument, which is comprised of vignettes designed to assess the competency for people with dementia (Marson, Ingram, Cody, Harrell, 1995; Glass, 1997, p19).

Sullivan cities an additional nine tests designed specifically for capacity assessment (2005), indicating the broad range and variation of approaches.

Appendix 3 Ethics Approval letter 1

From: Stewart-Campbell, Bev (Health)
[mailto:Bev.Stewart-campbell@health.sa. gov.au]

Sent: Tuesday, 16 November 2010 11:10 AM
To: 'Sue Jarrad'
Subject: 360.10 APPROVAL

Dear Sue

This is a formal correspondence from the Southern Adelaide Health Service / Flinders University Human Research Ethics Committee. This committee was renamed to reflect the regional nature of the committee and the fact that the committee is jointly hosted by the Flinders University. This committee used to be known as the Flinders Clinical Research Ethics Committee. Whilst this official title of the committee has changed the committee is still properly constituted under AHEC requirements with the registration number EC00188. This committee operates in accordance with the "National Statement on Ethical Conduct in Human Research (2007)." This department only uses email correspondence for all documents unless prior arrangements have been made with the manager. No hard copy correspondence will be issued.

Application Number: 360/10

Title: Exploration of law and practice related to decision-making capacity of people with dementia in a medical and social setting

Chief investigator: Sue Jarrad

The Issue: The Southern Adelaide Health Service / Flinders University Human Research Ethics Committee (SAFUHREC) have reviewed and approved the above application. Your project may now commence. The approval extends to the following documents:

- Full Application
- Revised Participation Information Sheet of October 2010

Approval Period: 16 November 2010 to 16 November 2013
Please retain a copy of this approval for your records.

TERMS AND CONDITIONS OF ETHICAL APPROVAL

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. Compliance with the *National Statement on Ethical Conduct in Human Research* (2007) & the *Australian Code for the Responsible Conduct of Research* (2007)
2. To immediately report to FCREC anything that may change the ethical or scientific integrity of the project.
3. To regularly review the FCREC website and comply with all submission requirements as they change from time to time.
4. Submit an annual report on each anniversary of the date of final approval and in the correct template from the FCREC website.
5. Confidentiality of research participants MUST be maintained at all times.
6. A copy of the signed consent form must be given to the participant unless the project is an audit.
7. Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.
8. Report Significant Adverse events (SAE's) as per SAE requirements available at our website.
9. The researchers agree to use electronic format for all correspondence with this department.
10. All requests for access to medical records at any SAHS site must be accompanied by this approval email.

Kind regards

BEV

Bev Stewart-Campbell
A/Executive Officer
Human Research Ethics Committee

Sthn Adel Health Serv/Flinders Univ
Room 2A 221
Flinders Medical Centre, Bedford Park SA 5042

T: 08 8204 6453 F: 8204 4586
E: research.ethics@fmc.sa.gov.au

Appendix 4 Ethics Approval letter 2

From: Health:FMC Research Ethics [mailto:FMCResearchEthics@health.sa.gov.au]

Sent: Monday, 26 September 2011 11:07 AM

To: Sue Jarrad (sue.jarrad@internode.on.net)

Subject: 360.10: Amendment (PISCF) approved by Ethics

Dear Sue

This is a formal correspondence from the ***Southern Adelaide Clinical Human Research Ethics Committee****. Whilst this official title of the committee has changed the committee is still properly constituted under AHEC requirements. This committee operates in accordance with the "National Statement on Ethical Conduct in Human Research (2007)." This department only uses email correspondence for all documents unless prior arrangements have been made with the manager. No hard copy correspondence will be issued.*

Application Number: 360.10

Title: Exploration of law and practice related to decision making capacity for people with dementia in a medical and social setting.

Chief investigator: Sue Jarrad

The Issue: The Southern Adelaide Clinical Human Research Ethics Committee (SACHREC) has approved the above project amendment. Your project may now incorporate these amendments into your research. The approval extends to the following documents/changes:

- Project amendment application form, dated 20 September 2011. (*including summary of changes*)
- Family members: Participant information sheet, consent form and third party consent form.
- Consultant geriatricians: Participant information sheet, consent form and third party consent form.
- Letter of support from Craig Whitehead.

Please retain a copy of this approval for your records. You are reminded of the terms of continued ethical approval below.

TERMS AND CONDITIONS OF ETHICAL APPROVAL

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. Compliance with the *National Statement on Ethical Conduct in Human Research* (2007) & the *Australian Code for the Responsible Conduct of Research* (2007).

2. To immediately report to SACHREC anything that may change the ethical or scientific integrity of the project.

3. To regularly review the SACHREC website and comply with all submission requirements as they change from time to time.

4. Submit an annual report on each anniversary of the date of final approval and in the correct template from the SACHREC website

5. Confidentiality of research participants MUST be maintained at all times.

6. A copy of the signed consent form must be given to the participant unless the project is an audit

7. Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.

8. Report Significant Adverse events (SAE's) as per SAE requirements available at our website.

9. The researchers agree to use electronic format for all correspondence with this department.

10. All requests for access to medical records at any SAHS site must be accompanied by this approval email.

Please feel welcome to contact research.ethics@health.sa.gov.au with any enquiries you may have on this matter and we will be happy to assist.

Kind Regards,

Monika Malik

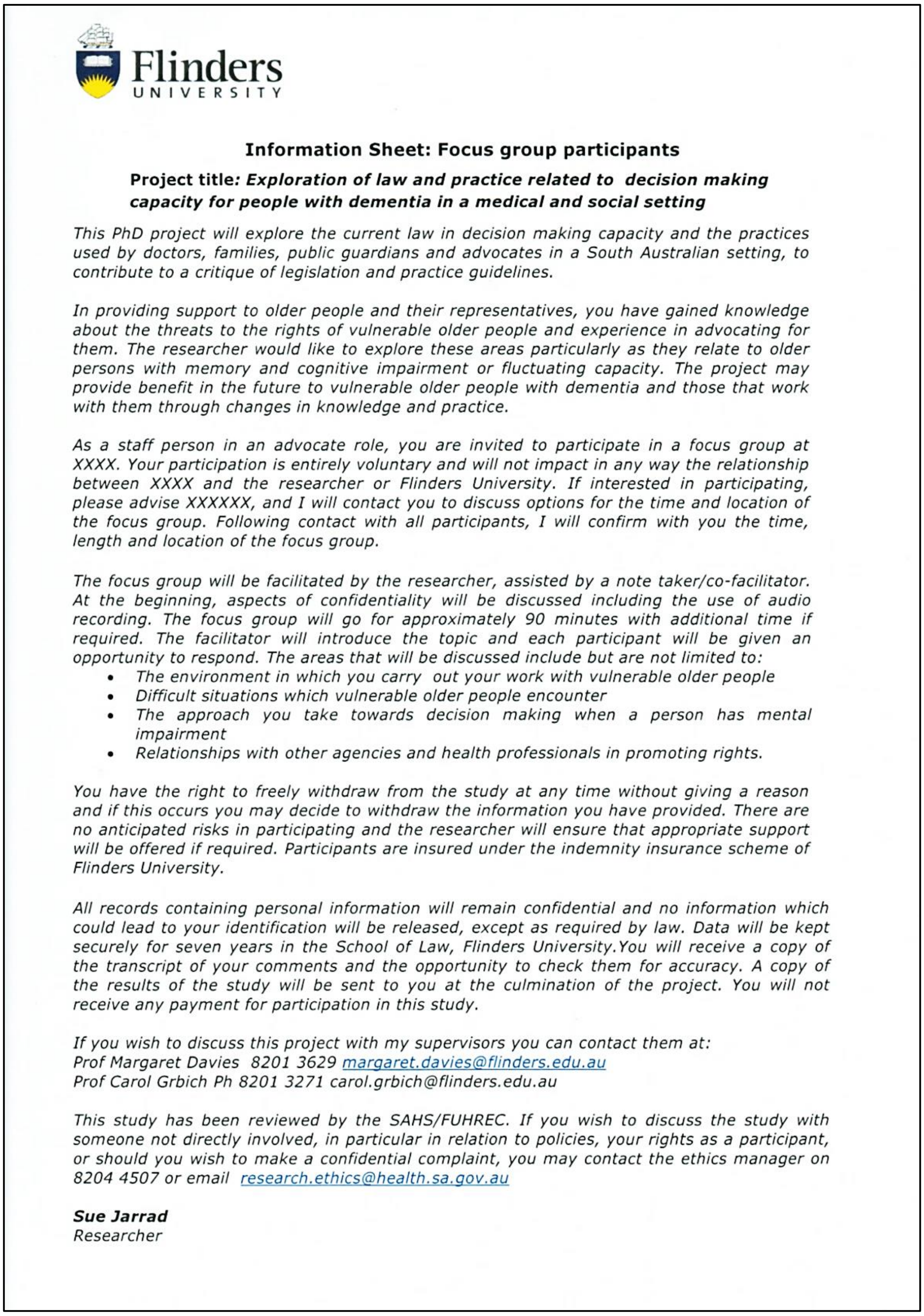
A/Administrative Services Officer
Southern Adelaide Clinical Human Research Ethics Committee
SA Local Health Network
Room 2A221 - Inside Human Resources
Flinders Medical Centre, Bedford Park SA 5042

Tel: 08 8204 6453
Fax: 08 8204 4586
Email: research.ethics@health.sa.gov.au

Website: http://www.flinders.sa.gov.au/research/pages/ethics/6590/

Appendix 5 Participant Information and Consent Sheets

1a Information Sheet for Focus Group Participants



Flinders
UNIVERSITY

Information Sheet: Focus group participants

Project title*: Exploration of law and practice related to decision making capacity for people with dementia in a medical and social setting*

This PhD project will explore the current law in decision making capacity and the practices used by doctors, families, public guardians and advocates in a South Australian setting, to contribute to a critique of legislation and practice guidelines.

In providing support to older people and their representatives, you have gained knowledge about the threats to the rights of vulnerable older people and experience in advocating for them. The researcher would like to explore these areas particularly as they relate to older persons with memory and cognitive impairment or fluctuating capacity. The project may provide benefit in the future to vulnerable older people with dementia and those that work with them through changes in knowledge and practice.

As a staff person in an advocate role, you are invited to participate in a focus group at XXXX. Your participation is entirely voluntary and will not impact in any way the relationship between XXXX and the researcher or Flinders University. If interested in participating, please advise XXXXXX, and I will contact you to discuss options for the time and location of the focus group. Following contact with all participants, I will confirm with you the time, length and location of the focus group.

The focus group will be facilitated by the researcher, assisted by a note taker/co-facilitator. At the beginning, aspects of confidentiality will be discussed including the use of audio recording. The focus group will go for approximately 90 minutes with additional time if required. The facilitator will introduce the topic and each participant will be given an opportunity to respond. The areas that will be discussed include but are not limited to:

- *The environment in which you carry out your work with vulnerable older people*
- *Difficult situations which vulnerable older people encounter*
- *The approach you take towards decision making when a person has mental impairment*
- *Relationships with other agencies and health professionals in promoting rights.*

You have the right to freely withdraw from the study at any time without giving a reason and if this occurs you may decide to withdraw the information you have provided. There are no anticipated risks in participating and the researcher will ensure that appropriate support will be offered if required. Participants are insured under the indemnity insurance scheme of Flinders University.

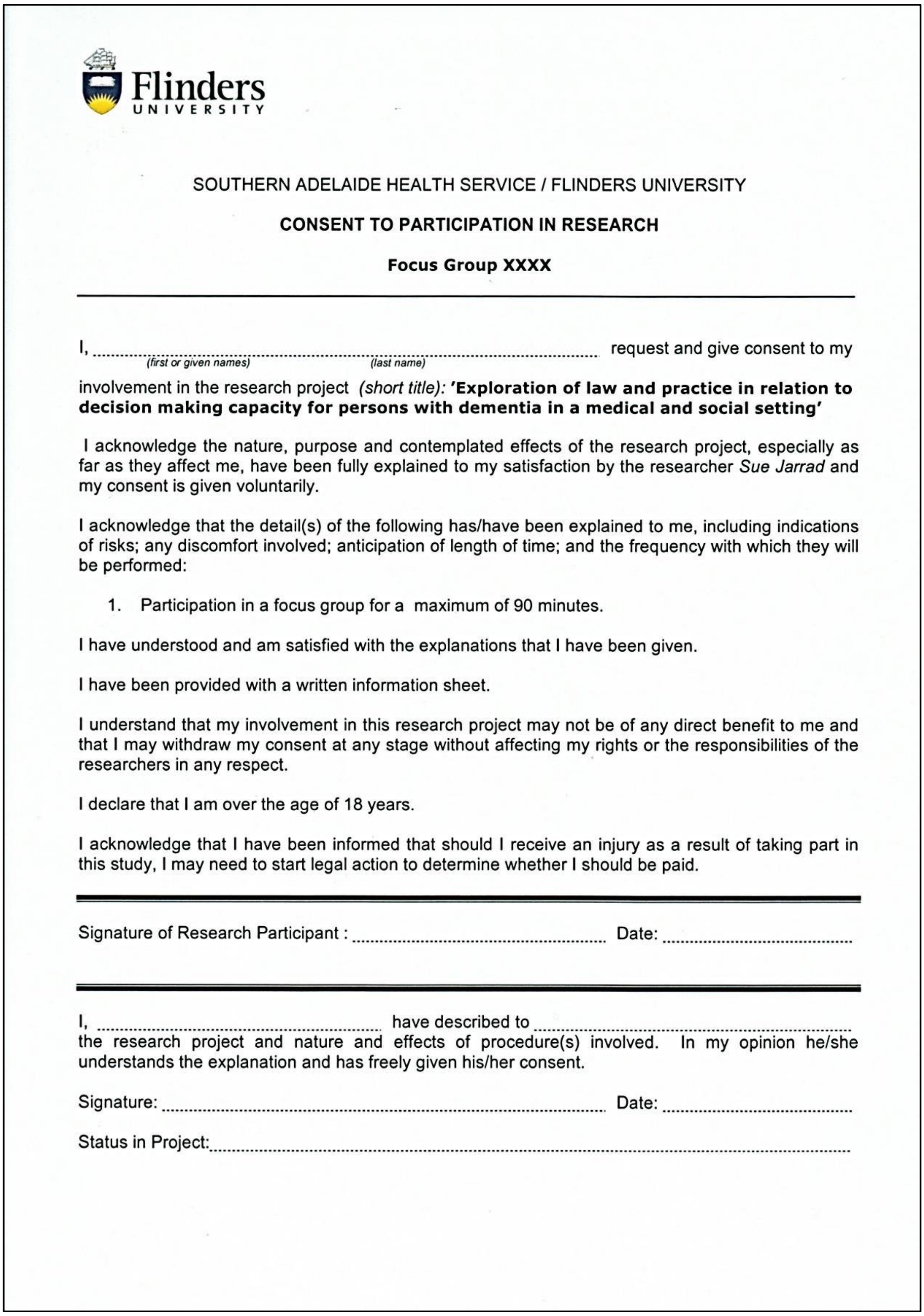
All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law. Data will be kept securely for seven years in the School of Law, Flinders University.You will receive a copy of the transcript of your comments and the opportunity to check them for accuracy. A copy of the results of the study will be sent to you at the culmination of the project. You will not receive any payment for participation in this study.

If you wish to discuss this project with my supervisors you can contact them at:
Prof Margaret Davies 8201 3629 margaret.davies@flinders.edu.au
Prof Carol Grbich Ph 8201 3271 carol.grbich@flinders.edu.au

This study has been reviewed by the SAHS/FUHREC. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the ethics manager on 8204 4507 or email research.ethics@health.sa.gov.au

Sue Jarrad
Researcher

1b Consent form for Focus Group Participants



Flinders
UNIVERSITY

SOUTHERN ADELAIDE HEALTH SERVICE / FLINDERS UNIVERSITY

CONSENT TO PARTICIPATION IN RESEARCH

Focus Group XXXX

I, ... request and give consent to my
(first or given names) *(last name)*

involvement in the research project *(short title):* **'Exploration of law and practice in relation to decision making capacity for persons with dementia in a medical and social setting'**

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect me, have been fully explained to my satisfaction by the researcher *Sue Jarrad* and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. Participation in a focus group for a maximum of 90 minutes.

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action to determine whether I should be paid.

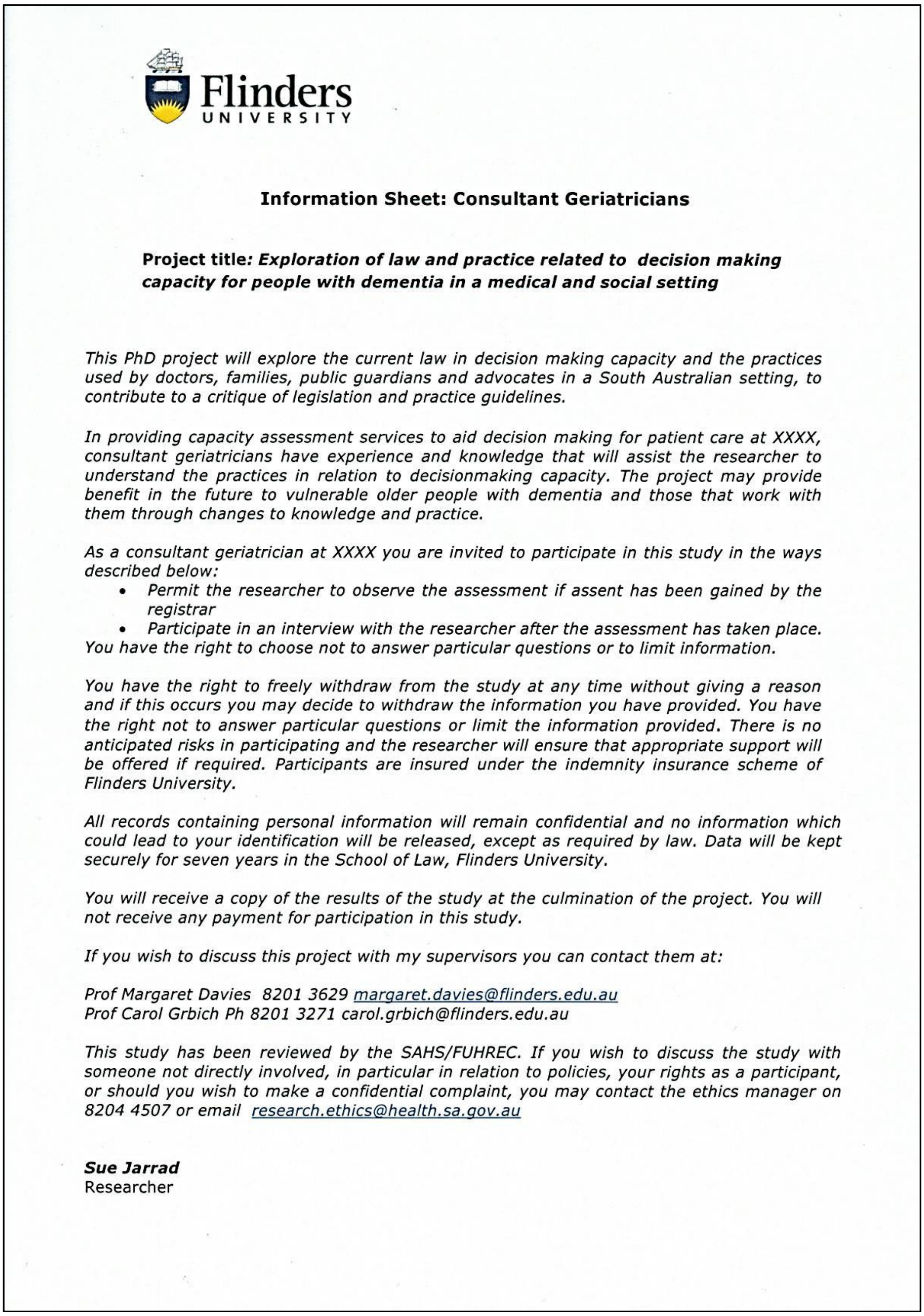
Signature of Research Participant : .... Date: ....

