

**The politics of participation: A critical occupational science analysis  
of social inclusion policy and entrenched disadvantage**

**Robert Bernard Pereira**

Bachelor of Occupational Therapy (Honours)

A thesis submitted in fulfilment of the requirements  
for the degree of Doctor of Philosophy

**Department of Sociology  
Faculty of Arts**

**Macquarie University**

**February 2013**



# Table of Contents

<b>List of tables and figures</b>	<b>vii</b>
<b>Declaration of authorship and originality</b>	<b>viii</b>
<b>Acknowledgements</b>	<b>ix</b>
<b>Ethics approval</b>	<b>xiii</b>
<b>Publications and conference presentations</b>	<b>xv</b>
<b>Abstract</b>	<b>1</b>
<b>Chapter One – Introduction</b>	<b>2</b>
Background to the research	6
Purpose	7
Relevance and significance	8
Critical reflexivity	10
Thesis structure	12
<b>Chapter Two – Literature Review</b>	<b>15</b>
Introduction	16
Social inclusion: Background, context and emergence	17
The Lisbon Strategy	18
Social policy development: From Europe to the United Kingdom	19
The introduction of social inclusion in Australian political discourse	19
Social inclusion: Definitional development	21
Social inclusion as ‘process’ and ‘outcome’	23
Social inclusion, poverty and disadvantage	24
General and operational definition	27
Institutional foundations of social inclusion	30
Social inclusion and human rights	34
Social model of disability	34
Inclusion-as-a-right paradigm	35
Conceptual and theoretical underpinnings of social inclusion	36
Theories of recognition	36
Inter-subjective recognition	36

The political philosophy of recognition vis-à-vis redistribution	38
The capabilities approach	40
Connectedness: A cross-cultural understanding	42
<i>Ubuntu</i> , interconnectedness and social inclusion	43
Introducing an occupational perspective of social inclusion:	
Occupation, justice and participation considered	49
Definition of occupation: Key terms and concepts	50
Empowerment in context with justice	53
Occupation in context	54
Occupational rights and occupational justice	56
Occupational justice and social inclusion	58
Occupational deprivation	60
Participation and social inclusion	61
Relevance of an occupational perspective of social inclusion to marginalised populations:	
A focus on citizens living with poverty and disability	66
Summary	72
 <b>Chapter Three – Methodology</b>	 <b>74</b>
Purpose of the research	74
Research questions	75
Qualitative research and its application to research into entrenched disadvantage from a critical occupational science perspective	77
Qualitative methods: An introduction to an ‘analysis of discourses’ (Bacchi, 2005) methodology	78
Part 1: Answering the first question – Methodology for policy analysis	80
Discourse and discourse analysis	80
Discourse analysis and power	82
Analysis of discourses: Bacchi’s (2009) WPR approach	83
Introduction to the WPR approach	84
Bacchi’s (2009) WPR methodological approach to policy analysis	85
Goals, assumptions and propositions within Bacchi’s WPR methodology	87
Bacchi’s six-question model for the analysis of policy-as-discourse	88
Michel Foucault’s influence on Bacchi’s (2009) WPR methodological approach	90
Foucault’s <i>Archaeology</i> and <i>Geneology</i> in brief	91
An analysis of discourses from a critical occupational science perspective: Whiteford and	

Townsend's (2011) 'Participatory Occupational Justice Framework' (POJF) 2010	92
Whiteford and Townsend's (2011) POJF 2010	94
Rationale for the selection of social inclusion policy discourses for analysis	
through the application of a critical analysis of discourses methodology	96
Part 2: Answering the second question – Methodology for narrative inquiry	97
Narrative inquiry: Narrative defined	97
Narrative inquiry: Life history methodology	99
Applying an occupational perspective to life history methodology	100
Storytelling in context: Exploring the lives of citizens	
living with entrenched disadvantage	101
Ethics, respect and sensitivity with life history methodology	102
Setting for study	103
Process undertaken to choosing the study's settings	104
Ability Options	105
Parramatta Mission	106
Study sequence and rationale	107
Ethics approval	107
Participant recruitment process	107
Recruitment process at Parramatta Mission	109
Recruitment process at Ability Options	110
Introducing the participants	110
Maintaining participant anonymity and confidentiality	112
Information gathering and transcription	112
Analysis of findings	114
Analysis processes	115
Coding, theme generation and interpretation	115
Authenticity and trustworthiness of the findings	117
Research limitations	117
Summary	118
 <b>Chapter Four – <i>Being me: Identity and personhood</i></b>	 119
<i>Wanting to do something that counts</i>	125
<i>Doing things to pass time; doing things that are meaningful</i>	130
Diversity of meaningful occupations	130

Exploring the meaningful leisure occupation of basketball as an ‘occupation-as-metaphor’	132
<i>Having and upholding values</i>	135
<i>Having faith</i>	139
<i>Living for my family</i>	142
<i>Having hopes and goals</i>	143
<i>Being strong and resilient</i>	146
Conclusion	149
 <b>Chapter Five – <i>Being in the world</i>: Existential realities</b>	 151
<i>“Living with disability is one of the hardest things”</i>	153
<i>I can’t afford to live</i>	162
<i>Feeling excluded and having little hope</i>	170
<i>Living in a community lacking compassion</i>	174
<i>Feeling lonely and isolated</i>	179
Conclusion	183
 <b>Chapter Six – <i>Being in the system</i>: Experiencing disadvantage and exclusion</b>	 186
<i>Being in the system: Systemic disablement and its effects on participation and social inclusion</i>	188
<i>Being told what to do</i>	189
<i>Not getting a “fair go” and being powerless</i>	202
<i>Feeling demoralised</i>	206
<i>“I don’t know what to do or where to go”</i>	208
<i>“Falling through the cracks”</i>	210
<i>It’s too complicated</i>	212
<i>Experiencing a lack of compassion and empathy</i>	213
Conclusion	215
 <b>Chapter Seven – <i>Being the policy</i>: A critical analysis of policy-as-discourse</b>	 218
Introduction	218
Theme One: A brief historico-political overview of Australian social inclusion policy discourse – Introducing a WPR approach (Bacchi, 2009)	223
Theme 2: Social inclusion policy’s focus on ‘productivity’ in context with the ‘Active Society’ (Walters, 1997)	228

The Active Society (Walters, 1997)	229
Introducing the ‘participation hierarchy’	231
Deconstructing Labor’s social inclusion policy:	
Third way politics, work and ethical citizenship	233
Theme three: Social inclusion – Policy or ideology?	235
Theme four: Applying an occupational justice framework to critically analyse social inclusion policy discourse	240
Occupational misrecognition	244
The taken-for-grantedness of participation	246
Conclusion	249
 <b>Chapter Eight – Discussion and <i>Moving Forward</i>*</b>	 251
Understanding systemic disablement in context	253
Ideological influences on social inclusion policy: Occupational implications	256
Challenging Australian values and constructions of normalcy: Providing context to denied occupational alternatives	258
Cultural tensions and the influence of Western ideologies on inclusion	259
Models of disability: Missing links and implications	261
The salience of the capabilities approach	263
Occupation as justice	266
The salience of theories of recognition: Contextualising occupational misrecognition	268
The Social Inclusion Framework (SIF): Introducing a visual meta-synthesis of the findings	271
The flow-on effect of needs not being met	274
Summary of the discussion	275
Conclusion: <i>Moving forward</i> *	278
Implications of the research for theoretical development	279
Implications of the research for inclusive practice and policy	280
Research limitations, strengths and future research possibilities	282
Recommendations to <i>move forward</i> *	283
 <b>References</b>	 287

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\* “Moving forward” is a play on words used by current Australian Prime Minister The Hon Julia Gillard MP which was the Labor Party’s main political slogan during the 2010 Federal Election.

<b>Appendices</b>	<b>330</b>
Appendix A: Definitions of social inclusion or exclusion	<b>330</b>
Appendix B: Key Rudd Labor Government publications on social inclusion	<b>332</b>
Appendix C: Speeches and press releases made by The Hon Julia Gillard on social inclusion during the Rudd Labor Government	<b>333</b>
Appendix D: Participant recruitment form	<b>338</b>
Appendix E: Participant information form and consent form	<b>339</b>
Appendix F: Examples of reflexive diary entries, data coding processes and mind mapping	<b>341</b>
Appendix G: Broad interview guide	<b>353</b>
Appendix H: Examples of participants' meaningful occupations	<b>355</b>

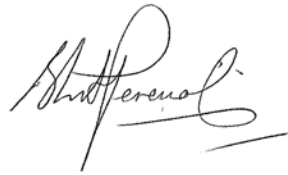


## **List of tables and figures**

Table 1: Framings of social inclusion	<b>46</b>
Table 2: Bacchi's six-question model for policy-as-discourse analysis	<b>89</b>
Table 3: Participant demographics	<b>111</b>
Table 4: Findings from the life history study	<b>124</b>
Table 5: Participants' life values which guided occupational transactions in context	<b>138</b>
Table 6: Findings from the life history study	<b>153</b>
Table 7: Experiential labels associated with experiences of exclusion	<b>171</b>
Table 8: Findings from the life history study	<b>188</b>
Table 9: WPR approach questions	<b>220</b>
Figure 1: Gillard's key terminology used during her speeches and media releases	<b>236</b>
Figure 2: Labor's frequently used terminology within social inclusion <i>texts</i>	<b>236</b>
Figure 3: Social Inclusion Framework (SIF)	<b>272</b>

## **Declaration of authorship and originality**

I, Robert Bernard Pereira, hereby declare that this PhD Thesis is my own original work and that to the best of my knowledge it contains no material previously published or written by any other person, nor material that has been accepted for the award of another degree of a university, or other higher education institution, except where due acknowledgement is made in the text. The studies documented in this thesis received ethics approval from the Macquarie University Human Research Ethics Committee (Reference Number 5201001416).

A handwritten signature in black ink, appearing to read 'Robert Bernard Pereira', with a stylized flourish at the end.

Robert Bernard Pereira

## Acknowledgements

To my dear friend and principal PhD supervisor, Professor Gail Whiteford and her family. I have always said that moving to Sydney to have you as my supervisor was one of the best decisions I have made thus far. Thank you for your scholarship, leadership, professionalism, passion, expertise, honesty, support and belief in me. You are a truly remarkable person and I am so proud to call you my colleague and friend. ¡Muchas gracias por todo!

To my associate supervisor, Associate Professor Ellie Vasta. Thank you so much for your interest and belief in my research, academic support, helping me to think critically about my work as well as for your constant encouragement throughout my PhD journey.

I would like to acknowledge Professors Ann Wilcock and Liz Townsend for their leadership in the discipline of occupational science, who have inspired me to pursue endless possibilities through researching and enabling occupation. I am gratefully indebted to you. Thank you.

My parents Heinz and Doris Pereira – Gracias por todo lo que han hecho para David y yo! Por medio de su gran esfuerzo como padres, los agradezco por darme todas las oportunidades para demostrar al mundo que todos podemos luchar y lograr nuestros sueños con una firme base de amor y cariño. Gracias por su apoyo eterno. Los quiero mucho. Me alegra mucho decir que son mis padres, y que se sientan orgulloso de mi. I dedicate my PhD thesis to you.

To my brother David, Alexis and Ariana – I wouldn't be here if it wasn't for your neverending love, support and belief in me! I am so proud to be your brother and uncle. Family is everything to me. Thank you so much bro, sis and sobrinita!

Para mis abuelos: Yo se que me estan cuidando y guiando. Nuestra sangre es tan importante para mi y sé que estan orgullosos de mi.

Agradezco a toda mi familia en Chile por su amor, amistad y apoyo durante mi vida, y especialmente durante esta epoca de mi doctorado. Mil gracias, si po!

Para Tía Rosa: Gracias Tía por tu amor, fe en mi y fe en Dios. Tu me mostrastes y guiastes como ser una persona buena y cariñosa quien puede servir a los demas. Gracias mi abuela; mi ángel que me cuida siempre.