I, ... have described to ....
the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: .... Date: ....

Status in Project:..

2a Information Sheet for Consultant Geriatrician H1



Flinders
UNIVERSITY

Information Sheet: Consultant Geriatricians

Project title***: Exploration of law and practice related to decision making capacity for people with dementia in a medical and social setting***

This PhD project will explore the current law in decision making capacity and the practices used by doctors, families, public guardians and advocates in a South Australian setting, to contribute to a critique of legislation and practice guidelines.

In providing capacity assessment services to aid decision making for patient care at XXXX, consultant geriatricians have experience and knowledge that will assist the researcher to understand the practices in relation to decisionmaking capacity. The project may provide benefit in the future to vulnerable older people with dementia and those that work with them through changes to knowledge and practice.

As a consultant geriatrician at XXXX you are invited to participate in this study in the ways described below:

- *Permit the researcher to observe the assessment if assent has been gained by the registrar*
- *Participate in an interview with the researcher after the assessment has taken place.*

You have the right to choose not to answer particular questions or to limit information.

You have the right to freely withdraw from the study at any time without giving a reason and if this occurs you may decide to withdraw the information you have provided. You have the right not to answer particular questions or limit the information provided. There is no anticipated risks in participating and the researcher will ensure that appropriate support will be offered if required. Participants are insured under the indemnity insurance scheme of Flinders University.

All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law. Data will be kept securely for seven years in the School of Law, Flinders University.

You will receive a copy of the results of the study at the culmination of the project. You will not receive any payment for participation in this study.

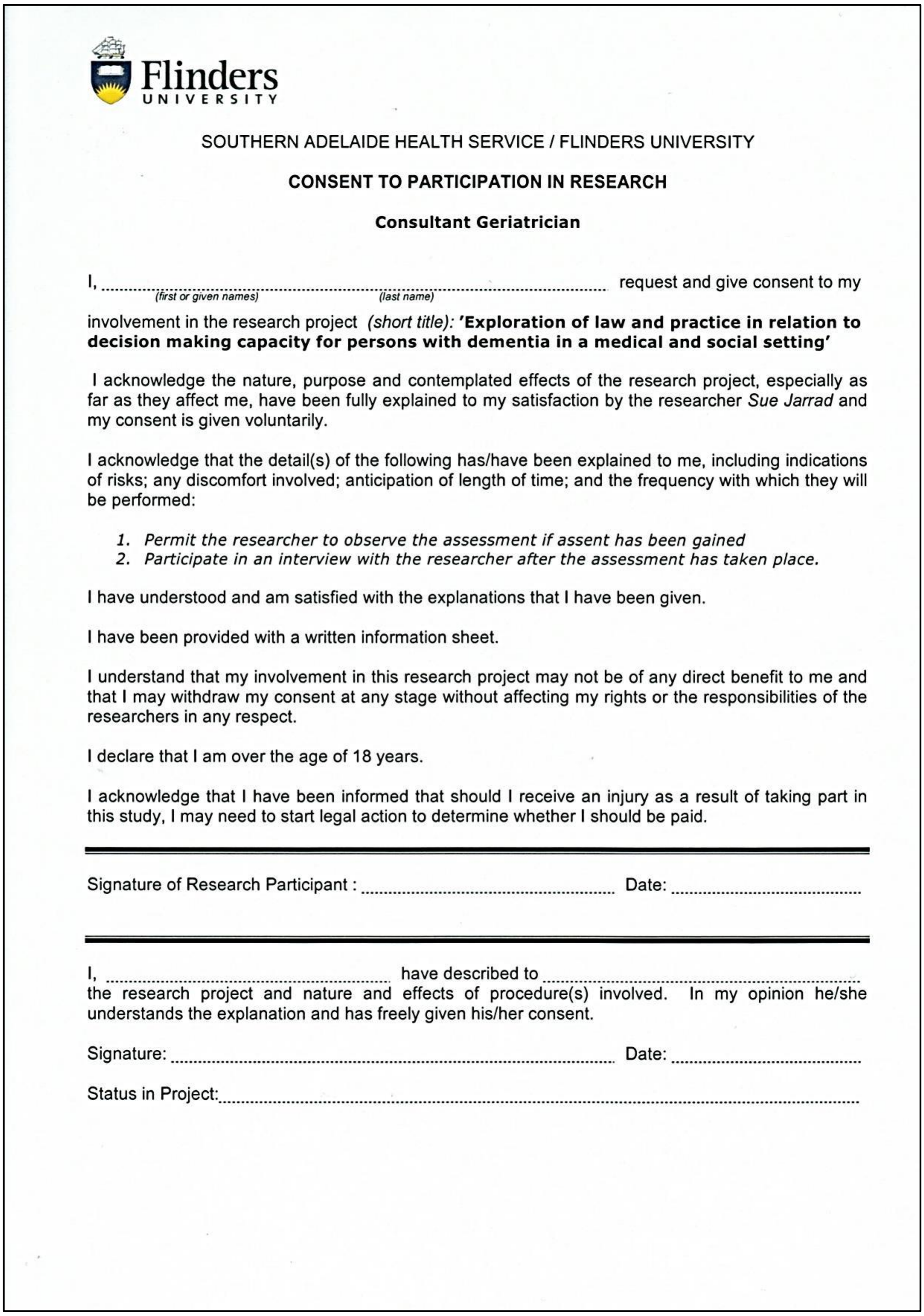
If you wish to discuss this project with my supervisors you can contact them at:

Prof Margaret Davies 8201 3629 margaret.davies@flinders.edu.au
Prof Carol Grbich Ph 8201 3271 carol.grbich@flinders.edu.au

This study has been reviewed by the SAHS/FUHREC. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the ethics manager on 8204 4507 or email research.ethics@health.sa.gov.au

Sue Jarrad
Researcher

2b Consent Form for Consultant Geriatrician H1



Flinders
UNIVERSITY

SOUTHERN ADELAIDE HEALTH SERVICE / FLINDERS UNIVERSITY

CONSENT TO PARTICIPATION IN RESEARCH

Consultant Geriatrician

I, ... request and give consent to my
(first or given names) *(last name)*

involvement in the research project *(short title)*: **'Exploration of law and practice in relation to decision making capacity for persons with dementia in a medical and social setting'**

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect me, have been fully explained to my satisfaction by the researcher *Sue Jarrad* and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. *Permit the researcher to observe the assessment if assent has been gained*
2. *Participate in an interview with the researcher after the assessment has taken place.*

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action to determine whether I should be paid.

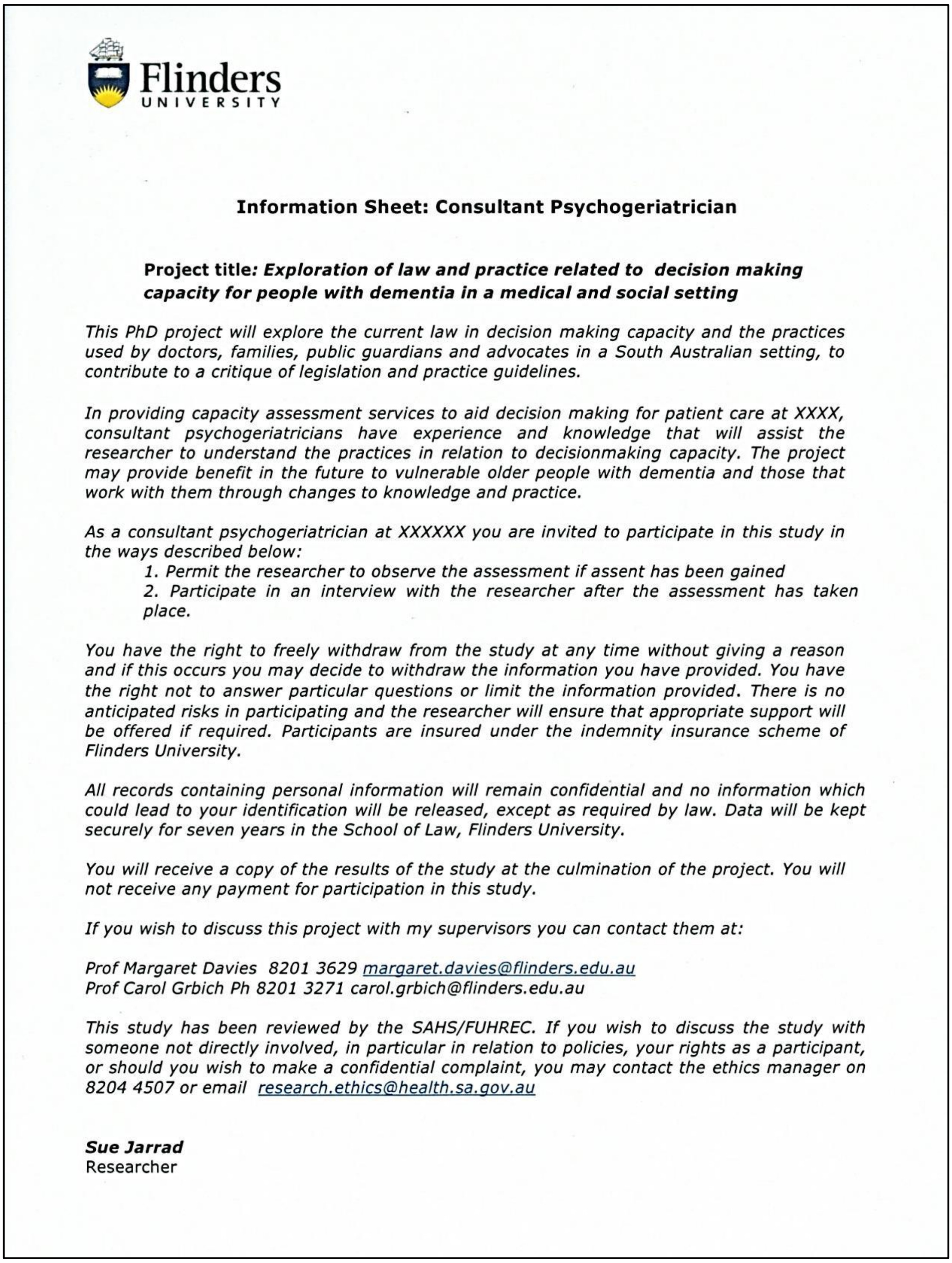
Signature of Research Participant : .... Date: ....

I, ... have described to ....
the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: .... Date: ....

Status in Project:..

3a Information Sheet for Consultant Psychogeriatrician H1



Flinders
UNIVERSITY

Information Sheet: Consultant Psychogeriatrician

Project title*: Exploration of law and practice related to decision making capacity for people with dementia in a medical and social setting*

This PhD project will explore the current law in decision making capacity and the practices used by doctors, families, public guardians and advocates in a South Australian setting, to contribute to a critique of legislation and practice guidelines.

In providing capacity assessment services to aid decision making for patient care at XXXX, consultant psychogeriatricians have experience and knowledge that will assist the researcher to understand the practices in relation to decisionmaking capacity. The project may provide benefit in the future to vulnerable older people with dementia and those that work with them through changes to knowledge and practice.

As a consultant psychogeriatrician at XXXXXX you are invited to participate in this study in the ways described below:

1. *Permit the researcher to observe the assessment if assent has been gained*
2. *Participate in an interview with the researcher after the assessment has taken place.*

You have the right to freely withdraw from the study at any time without giving a reason and if this occurs you may decide to withdraw the information you have provided. You have the right not to answer particular questions or limit the information provided. There is no anticipated risks in participating and the researcher will ensure that appropriate support will be offered if required. Participants are insured under the indemnity insurance scheme of Flinders University.

All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law. Data will be kept securely for seven years in the School of Law, Flinders University.

You will receive a copy of the results of the study at the culmination of the project. You will not receive any payment for participation in this study.

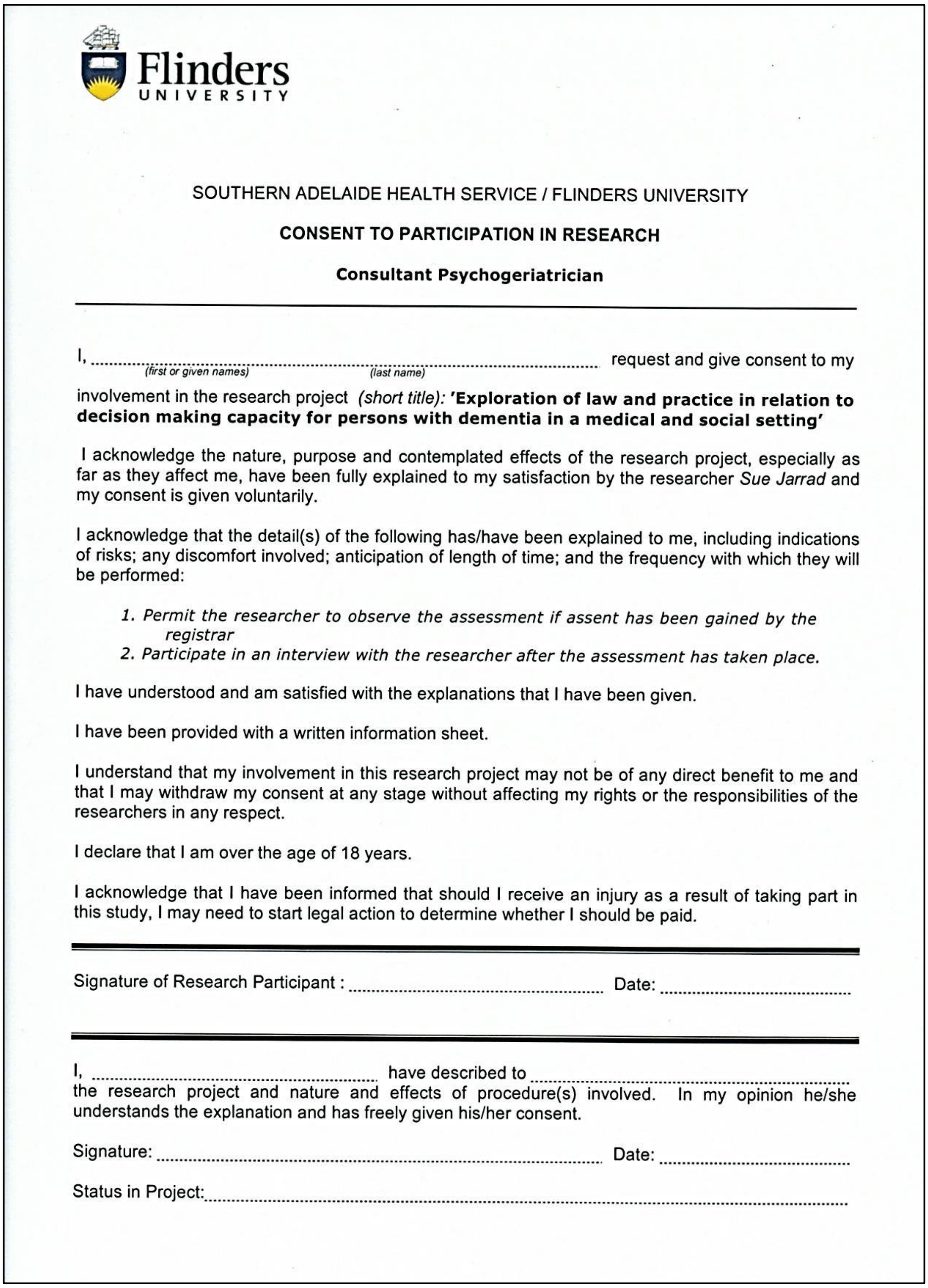
If you wish to discuss this project with my supervisors you can contact them at:

Prof Margaret Davies 8201 3629 margaret.davies@flinders.edu.au
Prof Carol Grbich Ph 8201 3271 carol.grbich@flinders.edu.au

This study has been reviewed by the SAHS/FUHREC. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the ethics manager on 8204 4507 or email research.ethics@health.sa.gov.au

Sue Jarrad
Researcher

3b Consent Form for Consultant Psychogeriatrician H1



Flinders
UNIVERSITY

SOUTHERN ADELAIDE HEALTH SERVICE / FLINDERS UNIVERSITY

CONSENT TO PARTICIPATION IN RESEARCH

Consultant Psychogeriatrician

I, ... request and give consent to my
(first or given names) *(last name)*

involvement in the research project *(short title):* **'Exploration of law and practice in relation to decision making capacity for persons with dementia in a medical and social setting'**

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect me, have been fully explained to my satisfaction by the researcher *Sue Jarrad* and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. *Permit the researcher to observe the assessment if assent has been gained by the registrar*
2. *Participate in an interview with the researcher after the assessment has taken place.*

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action to determine whether I should be paid.

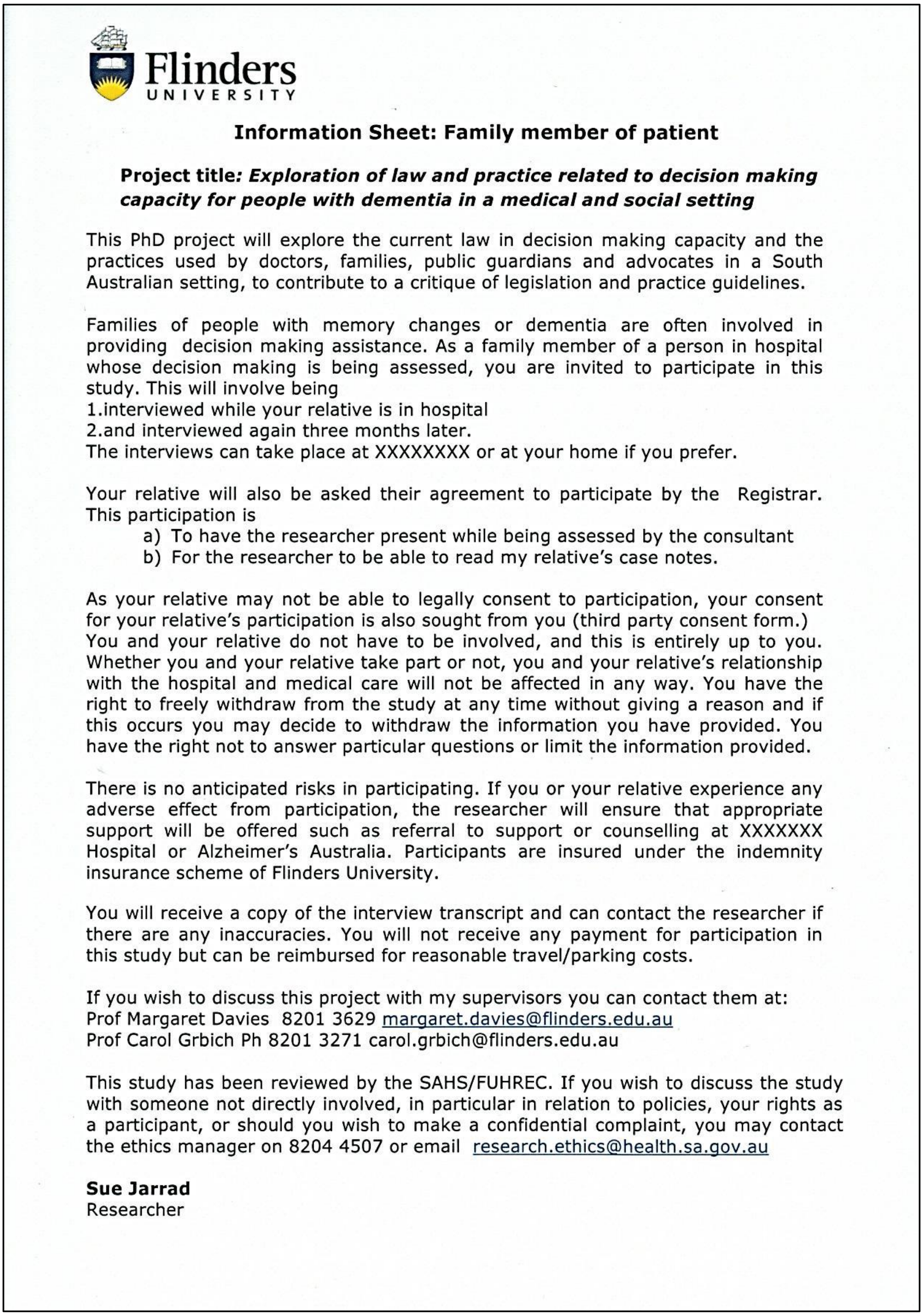
Signature of Research Participant : .... Date: ....