To my Beautiful Lori Clark. Thank you for coming into my life and being such an incredible support to me. I love you. Baila conmigo en nuestro muelle en mis sueños.

Mrs Coral Kamp, my Grade Prep and One primary school teacher, thank you for believing in me and my family and educating me with passion, dedication and love.

Dr Bill McKellar, I appreciate and thank you for looking after me and inspiring me to pursue a career in health. I have never looked back.

Dr Alison Wicks, thank you for being a tremendous support and mentor to me throughout my PhD journey. I am proud to call you both my close friend and colleague. I also want to acknowledge your leadership and academic savviness in growing Australasian occupational science into the flourishing interdisciplinary discipline that it is today which is shared by many thanks to you.

Thank you to Naomi Gray for being a huge support all the way through my PhD. I sincerely appreciate everything that you have done for me. You are a gem.

To my occupational science and occupational therapy friends, colleagues and scholars who I look up to: Daniela Olivares Aising, Lori Breeden, Aakifah Suleman, Richard Reed, Clarissa Adriel, Clare Hocking, Valerie Wright-St Clair, Shanon Phelan, Beccy Aldrich, Debbie Laliberte Rudman, Matthew Molineux, Michael Iwama, Arelis Sumabila, Karen Stagnitti, Matthew Ebden, Rodolfo Morrison and Jyothi Gupta. Thank you for your scholarship, dedication and passion for what you do. Thank you for helping me to develop my own 'ways of doing and being' throughout my PhD journey.

My CRSI family: Mersina Tonys-Soulos, Bona Anna, Gai Scott, Radhika Mittal, Liberty Orbe-Taruc, Michael Fine, Amanda Wise, Debbie Bird Rose, Lorraine Gibson, Gillian Vogl, Virginia Simpson-Young, Kate Wright, Claire Farrugia, Chand Somaiah and colleagues – Thank you for 'including' me and helping me think the way that I do. You have all played an important part in my academic and personal development.

To my amazing housemate and friend, Debbie Cations (Crydal Gel) and Brett Collins. Thank you for being the best housemate ever and for putting up with me and tolerating my obsessions of

everything occupational science and therapy related. Dave doesn't know how you did it. Thank you!

To the amazing friends who I have made in Sydney and will never forget: Justine Jeddy (Bonsai), Deborah and Daryl Kunicki, Jay Mitra and Jen Greiss, Siham Yahya and Itay Dagan, Emmanuelle Lerible, Audrey Silvestri, José María González Jiménez, Michael Nicholls, Shahd Al-Janabi, Robert Ross, Rodrigo Acuña and Mary-Anna Duran, Darryl Soh and my Drummoyne community. Thank you for being awesome and making my life in the big smoke that much more unreal! I will miss you big time.

Thank you to my occupational science and therapy friends and colleagues throughout my social network community online. I would like to especially acknowledge the OT4OT Team: Anita and Alec Hamilton, Susan Burwash and John Vellacott, Merrolee Penman, Brock Cook, Sarah Bodell, Angela Hook and Karen Jacobs. Thank you for your leadership and amazing work in showing us all that through being connected, we can become a new driving force towards creating inclusive and innovative ideas together.

Thank you to my Macquarie University Campus Wellbeing friends and colleagues for all of your support over the past few years! Working with you has been fantastic: Steve Bailey, Ben Wilkes, Nicole Saunders, Sondra Wibberley, Vivienne Burridge, Michelle Corbett, Maria Youssef, Ginny Daldanian, Kelly Piper, Bareena Johnson, Liz Gray, Vicki Neale, Melinda Varhegyi, Kerri Thomas, Brendan McNicholas, Dorian Richards, Richa Gupta, Carmen Germain, Tamara Brkic, Pravania Sharma, Rochane Smith, Jenni Irving, Kanchan Kaur, Tina Li, Cherag Kalapesi, Tania Currie, Serene Lin-Stephens, David-Jack Fletcher, Nick Commins, Penny Huisman, John Machlin, Jacquie Henrisson and admin staff.

To my family friends and friends back home and overseas – thank you for believing in me and being such a great support: Natalia Garcia and Brendan Fitzgerald, Tim Mann and Marisa Barker, Sara De La Cruz, Matthew and Brooke De Propertis, Adam Ferfoggia, Chris De Propertis, Glenn Papke, Mark and Christina Carter, Rachel and Mo Azmi, Daniela Andalaro, Fatima Moneta, Nathan Lenehan, Jodie and Josh Mackley, Kate and John Hutchinson, Susan Hayward, Matt Knox, Ovee Bhuyan, Michelle Caddy, Aaron Beck, Aaron Marchant, Marlies Wanasili, Tania Harvey, Kylie Harvey, Dawn Harvey, Jeff and Jess Butler, Bianca Cassar, Maria Dionyssopoulos, Danielle Marcos, Debbie Verikios, Judy McKenzie, Zoe Jaboor, Amy Zuluaga, Tim and Mandy De Souza, Judy and John Davies, and the Ryan, Carreño, Wendrich, De La Cruz, Rebula and

Rodríguez families. I would also like to express my gratitude to José Rodríguez for his awesome design skills.

I would like to say a special thank you to Trish Kinrade and Lisa-Jane Moody. It has been really special to share our professional and PhD journeys together, which started several years ago on the wards of The Geelong Hospital. Thank you for your constant words of wisdom and sharing your expertise with me. Thank you also for your editing advice and prowess with my abstract and thesis title. Much appreciated!

To my HARP Buddies, Best Team Ever! Thank you for your continual support and for encouraging me to think critically about complex issues: Gerry McMeel, Suzy Russell, Paul Thornton, Jan Byrnes, Helen Fay, Ken Vincent, Chelsea Gielen, Linda Kar, Cico Lobbert, Judy Browning, Michelle Scott, and the CHF and COAD teams.

I would especially like to thank Macquarie University and the Australian Government for granting me an Australian Postgraduate Award Scholarship which has enabled me to pursue my life-long academic dream.

I would like to acknowledge and sincerely thank Parramatta Mission and Ability Options for their support, accessibility and involvement in my doctoral research.

Finally, I would like to express my gratitude to the seven participants who shared their stories with me. I hope that this thesis does justice to your histories and journeys of courage, hope and determination.

# Ethics approval



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## Final Approval- Ethics application reference-5201001416

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**Ethics Secretariat** <ethics.secretariat@mq.edu.au>

Thu, Dec 23, 2010 at 11:30 AM

To: Gail Whiteford <gail.whiteford@mq.edu.au>

Cc: Robert Pereira <robert.pereira@mq.edu.au>

Dear Prof Whiteford

Re: "Social inclusion policy, participation and the perspectives of citizens living with socioeconomic disadvantage and disability or chronic illness" (Ethics Ref: 5201001416)

Thank you for your recent correspondence. Your response has addressed the issues raised by the Human Research Ethics Committee and you may now commence your research.

The following personnel are authorised to conduct this research:

Prof Gail Whiteford- Chief Investigator/Supervisor

Mr Robert Pereira- Co-Investigator

NB. STUDENTS: IT IS YOUR RESPONSIBILITY TO KEEP A COPY OF THIS APPROVAL EMAIL TO SUBMIT WITH YOUR THESIS.

Please note the following standard requirements of approval:

1. The approval of this project is conditional upon your continuing compliance with the National Statement on Ethical Conduct in Human Research (2007).
2. Approval will be for a period of five (5) years subject to the provision of annual reports. Your first progress report is due on 23 December 2011.

If you complete the work earlier than you had planned you must submit a Final Report as soon as the work is completed. If the project has been discontinued or not commenced for any reason, you are also required to submit a Final Report for the project.

Progress reports and Final Reports are available at the following website:

[http://www.research.mq.edu.au/for/researchers/how\\_to\\_obtain\\_ethics\\_approval/human\\_research\\_ethics/forms](http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/forms)

3. If the project has run for more than five (5) years you cannot renew approval for the project. You will need to complete and submit a Final Report and submit a new application for the project. (The five year limit on renewal of approvals allows the Committee to fully re-review research in an environment where legislation, guidelines and requirements are continually changing, for example, new child protection and privacy laws).

4. All amendments to the project must be reviewed and approved by the Committee before implementation. Please complete and submit a Request for Amendment Form available at the following website:

[http://www.research.mq.edu.au/for/researchers/how\\_to\\_obtain\\_ethics\\_approval/human\\_research\\_ethics/forms](http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/forms)

[s/forms](#)

5. Please notify the Committee immediately in the event of any adverse effects on participants or of any unforeseen events that affect the continued ethical acceptability of the project.

6. At all times you are responsible for the ethical conduct of your research in accordance with the guidelines established by the University. This information is available at the following websites:

<http://www.mq.edu.au/policy/>

[http://www.research.mq.edu.au/for/researchers/how\\_to\\_obtain\\_ethics\\_approval/human\\_research\\_ethics/policy](http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/policy)

If you will be applying for or have applied for internal or external funding for the above project it is your responsibility to provide the Macquarie University's Research Grants Management Assistant with a copy of this email as soon as possible. Internal and External funding agencies will not be informed that you have final approval for your project and funds will not be released until the Research Grants Management Assistant has received a copy of this email.

If you need to provide a hard copy letter of Final Approval to an external organisation as evidence that you have Final Approval, please do not hesitate to contact the Ethics Secretariat at the address below.

Please retain a copy of this email as this is your official notification of final ethics approval.

Yours sincerely  
Dr Karolyn White  
Director of Research Ethics  
Chair, Human Research Ethics Committee



## Publications and Conference Presentations

Below is a list of publications and presentations that have been respectively published and presented which pertain to the studies documented in this thesis.

### Book chapter publication:

Whiteford, G. E. & Pereira, R. B. (2012). Occupation, inclusion and participation. In G. E. Whiteford & C. Hocking (Eds.), *Occupational science: Society, inclusion, participation* (pp. 187-208). West Sussex, United Kingdom: Blackwell Publishing Ltd.

### Peer-reviewed journal article publications:

Pereira, R. B. (In press). Using critical policy analysis in occupational science research: Exploring Bacchi's methodology. *Journal of Occupational Science*. doi: 10.1080/14427591.2013.806207

Pereira, R. B. & Whiteford, G. E. (2013). Understanding social inclusion as an international discourse: Implications for enabling participation. *British Journal of Occupational Therapy*, 76(2), 112-115. doi: 10.4276/030802213X13603244419392

Pereira, R. B. (2012). The potential of occupational therapy services for students with disabilities within tertiary education settings. *Australian Occupational Therapy Journal*, 59(5), 393-396. Doi: 10.1111/j.1440-1630.2012.01037.x

### Other publications:

Pereira, R. B. (2011). Stimulating the need for healthy critique in occupational therapy. *Australian Occupational Therapy Journal*, 58(3), 220-220. doi: 10.1111/j.1440-1630.2011.00924.x

Pereira, R. B. (2010). Book review: Theorising social exclusion. *Journal of Occupational Science*, 17(3), 191-191. doi: 10.1080/14427591.2010.9686694

National and international conference and seminar presentations:

Pereira, R. B. (2013). Dignified participation: Promoting possibilities for social transformation.

*Keynote address at the NSW Department of Families and Community Services – Ageing, Disability & Home Care Division Community Access Forum, Hunter Region, Warners Bay, Australia.*

Pereira, R. B. (2012). The *ideal* of balance: Considering entrenched disadvantage and policy in

context. *Paper presented at the 'Third Occupational Therapy 24 Hour Virtual Exchange (OT24Vx) Conference', Online.* Abstract available from <http://ot4ot.com/ot24vx2012/>.