I, ... have described to ....
the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: .... Date: ....

Status in Project:...

4a Information Sheet for Family Member H1



Flinders
UNIVERSITY

Information Sheet: Family member of patient

Project title*: Exploration of law and practice related to decision making capacity for people with dementia in a medical and social setting*

This PhD project will explore the current law in decision making capacity and the practices used by doctors, families, public guardians and advocates in a South Australian setting, to contribute to a critique of legislation and practice guidelines.

Families of people with memory changes or dementia are often involved in providing decision making assistance. As a family member of a person in hospital whose decision making is being assessed, you are invited to participate in this study. This will involve being
1.interviewed while your relative is in hospital
2.and interviewed again three months later.
The interviews can take place at XXXXXXXX or at your home if you prefer.

Your relative will also be asked their agreement to participate by the Registrar. This participation is

a) To have the researcher present while being assessed by the consultant
b) For the researcher to be able to read my relative's case notes.

As your relative may not be able to legally consent to participation, your consent for your relative's participation is also sought from you (third party consent form.) You and your relative do not have to be involved, and this is entirely up to you. Whether you and your relative take part or not, you and your relative's relationship with the hospital and medical care will not be affected in any way. You have the right to freely withdraw from the study at any time without giving a reason and if this occurs you may decide to withdraw the information you have provided. You have the right not to answer particular questions or limit the information provided.

There is no anticipated risks in participating. If you or your relative experience any adverse effect from participation, the researcher will ensure that appropriate support will be offered such as referral to support or counselling at XXXXXXX Hospital or Alzheimer's Australia. Participants are insured under the indemnity insurance scheme of Flinders University.

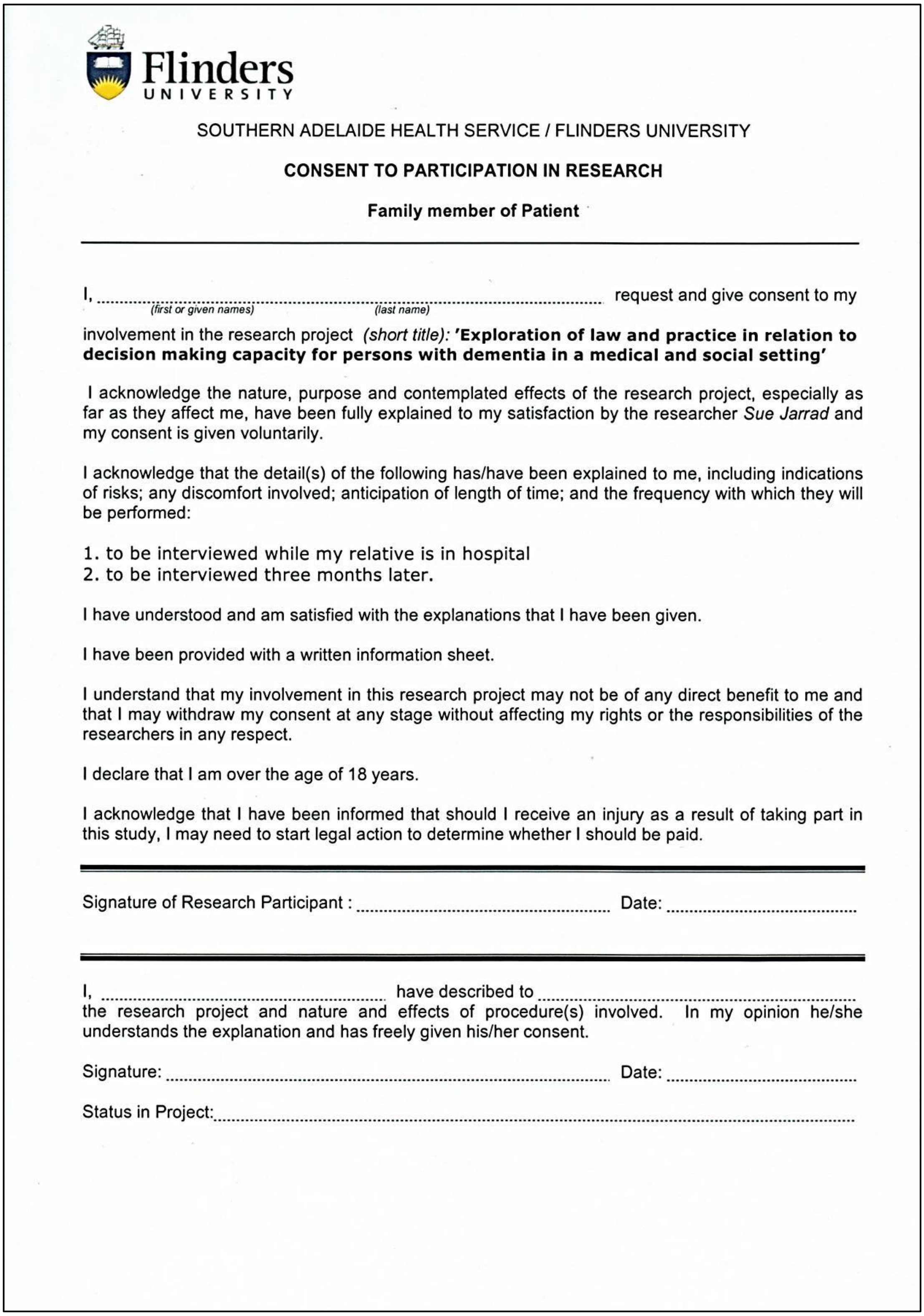
You will receive a copy of the interview transcript and can contact the researcher if there are any inaccuracies. You will not receive any payment for participation in this study but can be reimbursed for reasonable travel/parking costs.

If you wish to discuss this project with my supervisors you can contact them at:
Prof Margaret Davies 8201 3629 margaret.davies@flinders.edu.au
Prof Carol Grbich Ph 8201 3271 carol.grbich@flinders.edu.au

This study has been reviewed by the SAHS/FUHREC. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the ethics manager on 8204 4507 or email research.ethics@health.sa.gov.au

Sue Jarrad
Researcher

4b Consent Form for Family Member H1



Flinders
UNIVERSITY

SOUTHERN ADELAIDE HEALTH SERVICE / FLINDERS UNIVERSITY

CONSENT TO PARTICIPATION IN RESEARCH

Family member of Patient

I, ... request and give consent to my
(first or given names) *(last name)*

involvement in the research project *(short title):* **'Exploration of law and practice in relation to decision making capacity for persons with dementia in a medical and social setting'**

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect me, have been fully explained to my satisfaction by the researcher *Sue Jarrad* and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. to be interviewed while my relative is in hospital
2. to be interviewed three months later.

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action to determine whether I should be paid.

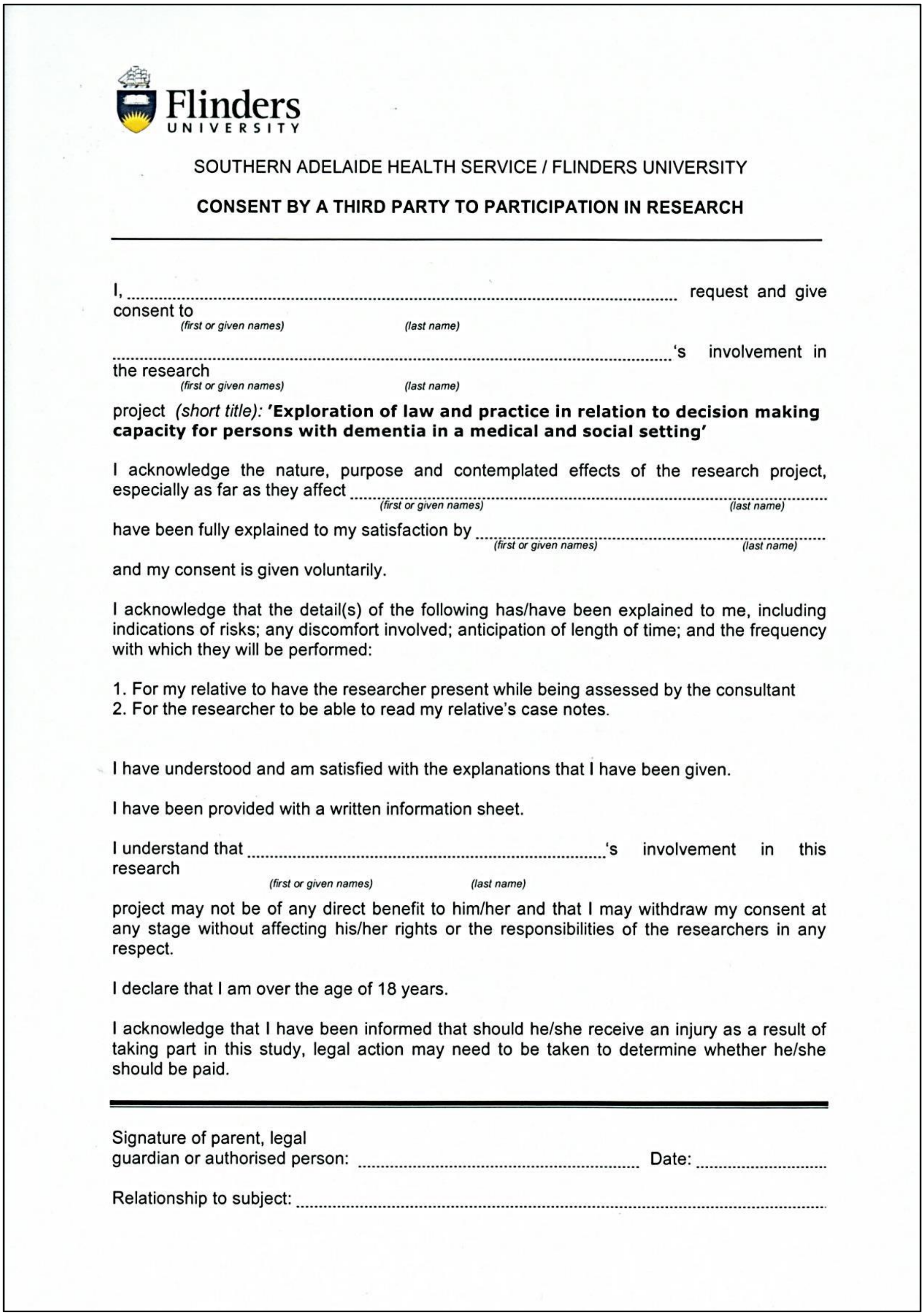
Signature of Research Participant : .... Date: ....

I, ... have described to ....
the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: .... Date: ....

Status in Project:..

4c Consent Form for Third Party Consent H1



Flinders UNIVERSITY

SOUTHERN ADELAIDE HEALTH SERVICE / FLINDERS UNIVERSITY

CONSENT BY A THIRD PARTY TO PARTICIPATION IN RESEARCH

I, ... request and give consent to
(first or given names) *(last name)*

....'s involvement in the research
(first or given names) *(last name)*

project *(short title)*: **'Exploration of law and practice in relation to decision making capacity for persons with dementia in a medical and social setting'**

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect ....
(first or given names) *(last name)*

have been fully explained to my satisfaction by ....
(first or given names) *(last name)*

and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. For my relative to have the researcher present while being assessed by the consultant
2. For the researcher to be able to read my relative's case notes.

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that ....'s involvement in this research
(first or given names) *(last name)*

project may not be of any direct benefit to him/her and that I may withdraw my consent at any stage without affecting his/her rights or the responsibilities of the researchers in any respect.

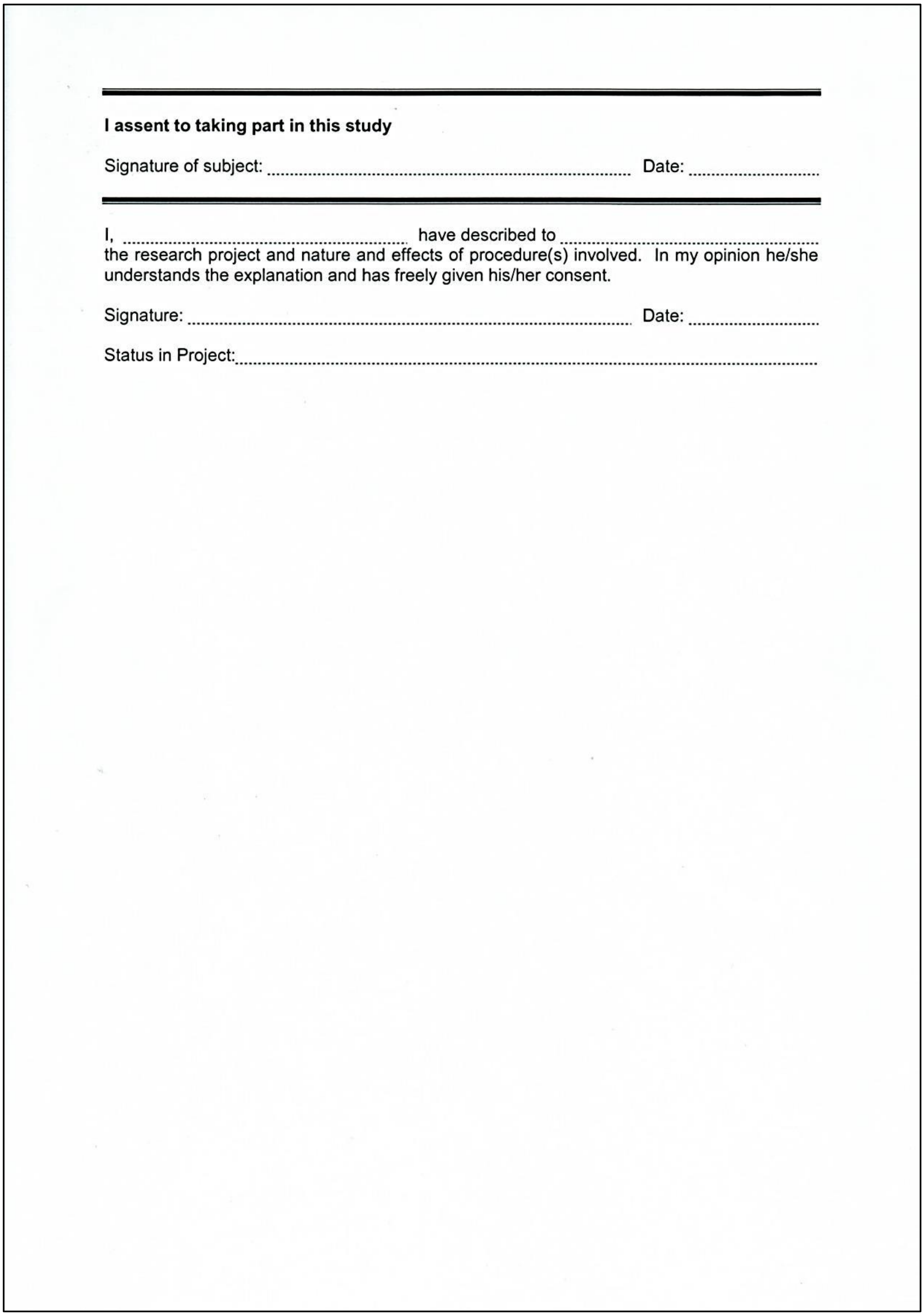
I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should he/she receive an injury as a result of taking part in this study, legal action may need to be taken to determine whether he/she should be paid.

Signature of parent, legal guardian or authorised person: .... Date: ....

Relationship to subject: ....

4d Assent Form for Patient H1



I assent to taking part in this study

Signature of subject: .... Date: ....

I, ... have described to .... the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: .... Date: ....

Status in Project:...

5a Information Sheet for Individual Interviews

Flinders
UNIVERSITY

Information Sheet for Individual Interviews

Project title*: Exploration of law and practice related to decision making capacity for people with dementia in a medical and social setting*

This PhD project will explore the current law in decision making capacity and the practices used by doctors, families, public guardians and advocates in a South Australian setting, to contribute to a critique of legislation and practice guidelines.

You have been identified as a person who has experience and knowledge that will assist the researcher to understand the practices in relation to decisionmaking capacity. The project may provide benefit in the future to vulnerable older people with dementia and those that work with them through changes to knowledge and practice.

As a person with expert knowledge you are invited to participate in this study in the ways described below:

- *Participate in an interview with the researcher.*

You have the right to choose not to answer particular questions or to limit information.

You have the right to freely withdraw from the study at any time without giving a reason and if this occurs you may decide to withdraw the information you have provided. You have the right not to answer particular questions or limit the information provided. There is no anticipated risks in participating and the researcher will ensure that appropriate support will be offered if required. Participants are insured under the indemnity insurance scheme of Flinders University.

All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law. Data will be kept securely for seven years in the School of Law, Flinders University.

You will receive a copy of the results of the study at the culmination of the project. You will not receive any payment for participation in this study.

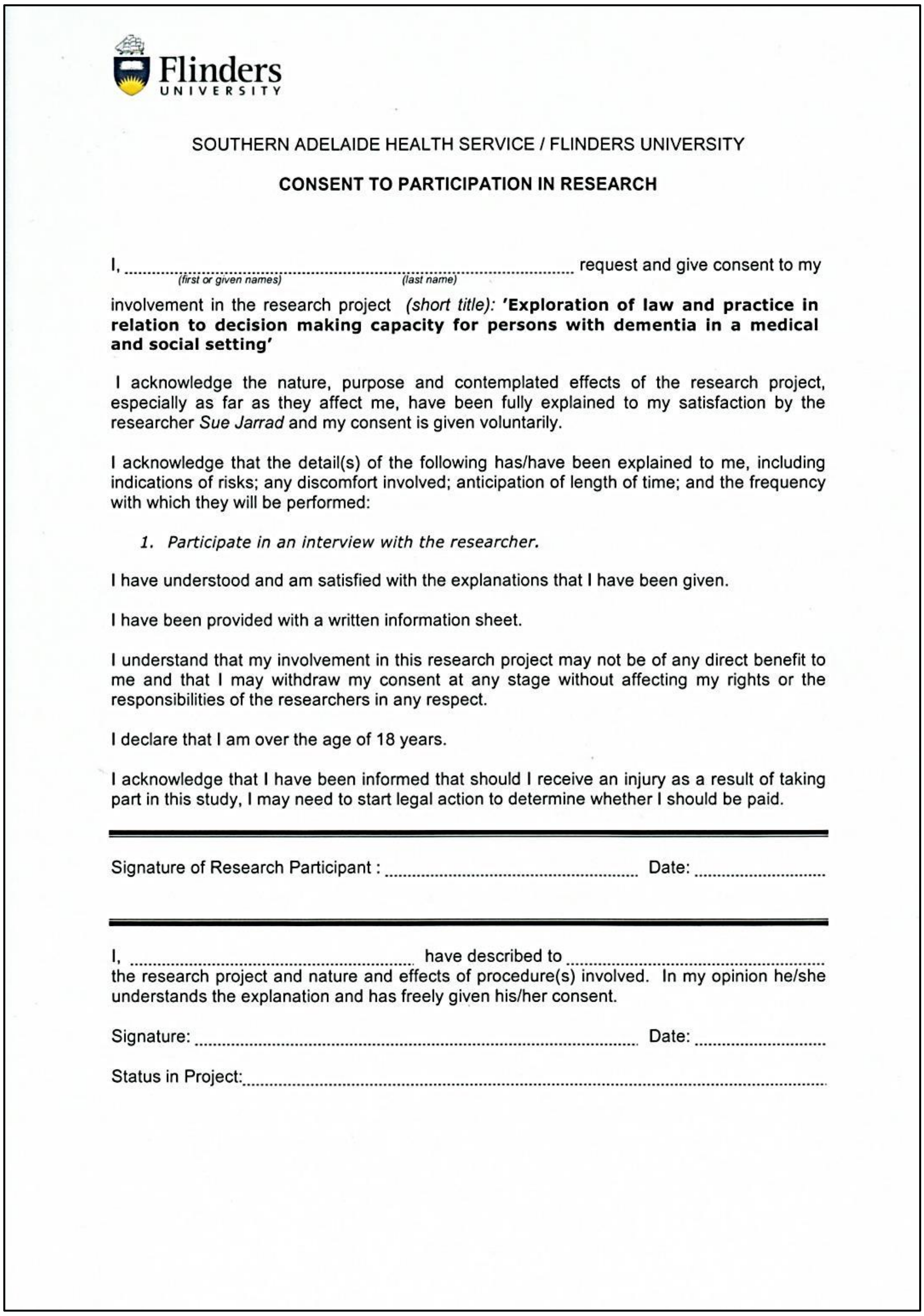
If you wish to discuss this project with my supervisors you can contact them at:

Prof Margaret Davies 8201 3629 margaret.davies@flinders.edu.au
Prof Carol Grbich Ph 8201 3271 carol.grbich@flinders.edu.au

This study has been reviewed by the SAHS/FUHREC. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the ethics manager on 8204 4507 or email research.ethics@health.sa.gov.au

Sue Jarrad
Researcher

5b Consent Form for Individual Interviews



Flinders
UNIVERSITY

SOUTHERN ADELAIDE HEALTH SERVICE / FLINDERS UNIVERSITY

CONSENT TO PARTICIPATION IN RESEARCH

I, ... request and give consent to my
(first or given names) *(last name)*

involvement in the research project *(short title):* **'Exploration of law and practice in relation to decision making capacity for persons with dementia in a medical and social setting'**

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect me, have been fully explained to my satisfaction by the researcher *Sue Jarrad* and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. *Participate in an interview with the researcher.*

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action to determine whether I should be paid.

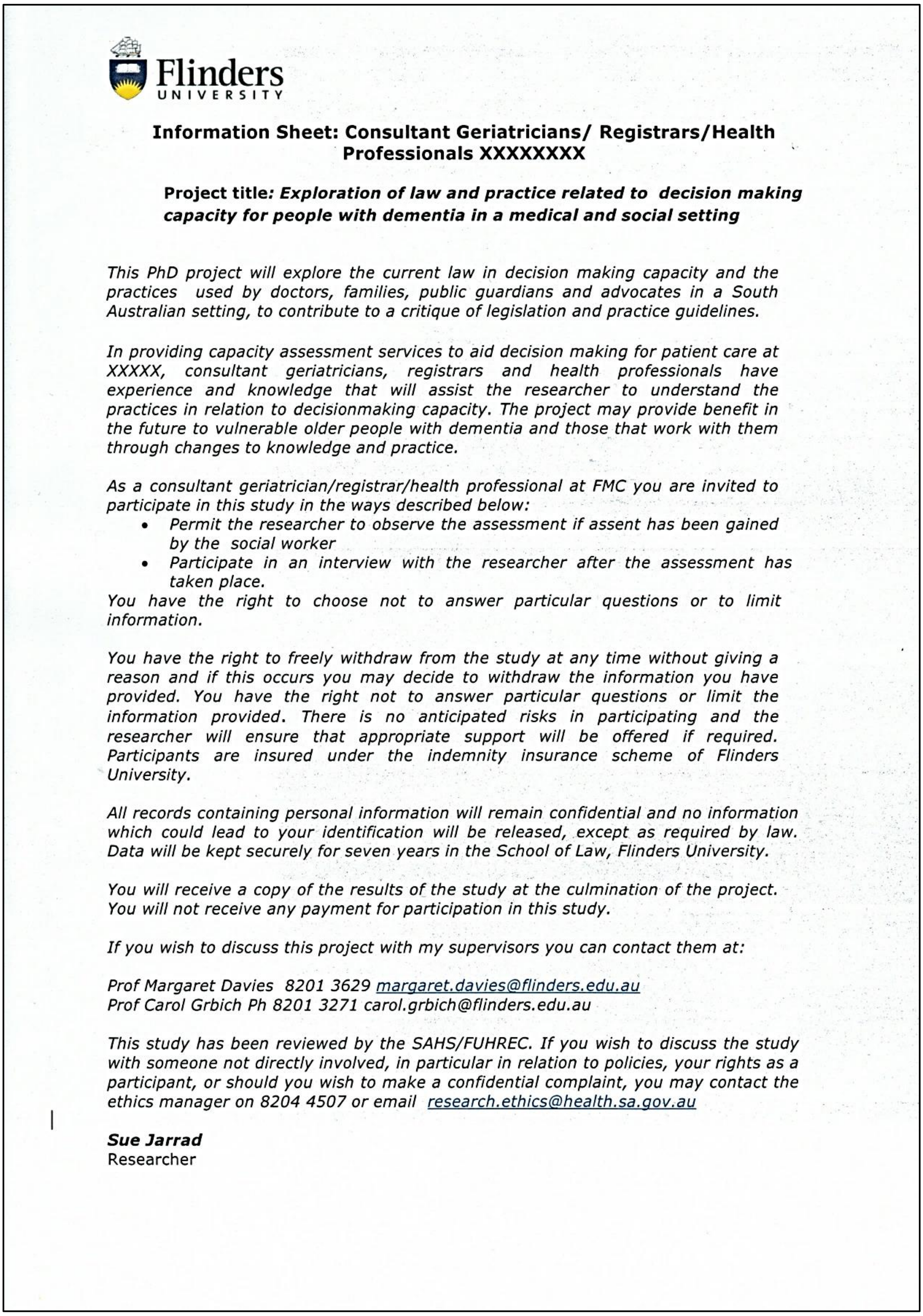
Signature of Research Participant : .... Date: ....

I, ... have described to ....
the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: .... Date: ....

Status in Project:..

6a Information Sheet for Health Professionals H2



Flinders
UNIVERSITY

Information Sheet: Consultant Geriatricians/ Registrars/Health Professionals XXXXXXXX

Project title*: Exploration of law and practice related to decision making capacity for people with dementia in a medical and social setting*

This PhD project will explore the current law in decision making capacity and the practices used by doctors, families, public guardians and advocates in a South Australian setting, to contribute to a critique of legislation and practice guidelines.

In providing capacity assessment services to aid decision making for patient care at XXXXX, consultant geriatricians, registrars and health professionals have experience and knowledge that will assist the researcher to understand the practices in relation to decisionmaking capacity. The project may provide benefit in the future to vulnerable older people with dementia and those that work with them through changes to knowledge and practice.

As a consultant geriatrician/registrar/health professional at FMC you are invited to participate in this study in the ways described below:

- *Permit the researcher to observe the assessment if assent has been gained by the social worker*
- *Participate in an interview with the researcher after the assessment has taken place.*

You have the right to choose not to answer particular questions or to limit information.

You have the right to freely withdraw from the study at any time without giving a reason and if this occurs you may decide to withdraw the information you have provided. You have the right not to answer particular questions or limit the information provided. There is no anticipated risks in participating and the researcher will ensure that appropriate support will be offered if required. Participants are insured under the indemnity insurance scheme of Flinders University.

All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law. Data will be kept securely for seven years in the School of Law, Flinders University.

You will receive a copy of the results of the study at the culmination of the project. You will not receive any payment for participation in this study.

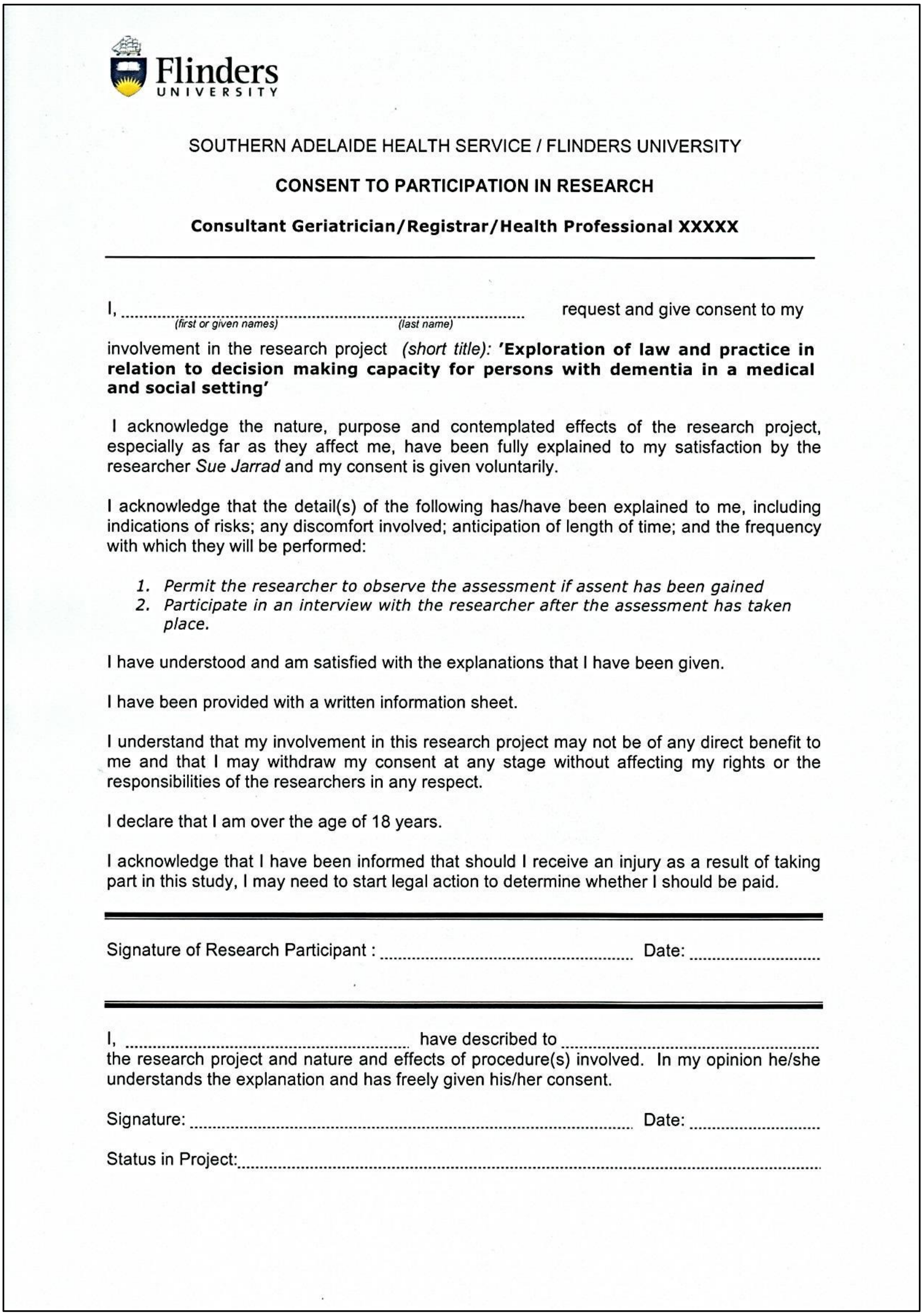
If you wish to discuss this project with my supervisors you can contact them at:

Prof Margaret Davies 8201 3629 margaret.davies@flinders.edu.au
Prof Carol Grbich Ph 8201 3271 carol.grbich@flinders.edu.au

This study has been reviewed by the SAHS/FUHREC. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the ethics manager on 8204 4507 or email research.ethics@health.sa.gov.au

Sue Jarrad
Researcher

6b Consent Form for Health Professionals H2



Flinders
UNIVERSITY

SOUTHERN ADELAIDE HEALTH SERVICE / FLINDERS UNIVERSITY

CONSENT TO PARTICIPATION IN RESEARCH

Consultant Geriatrician/Registrar/Health Professional XXXXX

I, ... request and give consent to my
(first or given names) *(last name)*

involvement in the research project *(short title):* **'Exploration of law and practice in relation to decision making capacity for persons with dementia in a medical and social setting'**

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect me, have been fully explained to my satisfaction by the researcher *Sue Jarrad* and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. *Permit the researcher to observe the assessment if assent has been gained*
2. *Participate in an interview with the researcher after the assessment has taken place.*

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action to determine whether I should be paid.

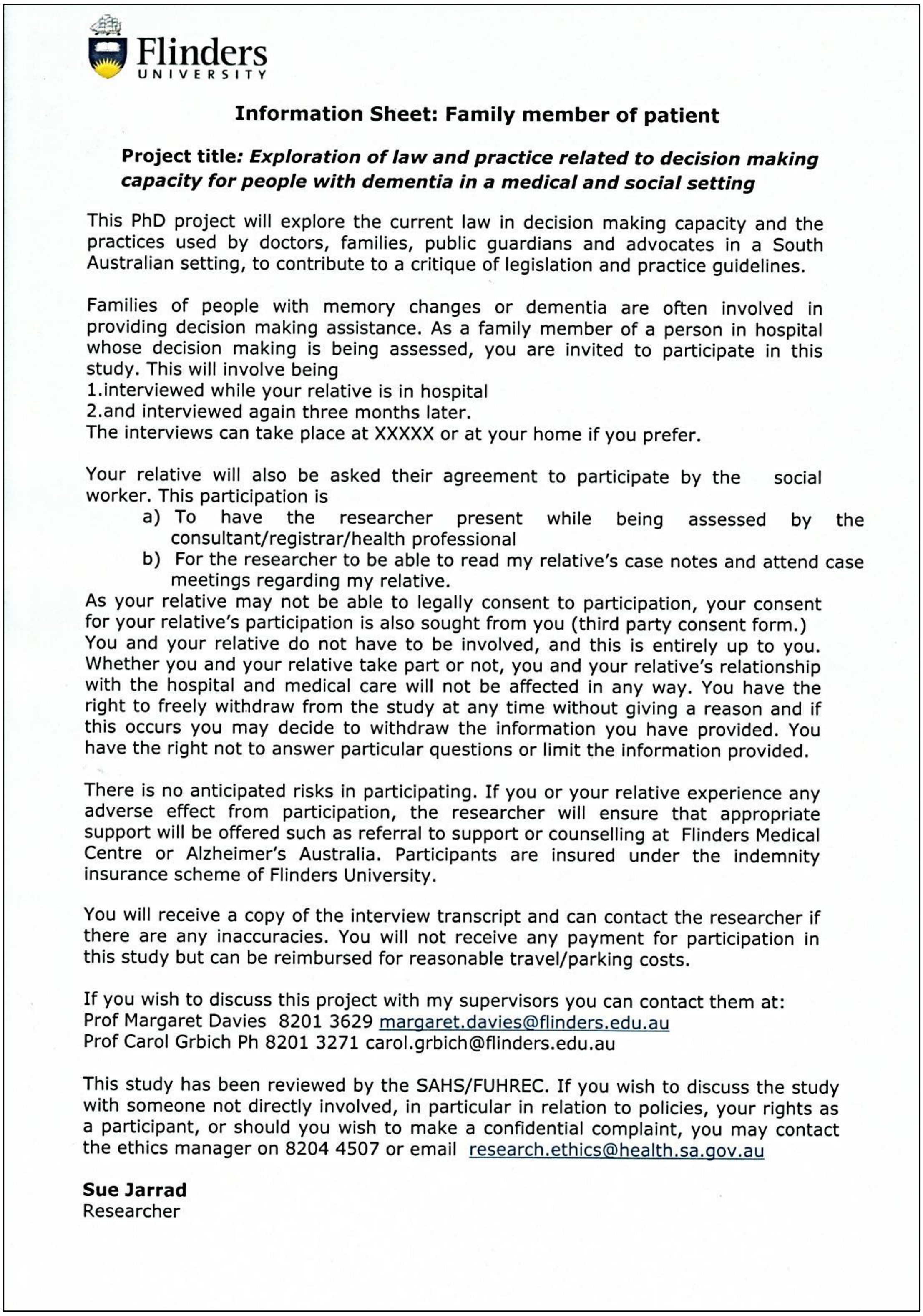
Signature of Research Participant : .... Date: ....

I, ... have described to ....
the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: .... Date: ....

Status in Project:..

7a Information Sheet for Family Members H2



Flinders
UNIVERSITY

Information Sheet: Family member of patient

Project title: ***Exploration of law and practice related to decision making capacity for people with dementia in a medical and social setting***

This PhD project will explore the current law in decision making capacity and the practices used by doctors, families, public guardians and advocates in a South Australian setting, to contribute to a critique of legislation and practice guidelines.

Families of people with memory changes or dementia are often involved in providing decision making assistance. As a family member of a person in hospital whose decision making is being assessed, you are invited to participate in this study. This will involve being
1.interviewed while your relative is in hospital
2.and interviewed again three months later.
The interviews can take place at XXXXX or at your home if you prefer.

Your relative will also be asked their agreement to participate by the social worker. This participation is

a) To have the researcher present while being assessed by the consultant/registrar/health professional
b) For the researcher to be able to read my relative's case notes and attend case meetings regarding my relative.

As your relative may not be able to legally consent to participation, your consent for your relative's participation is also sought from you (third party consent form.) You and your relative do not have to be involved, and this is entirely up to you. Whether you and your relative take part or not, you and your relative's relationship with the hospital and medical care will not be affected in any way. You have the right to freely withdraw from the study at any time without giving a reason and if this occurs you may decide to withdraw the information you have provided. You have the right not to answer particular questions or limit the information provided.

There is no anticipated risks in participating. If you or your relative experience any adverse effect from participation, the researcher will ensure that appropriate support will be offered such as referral to support or counselling at Flinders Medical Centre or Alzheimer's Australia. Participants are insured under the indemnity insurance scheme of Flinders University.