Pereira, R. B. (2012). The taken-for-grantedness of 'participation' in Australian social inclusion

policy. *Panel paper presented at the 'SSO:USA 11<sup>th</sup> Annual Research Conference', Portland, Oregon, USA.*

Pereira, R.B. (2012). Methodological considerations for occupational science research: Exploring

Bacchi's 'What's the problem represented to be?' approach. *Paper presented at the 'Canadian Society of Occupational Scientists Conference', Edmonton, Canada.*

Pereira, R. B. & Whiteford, G. (2012). Where economics meets occupational science: Expanding

occupational deprivation discourse through Amartya Sen's capability approach. *Paper presented at the 'Canadian Society of Occupational Scientists Conference', Edmonton, Canada.*

Pereira, R. B. (2011). "All I want is a roof over my head": Systemic influences on participation

and social inclusion for citizens living with multiple disadvantage. *Paper presented at the 'SSO:USA 10<sup>th</sup> Annual Research Conference', Park City, Utah, USA.*

Pereira, R. B. (2011). Expanding our knowledge of social inclusion: Occupation and participation

considered. *Paper presented at the 'Inclusive Futures Conference', Sydney, Australia.*

Pereira, R. B. (2011). Methodological considerations in occupational science research. *Paper*

*presented at the Centre for Research on Social Inclusion Seminar Series, Macquarie University, Sydney, Australia.*

Pereira, R. B. & Whiteford, G. (2010). Social inclusion as an agenda in occupational therapy practice: An Australian perspective. *Paper presented at the '15th World Federation of Occupational Therapists Congress', Santiago, Chile.*



## Abstract

This thesis reports on two linked studies which focus on entrenched disadvantage from a personal and policy perspective. Entrenched disadvantage is characterised by poverty, disability and social exclusion. The first study provides a life history exploration of seven citizens living with entrenched disadvantage. Their stories are then contextualised through a second study which analyses Australian social inclusion policy discourse through a critical occupational science lens.

Several theoretical orientations guided this thesis. These included occupational science supported by interdisciplinary theories from political philosophy, economics and the sociology of disability. The first study employed life history methodology which enabled an in-depth examination of the participants' lived experiences of entrenched disadvantage over the life course. The second study was complemented by Bacchi's (2009) methodological approach specific to policy analysis.

The life history study revealed that the participants' identities and existential realities were mitigated by systemic disablement. As a result, occupational possibilities for dignified participation and capability enablement were inherently denied. The policy analysis identified that discourses were framed by an 'inclusion through paid employment' agenda. Consequently, policy references to 'participation' were interpreted through two narrow participation typologies within a hierarchy: 'active/productive participation' and 'inactive/passive participation'.

Areas of confluence to both study findings highlighted that through a *participation hierarchy*, the discourse revealed a new form of occupational injustice, termed *occupational misrecognition*. Occupational misrecognition is defined as the act of promoting, recognising and legitimising certain types of occupations (i.e. paid employment) over others in the interests of hegemonic practices. These concepts highlight the taken-for-grantedness and political misrecognition of the depth, breadth and potential of occupational participation.

These findings have significant implications for inclusive policy, occupational science theory and the enablement of person-centred practice within institutional processes. This thesis includes recommendations which consider social transformation possibilities that highlight the *ends* of social inclusion.

# Chapter One

## Introduction



*Sometimes the strongest  
People are the ones who  
Love beyond all faults,  
Cry behind closed doors  
And fight battles  
That nobody knows about*

- Unknown

The message of this picture and related poem lies at the heart of the studies documented in this thesis. This thesis set out to explore everyday occupational realities (Hasselkus, 2006, 2011) through a qualitative life history study of seven citizens living with entrenched disadvantage in the socially disadvantaged geographical area of Western Sydney, New South Wales, Australia. In this thesis, entrenched disadvantage is specifically characterised by poverty, disability and other social issues relevant to matters of social exclusion. These citizens' life stories were juxtaposed and considered in context with the findings of a second complementary study which documented a critical discourse analysis of Australian federal social inclusion policy discourses published during the period of the Rudd Labor Government (November 2007 – June 2010).

One of the purposes of the research was to illuminate real stories of lived experiences and existential realities of what it is like to live with entrenched disadvantage in Australia. This was due to the need to hear life stories in unedited and transparent ways. These stories are often absent discourses that statistics and policy making, implementation and documentation processes inherently erase (i.e. 'Shut Out' report; National People with Disabilities and Carer Council, 2009; Smith, 2008). The second purpose was to critically interrogate to what extent narrative accounts of disadvantage, exclusion and occupational participation were considered and problematised at the policy level (Bacchi, 2009). The complementary analysis of social inclusion policy discourses informed by political science (Bacchi, 2000, 2009) and occupational justice methodologies (Whiteford & Townsend, 2011), enabled the research findings to be interpreted through a critical occupational science lens (Laliberte Rudman, 2013; Whiteford & Hocking, 2012) as well as epistemologically plural perspectives (Kinsella, 2012). Such perspectives included critical occupational therapy (Hammell & Iwama, 2012; Townsend & Whiteford, 2005; Whiteford & Townsend), critical theory, political philosophy, economics theory, social psychology, development studies and the sociology of disability and health.

The findings of both the life history exploration and the critical discourse analysis have the potential to contribute in theoretical, sociocultural, political and practical ways. As suggested, this thesis is informed by various theoretical underpinnings inclusive of occupation-based disciplines

(Phelan & Kinsella, 2009; Sellar, 2012). The main theoretical framework guiding this thesis originated from occupational science, which is the systematic study of humans as occupational beings (Yerxa et al., 1990; Wilcock, 1998, 2006). Therefore, the studies reported in this thesis could inform the theoretical development of critical occupational science (Cutchin & Dickie, 2013; Whiteford & Hocking, 2012) because of the way in which they have explored the situated nature of occupation in context with macro influences, such as government policies on occupational possibilities at the everyday level (Jongbloed, 1998; Laliberte Rudman, 2005, 2006, 2010; Laliberte Rudman & Huot, 2013). Laliberte Rudman's construct of 'occupational possibilities' significantly resonates with the research documented in this thesis. Laliberte Rudman (2010) proposed that occupational possibilities are those

“...ways and types of doing that come to be viewed as ideal and possible with a specific sociohistorical context, and that come to be promoted and made available within that context. Occupational possibilities refer to what people take for granted as what they can and should do, and the occupations that are supported and promoted by various aspects of the broader systems and structures in which their lives are lived” (p. 55).

As this thesis has also specifically focused on the way in which policy has tacitly and explicitly influenced the everyday realities of citizens living with entrenched disadvantage, it is hoped that it can be used as a direct advocacy tool at the policy level to inform just and morally conscious policy (Wright-St Clair & Seedhouse, 2005). Moral consciousness involves being conscious of the everyday moral dimensions of people and practice (Wright-St Clair & Seedhouse) in context with the broader environment. Having politics, policies and communities that are morally conscious (Wright-St Clair & Seedhouse) can enable the occupational and wellbeing needs of the participants and individuals like them in Australian society to be recognised with dignity, equity and respect (Honneth, 1992, 1995; Venkatapuram, 2011).

Consequently, adopting a morally conscious ethos (Wright-St Clair & Seedhouse, 2005) can directly impact on changes which meet the *ends* of social inclusion (Whiteford, 2011) at both the sociocultural and political level. This means that *all* people, including traditionally marginalised and oppressed individuals, would have the opportunities, resources, capabilities (Sen, 1999), choices and political recognition (Honneth, 1995) to achieve their human and occupational



potential (Gidley, Hampson, Wheeler & Bereded-Samuel, 2010a, 2010b; Wicks, 2003) leading to social transformation (Frank & Zemke, 2009; Gidley et al.), positive wellbeing and living a flourishing life that they have reason to value (Nussbaum, 2011; Venkatapuram, 2011).

From a practical perspective, it is hoped that this thesis influences occupation-focused and institutional practices and processes. This would be achieved through adopting a morally conscious (Wright-St Clair & Seedhouse, 2005), person-centred (Townsend & Polatajko, 2007; Whiteford & Townsend, 2011) and inclusive ethos of practice (Lombe & Sherraden, 2008), which provides a clearer understanding of the complexities of individuals' social ontologies, wellbeing and occupational needs. Further, it is also hoped that the direct impact of context and other macro influences on individuals' occupational lives is made explicit (Jongbloed, 1998; Laliberte Rudman, 2012; Laliberte Rudman & Huot, 2013; Whiteford, 2010), to prevent occupational injustices and other forms of prejudice and exclusion across interpersonal, institutional, community, policy and sociocultural levels.

Finally, a consideration of the 'taken-for-grantedness' of participation (Hasselkus, 2006) from an occupational perspective (Njelesani, Tang, Jonsson & Polatajko, In press) lies at the heart of this thesis. How processes and systems of governance interpret, problematise and position 'participation' in policy making requires a deeper critique. Adopting a more expansive consideration into the depth, breadth and potential of participation from an occupational perspective, as this thesis suggests, could lead to greater inclusion and occupational possibilities (Laliberte Rudman, 2010) at the everyday level (Hasselkus). As a result, the nexus between occupation, participation and inclusion would also become more explicit and warrant serious consideration for more inclusive policy making and delivery.

As this thesis sought to explore storied lives in context with broader policies (Cole & Knowles, 2001), two distinct qualitative research methodologies were employed. Life history was the approach used which enabled an in-depth exploration of the participants' narrative stories. Seven people living in the Parramatta and Blacktown Local Government Areas (LGAs) of Western Sydney were purposefully selected from a non-government organisation (NGO) and a

disability employment service (DES). Each individual volunteered to participate in the research. These participants were involved in up to three interviews, which uncovered some of their life stories about everyday realities of participation, social inclusion and exclusion. Regarding the other complementary methodology, political scientist Carol Bacchi's (2009) 'what's the problem represented to be?' (WPR) approach was used for policy-as-discourse analysis (Bacchi, 2000) of social inclusion policy texts. Data from both parts of the studies were analysed critically and inductively, and meta-themes and sub-themes were extrapolated. Findings are based on the data analysis and meta-synthesis of the findings.

### ***Background to the research***

As the researcher and author of this thesis, my life experiences of growing up in a socially disadvantaged area of Victoria, Australia and living with a chronic health condition, as well as my professional interest in issues relating to the social determinants of health (Commission on Social Determinants of Health [CSDH], 2008), disability, health promotion and policy development, were major influences on the origins of this thesis. Prior to commencing this research, I worked as an occupational therapist in a variety of workplace settings spanning the public health system, private, government and voluntary sectors in rural and regional areas across Australia.

However, it was not until my work as a chronic disease case manager in the public health system where the complexities of negotiating broader systems together with addressing my clients' chronic and complex social, health and disability issues became apparent. In my professional role, I was intrigued by what I observed as challenges and preventable barriers experienced by my clients between realising sustainable and seamless health care within the politics of service systems. Despite practising from a person- and occupation-centred perspective (Townsend & Polatajko, 2007), my interdisciplinary health team and I experienced constant difficulties to address our clients' social and health promotion needs due to inconsistent systemic support. Further, health and community services involved in my clients' care management appeared to predominantly focus on their health over other more complex social issues (i.e. living

with low income, intergenerational poverty, sub-standard housing and welfare dependence). These observations proved to be consistent with literature which indicates that the level of risk to wellbeing increased during life transitions and cycles of disadvantage if social and health matters are not adequately addressed (Blair, 2000; CSDH, 2008; Department of the Prime Minister and Cabinet, 2009a, 2009b). Therefore, I wanted to investigate how such complex issues impacted upon individuals' ways of doing (Laliberte Rudman, 2005; Wicks, 2003, 2006), or participation in life, in context with their social worlds from a critical occupational science perspective (Cutchin & Dickie, 2013; Whiteford & Hocking, 2012).

Following a research proposal for the studies documented in this thesis, I conducted an in-depth literature review which spanned interdisciplinary discourses. Such discourses included theoretical and empirical research literature from occupational science, occupational therapy, sociology, political science, moral and political philosophy, health sciences, economics, disability studies as well as international and national government reports and statistics on issues related to social inclusion, such as poverty, productivity, participation and disability. As the historical nature of social inclusion in theory and political discourse was so broad, a complex review of interdisciplinary literature was imperative.