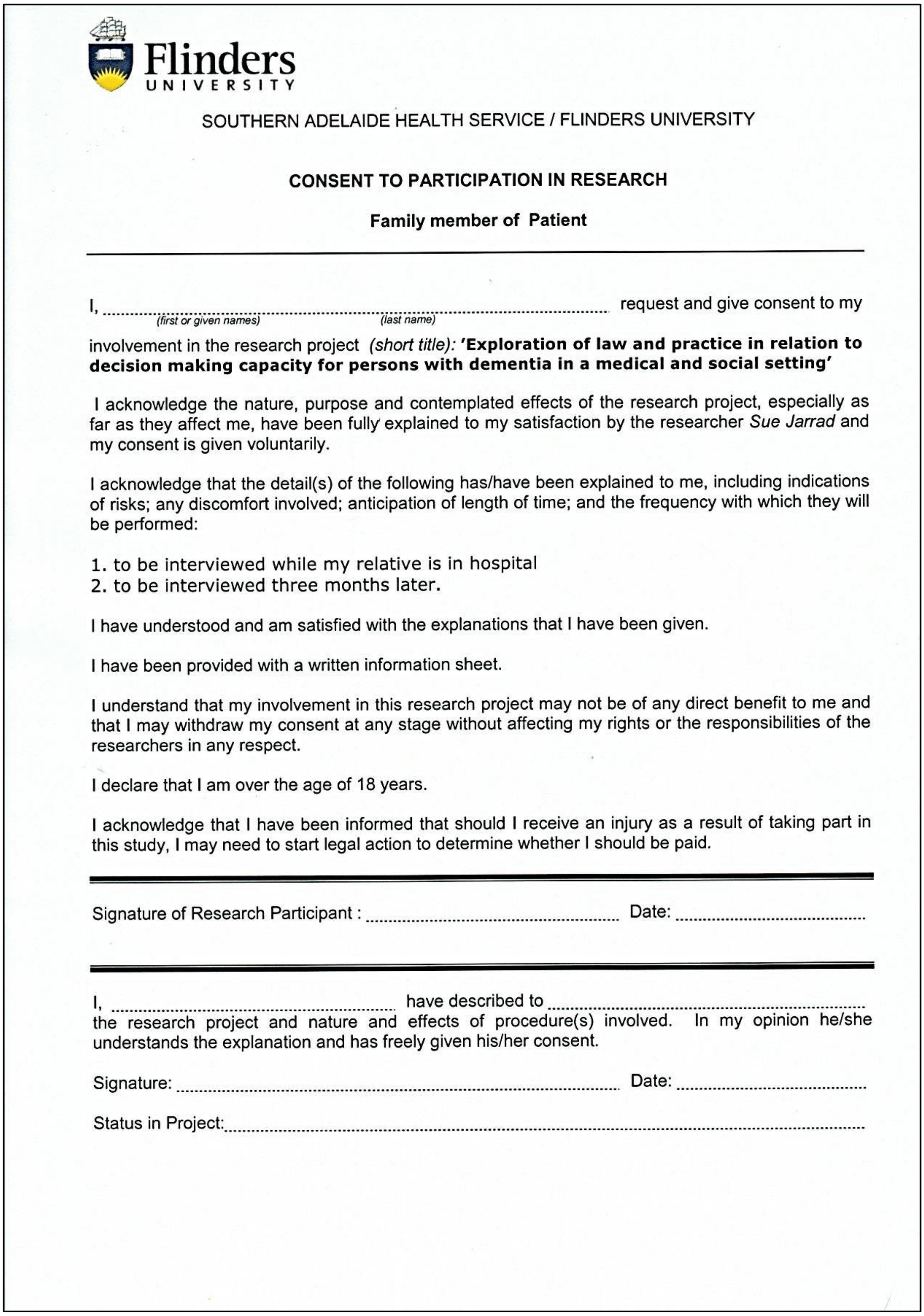
You will receive a copy of the interview transcript and can contact the researcher if there are any inaccuracies. You will not receive any payment for participation in this study but can be reimbursed for reasonable travel/parking costs.

If you wish to discuss this project with my supervisors you can contact them at:
Prof Margaret Davies 8201 3629 margaret.davies@flinders.edu.au
Prof Carol Grbich Ph 8201 3271 carol.grbich@flinders.edu.au

This study has been reviewed by the SAHS/FUHREC. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the ethics manager on 8204 4507 or email research.ethics@health.sa.gov.au

Sue Jarrad
Researcher

7b Consent Form for Family Members H2



Flinders
UNIVERSITY

SOUTHERN ADELAIDE HEALTH SERVICE / FLINDERS UNIVERSITY

CONSENT TO PARTICIPATION IN RESEARCH

Family member of Patient

I, ... request and give consent to my
(first or given names) *(last name)*

involvement in the research project *(short title):* **'Exploration of law and practice in relation to decision making capacity for persons with dementia in a medical and social setting'**

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect me, have been fully explained to my satisfaction by the researcher *Sue Jarrad* and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. to be interviewed while my relative is in hospital
2. to be interviewed three months later.

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action to determine whether I should be paid.

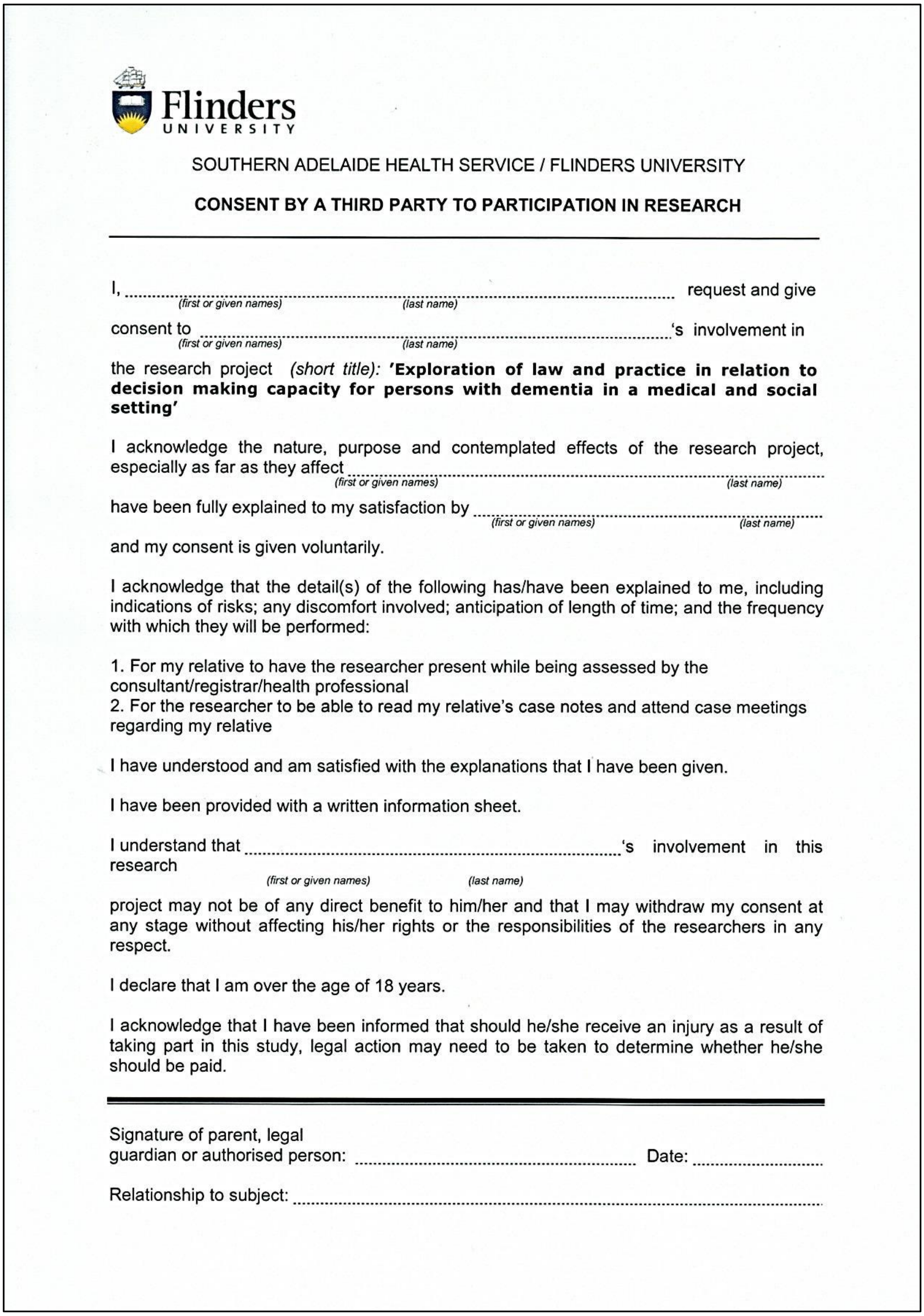
Signature of Research Participant : .... Date: ....

I, ... have described to ....
the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: .... Date: ....

Status in Project:..

7c Consent Form for Third Party Consent H2



Flinders UNIVERSITY

SOUTHERN ADELAIDE HEALTH SERVICE / FLINDERS UNIVERSITY

CONSENT BY A THIRD PARTY TO PARTICIPATION IN RESEARCH

I, ... request and give
(first or given names) *(last name)*

consent to ....'s involvement in
(first or given names) *(last name)*

the research project *(short title):* **'Exploration of law and practice in relation to decision making capacity for persons with dementia in a medical and social setting'**

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect ....
(first or given names) *(last name)*

have been fully explained to my satisfaction by ....
(first or given names) *(last name)*

and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. For my relative to have the researcher present while being assessed by the consultant/registrar/health professional
2. For the researcher to be able to read my relative's case notes and attend case meetings regarding my relative

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that ....'s involvement in this research
(first or given names) *(last name)*

project may not be of any direct benefit to him/her and that I may withdraw my consent at any stage without affecting his/her rights or the responsibilities of the researchers in any respect.

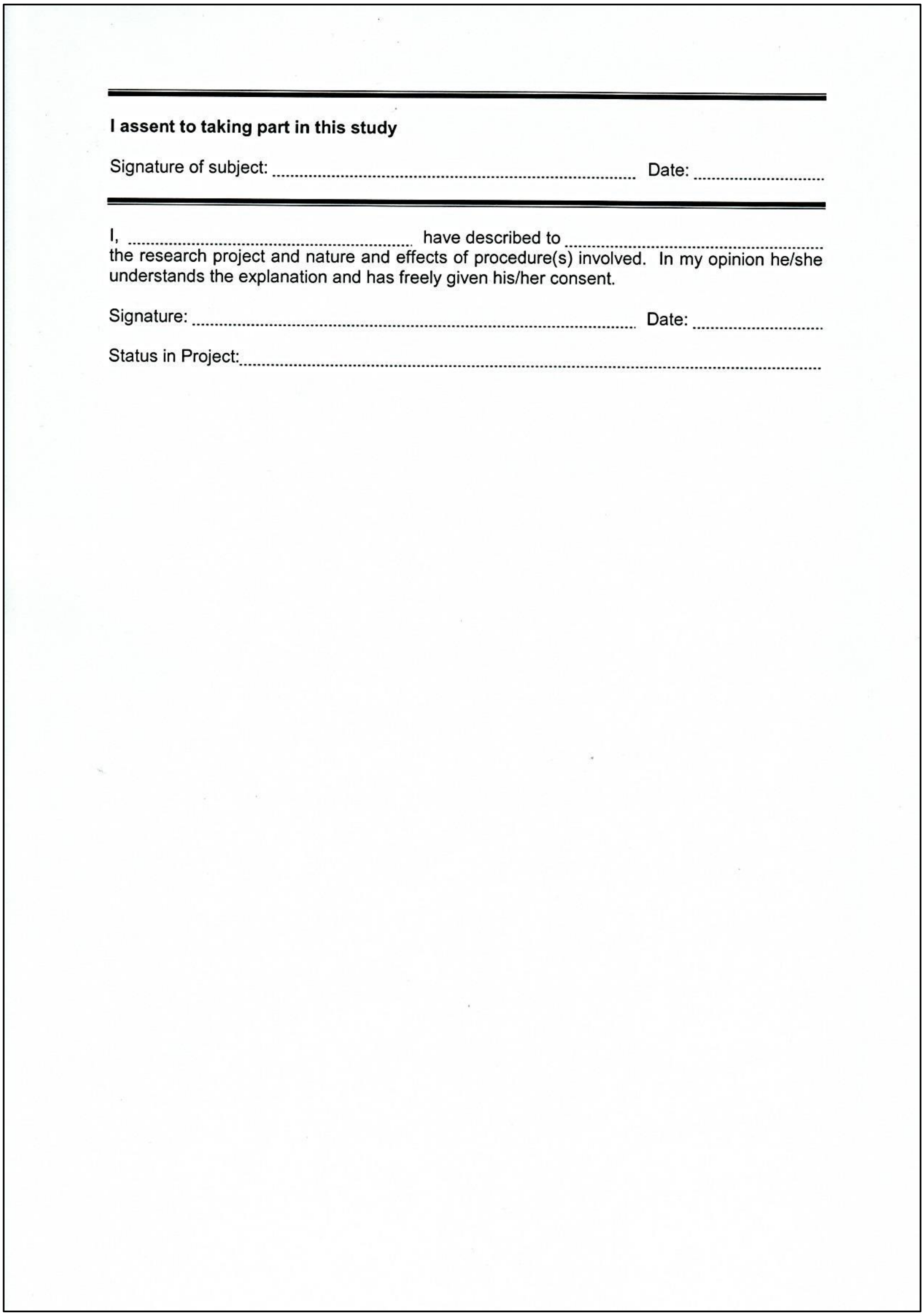
I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should he/she receive an injury as a result of taking part in this study, legal action may need to be taken to determine whether he/she should be paid.

Signature of parent, legal
guardian or authorised person: .... Date: ....

Relationship to subject: ....

7d Assent Form for Patient H2



I assent to taking part in this study

Signature of subject: .... Date: ....

I, ... have described to .... the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: .... Date: ....

Status in Project:..

Appendix 6 Questions for focus group participants

What is your role and professional background?

What do you find rewarding in your role?

What do you find are the most difficult situations to deal with in your work?

Can you tell me about your view of rights and self-determination and their relationship to capacity?

If not making decisions themselves, how are the rights for self-determination of an older person expressed by their substitute decision-maker?

What would you consider to be an alternative to the cognitive, rational model of assessing and determining someone's abilities to make decisions?

How do residential and community services approach the empowerment and engagement of the older person? What are the approaches that you see in hospitals?

How do you define duty of care?

What about risk?

What do you think is needed to make your role easier? What would you like to see changed?

What do you think is needed in the system to better protect the rights of vulnerable people?

What do you see as the role of legislation?

What authority do you use to promote the rights of older persons and support your position?

Appendix 7 Interview questions for family members

Tell me about the patient- what is important to him/her, his/her values and preferences.

How does decision-making work between you and your relative?

What led to his/her admission?

What happened in hospital?

There was a case conference- what was its purpose?

What outcomes were there?

What was most important for you out of that meeting? Did they assist/not assist the process?

There was a request for a capacity assessment- what did you expect or understand about that?

What information about the results did you get, and what impact did they have?

The role of the social worker and other professionals in the decision-making process?

How was the decision about care finally made?

How is your father coping with this change?

What was helpful in this whole process?

What was unhelpful?

What else might have been needed?

Any questions?

Can I contact you in three months to see how she/he is going?

Appendix 8 A person centred decision-making schema

This schema is designed to support personhood and respect preferences of the person in decision-making of a personal and social nature, in contrast to healthcare decisions. It contains a list of principles that underpin the approach, being:

- Each person has unique worth; The person is multi-dimensional and not defined by cognition;
- Autonomy is not defined by cognition and incorporates values and intuition;
- Self-determination is intrinsic to well-being;
- Persons are social beings and relationships can enhance or diminish autonomy; and
- The person has a right to be free from other's judgments, oppression and control.

The schema has four broad stages, along with recommended processes within each stage. The legal capacity approach is the default approach if this schema does not achieve resolution. Before undertaking this decision-making approach, it is necessary to identify whether there are any significant fluctuations in cognition and health due to illness. If so, the process is delayed until the person's autonomy is considered stable and maximised.

Table The stages of the person centred decision-making schema

Stage	**Tasks**
Assuming capacity	Involves a focused attitude on the person as a adult with preferences developed over a long period of time
Knowing the person	Involves gaining an understanding of the person's life, its meaning, and the role of significant others. A list of strengths is compiled, and the values of the person and family in relation to the current situation identified in dialogue, along with barriers.
Creating choices	Involves exploring, creating, maximising and facilitating choices for the person in relation to their situation and preferences, and clarifying risks and identifying resources that could assist with the preferred outcome.
Supporting decision-making	Time is spent with the person discussing the relevant information, choices and concerns of others, leading to the development of a collaborative plan.
Default legal capacity approach	If the issue remains unresolved, or unsurmountable barriers restrict the person's choice, legal capacity is assessed using a value-neutral procedural approach. Support is given to the substitute decision-maker in making any decision.

Stages

1 Assuming the person as having capacity for the decision.

Capacity is not in question but respect for the person and their views is paramount.

2 Understanding the person and their context

In this stage, the decision-making facilitator spends time getting to know the person and their values, goals, preferences and life story. They gain an understanding of the significance of illness/admission to them in their life story, listen to their concerns, and seek to understand their current needs. They aim to achieve an understanding of the person's significant relationships.

The facilitator spends time with the person's family and significant others to gain their contribution to the life story of the patient, and identify their concerns, needs and values. The facilitator identifies the different perspectives to the situation and clarifies any identified conflicts of interest, and by whom. If in hospital, the facilitator will seek salient information from the treating doctor and social worker, and the case file.

The contextual issues of the situation can be analysed using a 'SWOT' approach (Strengths, Weaknesses, Opportunities, and Threats), in learning about the person, and analysing their relationships, environment, resources.

The facilitator can consider 'how weaknesses can be transformed to strengths, and threats to opportunities'. The SWOT analysis aids in the identification of available resources, both formal and informal, and potential directions.

3 Creating choices

In this stage different potential options are 'brainstormed'. This is based on the understanding that it is just to have choices, and that there is always more than one choice in a situation. The person and family can be asked about options that they can see, if these have not emerged in the earlier stage. Options can be identified or 'brainstormed' using creative thinking, but not evaluated at this stage. A list can then be made as to what is required to make each choice workable.

The facilitator asks and records preferences of the older person in relation to options:

- What is most important to the person (well-being scales can be utilised)
- What needs and important preferences are not being met in each option
- Identify what would meet these needs
- Identify what has been tried and not tried
- Identify which option meets the most important need.

The facilitator identifies the resources needed for each choice; identifies any known structural limitations to each choice; and analyses physical and psychological benefits to the person, and potential harms to the person or others of each option. The facilitator needs to be aware of pressure for seeking the tidy expedient solution in anticipating the future that is more than is required for the current situation.

To achieve this, the following steps are taken:

- Identify the value judgments about risk by the person concerned and their significant others (it is what matters is tolerable to person, and then those living with these risks as well).
- Identify which risks were present when the person was not subject to public hospital scrutiny, and whether they contributed to admission. Are there any new risks, and are they acceptable to the person and their significant others - how might preferred option affect others?
- Quantify the risk –-how likely are they to occur, and will they occur in any other of the options? Can they be minimised?
- Identify who has a duty of care and what is the specific duty?
- Identify if freedoms might be restricted, and the least restrictive option.
- Liaise with key services regarding potential choices, options and barriers.

4 Supporting decision-making

The facilitator engages the patient and supporter/family/substitute decision-maker in conversation, and in identifying possible solutions. This requires a level of transparency and honesty between parties. The facilitator acknowledges the losses expressed by the person that may be contributing to significant changes in the person’s life and limiting future choices. The different options are discussed, and those of most interest to the person are given primary consideration. The consequences of each option are discussed, assisting the person to use reflective thinking (slow thinking) to maximise autonomy and informed choice. These consequences include the effect on others of the choice made.

Formulate a plan with the older person and significant others. This may include a trial at home, or respite or recuperative care where the person’s health is not optimal, or if there is uncertainty or strong barriers by others. The facilitator needs to be aware of their own and others attitudes in this process.

- Avoid diminishment of autonomy through control, dominance, coercion, lack of any real choice.
- Avoid forcing a solution on the person- there is also room for learning, trial and transition (process of adjustment equally important – sensitivity and compassion).
- Ask if the planned outcome is fair to the person? Is it irreversible? (Consider the concept of preserving future autonomy and choices (Marguilies 1994).
- Develop a back-up plan or contingency plan- give essential resource information about community support persons/services outside of hospital; case management follow-up.
- Engage and handover to relevant community services with a focus on building relationships with the older person and family.

If, after all efforts to enhance autonomy and support the goals of the person have occurred, there may be an impasse in finding a way forward. There may be strong concerns regarding the practicality or potential harm for the person, or resistance by those in significant relationship to the person.

An analysis of the barriers is helpful. Arising from the previous process, this assessment forms part of the threshold information for proceeding with a procedural capacity assessment, and analyses conflicts of interest, value judgments and structural causes.

- Analyse the problem e.g. lack of resources (structural); identify different values (what are they and who holds them); identify conflicts of interest (make transparent); identify concerns for risk of harm (investigate the perception of risk and who holds it)
- Clarify who is the substitute decision-maker
- Ensure that a diagnosis of brain impairment related to decision-making exists.

5 The default legal capacity model

If transparency about these issues does not assist in achieving a plan, proceed to a capacity assessment process, unless the person has an Advance Directive in place, where in South Australia mediation can be pursued with the Office of the Public Advocate.

Capacity determinations are neutral in value to the outcome, and follow common law principles, requiring evidence of brain impairment related to decision-making.
A clear diagnosis, related to decision-making, is firstly necessary to ensure the common law approach has jurisdiction. The capacity assessment determines objectively, based on the rational-cognitive legal standard of understanding, if the person has the ability to make the decision. Procedural approaches such as in Darzin's model (2000) measure the rational-cognitive ability of the person to understand their context, choices and consequences of these choices. The professional undertaking the assessment is required to suspend personal and professional value judgments, and be free of conflicts of interest arising from the situation.

If the assessment finds the person can understand their choice and its implications, they are supported to achieve their choice. If the determination concludes that the person's understanding does not meet the minimum threshold, the person's substitute decision-maker or close family member makes the decision. The *Advance Care Directives Act 2013* (SA) requires the substitute decision-maker to take into account the preferences and well-being of the person and to pursue outcomes, where possible, that are congruent with the person's needs and preferences as they perceive them. This utilises an empathic person-centred 'substituted judgement' approach towards the person’s life choices. This is taking the viewpoint of the person in relation to their life meaning, with neutrality by the substitute decision-maker. The substitute decision-maker may also require support in this process, and to be protected from other’s conflicts of interest.

Where concerns by others as to the outcome remains, or significant conflicts of interest, an application can be made to the appropriate tribunal for resolution.

Bibliography

Access Economics 2003, *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*, Alzheimer’s Australia, Canberra.

—— 2005, *Dementia Estimates and Projections: Australian states and territories*, Alzheimer’s Australia, Canberra.

Aged Rights Advocacy Service 2010, *Aged Rights Advocacy Service*, ARAS, viewed 21/6/10, <http://www.sa.agedrights.asn.au/ history_what.html>.

Agich, GJ 1990, 'Reassessing Autonomy in Long-Term Care', *The Hastings Center Report*, vol. 20, no. 6, pp. 12-7.

—— 2003, *Dependence and Autonomy in Old Age: An ethical framework for long-term care*, Cambridge University Press, Cambridge.

Alzheimer's Australia 2006, *100 Years of Alzheimer's Disease 1906-2006: Towards a world without dementia*, Paper no 9, Alzheimer's Australia, Canberra, viewed 13 March 2015, < https://fightdementia.org.au/sites/default/files/ 20060000_Nat_NP_9100YrsAlz.pdf>.

—— 2010, *Consumer involvement in dementia research: Alzheimer's Australia's Consumer Dementia Research Network*, Paper no 22, Alzheimer's Australia, Canberra, viewed 30 March 2015, <https://fightdementia.org.au /sites/default/files/20100906-NAT-NP-Alzheimers-Australia-Consumer-Involvement-in-Dementia-Research-Paper-22-final.pdf>.

—— 2012a, *What is Dementia*, Alzheimer's Australia, Canberra, viewed 28 April14, <http://www.fightdementia.org.au/common/files/NAT/ 20130912_NAT_HS_AboutDementiaHelpSheet_1.pdf>.

—— 2012b, *Statistics*, Alzheimer's Australia, Canberra, viewed 1 June 2014, <http://www.fightdementia.org.au/understanding-dementia/statistics.aspx>.

—— 2014, *Living with dementia program*, Alzheimer’s Australia, Canberra, viewed 30 March 2015, <https://fightdementia.org.au/sites /default /files /20140612_-_National_-_Services_Support_-_Living_with_Dementia.pdf>.

—— 2011, *Pfizer Health Report Dementia: Dementia is everyone’s business*, Alzheimer’s Australia, Canberra, viewed 18 June 2014, <https://fight dementia.org.au/ research-and-publications/reports-and-publications/pfizer-health-reports>.

Alzheimer's Australia Dementia Research Foundation 2014, *‘Who we are’,* ADDRF, viewed 19 June 2014, <http://www.dementiaresearchfoundation.org.au/who-are-we>.

Asmussen, K & Creswell, J 1995, 'Campus response to a gunman', *Journal of Higher Education*, vol. 66, no. 575- 591.

Australian Bureau of Statistics 2013, *Gender Indicators- Life Expectancy*, ABS, Canberra, viewed 1/3/15, <http://www.abs.gov.au/ausstats/abs@.nsf /Lookup/4125.0main+features3110Jan%202013>.

Australian Commission on Safety and Quality in Healthcare 2011, *Patient-Centred Care: Improving quality and Safety through partnerships with patients and consumers*, ACSQHC, Sydney.

Australian Department of Social Services 2015, *Australian Government programmes to Support People with Dementia, Their Families and Carers*, Dept. of Social Services, Canberra, viewed 22 April 2015, <https://www.dss.gov.au/our-responsibilities/ageing-and-aged-care/older-people-their-families-and-carers/dementia/australian-government-programmes-to-support-people-with-dementia-their-families-and-carers>.

Australian Institute of Health and Welfare, *Dementia*, AIHW, Canberra, viewed 1 June 2014, <http://www.aihw.gov.au/dementia>.

Australian Law Reform Commission 2014, *Equality, Capacity and Disability in Commonwealth Laws*, ALRC Report 124, Sydney.

Barnes, M & Brannelly, T 2008, 'Achieving Care and Social Justice for People with Dementia', *Nursing Ethics*, vol. 15, no. 3, pp. 384-95.

Batsch, N & Mittelman, M 2012, *World Alzheimer Report 2012: Overcoming the stigma of dementia*, Alzheimer's Disease International, London, viewed 21 February 2014, <http://www.alz.org/documents_custom/ world_report_2012_final.pdf>.

Beauchamp, TL & Childress, JF 1994, *Principles of Biomedical Ethics*, 4th edn, Oxford University Press, New York.

—— 2001, *Principles of Biomedical ethics*, 5th edn, Oxford University Press, New York.

Becker, G 1994, 'The oldest old: Autonomy in the face of frailty', *Journal of Aging Studies*, vol. 8, no. 1, pp. 59-76.

Benaroyo, L & Widdershoven, G 2004, 'Competence in Mental Health Care: A Hermeneutic Perspective', *Health Care Analysis*, vol. 12, pp. 295- 8.

Benson, P 1994, 'Free Agency and Self-Worth', *Journal of Philosophy*, vol. 91, no. 650-668.

—— 2005, 'Feminist Intuitions and the Normative Substance of Autonomy', in JS Taylor (ed.), *Personal Autonomy: New Essays on Personal Autonomy and its Role in Contemporary Moral Philosophy*, Cambridge University Press, Cambridge.

Berg, JW, Appelbaum, P & Grisso, T 1996, 'Constructing Competence: Formulating Standards of Legal Competence to Make Legal Decisions', *Rutgers Law Review*, vol. 48, no. 2, pp. 345-71.

Berghmans, R, Dickenson, D & Rudd, TM 2004, 'Mental Capacity: In Search of Alternative Perspectives', *Health Care Analysis*, vol. 12, no. 4, pp. 251-63.

Berlin, I. (1958), *Two Concepts of Liberty*, In Berlin I (1969) Four Essays on Liberty. Oxford: Oxford University Press.

Berlin, I. 1969, *Four Essays on Liberty*, Oxford University Press, Oxford.

Blay, S 2006, *Torts*, 5th edn, Lawbook.Co, Sydney.

Blustein, J 1999, ‘Choosing for Others as Continuing a Life Story: The Problem of Personal Identity’, *Journal of Law, Medicine & Ethics*, vol. 27, no. 1, pp. 20-31.

Bolman, L & Deal, T 1991, *Reframing Organisations*, Jossey-Bass Publishers, San Francisco.

Bond, J 1992, 'The Medicalization of Dementia', *Journal of Aging Studies*, vol. 6, no. 4, pp. 397-403.

Bond, J, Corner, L, Lilley, A & Ellwood, C 2002, 'Medicalization of Insight and Caregivers' Responses to Risk in Dementia', *Dementia*, vol. 1, no. 3, pp. 318-28.

Boulis, A & Jacobs, J 2010, *The Changing Face of Medicine: Women Doctors and the Evolution of Health*, Cornell University Press, Ithaca and London.

Brazier, M & Lobjoit, M (eds) 1991, *Protecting the Vulnerable: Autonomy and Consent in Health Care*, Routledge, London.

Breden, TM & Vollman, J 2004, 'The Cognitive Based Approach of Capacity Assessment in Psychiatry: A Philosophical Critique of the MacCAT-T', *Health Care Analysis*, vol. 273, p. 276.

Brock, DW 1991, 'Decision Making Competence and Risk', *Bioethics*, vol. 5, no. 2, pp. 105-12.

Brooker, D 2004, 'What is person-centred care in dementia?', *Reviews in Clinical Gerontology*, vol. 13, pp. 215-22.

Browning , M, Bigby C, Douglas, J 2014, ‘Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice’, *Research and Practice in Intellectual and Developmental Disabilities,* vol. 1, no. 1, pp 34-45, DOI:10.1080/23297018.

Bryden, C 2012, *Who will I be when I die?*, Jessica Kingsley Publishers London.

Butler, R 1969, 'Ageism: Another form of bigotry', *The Gerontologist*, vol. 9, no. 4, pp. 243-6.

Caffrey, B 1991, *Guidebook to Contract Law in Australia*, CCH Australia, North Ryde, NSW.

Callahan, D 1984, 'Autonomy: a moral good not a moral obsession', *Hastings Center Report*, vol. 14, pp. 40-2.

Carney, T 1991, *Law at the Margins*, Oxford University Press, Melbourne.

—— 1997, 'Introduction: Competence', *International Journal of Law and Psychiatry*, vol. 20, no. 1, pp. 1-4.

Carney, T & Tait, D 1991, 'Guardianship Dilemmas and Care of the Aged', *Sydney Law Review*, vol. 13, no. 1, pp. 62-84.

Cassell, E 1977, 'The Function of Medicine', *Hastings Center Report*, December, pp. 16-9.

Chappell, N & Reid, C 2002, 'Burden and Well-being Among Caregivers: Examining the Distinction', *The Gerontologist*, vol. 42, no. 6, pp. 772-80.

Charland, L 1998, 'Is Mr Spock Mentally Competent: Competence to Consent and Emotion', *Philosophy, Psychiatry, Psychology*, vol. 5, no. 1, pp. 67-81.

—— 2001, 'Mental Competence and Value: the Problem of Normativity in the Assessment of Decisional Capacity', *Psychiatry, Psychology and the Law*, vol. 8, no. 2, pp. 135-45.

—— 2008, *Decision-Making Capacity*, viewed 6 May 2014, <http://plato. stanford.edu/entries/decision-capacity/>.

Charmaz, K 2006, *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*, Sage, Thousand Oaks CA.

Cheek, J & Rudge, T 1994, 'Webs of documentation: The discourse of case notes', *Australian Journal of Communication*, vol. 21, no. 2, pp. 41-52.

Christman, J 2003, ‘Autonomy in Moral and Political Philosophy’, *The Stanford Encyclopaedia of Philosophy*, viewed 11 December 2008, <http://plato.stanford.edu/entries/autonomy-moral/>.

—— 2011, ‘Autonomy in Moral and Political Philosophy’, *The Stanford Encyclopaedia of Philosophy*, Spring 2011 edn, viewed 3 September 2013, <http://plato.stanford.edu/archives/spr2011/ entries/autonomy-moral>.

Church, M & Watts, S 2007, 'Assessment of mental capacity: a flow chart guide', *The Psychiatrist*, vol. 31, pp. 304-7.

Clarke, A, Hanson, E, Ross, H 2003, ‘Seeing the person behind the patient: enhancing the care of older people using a biographical approach’, *Journal of Clinical Nursing*, vol. 12, no. 5, pp.697-706.

Clarke, C, Keady, J, Wilkinson, H, Gibb, C, Luce, A, Cook, A & Williams, L 2010, 'Dementia and risk: contested territories of everyday life', *Journal of nursing and healthcare of chronic illness*, vol. 2, no. 2, pp. 102-12.

Cohen, D & Eisdorfer, C 1986, *The Loss of Self: A Family Resource for the Care of Alzheimer's Disease and Related Disorders*, W.W. Norton, London.

Cohen, ES 1990, 'The elderly mystique: Impediment to advocacy and empowerment', *Generations: Journal of the American Society on Aging*, vol. 14, pp. 13-6.

Conrad, P 2007, *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Conditions*, The John Hopkins University Press, Baltimore.

Cook, C, Creyke, R, R, G & Hamer, D (eds) 2005, *Laying down the Law*, 6th edn, LexisNexis Butterworths, Chatswood, NSW.

COTA 2014, *A new system for better employment and social outcomes*, Council on the Ageing, Adelaide.

COTA 2015, *Every Generation Festival,* Council on the Ageing, Adelaide, viewed 20 March 2015, <https://www.cotasa.org.au/programs/festival/ default.aspx>.

Cotterrell, R 1992, *The Sociology of Law: An introduction*, Butterworths, London.

—— 2006, *Law, Society and Culture: Legal Ideas in the Mirror of Social Theory*, Ashgate Publishing, Aldershot.

Creswell, J 2007, *Qualitative Inquiry and Research Design*, Sage Publications, Thousand Oaks.

Crotty, M 1998, *The Foundations of Social Science Research*, Allen and Unwin, St Leonards, New South Wales.

Cudd, A 2006, *Analyzing Oppression*, Oxford University Press, NY.

Cuddy, A & Fiske, S 2004, 'Doddering but Dear: Process, Content, and Function in Stereotyping of Older Persons', in T Nelson (ed.), *Ageism: Stereotyping and Prejudice against Older Persons*, paperback edn, MIT Press, Massachusetts.

Cuddy, A, Norton, M & Fiske, S 2005, 'This Old Stereotype: The Pervasiveness and Persistence of the Elderly Stereotype ', *Journal of Social Issues*, vol. 61, no. 2, pp. 267-85.

Cutter, MAG & Shelp, EE (eds) 1991, *Competency: a Study of Informal Competency Determinations in Primary Health Care*, Kluwer Academic, Dordrecht.

Damasio, A 1994, *Descartes' Error: Emotion, Reason and the Human Brain*, Grossett and Putman, New York.

Darley, JM & Fazio, RH 1980, 'Expectancy-confirmation processes arising in the social interaction sequence', *American Psychologist*, vol. 35, pp. 867-81.

Darzins, P, Molloy, DW & Strang, D 2000, *Who Can Decide? The six step capacity assessment process*, Memory Australia Press, Adelaide.

Davies, M 2008, *Asking the Law Question*, third edn, Thomson Lawbook Co, Sydney.

Davies, M & Naffine, N 2001, *Are Persons Property? Legal Debates About Property and Personality*, Ashgate Press, Aldershot, England.

Davis, D 2004, 'Dementia: sociological and philosophical constructions', *Social Science and Medicine*, vol. 58, pp. 369-78.

Davis, J 2012, *Connecting with Tort Law*, Oxford University Press, South Melbourne, Victoria.

De Certeau, M 1984, *The Practice of Everyday Life*, University of California Press, berkely and Los Angeles.

Deci, E 1980, *The Psychology of Self-Determination*, Lexington Books.

Deloitte Access Economics 2011, *Dementia Across Australia 2011-2050*, Alzheimer’s Australia, Canberra, viewed 31 March 2015, <https://fight dementia.org.au/sites/default/files/20111014_Nat_Access_DemAcrossAust.pdf >.

Denson, L 2006, *Values and long-term care decision making for frail elderly people*, PhD thesis, University of Adelaide.

Denson, L, Winefield, H & Beilby, J 2013, 'Discharge-planning for long-term needs: the values and priorities of older people, their younger relatives and health professionals', *Scandinavian Journal of Caring Sciences*, vol. 27, no. 1, pp. 3-12.

Denzin NK1970, *The Research Act*, Aldine, Chicago.

–––1989, *Interpretive Interactionism*, Sage Publications, Newbury Park CA.

Denzin, NK & Lincoln, YS (eds) 2000, *Handbook of Qualitative Research*, 2nd edn, Sage Publications, Thousand Oaks California.

–––2005, *The Sage Handbook of qualitative research*, 3rd edn, Sage Publications, Thousand Oaks

Devereaux, J 1999, 'Competency to Consent to Treatment: An Introduction', in I Freckleton & K Peterson (eds), *Controversies in Health Law*, The Federation Press, Sydney.

Devereaux, J & Parker, M 2006, 'Competency Issues for young persons and older persons', in I Freckleton & K Peterson (eds), *Disputes and Dilemmas in Health Care*, The Federation Press, Sydney.

Donaldson, C & Burns, A 1999, 'Burden of Alzheimer's Disease: Helping the Patient and Caregiver', *J Geriatric Psychiatry Neurol*, vol. 12, no. 1, pp. 21-8.

Donchin, A 2001, 'Understanding Autonomy Relationally: Toward a Reconfiguration of Bioethical Principles', *Journal of Medicine and Philosophy*, vol. 26, no. 4, pp. 365-86.

Donnelly, M 2009, 'Capacity assessment under the Mental Capacity Act 2005:Delivering on the functional approach?', *Legal Studies*, vol. 29, no. 3, pp. 464-91.

——2010, *Healthcare Decision-Making and the Law*, Cambridge University Press, Cambridge UK.

—— 2014, 'A Legal Overview', in C Foster, J Herring & I Doron (eds), *The Law and Ethics of Dementia*, Hart Publishing, Oxford, pp. 271-81.

Downie, J & Llewellyn, J 2008, 'Relational Theory and Health Law Policy', *Special E. Health Law Journal*, pp. 193-210.

—— (eds) 2012, *Being Relational: Reflections on Relational Theory and Health Law*, UBC Press, Vancouver.

Downs, M 1997, 'The Emergence of the Person in Dementia Research', *Ageing and Society*, vol. 17, pp. 597-607.

Dryden, J 2010, ‘Autonomy: An Overview’, *Internet Encyclopedia of Philosophy*, viewed 19 December 2013, <www.iep.utm.edu/autonomy/>.

Dubler, NN 1985, 'Some Legal and Moral issues Surrounding Informed Consent for Treatment and Research Involving the Cognitively Impaired Elderly', in MB Kapp, HE Pies & AE Doudera (eds), *Legal and Ethical Aspects of Health Care*, Health Administration Press, Ann Arbor.

Dunn, L, Nowrangi, M, Palmer, B, Jeste, D & Saks, E 2006, 'Assessing Decisional Capacity for Clinical Research or Treatment: A Review of Instruments', *American Journal of Psychiatry*, vol. 163, no. 8, pp. 1323-34.