The thorough review of the literature revealed a paucity of research into both the lived experience of entrenched disadvantage characterised by poverty, disability and other social issues, as well as a lack of critical analysis into the influences of social policies on everyday occupational realities (i.e. Jongbloed, 1998; Vrkljan, 2005). Further, research into such complex issues from a critical occupational science perspective (Laliberte Rudman, 2012; Whiteford & Townsend, 2011) appeared to also be significantly limited and in need of academic exploration and comment.

## ***Purpose***

The purpose of the research described in this thesis was to explore some of the complexities inherent in the lives of, and occupational possibilities available to (Laliberte Rudman, 2010), seven Australian citizens who live with entrenched disadvantage. Their stories

were contextualised through a critical discourse analysis of Australian social inclusion policy texts during the Rudd Labor Government (November 2007 – June 2010).

Two research questions informed the research and guided its structure throughout. They included:

1. How was ‘participation’ conceptualised and problematised in social inclusion policy whilst Australia’s Rudd Labor Government was in power?
  - How did the policy aim to address the ‘social inclusion’ of citizens living with entrenched disadvantage? What was the ‘problem’ represented to be? (Bacchi, 2009),
  - To what extent did the policy enable or constrain participation? and
2. What were the experiential perspectives of citizens living in poverty with disability?

In seeking to answer these questions, a third question presented as a corollary to the above, which was:

3. To what extent does social inclusion policy in Australia address everyday realities for people at risk of exclusion because of poverty and disability?

### ***Relevance and significance***

As previously suggested, the findings documented in this thesis are relevant and significant in theoretical, practical and policy development ways. At a theoretical level, the meta-synthesis of the findings has expanded knowledge generation into the critical study of occupational issues, or critical occupational science (Cutchin & Dickie, 2013; Laliberte Rudman, 2012, 2013; Townsend, 2012; Whiteford & Hocking, 2012). It has specifically done so through providing a critique of social inclusion policy discourses in context with narrative accounts of living with entrenched disadvantage through an occupational perspective (Njelesani, Tang, Jonsson & Polatajko, In press). It has also expanded theories of human development economics and political philosophy, such as extending the capabilities approach (Nussbaum, 2011; Sen, 1999) and theories of recognition and misrecognition (Fraser, 1995, 2000, 2001, 2008; Honneth, 1992, 1995, 2001; Thompson & Yar, 2011) respectively, through empirical research findings presented in this

thesis. This is the first study that I am aware of which has considered the situated nature of occupation and participation in context with social policies from such complementary and epistemologically plural perspectives (Kinsella, 2012; Laliberte Rudman & Huot, 2013). Theoretical complementarity was made possible due to the centrality of matters of *justice* and *equity* in each theory. As occupational justice and injustice issues were critically explored in this thesis across micro- (personal and interpersonal), meso- (community and institutional) and macro- (sociopolitical) levels, such theoretical complementarity was relevant. It was also useful to provide a multilayered view of justice at the everyday level in context with broader influences on occupational possibilities (Laliberte Rudman, 2010).

The meta-synthesis of the findings presented in this thesis is also relevant and significant for professional and institutional practices which are founded and influenced by ethical, moral and just principles. In particular, the findings which highlight locations, processes and moments where exclusion occurred at the everyday level which impacted on possibilities for social transformation and flourishing, can inform such practices to prevent ongoing exclusion which feed into cycles of disadvantage. Through employing an ethos of moral consciousness (Wright-St Clair & Seedhouse, 2005) which is also person-centred (Townsend & Polatajko, 2007; Whiteford & Townsend, 2011), professionals and workers within systems of governance can promote wellbeing through innovative ways, such as targeting at-risk individuals for enablement opportunities (Townsend & Polatajko). In this sense, wellbeing is considered beyond a health paradigm through holistically valuing the economic, capability, recognition, social and occupational participation needs of individuals. Further, individuals and communities can also adopt an inclusive ethos so that fellow citizens who have been marginalised and oppressed can be socially recognised with respect and dignity (Honneth, 1992, 1995).

The findings from the studies documented in this thesis also have relevance and significance to policy development, implementation and evaluation processes, especially across economic, education, social and health sectors. The findings of the studies from both the critical discourse analysis and life history study particularly suggest that policymaking processes need to

account for a *participation hierarchy* that exists within the current Australian political climate and its ideological influences. These influences inherently narrow possibilities for participation within the “non-economic spheres of life” (Vellacott, 2011, p. 246), which appear to be significantly taken-for-granted at the political level, leading to a new form of occupational injustice which I have labelled *occupational misrecognition*. Recognising a participation hierarchy and occupational misrecognition is relevant and significant towards building more effective and inclusive public policy. Public policies across the sectors mentioned earlier which address the limited nature of occupational possibilities (Laliberte Rudman, 2010) by recognising broader social inclusion ideologies (i.e. social transformation and human potential ideologies; Gidley et al., 2010a, 2010b) can directly expand how participation and disadvantage are framed, problematised and addressed (Bacchi, 2009). Direct outcomes can include more inclusive interventions leading to greater enablement opportunities for occupation, participation and inclusion at the everyday level (Townsend & Polatajko, 2007). Political and policy leadership framed in such a way can have a positive cultural flow-on effect which could dispel significant social stigma surrounding poverty, disability, mental illness and welfare recipient status.

### ***Critical reflexivity***

As qualitative research is interpretative in nature, it was important to adopt and maintain those principles commensurate with critical reflexivity (Denzin & Lincoln, 2005; Phelan, 2011). It was also important to situate my own assumptions, biases, values and power position (Trentham & Kirsh, 2007), or social location, when exploring the policy-as-discourse analysis (Bacchi, 2000) together with the participants’ narrative accounts into their everyday realities of entrenched disadvantage, marginalization and oppression. Critical reflexivity is a process which aims to surpass the reflective practice of serious thought and consideration by critically interrogating and questioning how knowledge and discourses have come to be the way that they are (Kinsella & Whiteford, 2009). In addition, ‘social location’ is described as an individual’s situation within a

social, cultural and historical matrix which determines and can influence the researcher's statements and critiques (Kirsh, Trentham & Cole, 2006; Moya, 2002). Presenting my social location, epistemological and ontological influences invites the reader to understand my own context inclusive of cultural, social, political and other life influences which led me to conduct the studies documented in this thesis through a critically reflexive lens.

A major assumption underpinning this thesis is that humans are occupational beings (Wilcock, 1993, 1998, 2006; Yerxa et al., 1990). Through everyday doing (occupation), being, becoming and belonging, occupational beings ascribe meaning and purpose to their lives which have a direct influence on their health, wellbeing and occupational potential (Asaba & Wicks, 2010; Wicks, 2001, 2003; Wilcock, 2006). Another major philosophical assumption is that all occupational beings have a right to occupation (Hammell, 2008), consistent with the developing discourse in occupation-based disciplines (Phelan & Kinsella, 2009; Sellar, 2012) and occupational justice (Townsend & Wilcock, 2004a, 2004b; Wilcock & Townsend, 2000). Various barriers ranging from attitudinal to institutional and cultural ones (Barclay, 2012a, 2012b; McDermott & Varenne, 1995) exist which limit opportunities, resources, capabilities and choices for occupational beings living with entrenched disadvantage to live dignified lives that they have reason to value (Sen, 1999).

My own experiences of living with a chronic health condition, growing up in a socially disadvantaged area, working as an occupational therapist with citizens living with disabilities and other complex social issues, as well as advocating for their occupational needs and rights (Hammell, 2008), has led me to assume that occupational possibilities (Laliberte Rudman, 2010) can be significantly limited and barriers to occupational participation in its broadest sense can be prevented. As a result, I assumed that I would be able to obtain deep insights into these complex issues impacting on everyday participation through conducting consecutive in-depth interviews with individuals living such realities. I also assumed that conducting a critical discourse analysis of social inclusion policy would enable their experiences of entrenched disadvantage to be

contextualised, highlighting potential locations of (dis)connect between their life stories and ambitions for their social inclusion at the policy level.

### ***Thesis structure***

This thesis has eight chapters. This first chapter, Chapter One, introduces the studies documented in this thesis. It commences by presenting the background and rationale for the research undertaken. It then documents its purpose and relevance to theoretical, practical and policy development. It concludes by suggesting some personal and theoretical assumptions that have influenced the studies before presenting an overview of the thesis structure.

Chapter Two provides a thorough review of interdisciplinary literature relevant to the themes of the studies documented in this thesis. Firstly, the chapter provides an overview of social inclusion, including its political, definitional and theoretical development. It then explores social inclusion from an occupational perspective by examining literature relevant to the studies from occupation-based disciplines i.e. occupational science and occupational therapy. It concludes by providing an overview of issues relevant to social exclusion, entrenched disadvantage, poverty and disability which makes the need for critical occupational science research into the politics of participation and everyday realities explicit.

Chapter Three describes the research questions, methodologies and methods that guided and were employed in this research. As it had two main research questions, two distinct research studies were conducted which required two different methodologies. Consequently, Chapter Three is divided into two parts. Part one highlights the methodology and methods used to analyse Australian social inclusion policy texts from critical policy and critical occupational science perspectives using complementary methodologies from political science and occupational science (Bacchi, 2009; Whiteford & Townsend, 2011). Part two presents the rationale for using life history methodology which guided the method used to answer the second research question which explored the storied lives of by seven citizens living with entrenched disadvantage including their occupational experiences over the life course (Cole & Knowles, 2001; Wicks,



2003). The chapter then explores ethics approval, study settings, participant recruitment processes. It introduces the participants before describing the research processes which were involved to collect, analyse and interpret the data. Finally, issues relating to the authenticity and trustworthiness of the studies are explored before suggesting some limitations of the studies.

The following three chapters (Chapters Four, Five and Six) describe the key findings of the life history study. There were three meta-themes that were extrapolated from data analysis. They were: 'being me', 'being in the world' and 'being in the system' with each meta-theme being explored in their own chapter. Chapter Four explored issues pertaining to the participants' identities and senses of personhood which influenced their occupational realities of inclusion and exclusion. Chapter Five expanded the issues presented in Chapter Four by documenting some narrative accounts into the existential realities of what it was like to live with entrenched disadvantage, which highlighted the challenges and triumphs that the participants in this research experienced. The major meta-theme of the life history study entitled 'being in the system' was illuminated in Chapter Six which uncovered how the participants' identities and existential realities were mitigated by their experiences with interactions and transactions with systems of governance, which directly limited occupational and social transformation possibilities (Breedon, 2008, 2012; Frank & Zemke, 2009; Laliberte Rudman, 2010; Townsend, 1997b).

Moving from the life history study findings, Chapter Seven presents the findings of the critical policy analysis (Bacchi, 2009) of Australian social inclusion policy texts published during the time of the Rudd Labor Government (November 2007 – June 2010) through a critical occupational science lens (Whiteford & Hocking, 2012). Finally, Chapter Eight presents a meta-synthesis of the findings of the studies documented in this thesis through a critical discussion of its key themes. The chapter substantiates and provides an argument which empirically supports the theory of occupational justice (Stadnyk, Townsend and Wilcock, 2010). Through a visual schema which analyses the meta-synthesis of the findings, termed the 'social inclusion framework' (SIF), the saliency of the theory of occupational justice (Stadnyk et al.) to the research is justified. The chapter then answers the corollary of the two main research questions

presented in Chapter Three which summarises the discussion section. The thesis concludes by presenting recommendations for theoretical development in occupational science, practical strategies to enable social inclusion for marginalised individuals, as well as suggestions to promote more inclusive policies, professional practices and institutional processes to enable the *ends* of social inclusion (Whiteford, 2011).

## **Chapter Two**

### **Literature Review**

The purpose of this chapter is to present the results of an exhaustive review of interdisciplinary literature on the topic of social inclusion. This included how it has been conceptualised historically and politically, as well as how it emerged as an Australian political agenda. The chapter presents some of the key theoretical frameworks that guide this thesis respectively, which include occupational science theory, the capabilities approach (Nussbaum, 2011; Sen, 1999) and theories of recognition (Fraser, 1995, 2000, 2001, 2008; Honneth, 1992, 1995, 2001). The chapter attempts to frame social inclusion from an occupational perspective before focusing on the imperative need for critical occupational science research into the link between policy and its effects on ‘entrenched disadvantage’ characterised by the existential realities of poverty, disability and other psychosocial issues.