Dworkin, G 1971, ‘Paternalism’, in R Wasserstrom (ed), *Morality and the Law*, Wadsworth, Belmont, Calif.

——1988, *The Theory and Practice of Autonomy*, Cambridge University Press, Cambridge.

——1993, 'Autonomy', in R Goodwin & P Pettit (eds), *A Companion to Contemporary Political Philosophy*, Blackwell.
Dworkin, R 1977, *Taking Rights Seriously*, Harvard University Press, Cambridge.

Edvardsson, D, Winblad, B, Sandman, P 2008, ‘Person-centred care for people with severe Alzheimer’s Disease: current status and ways forward’, *The Lancet Neurology*, vol.7, pp. 362-67.

Engel, D 1995, 'Law in the Domains of Everyday Life: The Construction of Community and Difference', in A Sarat & TR Kearns (eds), *Law in Everyday Life*, First paperback edition edn, University of Michigan, Ann Arbor, pp. 123-70.

Epp, TD 2003, 'Person-centred Dementia Care: A Vision to be Refined', *The Canadian Alzheimer Disease Review*, April.

Erde, EL 1991, 'Breaking up the Shell Game of Consequentialism: Incompetence-Concept and Ethics', in MAG Cutter & EE Shelp (eds), *Competency*, Springer, Netherlands, pp. 237-52.

Erikson, EH, Erikson, JM & Kivnick, HQ 1994, *Vital Involvement in Old Age*, WW Norton & Company, Canada and USA.

Ewick, P & Silbey, S 1998, *The Common Place of Law*, First paperback edition edn, University of Chicago Press, Chicago.

Faden, R, Beauchamp, T & King, N 1986, *History and Theory of Informed Consent*, Oxford University Press, New York.

Fazel, S, Hope, T & Jacoby, R 1999, 'Assessment of competence to complete advance directives: validation of a patient centred approach', *BMJ*, vol. 318, pp. 493-7.

Finucane, P, Myser, C & Ticehurst, S 1993, 'Is she fit to sign, doctor? Practical ethical issues in assessing the competence of elderly patients', *Medical Journal of Australia*, vol. 159, pp. 400-3.

Flegel, K & MacDonald, N 2008, 'Decision-making capacity in an age of control', *Canadian Medical Association Journal*, vol. 178, no. 2, p. 127.

Flick, U 2007, *Managing Quality in Qualitative Research*, Sage Publications Ltd, London.

Flynn, E & Arstein-Kerslake, A 2014, 'Legislating personhood: realising the right to support in exercising legal capacity', *International Journal of Law in Context*, vol. 10, no. 1, pp. 81-104.

Foster, C 2009, *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law*, Hart Publishing, Oxford.

Foucault, M 1982, 'Afterword: The Subject and Power', in H Dreyfus & P Rabinow (eds), *Michel Foucault: Beyond Structuralism and Hermeneutics*, University of Chicago Press, Chicago.

—–1991, 'Governmentality', in G Burchell, C Gordon & P Miller (eds), *The Foucault Effect: Studies in Governmentality*, Harvester Wheatsheaf, London, pp. 87-104.

—– 2000, *The birth of the clinic: An archaeology of medical perception*, Routledge, London.

Fox, R 2000, 'Medical Uncertainty Revisited', in G Albrecht, R Fitzpatrick & S Scrimshaw (eds), *Handbook of Social Studies in Health and Medicine*, Sage Publications, London pp. p 409-35.

Freedman, B 1981, 'Competence: Marginal and Otherwise', *International Journal of Law and Psychiatry*, vol. 4, pp. 53-72.

Friedman, M 1990, 'Feminist and Modern Friendship: Dislocating the Community', in C Sunstein (ed.), *Feminism and Political Theory*, University of Chicago Press, Chicago.

—– 2003, *Autonomy, Gender, Politics*, Oxford University Press, New York.

Friel-McGowin, D 1993, *Living the Labryinth: a personal journey through the maze of Alzheimer's*, Elder, San Francisco.

Gadamer, HG 1988, *Truth and method*, Continuum, NY.

Galanter, M 1981, 'Justice in Many Rooms: Private Ordering, and Indigenous Law', *Journal of Legal Pluralism*, vol. 13, no. 19, pp. 1-47.

Ganzini, L, Volicer, L, Nelson, W & Derse, A 2003, 'Pitfalls in assessment of decision-making capacity', *Psychosomatics*, vol. 44, no. 3, pp. 237-43.

Geertz , C 1973, *The Interpretation of Cultures: Selected Essays*, Basic Books, NY.

Gilligan, C 1982, *In a Different Voice: Psychological Theory and Women's Development*, Harvard University Press, Cambridge MA.

Gillon, R 1985, *Philosophical Medical Ethics*, John Wiley & Sons, Chichester UK.

—– 2003, 'Ethics needs principles - four can encompass the rest- and respect for autonomy should be the first among equals', *Journal of Medical Ethics*, vol. 29, no. 5, p. 307.

Glass, K 1997, 'Redefining Definitions and Devising Instruments: Two Decades of Assessing Competence', *International Journal of Law and Psychiatry*, vol. 20, pp. 1-29.

Goffman, E 1961, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, Anchor Books, Garden City, New York.

—— 1963, *Stigma: Notes on the Management of Spoiled Identity*, Penguin Books, New Jersey.

Gooding, P 2013, ‘Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law’, *Psychiatry, Psychology and Law*, vol. 20, no.3, pp 431-451.

Gordon, R & Verdun-Jones, S 1992, *Adult Guardianship Law in Canada*, Carswell Thomson Professional Publishing, Toronto, Canada.

Grbich, C 2007, *'Qualitative Data Analysis: An Introduction'*, Sage Publications, London, Thousand Oaks.

Grisso, T & Appelbaum P 1998, *Assessing competence to consent to treatment: A guide for physicians and other health professionals*, Oxford University Press.

Guba, E & Lincoln, YS 1988, 'Do Inquiry Paradigms Imply Inquiry Methodologies?', in DM Fetterman (ed.), *Qualitative Approaches to Evaluation in Education,* Praeger, New York.

Hall, M 2009, 'Capacity, Vulnerability, Risk and Consent', in D O'Connor & B Purves (eds), *Decision-making, Personhood and Dementia: Exploring the interface*, Jessica Kingsley Publishers, London.

Harding, R 2006, 'Dogs Are 'Registered', People Shouldn't Be: Legal Consciousness and Lesbian and Gay Rights', *Social and Legal Studies*, vol. 15, pp. 511-33.

—— 2011, *Regulating sexuality: Legal consciousness in lesbian and gay lives*, Routledge.

—— 2014, 'Dementia and Carers: Relationality and Informal Carers' Experiences', in C Foster, J Herring & I Doron (eds), *The Law and Ethics of Dementia*, Hart Publishing, Oxford, pp. 379- 91.

Heidegger, M 1992, *Being and Time,* Blackwell, Oxford.

Held, V 1993, *Feminist Morality,* University of Chicago Press, Chicago.

Hellstrom, I, Nolan, M, Nordenfelt, L & Lundh, U 2007, 'Ethical and Methodological Issues in Interviewing Persons with Dementia', *Nursing Ethics*, vol. 14, no. 5, p. 608.

Herring, J 2009, 'Losing it? Losing what? The law and dementia', *Child and Family Law Quarterly*, vol. 21, no. 3-26.

Hesse-Biber, S and Leavy, P 2005, *The Practice of Qualitative Research*, Sage Publications, Thousand Oaks, CA.

Higgs, R 2004, 'The Contribution of Narrative Ethics to Issues of Capacity in Psychiatry', *Health Care Analysis*, vol. 12, no. 4, pp. 307-16.

Holstein, J & Gubrium, JF 1995, *The Active Interview*, Sage Publications, Thousand Oaks CA.

House of Representatives Standing Committee 2007, *Older People and the Law*, Commonwealth of Australia, Report, Canberra.

Huberman, AM & Miles, MB 1998, 'Data management and analysis methods', in NK Denzin & YS Lincoln (eds), *Collecting and Interpreting Qualitative Materials*, Sage, London, pp. 179-211.

Huby, G, Stewart, J, Tierney, A & Rogers, W 2004, 'Planning older people's discharge form acute hospital care: linking risk management and patient participation in decision-making', *Health, Risk & Society*, vol. 6, no. 2.

Hughes, JC 2001, 'Views of the Person with Dementia', *Journal of Medical Ethics*, vol. 27, pp. 86-91.

Hughes, JC, Louw, SJ & Sabat, S (eds) 2006, *Dementia: mind, meaning and person*, Oxford University Press, Oxford.

Hull, KE 2003, 'The Cultural Power of Law and the Cultural Enactment of Legality: The Case for Same-sex Marriage', *Law and Social Inquiry*, vol. 28, no. 2, pp. 629-56.

Hummert, ML, Garstka, TA, Shaner, JL & Strahm, S 1994, 'Stereotypes of the elderly held by young, middle-aged, and elderly adults', *Journal of Gerontology*, vol. 49, no. 5, pp. 240-9.

Hurst, S 2004, 'When Patients Refuse Assessment of Decision-Making Capacity: How Should Clinicians Respond?', *Archives of Internal Medicine*, vol. 164, pp. 1757-60.

Illich, I 1976, *Limits to Medicine; Medical Nemesis: The Expropriation of Health*, Marion Boyars, Chicago.

Iverson, T, Larsen, L, and Solem, P 2009, ‘A conceptual analysis of ageism’, *Nordic Psychology*, vol. 61, no. 3, pp. 4-22.

James, W 1952, *The Principles of Psychology*, William Benton, Chicago.

Jaworska, A 1999, 'Respecting the Margins of Agency: Alzheimer's Patients and the Capacity of Value', *Philosophy and Public Affairs*, vol. 28, no. 2, pp. 105-38.

Joffe, S, Manocchia, M, Weeks, J & Cleary, P 2003, 'What do patients value in their hospital care? An empirical perspective on autonomy centred bioethics', *Journal of Medical Ethics*, vol. 29, pp. 103-8.

Jones, D 2009, 'Incapacity and Personhood: Respecting the non-autonomous self', in H Watt (ed.), *Incapacity and Care: Controversies in Healthcare and Research*, The Linacre Centre, Oxford.

Jourdan, J & Glickman, L 1991, 'Reasons for Requests for Evaluation of Competency in a Municipal General Hospital', *Psychosomatics*, vol. 32, no. 4, pp. 413-6.

Kahneman, D 2012, *Thinking, Fast and Slow*, Penguin Books, London.

Kakkori, L 2009, 'Hermeneutics and Phenomenology Problems When Applying Hermeneutic Phenomenological Method in Educational Qualitative Research', *Padeusis*, vol. 18, no. 2, pp. 19-27.

Kapp, MB 2002, 'Decisional capacity in theory and practice: Legal process versus 'bumbling through'', *Aging and Mental Health*, vol. 6, no. 4, pp. 413-7.

Kapp, M & Mossman, D 1996, 'Measuring Decisional Capacity: Cautions on the construction of a "Capacimeter"', *Psychology, Public Policy, and the Law*, vol. 2, no. 1, pp. 73-95.

Karel, MJ 2007, 'Culture and Medical Decision Making', in SH Qualls & MA Smyer (eds), *Changes in Decison-Making Capacity in Older Adults: Assessment and Intervention*, Hoboken, NJ.

Katz, S 1996, *Disciplining old age: The formation of gerontological knowledge*, University Press of Virginia, Charlottesville.

Katzen, H & Douglas R 1999, *Administrative Law*, Butterworths, Sydney.
Kaufman, S 1995, 'Decision Making, Responsibility, and Advocacy in Geriatric Medicine: Physician Dilemmas with Elderly in the Community', *The Gerontologist*, vol. 35, no. 4, pp. 481-8.

Kennedy, R 2009, *Duty of Care in the Human Services: Mishaps, Misdeeds and the Law*, Oxford University Press, Melbourne.

Kennedy, R, Richards, J & Leiman, T 2013, *Integrating Human Service Law, Ethics and Practice*, 3rd edn, Oxford University Press, Sth Melbourne.

Kerridge, I, Lowe, M & McPhee, J 1998, *Ethics and Law for the Health Professional*, Social Science Press, Katoomba.

Kerridge, I, Lowe, M & Stewart, C 2009, *Ethics and Law for the Health Professions*, The Federation Press, Sydney.

Killoran, E 2011, *Smoking is no longer cool*, International Business Times, viewed 9/3/15 2015, <http://www.ibtimes.com/its-official-smoking-no-longer-cool-310822>.

Kinsella, EA 2006, 'Hermeneutics and Critical Hermeneutics: Exploring Possibilities Within the Art of Interpretation', *Forum: Qualitative Social Research*, vol. 7, no. 3.

Kite, M & Wagner, L 2004, 'Attitude towards Older Adults', in T Nelson (ed.), *Ageism: Stereotyping and Prejudice against Older Adults*, MIT Press, Massachusetts, pp. 129-61.

Kitwood, T 1997, *Dementia Reconsidered: the person comes first*, Open University Press, Buckingham.

Kitwood, T & Benson, S 1995, *The New Culture of Dementia Care*, Hawker, London.

Kleinig, J 1983, *Paternalism*, Manchester University Press, Manchester.

Kluge, E, K 2005, 'Competence, capacity and informed consent: beyond the cognitive-competence model', *Canadian Journal of Aging*, vol. 24, no. 3, pp. 295-304.

Kukathas, C 1993, 'Liberty', in R Goodin & P Pettit (eds), *A Companion to Contemporary Political Philosophy*, Blackwell.

Kymlicka, W 1989, 'Liberal Individualism and Liberal Neutrality', *Ethics,* vol. 99, no. 4, pp. 883-905.

Lamers, C, Gammon, E, Jones, E & Owen, R 2005, 'Decision making processes in dementia care', paper presented to Journal of Dementia Care Conference 2005, UK.

Levinas, E 1981, *Otherwise than Being or Beyond Essence,* Martinus Nijhoff, The Hague.

Liamputtong, P 2009, *Qualitative Research Methods*, 3rd edn, Oxford University Press, South Melbourne, Victoria.

Liamputtong, P & Ezzy, D 2005, *Qualitative Research Methods*, Oxford University Press, New York.

Lincoln, YS & Guba, E 1985, ‘Emerging criteria for quality in qualitative and interpretive research’, *Qualitative Inquiry*, vol. 1, pp 275-89.

—— 2000, 'Paradigmatic Controversies, Contradictions, and Emerging Confluences', in NK Denzin & YS Lincoln (eds), *Handbook of Qualitative Research*, 2nd edn, Sage Publications, Thousand Oaks California.

—— 2002, 'Judging the Quality of Case Study Reports', in AM Huberman & MB Miles (eds), *The Qualitative Researcher's Companion*, Sage Publications Thousand Oaks California, pp. 205-15.

Lock, M 2013, *The Alzheimer Conundrum: Entanglements of Dementia and Aging*, Princeton University Press, Princeton NJ.

Lothian, K & Philp, I 2001, 'Care of older people: Maintaining the dignity and autonomy of older people in the healthcare setting', *BMJ: British Medical Journal*, vol. 322, no. 7287, pp. 668-70.

Lovitt, L & Wilkinson, B 2010, 'The right care for the elderly', *The Health Advocate*, vol. 3, April, pp. 30-32.

Lyman, K 1989, 'Bringing the social back in: A Critique of the Biomedicalization of Dementia', *the Gerontologist*, vol. 29, no. 5, pp. 597-605.

Lysaught, MT 2004, 'Respect: Or, How Respect for Persons Became Respect for Autonomy', *Journal of Medicine and Philosophy*, vol. 29, no. 6, pp. 655-80.

Mackenzie, C & Rogers, W 2013, 'Autonomy, vulnerability and capacity: a philosophical appraisal of the Mental Capacity Act', *International Journal of Law in Context*, vol. 9, no. Special Issue 01, pp. 37-52.

Mackenzie, C & Stoljar, N 2003, *Relational Autonomy: Feminist essays on autonomy, agency and the social self*, Oxford University Press, New York.

Macnaghten, P & Myers, G 2004, 'Focus Groups', in C Seale, JF Gobo, JE Gubrium & D Silverman (eds), *Qualitative Research Practice*, Sage Publications, London.
Maguire, CP, et al 1996, 'Family members attitudes toward telling the patient with Alzheimer's Disease their diagnosis', *British Medical Journal*, no. 313, pp. 529-30.

Major, B & O'Brien, L 2005, 'The Social Psychology of Stigma', *Annual Review of Psychology*, vol. 56, no. 1, pp. 393-421.

Mappes, T & Zembaty, J 1994, 'Patient choices, family interests and physician obligations', *Kennedy Institute of Ethics Journal*, vol. 4, pp. 27-46.

Margulies 1994, 'Access, Connection and Voice: A Contextual Approach to Representing Senior Citizens of Questionable Capacity', *Fordham Law Review*, vol. 62, no. 5.

Marshall, A & Barclay, S 2003, 'In Their Own Words: How Ordinary People Construct the Legal World', *Law and Social Inquiry*, vol. 28, no. 3, pp. 617-28.

Marson, D, Chatterjee, A, Ingram, K & Harrell, L 1996, 'Toward a neurologic Model of Competency: Cognitive Predictors of Capacity to Consent in Alzheimer's Disease Using Three Different Standards', *Neurology*, vol. 46, no. 3, pp. 666-72.

Marson, D, Earnst, K, Jamil, F, Bartolucci, A & Harrell, L 2000, 'Consistency of physician's legal standard and personal judgements of competency in patients with Alzheimer's Disease', *Journal of the American Geriatrics Society*, vol. 48, no. 8.

Marson, D, Ingram, K, Cody, H & Harrell, L 1995, 'Assessing the Competency of Patients with Alzheimer's Disease under Different Legal Standards: A Prototype Instrument', *Archives of Neurology*, vol. 52, pp. 949-54.

McCall Smith, A 1997-1998, 'Beyond Autonomy', *Journal of Contemporary Health Law and Policy*, vol. 14, no. 23, pp. 23-39.

McCann, M & March, T 1996, 'Law and Everyday Forms of Resistance: A Socio-political Assessment', *Studies in Law, Politics and Society*, vol. 15, pp. 207-36.

McCullough, L, Wilson, N, Teasdale, T, Lopakchi, A & Skelly, J 1993, 'Mapping Personal, Familial, and Professional Values in Long-term Care Decisions', *The Gerontologist*, vol. 33, no. 3, pp. 324-32.

McLeod, C 2002, *Self-Trust and Reproductive Autonomy*, MIT Press, Cambridge MA.

Mendelsen, D & Ashby, M 2006, 'Arbitrating "end-of-life" decisions: issues, processes, and the role of the law', in I Freckleton & K Peterson (eds), *Disputes and Dilemmas in Health Law*, The Federation Press, Annadale, NSW.

Merry, SE 1988, 'Legal Pluralism', *Law and Society Review*, vol. 22, no. 5, pp. 869-96.

Merton, RK 1968, *Social Theory and Social Structure*, Simon and Schuster.

Mezey, N 2001, 'Out of the Ordinary: Law, Power, Culture, and the Commonplace', *Law and Social Inquiry*, vol. 26, no. 1, pp. 145-55.

Mezzich, J & van Weel, C 2009, *International College for Person-Centered Medicine*, viewed 21 August 2012, <http://www.personcenteredmedicine. org.php>.

Mikhail, M 1992, Psychological Responses to Relocation to a Nursing Home, *Journal of Gerontological Nursing*, vol.18, no. 3, pp 35-39.

Mill, JS 1906, *On Liberty*, Alfred A Knopf, New York.

Minichiello, V, Browne, J & Kendig, H 2000, 'Perceptions and consequences of ageism: views of older people', *Ageing and Society*, vol. 20, no. 3, pp. 253-78.

Moore, S 1973, 'Law and Social Change: The semi-autonomous social field as an appropriate subject of study', *Law and Society Review*, vol. 7, no. 1, pp. 719-46.

Morgan, DL 1997, *Focus groups as qualitative research*, 2nd edn, Sage Publications, Newbury Park CA.

Moulton, B & King, J 2010, 'Aligning Ethics with Medical Decision-Making: The Quest for Informed Patient Choice', *Journal of Law, Medicine & Ethics*, vol. 38, no. 1, pp. 85-97.

Moustakas, C 1990, *Heuristic Research: Design, Methodology and Applications*, Sage Publications, Newbury Park, California.

Moye, J 2007, 'Clinical Frameworks for Capacity Assessments', in SH Qualls & MA Smyer (eds), *Changes in Decision-Making Capacity in Older Adults: Assessment and Intervention*, John Wiley & Sons, Hoboken, NJ.

Moye, J & Braun, M 2007, 'Assessment of Medical Consent and Independent Living', in SH Qualls & MA Smyer (eds), *Changes in Decision Making Capacity in Older Adults: Assessment and Intervention*, John Wiley & Sons, Hoboken, NJ.

Moye, J & Marson, D 2007, 'Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research', *Journal of Gerontology SeriesB: Psychological Sciences and Social Sciences*, vol. 62, no. 1, pp. 3-11.

Naffine, N 2009, *Law's Meaning of Life: Philosophy, Religion, Darwin and the Legal Person*, Legal Theory Today, Hart Publishing, Oxford and Portland, Oregon.

Narayan, U 2002, 'Minds of Their Own: Choices, Autonomy, Cultural Practices and Other Women', in L Antony & C Witt (eds), *A Mind of One's Own. Feminist Essays on Reason and Objectivity*, Westview, Boulder, pp. 418-32.

Nay, R 2002, 'The Dignity of Risk', *Australian Nursing Journal*, vol. 9, no. 9, p. 33.

Nay, R, Bird, M, Evardsson, D, Fleming, R & Hill, R 2009, 'Person-centred care', in R Nay & S Garratt (eds), *Older People: Issues and Innovations in Care*, Churchill Livingstone, Elsevier, Sydney Australia.

Neal, M 2014, ‘Respect for human dignity as a “substantive basic norm”’, *International Journal of Law in Context*, vol.10, no. 1, pp.26-46.

Nedelsky, J 2011, *Law's Relations: A Relational Theory of Self, Autonomy, and Law*, Oxford University Press, New York.

Nelson, T 2005, 'Ageism: Prejudice Against Our Feared Future Self', *Journal of Social Issues*, vol. 61, no. 2, pp. 207-21.

Newberry, A & Pachet, A 2008, 'An innovative framework for psychosocial assessment in complex mental capacity evaluations', *Psychology, Health and Medicine*, vol. 13, no. 4, pp. 438-49.

NSW Attorney General's Dept. 2008, *Are the rights of people whose capacity is in question being adequately promoted and protected?*, Discussion paper, Government of New South Wales, Sydney.

NSW Attorney General's Dept 2008, *Capacity Toolkit*, Government of New South Wales, Sydney.

Nuffield Council of Bioethics 2009, *Dementia: ethical issues*, Nuffield Council on Bioethics, Cambridge.

Nussbaum, M 2001, 'Adaptive Preferences and Women's Options', *Economics and Philosophy*, vol. 17, pp. 67-88.

O'Connor, D & Purves, B (eds) 2009, *Decision-Making, Personhood and Dementia: Exploring the Interface,* Jessica Kingsley Publishers, London and Philadelphia.

Ontario Capacity Assessment Office 2005, *Guidelines for conducting Assessments of Capacity,* Ministry of the Attorney General Ontario, viewed 8 May 2015, <http://www.attorneygeneral.jus.gov.on.ca/ english/family/ pgt/capacity/2005-06/guide-0505.pdf>.

Osborne, G 1991, *The Hermeneutical Spiral: A Comprehensive Guide to Biblical Interpretation,* InterVarsity Press, Downers Grove, IL.

Oshana, M 2005, 'Autonomy and Self-Identity', in J Anderson & J Christman (eds), *Autonomy and the Challenges of Liberalism: New Essays,* Cambridge University Press, Cambridge.

Parens, E 2013, 'On good and bad forms of medicalization', *Bioethics*, vol. 27, no. 1, pp. 28-35.

Parker, M & Cartwright, C 2005, 'Mental capacity in Medical Practice and Advance Law Planning: Clinical, Ethical and Legal Issues', in B Collier, C Coyne & K Sullivan (eds), *Mental Capacity*, The Federation Press, Leichhardt, NSW.

Parsons, T 1951, ‘Illness and the role of the physician: a sociological perspective’ *American Journal of Orthopsychiatry,* vol. 21, no. 3, pp. 452-460.

Patton, MQ 1990, *Qualitative Evaluation and Research methods,* Sage, Newbury Park, CA.

—— 2002, *Qualitative Research and Evaluation Methods,* 3rd edn, Sage Publications, Thousand Oaks CA.

Perlin, M 2000, '"Their Promises of Paradise?" Will Olmsted v LC Resuscitate the 'Constitutional Least Restrictive Alternative" Principle in Mental Disability Law', *Houston Law Review*, vol. 37.

Phillips, J 2007, *Care*, Polity, Cambridge.

Phillipson, L, Magee, C, Jones, S & Skladzien, E 2012, *Exploring Dementia and Stigma Beliefs*, Alzheimer's Australia, Canberra.

Post, S 1995, *The Moral Challenge of Alzheimer's Disease*, The John Hopkins University Press, Baltimore, MD.

——2006, 'Respectare: moral respect for the lives of the deeply respectful', in JC Hughes, SJ Louw & S Sabat (eds), *Mind, Meaning, and the Person*, University Press, Oxford.

Pound, R 1959, *Jurisprudence*, vol. 4, West Publishing, St Paul, Minn.

Preston, N 1996, *Understanding ethics*, 3rd edn, The Federation Press, Sydney.

Productivity Commission 2011, *Caring for Older Australians: Overview*, Inquiry Report No 53, June 2011, Australian Government, Canberra.

Purser, K, Magner, E & Madison, J 2015, 'A therapeutic approach to assessing legal capacity in Australia', *International Journal of Law and Psychiatry,* vol.38, pp.18-28.

Qualls, S & Smyer M (eds) 2007, *Changes in Decision-Making Capacity in Older Adults : Assessment and Intervention*, John Wiley & Sons, Hoboken, NJ.

Quill, T & Suchman, A 1993, 'Uncertainty and control: learning to live with medicine's limitations', *Humane Medicine*, vol. 9, no. 2, pp. 109-20.

Quinn, G 2010, *Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD*, paper presented to HPOD Conference, Harvard Law School.

Quinn, G 2011, *Rethinking Personhood: New Directions in Legal Capacity, Law and Policy*, paper presented to Personhood and Disability Conference, 29 April 2011, Vancouver, Canada.

Rawls, J 1971, *A Theory of Justice*, Revised edition (1999) edn, Harvard University Press, Cambridge, MA.

Raz, J 1986, *The Morality of Freedom*, Oxford University Press, Oxford.

Regan, J 1971, 'Protective Services for the Elderly: commitment, Guardianship and Alternatives', *Wm and Mary Law Review*, vol. 13, no. 3, pp. 569-622.

Ritchie, J, Sklar, R & Steiner, W 1998, 'Advance Directives in Psychiatry: Resolving Issues of Autonomy and Competence', *International Journal of Law and Psychiatry*, vol. 21, no. 3, pp. 245-60.

Roberto, K 1999, 'Making critical health care decisions for older adults: Consensus among family members', *Family Relations*, vol. 48, pp. 167-75.

Robertson, A 1990, 'The Politics of Alzheimer's Disease: a case study in apocalyptic demography', *International Journal of Health Services*, vol. 20, no. 3, pp. 429-42.

Roter, D & Hall, J 2004, 'Physician Gender and Patient-Centred Communication: A Critical REview of Empirical Research', *Annu. Rev. Public Health*, vol. 25, pp. 497-519.

Sabat, S, Fath, H & Moghaddam, F 1999, 'The Maintenance of self-esteem: lessons from the culture of Alzheimer's Sufferers', *Culture and Psychology*, vol. 5, pp. 5-31.

Sabatino, C & Basinger, S 2000, 'Competency: Reforming Our Legal Fictions', *Journal of Mental Health and Aging*, vol. 6, no. 2, pp. 119-44.

Sarat, A & Kearns, T (eds) 1994, *Law in Everyday Life*, University of Michigan Press, Ann Arbor.

Schindler, M & Waksman, Y 2014, 'Restriction of Liberty', in C Foster, J Herring & I Doron (eds), *The Ethics and Law of Dementia*, Hart Publishing, Oxford, pp. 351-9.

Scholl, J, and Sabat, S 2008, ‘Stereotypes, stereotype threat and ageing: implications for the understanding and treatment of people with Alzheimer’s Disease’, *Ageing and society*, vol. 28, pp.103-130.

Schwandt, TA 2000, 'Three Epistomological Stances for Qualitative Inquiry: Interpretivism, Hermeneutics and Social Constructionism', in NK Denzin & YS Lincoln (eds), *Handbook of Qualitative Research*, 2nd edn, Sage Publications, Thousand Oaks California, pp. 189-214.

Seidman, I 1991, *Interviewing as qualitative research*, Teachers College Press, New York.

Sherwin, S 1992, *No Longer Patient: Feminist Ethics and Health Care*, Temple University Press, Philadelphia.

—— 2012, 'Relational Theory and Global Threats', in J Downie & J Llewellyn (eds), *Being Relational: Reflections on Relational Theory and Health Law*, UBC Press, Vancouver.

Silberfield, M, Corber, W & Checkland, D 1995, 'Acknowledgement of the Limitations and Understanding of their Consequences in Mental Capacity Assessments', *Behavioral Sciences and the Law*, vol. 13, pp. 381-90.

Skene, L 1998, *Law and Medical Practice: Rights, Duties, Claims and Defences*, Butterworths, Sydney.

Smebye, K, Kirkevold, M & Engedal, K 2012, 'How do persons with dementia participate in decision making related to health and daily care? A multi-case study', *BMC Health Services Research*, vol. 12, no. 1, viewed 1/10/13 <http://www.biomedcentral.com/1472-6963/12/241>.

South Australian Office of the SA Public Advocate 2009, *Annual Report 2009,* OPA, Adelaide.

South Australian Government 2007, *Planning ahead: your health, your money, your life*, Issues paper for the Review of South Australia’s Advance Directives, SA Govt., Adelaide, South Australia.

South Australian Government 2008, *Planning ahead: your health, your money, your life*, First report to the Review of South Australia’s Advance Directives, SA Govt., Adelaide, South Australia.

Sperling, R, Aisen, P, Beckett, L et al 2011, 'Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease', *Alzheimer's & Dementia: the journal of the Alzheimer's Association*, vol. 7, no. 3, pp. 280-92.

Stake, RE 2000, 'Case Studies', in NK Denzin & YS Lincoln (eds), *Handbook of Qualitative Research*, Sage Publications, Thousand Oaks California, pp. 435-54.

Stewart, C & Bieglar, P 2004, 'A Primer on the Law of Competence to Refuse Medical Treatment', *Australian Law Journal*, vol. 78, p. 325.

Stoljar, N 2013, *Feminist Perspectives on Autonomy*, Stanford University, Stanford CA, viewed 20 February 2014, <http://plato.stanford.edu/ entries/ feminism-autonomy>.

Stone, D 1991, 'Caring Work in a Liberal Polity', *Journal of Health Politics, Policy and Law*, vol. 16, no. 3, pp. 547-552.

Strang, D, Molloy, DW & Harrison, C 1998, 'Capacity to Choose Place of Residence: Autonomy vs beneficence?', *Journal of Palliative Care*, vol. 14, pp. 25-29.

Sullivan, K 2005, 'Measuring Mental Capacity: Models, Methods and Tests', in B Collier, C Coyne & K Sullivan (eds), *Mental Capacity: Powers of Attorney and Advance Directives*, Federation Press, Sydney.

Surtees, D 2014, 'Discrimination', in C Foster, J Herring & I Doron (eds), *The Law and Ethics of Dementia*, Hart Publishing, Oxford, pp. 445-55.

Swaffer, K 2014, *I repeat please don't call us sufferers*, 11 June, Adelaide, <http://kateswaffer.com/2014/05/09/i-repeat-please-don't-call-us-sufferers>.

Tamanaha, BZ 2000, 'A Non-Essentialist Version of of Legal Pluralism', *Journal of Law and Society*, vol. 27, no. 2, pp. 296-321.

Taylor, B 2006, 'Risk Management Paradigms in Health and Social Services for Professional Decision Making on the Long-Term Care of Older People', *British Journal of Social Work*, vol. 36, no. 1411-1429.

Taylor, C 1985, 'The Person', in M Carrithers, S Collins & S Lukes (eds), *The Category of the Person*, Cambridge University Press, Cambridge.

Tedeschi, JT 1970, *Threats and Promises*, Academic Press, New York.

Tetley, J, Grant, G & Davies, S 2009, 'Using Narratives to Understand Older People's Decision-Making Processes', *Qualitative Health Research*, vol. 19, no. 9, pp. 1273-83.

Thaler, R & Sunstein, C 2008, *Nudge: Improving decisions about health, wealth, and happiness*, Yale University Press, New Haven.

Thorngate, W 1999, 'Forget me not: some comments on self-esteem among Alzheimer's sufferers', *Culture and Psychology*, vol. 5, pp. 33-9.

Tsai, DF 2009, 'A Confucian Two-Dimensional Approach to Personhood, Dementia, and Decision-Making', in D O'Connor & B Purves (eds), *Decision-Making, Personhood and Dementia: Exploring the Interface*, Jessica Kingsley Publishers, London.

Tyrrell, J, Genin, N & Myslinski, M 2006, 'Freedom of choice and decision-making in health and social care: Views of older patients with early-stage dementia and their carers', *Dementia*, vol. 5, no. 4, pp. 479-502.

United Nations 2006, *Convention on the Rights of Persons with Disabilities*, UN, Geneva, viewed 13 May 2015, <http://www.un.org/disabilities/ convention/ conventionfull.shtml>.

Van Leeuwen, E & Vellinga, A 2004, 'Knowing Well or Living Well: Is Competence Relevant to Moral Experience and Capacity in Clinical Decision Making', in D Thomasma & D Weisstub (eds), *The Variables of Moral Capacity*, Dordrecht, Kluwer.

Van Manen, M 1990, *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*, Althouse Press, London, Ontario.

Varcoe, C, Rodney, P & McCormick, J 2003, 'Health Care Relationships in Context: an Analysis of Three Ethnographies', *Qualitative Health Research*, vol. 13, no. 7, pp. 957-73.

Veatch, RM 2009, *Patient Heal Thyself: How the New Medicine Puts the Patient in Charge*, Oxford University Press, Oxford.

Vellinga, A, Smit, J, Leeuwen, E, van Tilburg, W & Jonker, C 2004, 'Instruments to Assess Decision-making Capacity: An Overview', *International Geriatrics*, vol. 16, no. 4, pp. 397-419.

Verma, S & Silberfield, M 1997, 'Approaches to Capacity and Competency: the Canadian View', *International Journal of Law and Psychiatry*, vol. 20, no. 1, pp. 35-46.

Victorian Department of Health 2012, ‘Person-centred Practice’, *Best Care for Older People Everywhere: The Toolkit* by Victorian Department of Health, Victorian Government, viewed 5 June 2014, <http://www.health.vic. gov.au/older/toolkit/ 02PersonCentredPractice/index.htm >.

Victorian Law Reform Commission 2011, *Guardianship Consultation Paper- A summary*, Victorian Law Reform Commission, Melbourne.

Volicer, L & Ganzini, L 2003, 'Health professional's views on standards for decision-making capacity regarding refusal of medical treatment in mild Alzheimer's Disease', *Journal of the American Geriatrics Society*, vol. 51, no. 9, pp. 1270-4.

Von Zweck, C, Paterson, M & Pentland, W 2008, 'The Use of Hermaneutics in a Mixed Methods Design', *The Qualitative Report*, vol. 13, no. 1, pp. 116-34.

Waitzkin, H 1989, 'A Critical Theory of Medical Discourse: Ideology, Social Control, and the Processing of Social Context in Medical Encounters', *Journal of Health and Social Behaviour*, vol. 30, pp. 220-39.

Waugh, F 2009, 'Where does risk feature in community care practice with older people with dementia who live alone?', *Dementia*, vol. 8, no. 2, pp. 205-22.

Welie, S 2001, 'Criteria for Patient Decision Making (IN) Competence: A Review of and Commentary on some Empirical Approaches', *Medicine Health Care and Philosophy*, vol. 4, pp. 139-51.

Whitlatch, C, Piiparinen, R & Feinberg, L 2009, 'How well do family caregivers know their relative's care values and preferences?', *Dementia*, vol. 8, no. 2, pp. 223-43.

Wicclair, M 1991, 'Patient Decision Making Capacity and Risk', *Bioethics*, vol. 5, p. 91.

Winick, B 1996, ‘The Side Effects of Incompetency Labeling and the Implications for Mental Health Law’ in Wexler, D &Winick B (eds), *Law in a Therapeutic Key: Developments in Therapeutic Jurisprudence*, Carolina Academic Press, Durham, NC.

Wise, S 2000, *Rattling the Cage: Towards Legal Rights for Animals*, Perseus Books, Cambridge, Mass.

Wood, EF 2005, 'History of Guardianship', in MJ Quinn (ed.), G*uardianship of Adults: Achieving Justice, Autonomy, and Safety*, Springer Publishing Company, New York.

Wood, S 2007, 'The Role of Neuropsychological Assessment in Capacity Evaluations', in SH Qualls & MA Smyer (eds), *Changes in Decison Making Capacity in Older Adults: Assessment and Intervention*, Hoboken, NJ.

Wood, S & Tanius, BE 2007, 'Impact of Dementia on Decision-Making Abilities', in SH Qualls & MA Smyer (eds), *Changes in Decison-Making Capacity in Older Adults: Assessment and Intervention*, John Wiley & Sons, Hoboken, NJ.

Woods, B & Pratt, R 2005, 'Awareness in dementia: ethical and legal issues in relation to people with dementia', *Ageing and Mental Health*, vol. 9, no. 5, pp. 423-9.

Woods, R 1989, Alzheimer’s disease: Coping with a living death, Souvenir Press, London.

Woolhead, G, Calnan, M, Dieppe, P & Tadd, W 2004, 'Dignity in older age: what do older people in the United Kingdom think?', *Age and Ageing*, vol. 33, pp. 165-70.

World Health Organisation 1992-1994, *ICD-10: International statistical classification of diseases and related health problems*, WHO, Geneva.

World Health Organisation 2012, *Dementia* ,WHO, Geneva, viewed 28/5/14, <http://www.who.int/mediacentre/factsheets/fs362/en/>.

Young, I 2006, ‘Responsibility and Global Justice: A Social Connection Model’, *Social Philosophy and Policy*, vol. 23, no. 1, pp. 100-111.

Yin, RK 2003, *Case study design: design and method*, 3rd edn, Sage, Thousand Oaks, CA.

Zarit, S & Goodman, C 1990, 'Decision making and dementia', *American Journal of Alzheimer's Care and Related Disorders and Research*, vol. 5, no. 5, pp. 22-8.

Zola, IK 1972, 'Medicine as an Institution of Social Control', *The Sociological Review*, vol. 20, no. 4, pp. 487-504.