This chapter is divided into five sections. The first section introduces the historical context and genesis of social inclusion. The second section explores how social inclusion has been defined throughout the literature. This section particularly highlights the significant theoretical conceptualisations of social inclusion from interdisciplinary fields. The third section frames the chapter by exploring an occupational perspective of social inclusion through focusing on the phenomenon of occupation and how it relates to participation, justice and inclusion. This section addresses key occupational science terminologies relevant to matters of inclusion and exclusion such as occupational justice and occupational rights in context with the politics of social inclusion. Following on from political, theoretical and occupational framings and contextualisations of social inclusion, the chapter highlights the relationship between social inclusion and marginalisation through focusing on socioeconomic disadvantage and disability as a case in point for in-depth research from a critical occupational science perspective. Finally, the chapter concludes by providing a summary of themes presented in the literature review which puts forward an argument for the need to critically explore how social inclusion policy can

directly or indirectly impact upon the everyday needs and occupational possibilities (Laliberte Rudman, 2010) of citizens living with entrenched disadvantage in Australia.

## **Introduction**

Social inclusion as a construct is conceptually broad and has been shaped by a number of disciplinary discourses. Accordingly, the literature search strategies and parameters were correspondingly broad, embracing a wide range of disciplines. Such disciplines include anthropology, development studies, economics, education, health promotion, health sciences and public health, occupational science, occupational therapy, philosophy, political philosophy, political science, psychiatry, psychology, social work and sociology. Specific databases included EBSCOhost, CINAHL, MEDLINE, PubMed, Academic Search Premier, Google Scholar, Health Source: Nursing/Academic Edition, Humanities International Complete, Expanded Academic ASAP, Australian Policy Online, Informaworld, Social Science Research Network, Psychology and Behavioural Sciences Collection and PsychINFO. Search parameters included various combinations of key words which included but not limited to 'inclusion', 'social inclusion', 'social exclusion', 'exclusion', 'disability', 'poverty', 'chronic illness', 'policy', 'Australia', 'life history' and 'discourse analysis'. Other literature sources included government and social policy centre publications online on the topic of social inclusion and related areas in Australia, the United Kingdom, Ireland, the European Union and Canada. Finally, key texts were also manually sourced such as books on social inclusion theories, politics and social inclusion, the sociology of disability as well as texts from occupation-based disciplines (Phelan & Kinsella, 2009; Sellar, 2012). The literature search was conducted over a period of 15 months from September 2009 to December 2010. Periodic reviews of the literature occurred every three months after December 2010 until February 2013. The purpose of selecting the literature for this review was to highlight contested notions and agreements of what constitutes 'social inclusion' across disciplines as well as a charting of its evolution in contemporary international and

Australian politics. As a means of understanding this evolution over time, the first section of this review considers the historical antecedents which shaped its development.

### **Social inclusion: Background, context and emergence**

In the 1960s, the international disability rights movement created pathways for people with disabilities and special needs to participate in Western contexts (Grady, 1995). The global flow-on effect influenced French social reform in the 1970s (Buckmaster & Thomas, 2009). Such reform led to policy development championed by the French Secretary of State for Social Action, René Lenoir which addressed social exclusion (Béland, 2007; Buckmaster & Thomas). Specifically, the reforms highlighted the rights for marginalised communities such as single parents, people living with mental illness, people who were not participating in the workforce as well as people who lived below the poverty line (Béland; Buckmaster & Thomas; Hulse, Jacobs, Arthurson & Spinney, 2010; Lombe & Sherraden, 2008; Sen, 2000). In this thesis, *policy* is understood as being concerned with the principles and practices of government to pursue economic, political and social outcomes (Fawcett, Goodwin, Meagher & Phillips, 2010; Goodwin, 2011). During the 1980s, disparity continued in France (Buckmaster & Thomas). During this time, the French government initiated social programs in response to this growing disparity, aimed at fostering the integration of people who had experienced chronic unemployment (Buckmaster & Thomas), and as a corollary often had diminished social capital with families and other social groups. Researchers have suggested that these innovative programs of inclusion, or 'integration', demonstrated the French culture of social solidarity (Buckmaster & Thomas; Nelms & Tsingas, 2010; Wilson, 2006) in that the French state prioritised the repair of social fabric through targeted reform aimed at addressing isolation, marginalisation and limited opportunity (Buckmaster & Thomas). A key figure, instrumental in social policy transfer to the rest of Europe which targeted social exclusion initiatives, was Jacques Delors (Buckmaster & Thomas). In his role as President of the European Commission in the 1980s, Delors promoted the notion of integration (Buckmaster & Thomas). His efforts succeeded in 1989 when the

Council of Ministers of Social Affairs of the European Community passed a resolution to combat social exclusion through fostering integration and solidarity (Buckmaster & Thomas). Dehors' work culminated with the development of the 'European Social Protocol' in 1997 which was incorporated in the Amsterdam Treaty (Buckmaster & Thomas). This treaty was an agreement made between all member states of the European Union to guarantee and protect the fundamental human rights of equality, justice, democracy and citizenship (Europa, 2013).

#### The Lisbon Strategy.

Following the Amsterdam Treaty, the European Union established a set of key policy objectives for social and economic development during a summit in Lisbon, Portugal in March, 2000 (Buckmaster & Thomas, 2009). The European Union Council adopted the 'Lisbon Strategy' which aimed to "fight against social exclusion" (Daly & Silver, 2008, p. 542) through strategic and policy development between all member states. The Lisbon Strategy's main foci included (1) access to goods, services, resources and facilitating economic participation through employment; (2) prevention initiatives against homelessness and over-indebtedness; (3) vulnerability for marginalisation and promoting family and other social networks, and (4) creating partnerships and feedback opportunities between relevant bodies and stakeholders to promote participation (Buckmaster & Thomas). According to Daly and Silver (p. 542), "social exclusion has been one of the most influential ideas in the continuing reform of social policy". Daly and Silver further commended the Amsterdam Treaty, and in particular the Lisbon Strategy, as "one of the most expansive periods in the history of EU social policy" (p. 542). The Lisbon Strategy was also known as the 'social inclusion process'; the first time that the words 'social inclusion' were framed in European political discourse. Despite the overwhelming aim of the Lisbon Strategy to eradicate poverty by 2010 through fighting social exclusion, progress was slow towards meeting its objectives and targets agreed by member states (Buckmaster & Thomas, 2009; Nelms & Tsingas, 2010). This led to a second phase of the Strategy (2005-2010) by adopting a more

narrow focus on facilitating economic participation through work for citizens experiencing the most social disadvantage (Buckmaster & Thomas; Nelms & Tsingas).

#### Social policy development: From Europe to the United Kingdom.

In 1997, the Blair Labour Government was elected and was in office until 2007. With accepting the Amsterdam Treaty, the Blair Government promoted and introduced innovative social policy which targeted social exclusion as a key agenda (Buckmaster & Thomas, 2009; Daly & Silver, 2008; Hayes & Gray, 2008; Hulse, Jacobs, Arthurson & Spinney, 2010; Nelms & Tsingas, 2010; Saunders, 2003; Wilson, 2006). Together with other European member states, the Blair Government established a task force to introduce policy in areas such as education, employment, health and housing to combat social exclusion (Nelms & Tsingas). These policy areas were targeted, and programs were implemented “to better develop and deliver services to the most disadvantaged people in UK society; or...to deliver ‘joined-up solutions to joined-up problems [through a whole-of-government approach]” (Buckmaster & Thomas, p. 5). The political philosophy of mandating action on social exclusion during the Blair Government in the United Kingdom is synonymous with ‘third way’ politics (Béland, 2007; Buckmaster & Thomas; Whiteford, 2005). Buckmaster and Thomas described ‘third way’ politics as

“a centrist political philosophy that attempts to transcend left (democratic socialism) and right (market liberalism) wing politics through a synthesis of the two. As such, third way politics ‘is in favour of growth, entrepreneurship, enterprise and wealth creation but it is also in favour of greater social justice and it sees the state playing a major role in bringing this about’. The role of government is to ensure that citizens are able to participate in the economy and, thereby, in social life” (p. 6).

#### The introduction of social inclusion in Australian political discourse.

Directly modelled on the Blair Government’s social exclusion policy framework and political philosophy, social inclusion as a political discourse was introduced in Australia in 2002 through the ‘Social Inclusion Initiative’ of the South Australian Government (Buckmaster & Thomas, 2009; Daly & Silver, 2008; Government of South Australia, 2009; Hulse, Jacobs, Arthurson & Spinney, 2010; Nelms & Tsingas, 2010; Saunders, 2003). Noteworthy at this time

was the preferred use of the term ‘inclusion’ instead of ‘exclusion’. To reason with this development, the then Premier of South Australia Mike Rann stated “...‘inclusion’ is what we are about, I wanted the name to reflect that” (Government of South Australia, p. 2). Rann also became the inaugural Minister for Social Inclusion at the state level. The trend of a “change in nomenclature” (Buckmaster & Thomas, p. 6) also occurred in Europe with the European Commission and Council initially favouring ‘social inclusion’ but now preferring the term ‘social cohesion’ (Buckmaster & Thomas; Daly & Silver, 2008). Daly and Silver suggested that the shift occurred in Europe due to an attempt for a more ‘positive’ social framework:

“pronouncing a goal rather than describing a problem...Inclusion calls attention to the supposed “opportunity” and openness of society, beckoning outsiders in, whereas exclusion points at exclusionary mechanisms of society, its potential breakdown, disorder, or incoherence” (p. 551).

Social policy researcher Peter Saunders also noted this “more positive connotation” (as cited in Buckmaster & Thomas, p. 6). The Rann Government set up a similar task force in its ‘Social Inclusion Initiative’ to that of the Blair Government with the introduction of a Social Inclusion Unit within the Department of Premier and Cabinet, as well as an independent Social Inclusion Board (Buckmaster & Thomas, Government of South Australia). With South Australia’s leadership in Australia, other states followed their own social inclusion policy implementations (Nelms & Tsingas). These included the Australian Capital Territory, Victoria and Tasmania respectively (Nelms & Tsingas).

State Labor Party leadership in Australia, especially that of South Australia and its model of social policy governance, prompted the elevation of a National social inclusion policy agenda following the election of the Rudd Labor Government in November 2007. Using South Australia’s successful social policy governance as a political benchmark, the Rudd Government created a Social Inclusion Unit within the Department of Prime Minister and Cabinet and introduced an independent Social Inclusion Board. It also appointed the then Deputy Prime Minister, The Hon Julia Gillard MP, as the inaugural Federal Minister for Social Inclusion. Established in May 2008, the role of the Australian Social Inclusion Board was to be “the main



advisory body to the government [driving a whole-of-government approach through providing advice and information to the Minister for Social Inclusion] on ways to achieve better outcomes for the most disadvantaged in the community and to improve the social inclusion in society as a whole” (Australian Social Inclusion Board, 2011, p. 1). The Australian Government’s social inclusion policy agenda championed by Prime Minister Kevin Rudd is critically interrogated in Chapter Seven. The following section of this review introduces how social inclusion has been defined and conceptualised, followed by exploring some key theoretical underpinnings.

### **Social inclusion: Definitional development**

Social inclusion is one of those terms that is socioculturally constructed depending on several factors. Broadly and simply, social inclusion is about having opportunities to fully participate in life and be a contributing citizen in the society in which one lives. Further, “it provides an opportunity to analyse the multiplicity of ways that people may be denied full participation in society and the full rights of citizenship” (Lister 1999, as cited in Ward, 2009). In this context, social inclusion is as much part of social concern as it is part of its political discourse and epistemology. This statement is true to its origins in social policy reform explored in the previous section. However, attempts to condense and define social inclusion outside of its original political developments have been problematic and contested. Like numerous ideas in the social sciences, definitional constructions have mainly focused on Western social world applications. A wider view is sought and required for a greater understanding of its inherent aims. Researchers have questioned the pragmatics of the choice of the words of ‘social’ and ‘inclusion’ aimed to promote and enable participation (Labonte, 2004). Does the ‘social’ in social inclusion mean ‘in conjunction with’ another person or people? Does it mean being a member or citizen in a society or population? Is it individualistic or collective in nature, or a combination of both? Regarding ‘inclusion’, the majority of the critique is based around ‘inclusion into what?’ (Buckmaster & Thomas, 2009) as well as Labonte’s argument: “how can one ‘include’ people and

groups into structured systems that have systematically ‘excluded’ them in the first place?” (p. 115).

From a critical social work perspective, Gould (2006) identified that there has been an historical intuitive presumption in policy that has led to the absence of formal definitions of social inclusion or social exclusion until recently (i.e. in the United Kingdom). Atkinson et al. (as cited in Gould) argued that social inclusion and social exclusion have “rhetorical power” (p. 83) as exemplified in the lack of definitions across international social policies. Therefore, determining the success or failure of social inclusion policy may be difficult to judge (Gould). This is further supported by the European Union discourse on the social inclusion process as not explicitly defining social inclusion, but rather presenting it in response to poverty and social exclusion (European Commission, 2003; Nelms & Tsingas, 2010). Taket, Crisp, Nevill, Lamaro, Graham and Barter-Godfrey (2009) also considered ‘inclusion and participation’ as paternalistic and problematic in theory, policy-making and implementation. Edwards (2010) suggested that social inclusion “can mean different things in different contexts” (p. 17), having limited relationship with any history of ideas.

Therefore, there is little doubt that definitions and conceptualizations of social inclusion share “considerable disparity..., ambiguity and inconsistency in the use and meaning of the term” (Le Boutillier & Croucher, 2010). Social inclusion is a contested concept due to its multidimensional nature (Morrison, 2010; Rawal, 2008; Smyth, 2008, 2010; Taket et al., 2009). According to Smyth, there are two major ways to describe the ‘operation’ of social inclusion: “a new way of defining and measuring poverty and disadvantage; [and] a way of badging a new social policy paradigm” (p. 7). Morrison also supported the notion that social inclusion

“...is a multidimensional conceptualisation of poverty and disadvantage that promises to take both social and economic dimensions into account, and to focus not only on unequal outcomes, but on the processes that created them” (p. 6).

The Laidlaw Foundation (as cited in Bach, 2002, 2005) added that social inclusion was also a normative, or value-laden, concept based on a humanitarian perspective of advocacy and human rights. Prior to expanding on these elements that constitute the major themes of social inclusion

in the literature, social inclusion as ‘process’ as well as ‘outcome’ or ‘goal’ is discussed in the next section in order to highlight its multidimensional conceptualisations in theory and policy respectively.

#### Social inclusion as ‘process’ and ‘outcome’.

Despite its ambiguity, literature on social inclusion and related terms has clearly indicated that it is inherently a political term. Each attempt to define it into discrete categories to date has focused on some form of sociocultural or socioeconomic condition, variable or goal. Examples of these material conditions include accommodation, employment, education and service access. Social inclusion’s ideals (i.e. as a process or as an outcome or goal; ‘means’ and/or ‘ends’) are based on realistic vis-à-vis utopian principles set out in policies on inclusion. Outcomes for social inclusion go beyond social reform and policy. Other policies that explore ‘goals’ for social inclusion through identified ‘processes’ include economics (i.e. social inclusion through providing jobs for labour market participation), health (social inclusion through providing accessible community health centres for greater access and health promotion) and information, digital and communication technology (i.e. social inclusion through providing access to fast-speed internet for information sourcing and sharing in regional, rural and remote areas).

Social inclusion is therefore considered as the overarching process, or ‘means’ as well as ‘ends’ for participating in, and contributing to, society. This conceptualisation can be explained through using the metaphor of a football, or soccer match. Players go on a field with the aim of scoring a goal. The ‘process’ of playing together as a team (using strategy, sharing, communication, planning, decision-making, ability and skill), can lead towards scoring a winning goal (or at least attempting to score a goal). One cannot score a goal without the preceding process of working together. There are also barriers along the way (i.e. outskilling an opposition player, getting fouled, or being offside) that must be addressed or superseded for success. Community development research into disadvantaged communities in Australia over the past 40 years came to a similar conclusion as the football analogy: “...in order for services and

infrastructural interventions [process] to be effective in the long run, they must not only be useful in their own right [outcome] but simultaneously serve the end of strengthening the overall community [outcome]” (Vinson, 2009, p. 5). Most researchers on social inclusion have agreed and supported the idea that social inclusion can be conceptualised as a *process* for a person, group, community, organisation or population to ‘participate’ in their society (i.e. Democratic Dialogue, 1995; Levitas, 1996; Lister, 1998; Lombe & Sherraden, 2008; Morrison, 2010; Nelms & Tsingas, 2010; Saloojee, 2001; Saunders, 2003; Smyth, 2008, 2010; Ward, 2009; Whiteford & Townsend, 2011). Therefore, for social inclusion to be also seen as an outcome, or goal, there needs to be supportive mechanisms in place to enable such a goal to be achieved. This idea is explored later on in this literature review through exploring an occupational perspective of social inclusion that takes into account qualities consistent with ‘process’ (or ‘means’) and outcomes (or ‘ends’).

In their review of literature into social inclusion and how it relates to communication technologies, Sinclair, Bramley, Dobbie and Gillespie (2007) agreed with the notion of social inclusion as a ‘process’ but also related inclusion to full societal participation as well as having the capacity to realise social citizenship (outcome). The idea of social citizenship, or “social rights, obligations and institutions that play a role in developing and supporting equality of status in the community” (Buckmaster & Thomas, 2009, p. 16), developed by sociologist T. H. Marshall in the 1950s, is further supported by Buckmaster and Thomas (2009) in their research paper on social inclusion and social citizenship discourse in Australia.

#### Social inclusion, poverty and disadvantage.

The previous section demonstrates the diverse nature of social inclusion as well as definitional ambiguity of the various meanings of social inclusion, which have been adopted in policies and ideas in certain Western democracies. Discussion will now turn to social inclusion as a preferred alternative to understanding disadvantage and poverty beyond its historically narrow ‘material deprivation’ description (Lister, 1998; 2004). As Levitas (1998) and Silver (1994) attested, diverse perspectives of social inclusion reveal variable assumptions about its root causes

and solutions due to conflicting social science paradigms and ideologies (Mitchell & Shillington, 2002). This review now focuses on discourses on poverty, disadvantage and social inclusion, through exploring the impact of Neoliberalism as a ‘root cause’ for the popular paradigm of ‘inclusion through economic participation’ in the Western world (Levitas, 1996, 2001; Lister, 1998, 2010; Morrison, 2010; Saunders, 2003). The history of social inclusion is enmeshed with social, as well as economic policy. In her frequently cited paper on social exclusion in the United Kingdom, Levitas (1996) critiqued the rise of Neoliberalism during the 1980s, where civil society “collapsed into the market” (p. 16). She suggests that Neoliberalism’s impact on reducing civil society to the market was both a real and discursive phenomenon (Levitas). Apart from Neoliberalism’s impact on the marketplace, it has also played a significant role in reframing and placing a monetary value on occupations that were previously enjoyed in more inclusive places and spaces. One taken-for-granted example in Western democracies such as Australia is the commodification of leisure, such as paying money to engage in leisure such as frequenting a gym or taking dance classes (Neumayer & Wilding, 2005). This example shows how previous freedoms such as being active and meeting people through a meaningful leisure occupation (Pereira & Stagnitti, 2008) have been reduced to the market.

Levitas (1996) indicated that Neoliberalism’s effects on integration or ‘inclusion’ through paid employment was limited, naïve and ignorant to the realities of other roles, responsibilities and obligations such as women’s work. From Levitas’ perspective, society was more than market involvement. Levitas (1998) later conceptualised three discourses of social inclusion: social interactionist discourse (SID); redistributionist discourse (RED) and moral underclass discourse (MUD). In context, SID was identified as a narrowing of social exclusion/inclusion discourse to mean ‘participation in paid work’ (Levitas, 1998). Therefore, through SID, people who did not participate in the labour market were effectively considered ‘socially excluded’ and not ‘full’ members of society. Unemployment in this context was considered as the main cause for social exclusion (Mitchell & Shillington, 2002, 2005).

Government documents in the United Kingdom in the late 1980s and early 1990s prior to the Blair Labour Government, operated within a “consensual, functionalist model of society” (Levitas, 1996, p. 16). Despite widening social divisions or ‘social distance’ (Mitchell & Shillington, 2002, 2005) between the rich (people who had high paying jobs) and the poor (including people earning low wages; the ‘working poor’), the government at the time acknowledged that such a division had economic implications (Levitas). However, this contradiction, according to Levitas, did not overcome poverty solely through being attached to the labour market. Widening social distances were indications of a MUD, resulting from a sociocultural distinction between ‘privileged’ (Pease, 2009) or ‘mainstream’ members of society with an ‘underclass’ (Levitas, 1998). MUD classified ‘underclass’ as ‘others’ dependent on the state who did not engage in paid work such as single mothers, older people, people with disabilities and criminal young men (Levitas, 1998). Inequalities under a MUD discourse were ignored (Levitas, 1998). Levitas’ (1998) third discourse of social inclusion/exclusion was RED, where citizenship, social rights and the redistribution of power and wealth (Lister, 1998; Rawls, 1971; 1999) were favoured over the poverty discourse of material inequality (Levitas, 1998). RED conceptualised poverty as the main cause of exclusion (1998). Therefore, reducing poverty was achieved through increased benefits as well as focusing on the processes which produced inequality (Levitas, 1998). In lay terms, Levitas (1998) expressed that “...in RED, they have no money, in SID they have no work, in MUD they have no morals” (p. 27). RED can also be related to distributive justice focused on enhancing the possibilities to acquire financial benefits as well as goods and services (Rawls; Young, as cited in Stadnyk, Townsend & Wilcock, 2010).

Several causational factors also impeded ‘work as social inclusion’ through a SID (Levitas, 1996). Maximum work hours per week were not set (Levitas, 1996). This implied that ‘working class’ employees would have to work long hours at the expense of risking their other activities and life roles (i.e. father, mother, friend). Furthermore, paid employment was framed as a gendered endeavour (a ‘man’s’ role), with the undue lack of recognition of unpaid work and caring responsibilities typically performed by women or older people and citizens aged ‘outside’

of the work age (i.e. youth and older citizens; Levitas). Misrecognition of other roles and activities performed and experienced in society further hinders exclusion and unwillingly promotes 'otherness' or 'othering' (Colic-Peisker, 2005; Levitas; Lister, 2004; 2010), alienation, segregation and marginalisation. Levitas cited the theorist Durkheim when she interpreted the widening gap of exclusion and privilege (Pease, 2009) in the United Kingdom as "disruptive if it becomes too extreme-not as something which is an integral feature of a capitalist society" (p. 16). This provocative statement can be used as a metaphor for political attempts to blame those who do not work and praise those who do. Therefore, being excluded from cycles of opportunity is directly attributed to contemporary economic and social conditions (Levitas). As the critical discourse analysis of social inclusion policy in Australia demonstrates in Chapter Seven, these fundamental ideas of the 'inclusion through work' paradigm still strongly exist today. Levitas' critique of a Neoliberal and capitalist paradigm is further challenged by the following statement relating to including the 'other' through work:

"It is salutary to remember that even if women, ethnic minorities and disabled people achieve equal opportunities within the labour market, it will still be the case that what 'integration' means is participation in a capitalist economy driven by profit and based upon exploitation. The dichotomous model of exclusion and integration obscures this fact" (p. 18).

Furthermore, other critics of policy focused on addressing social inclusion through economic participation have indicated that there is a risk of exchanging one form of exclusion for another (i.e. employment versus marginal forms of employment; Mitchell & Shillington, 2002, 2005) as the demand and supply of sustainable employment is inconsistent and foster low skilled, low paid and unstable workers and working environments (i.e. in Canada; Mitchell & Shillington). Another critique is that developing social inclusion discourses have not precluded Neoliberal responses to policy (Edwards, 2010).

#### General and operational definitions.

As previously discussed, social inclusion is a term that some critics in social sciences literature describe as an abstract conceptual definition, requiring a practical approach to its use

and interpretation. Operational definitions translate abstract conceptual definitions and make them practical (Australian Social Inclusion Board, 2010). Levitas, Pantazis, Fahmy, Gordon, Lloyd and Patsios (2007) have succinctly captured social inclusion definitions from an operational perspective as have Taket et al (2009) in their publication on theorising social exclusion (See Appendix A). Levitas et al. indicated that such definitions are distinct from its poverty discourse. Furthermore, Taket et al also explored the works of Saunders, Naidoo and Griffiths (2007), Steinert (2007) and Renner, Prewitt, Watanabe and Gascho (2007) in describing a typology for understanding social exclusion not necessarily outside of a poverty discourse. The typology of social inclusion included delineating its forms (i.e. being disengaged), participation levels (i.e. social relations; access to clothing) and exclusionary relationships. Renner et al. separated exclusionary relationships into five approaches. The first was 'horizontal versus vertical' where horizontal exclusion involved being excluded from being a member of a group at the same hierarchical level, with vertical exclusion preventing climbing the hierarchical, or 'vertical' ladder (Renner et al.). The second was 'intentional versus unintentional' where discrimination was a common cause of intentional exclusion. The next typology was 'multiple factor social exclusion', or multiple disadvantage types experienced by a person or group (Renner et al.). The final typology as expressed by Renner et al. was 'reinforcing social exclusion' which resulted from one form of exclusion being linking to another and potentially causing a negative flow on effect.

Internationally, a common trend between the European Union, Ireland and the United Kingdom's operational definitions of social inclusion is that they all addressed social inclusion and exclusion as a 'process' rather than "focusing on the role of the individual and the need for individual change" (Ward, 2009, p. 241). These operational definitions explored what Ward has described as a 'material discursive perspective'. This perspective considered both the physical aspects of experience, such as poverty risk and unemployment, alongside constructionist perspectives on representations and discourse, which help us to understand "the way that different people's identities may be constructed" and assist with exploring the "lived realities"



(Ward, p. 239) of these identities. A material discursive analysis not only identifies or labels different factors which constitute elements of social inclusion as ‘material’ or ‘discursive’, but also “...considers the intersections between the two in order to analyse the processes which lead to exclusion and marginalisation” (Ward, p. 239-240). Sayce (2001) further supported working definitions of social inclusion which intentionally address issues of power and inequality through a material discursive analysis of exclusionary processes. According to Sayce, interventions or programs that enhance social inclusion are therefore proposed that go beyond promoting singular elements such as ‘social capital’. Social capital has been described as the bonds that tie people together (Putnam, 2000; VicHealth, 2005).

In Australia, the Rudd Government considered the following operational definition of social inclusion:

“Social inclusion means building a nation in which all Australians have the opportunity and support they need to participate fully in the nation’s economic and community life, develop their own potential and be treated with dignity and respect” (Department of the Prime Minister and Cabinet, 2009a, p. 2).

The Rudd Government also acknowledged that being *socially included* (original emphasis) meant that people had the resources, opportunities and capabilities they needed to ‘learn’ (participate in education and training); ‘work’ (participate in employment, unpaid or voluntary work including family and carer responsibilities); ‘engage’ (connect with people, use local services and participate in local, cultural, civic and recreational activities) and ‘have a voice’ (influence decisions that affect them) (Australian Social Inclusion Board, 2010; Department of Education, Employment and Workplace Relations, 2009; Department of the Prime Minister and Cabinet). Interestingly, the Rudd Government’s operational definition, which has not changed since Julia Gillard took over as Prime Minister on June 24, 2010, has a stronger focus on the material rather than more discursive aspects (Ward, 2009).

Despite the Rudd Government providing a set of social inclusion principles rather than a more formalised definition, the South Australian Government’s social inclusion initiative chaired

by Monsignor David Cappo AO (a former member of the Australian Social Inclusion Board) has formally defined it in its policy as:

“...the creation of a society where all people feel valued, their differences are respected, and their basic needs – both physical and emotional – are met...Social inclusion is about participation; it is a method for social justice. It is about increasing opportunities for people, especially the most disadvantaged people, to engage in all aspects of community life” (Government of South Australia, 2009).

The South Australian social inclusion initiative is considered as a world-leading and innovative one by the World Health Organization’s Commission on Social Determinants of Health (CSDH, 2008) which described it as valuing “political recognition and strong commitment to inclusion and health equity” (p. 160). From recognising direct government initiatives which have focused on addressing social exclusion at a systemic level, discussion follows by exploring the contribution of North American theorists towards leading principles of social inclusion specifically directed towards governments and policy-making.

#### Institutional foundations of social inclusion.

North American policy researchers have highlighted the importance of promoting a social inclusion agenda in social policy making. The Laidlaw Foundation and its members from Canada have been leaders on matters pertaining to child health development and children’s rights for social inclusion. Founded on humanistic principles as well as theory and research on policy drivers for social inclusion (similar to theory that will be explored later on in this chapter), the Laidlaw Foundation (as cited in Bach, 2002, 2005) developed a set of five *cornerstones*, or critical dimensions of social inclusion. The first is ‘valued recognition’ - granting recognition and respect towards citizens and grounds and groups. This first cornerstone was the most crucial element for social inclusion for the Laidlaw Foundation. The Laidlaw Foundation held the premise that every citizen was equal and stressed this imperative through validating and recognising shared lived experiences, commonalities and aspirations. This cornerstone has been supported by empirical research and epistemological development of theories of recognition, and the critical importance of being a valued and recognised citizen (i.e. Anna, 2012; Thompson & Yar, 2011). The second

cornerstone was ‘human development’ (Laidlaw Foundation). Typically, human development can be related to aspects of health. However, the Laidlaw Foundation acknowledged a more holistic approach to human development, where talents, capacities, skills, and choices would be nurtured so that each citizen could “flourish and contribute to society” (as cited in Bach, 2005, p. 10). The concept of human flourishing has been extensively critiqued in fields as diverse as economics of moral philosophy, and is strongly influenced by Aristotelian philosophy and further supported in theories of enablement, human survival as well as in the field of positive psychology championed by Martin Seligman (Nussbaum, 2003, 2011; Seligman, 2011; Sen, 2000; Wilcock, 1993).

Following the first two cornerstones of social inclusion identified by the Laidlaw Foundation (as cited in Bach, 2002, 2005) which have a more theoretical and epistemological orientation, the following three hold more practical applications. The third cornerstone is ‘involvement and engagement’, which is focused on the right to be involved in decision-making processes at the micro- (personal), meso- (community) and macro-level (societal) as well as participating in the life of one’s community (Laidlaw Foundation, as cited in Bach). Involvement in decision-making processes is consistent with occupational justice principles whereby having the right to participate in meaningful and productive occupations is supported by structural support and open communication (Whiteford & Townsend, 2011). The Laidlaw Foundation’s fourth cornerstone of social inclusion is ‘proximity’ which enables citizens to share physical and social spaces and environments as well as reducing “social distances” (Laidlaw Foundation, as cited in Bach, p. 10) between people through enabling opportunities for interaction. This cornerstone is similar to Renner et al.’s (2007) construct of ‘exclusionary relationships’ in a typology of social inclusion described in Taket et al. (2009). However, in contrast to these typologies, the cornerstone provides an example of addressing such exclusionary forces or relationships through community action from the bottom-up (citizen participation). The Laidlaw Foundation’s final cornerstone of social inclusion is ‘material wellbeing’, where each citizen has an adequate income beyond mere survival, as well as a safe and secure home. This cornerstone relates well to Fraser’s (1995) notion of a politics of redistribution and Sen’s (1999) capabilities

approach which welcomed material equality as well as recognising the need for adequate resources to enable wellbeing.

Together with this set of cornerstones that can guide an understanding of the humanistic potential of social inclusion, Anver Saloojee (2001), an affiliate of the Laidlaw Foundation and Canadian politics professor, suggested that democratic citizenship was at risk if there was a societal failure to develop the capacities and talents of its members. As an advocate for social inclusion and inclusive citizenship (Lister, 2010), Saloojee's 'inclusion-as-a-right' approach identified a collective responsibility and accountability for social inclusion through being proactive and supportive. Similar to the Laidlaw Foundation's five-step cornerstone approach to social inclusion, Saloojee suggested five ways to make social inclusion 'compelling' to citizens and policy-makers alike as opposed to supporting a discourse on exclusion.

Saloojee's (2001) first approach was for social inclusion to be a political response to exclusion. Part of such a political response could include the removal of systemic barriers to support participation, equity and opportunity, as well as instilling an inclusive vision across the political domain (Saloojee). Together with social inclusion being addressed at the political level, Saloojee also promoted a 'proactive' approach to social inclusion and citizenship. In this light, social inclusion would involve advocacy to address citizen rights as well as a call to government to be responsible for and adopt policies which ensured an inclusive agenda (Saloojee). Saloojee supported the fact that social inclusion was by virtue both 'process' and 'outcome', therefore holding institutions and governments accountable for their social policies. Accountability for Saloojee envisioned 'good' government to be measured "through the extent to which it advances the wellbeing of the most vulnerable and the most marginalised in society". Saloojee also conceptualised social inclusion as having transformative capacity to turn around political struggle towards promoting political will for equitable participation. This is ontologically consistent with theoretical assumptions (Frank & Zemke, 2009; Townsend, 1997b, 1998) and empirical support (Breedon, 2008, 2012) of promoting the transformative potential of occupation which encourages enablement across micro, meso and macro levels. Finally, Saloojee captured the humanitarian

aspect of social inclusion as one which embraces difference and diversity, with each citizen having entitlements for being and becoming part of a polity and not by virtue of one's formal status (i.e. as a citizen, refugee, being 'privileged' or being 'marginalised').

Similarly, Lombe & Sherraden (2008) also agreed that "inclusion creates a society of ownership and ensures better social, economic, and political outcomes" (p. 204), and further suggested the following 'institutional' constructs that could be used to study and inform innovations for social inclusion specifically throughout the policy development, implementation and evaluation processes:

1. *Access* meaning eligibility and availability;
2. *Information* on the purpose of participation and how to participate;
3. *Incentives*, financial or otherwise, to encourage participation;
4. *Expectations* for participation, expressed by both leaders and program structures;
5. *Facilitation*, meaning concrete assistance with participation; and
6. *Security*, meaning safety in participation" (p. 209).

Lombe and Sherraden supported Saloojee's (2001) critical perspectives on social inclusion and suggested that 'inclusion in the policy process' could also be 'transformative', pointing to necessary changes in public policies, attitudes, and institutional practices. Lombe and Sherraden further advocated for the main objective of social inclusion to extend beyond "bringing people in" (p. 211); but rather to ensure that all citizens irrespective of traditional social positions participated as valued societal members. Inclusion mattered because it was fundamental to the human dignity and right to participate (Lombe & Sherraden; Morrison, 2010). Advocates for inclusion in the policy process stipulated that such policy should involve participation through active citizen engagement beyond consultation (Edwards, 2008; Shergold, 2009) where citizens would become 'co-producers' of the resources required (Shergold). In support of active citizen engagement (Shergold), Saloojee's 'social inclusion as compelling' reasoning culminated in the following statement which holds most arguments and opinions that support the notion of social inclusion as 'process' and 'outcome':

"Social inclusion is about social cohesion plus, it is about citizenship plus, it is about the removal of barriers plus, it is anti-essentialist plus, it is about rights and responsibilities plus, it is about accommodation of differences plus, it is about democracy plus, and it is about a new way of thinking about the problems of injustice, inequalities and exclusion

plus. It is the combination of the various pluses that make the discourse on social inclusion so incredibly exciting”.

### Social inclusion and human rights.

At the inaugural Australian Government social inclusion conference in January 2010, the then Parliamentary Secretary for Social Inclusion, Senator Ursula Stephens claimed that “social inclusion goes hand-in-hand with human rights” (Stephens, 2010). Despite this claim, Australia is yet to mandate human rights in its constitution as compared to other Western developed nations such as Canada, United States, the United Kingdom or New Zealand. However, the ‘inclusion-as-a-right’ paradigm is frequently incorporated into humanitarian definitions of social inclusion. Due to the recent introduction of social inclusion policy discourse in Australia, it is unknown how the Universal Declaration of Human Rights (United Nations, 1948) is upheld in such policy, especially the declaration’s first, overarching article:

“All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood” (United Nations).

Despite the United Nations Declaration of Human Rights (United Nations, 1948) being a framework to enable and realise opportunities for social inclusion, it is a vision document requiring governments to mandate it (Stadnyk, Townsend & Wilcock, 2010). With regards to humanitarian definitions of social inclusion, United Kingdom’s disability rights commissioner, Liz Sayce (2001), developed a definition of social inclusion specifically focused on the human rights and advocacy of citizens living with disability. In her definition, Sayce described the virtues of social inclusion as including a combination of rights, social and economic access, opportunities, equality of status as well as supporting a social model of disability.

### Social model of disability.

The social model of disability dispelled the traditional medical, deficit model of disability where citizens living with disability were seen as ‘the problem’ (Goggin & Newell, 2005; Layton, 2009; Smith, 2009). The social model of disability claimed that inclusion was about removing

barriers across individual, physical, attitudinal and systemic levels of society (Kahane & Savulescu, 2009; Smith; Layton; Vehmas, 2004). Various theorists researching about the philosophy of disability, further attested that beyond outlining the removal of such barriers, the social model also asserted that disability was the result of unjust and oppressive social and ideological structures (Bickenbach; 2009; Hull, 2009a; Hull 2009b; Terzi, 2004, 2009; Vehmas & Mäkelä, 2009). This model promoted equity in favour of normalising citizens living with disability through prescription, cure or care (Layton). Further, it highlighted the importance of removing categorical definitions of disabilities as well as emphasising societal and governmental obligations to enact rights and law to ensure equity and full participation in society (Reiter, 2008).

#### Inclusion-as-a-right paradigm.

The ‘inclusion-as-a-right’ paradigm is further supported by Nelms and Tsingas (2010) in their critical review of social inclusion and labour force participation in Australia in response to the *Fair Work Act 2009*. The authors noted that such an important act only identified but did not define ‘social inclusion’. Nelms and Tsingas subsequently provided an ‘understanding’ of social inclusion, as the process or means through which citizens and/or groups “...are provided with the resources, rights, goods and services, and opportunities to engage in cultural, economic, political and social aspects of life” (p. 11). Lombe and Sherraden (2008) also supported this paradigm when they discussed the importance of marginalised groups being included in the policy process. The authors described human rights as being fundamental to creating and building an inclusive society. Inclusion to Lombe and Sherraden meant full participation across social, political, and economic processes.

Skeptics of the ‘inclusion-as-a-right’ paradigm criticised it as being too broad and therefore too difficult to make decisions for resource utilisation and other policy implementations (Renner et al. 2007). However, Renner et al. expressed that such critics were more accepting of a social exclusion rhetoric similar to that explored by Levitas (1998) and Sen (2000) in the context that some people “do not benefit from mainstream development efforts because of who they are or

where they live. In addition to poverty, they face discrimination based on social identity” (Renner et al.). Further, citizens have also experienced discrimination through a lack inter-subjective recognition and dignity (Honneth, 2001; Morrison, 2010). The following section explores these latter concepts in more detail through a critique of the theoretical terrain.

### **Conceptual and theoretical underpinnings of social inclusion**

The multidimensional nature of social inclusion and its interdisciplinary development pose several challenges to summarise its theoretical foundations. This review focused on an overview of key theories and ideas from sociology, political philosophy and occupational science which were most salient to an overarching conceptualisation that support an occupational perspective of social inclusion. The theories and assumptions explored specifically relate to the intrinsic and interpersonal precursors for social inclusion (Fraser, 1995; Honneth, 1995, 2001; Morrison, 2010; Nussbaum, 2003, 2011; Sen, 1999, 2000). Further, theoretical assumptions and values inherent in occupational science and occupational therapy about occupation, empowerment, enablement and justice were also included to highlight the nexus between occupation, participation and social inclusion relevant to the research described in this thesis.

#### Theories of recognition.

The first theory explored is the theory of recognition which is credited to philosopher Axel Honneth (1995); a theory which Honneth himself considers as a ‘work-in-progress’ (Ikäheimo, 2002). The following section introduces the principal tenets of the theory of recognition and compares its intrinsic nature to other notions of recognition from a social justice perspective.

#### Inter-subjective recognition.

Inter-subjective recognition is related to the concept of justice, as it acknowledges the recognition, acceptance, dignity and respect of a person’s or societal group’s difference and diversity (Honneth, 1992, 1995, 2001; Morrison, 2010). From an ethical perspective, Honneth



related recognition with “reciprocal respect for both the unique and equal status of all others” (p. 45). In developing the theory of recognition, Honneth based his philosophical concepts of recognition on the works of Hegel, who portrayed recognition as a vital human need beyond mere courtesy (Deranty; 2009; Taylor, as cited in Fraser, 1995). Compared to recognition as a human rights discourse, Honneth expressed that such a discourse would be limited and not cater for associations of recognition with social esteem and loving care (Honneth, 2001; Ikäheimo, 2009). Rather, recognition in this sense was more of a moral perspective than an exclusive human rights one (Honneth, 2001). Honneth (2001) also described a theory of recognition as a moral-practical philosophy to conceptualise social inclusion and exclusion:

“We are...dealing with the denial of rights and with social exclusion, where human beings suffer in their dignity through not being granted the moral rights and responsibilities of a full legal person within their own community. Accordingly, this type of disrespect has to have, as its corresponding relation, the reciprocal recognition through which individuals come to regard themselves as equal bearers of rights from the perspective of their fellows” (p. 49).

Social inclusion, to Honneth, is therefore recognition of equality and dignity, with self-respect as a product of an inclusive transaction between individuals or groups that takes place in moral and practical terms. According to Honneth, a ‘morality of recognition’ takes the form of a perfect example of the attitudes of mutual obligation that one must adopt “...to secure jointly the conditions of our personal integrity” (Honneth, as cited in Heidegren, 2002, p. 439). Furthermore, not only does Honneth’s theory of recognition pronounce the essential morality of recognising another as equal (Deranty), but it also provides positive outcomes for the other from the process of being recognised as a person (Ikäheimo, 2002, 2007, 2009; Ikäheimo & Laitinen, 2010). Such outcomes include positive self-esteem, self-realization, integrity, acceptance of egalitarian difference as well as love, appreciation for legal order and solidarity (Heidegren, 2002; Honneth).

Honneth’s (1995; 2001) theory of recognition together with Fraser’s extension of the theory to include a politics of redistribution (1995, 2000, 2001) have been applied to international political discourses on social inclusion. For example, Canadian disability rights activist, Michael

Bach (2002, 2005) questioned the realisation of recognition for all citizens, especially those who live with disability. Bach clearly distinguished a masking effect of 'inclusion' being supposedly realised under the guise of a human rights 'banner'. He therefore questioned the legitimacy of policies and practices which had yet to realise the recognition of 'othered', less privileged citizens: "This dilemma – of rights without recognition – is what we might call the dilemma of the 'rights revolution'" (Bach, 2002, p. 19). Bach praised Honneth's framework as an important one for conceptualising the dynamic and multifaceted process and outcome of social inclusion. In Bach's view, Honneth's theory of recognition allowed for valuing forms of knowledge and recognition as being central to realising human dignity and equal recognition of worth across interpersonal, institutional, and societal levels. In this context, Bach preferred social inclusion to be considered as invoking valued recognition through social solidarity as a uniting front (Bach, 2005, Heidegren, 2002; Honneth, 1992, 1995, 2001). Solidarity in this view acknowledges the Honnethian understanding of the term as "valuing forms of life characterised by many social differences" (Bach, 2005, p. 128). On solidarity, Bach stipulated:

"Fostering solidarity across differences in our society is an important step in creating a culture where citizenship rights people hold can be more fully realised in their daily lives...The vision of citizenship that a call for inclusion appeals to goes beyond the exercise of political rights, and social and economic claims on the state. It demands social, cultural, political and economic participation in all institutions of society... The calls from the disability movement for inclusion envision forms of social identity, reciprocity and solidarity that provide a foundation for rights to be realised in relation to others, for a life well-lived in community" (p. 128-130).

#### The political philosophy of recognition vis-à-vis redistribution.

From applying Honneth's (1995, 2001) theory of recognition to an understanding of social inclusion as solidarity (Bach, 2002; 2005), Honneth also related recognition with personal dignity and respect for oneself and others as opposed to the social justice term of 'redistribution' which "aims to achieve social equality through a redistribution of the material necessities for an existence as free subjects" (Honneth, 2001, p. 43). Theorists such as Nancy Fraser (1995, 2000, 2001, 2008) have challenged Honneth's original idea of inter-subjective, or intrinsic recognition

due to citizens' struggle for recognition resulting from an exacerbation of material inequality. Material inequality in this sense is understood beyond typical income and home ownership, to include "access to paid work, education, health care and leisure time;...caloric intake and exposure to environmental toxicity;...life expectancy and rates of morbidity and mortality" (Fraser, 1995, p. 68). Fraser (1995) called for the development of a 'critical' theory of recognition (original emphasis), which welcomed a combined understanding of a politics of difference and recognition (cultural justice), with that of a politics of equality through a 'politics of redistribution' (economic justice) (Morrison, 2010; Stadnyk, Townsend & Wilcock, 2010). Fraser (1995) indicated that both cultural justice and economic justice were, in fact, intertwined in reality. For example, economic disadvantage impacts upon

"...equal participation in the making of culture, in public spheres and in everyday life. The result is often a vicious circle of cultural and economic subordination" (Fraser, 1995, p. 72-73).

Fraser's (1995, 2000, 2001) conceptualisation of redistribution and a politics of recognition has been critiqued by poverty researcher, Ruth Lister, as overlooking injustices experienced by citizens living with disability (Lister, 2010). In her defense, disability activists have affirmed Fraser's (1995) acknowledgement of linking the combined and reinforcing approach of cultural and economic justice (politics of recognition and redistribution; i.e. Danermark & Coniavitis Gellerstedt, 2004). For example, in her public lecture presented in Australia in 2010, Lister cited disability theorist and activist Tom Shakespeare's explanation of supporting a politics of recognition and a politics of redistribution:

"...the social movement of disabled people is about the politics of recognition, as well as the politics of redistribution. Disabled people suffer socio-economic injustices, such as marginalisation and deprivation, as well as cultural injustices, such as non-recognition and disrespect".

Therefore, both Honneth's (Deranty, 2009; Ikäheimo, 2002; Heidegren, 2002; Honneth, 1992, 1995, 2001) and Fraser's (1995, 2000, 2001) contributions to a critical theory of recognition through supporting cultural justice (politics of recognition) and economic justice (politics of

redistribution) are both important for an understanding of personhood, rights and justice as a means to economic and social equality (Morrison, 2010).

#### The capabilities approach.

The second theory explored is the ‘capabilities approach’ developed and theorised by economist Amartya Sen (1992, 1993, 1999, 2000, 2001, 2004; Sen & Nussbaum, 1993) and philosopher, Martha Nussbaum (Nussbaum, 2003, 2011; Sen & Nussbaum) respectively. Nobel prize laureate Amartya Sen (2000) described poverty as not only based on being deprived of material necessities (i.e. food, water, income shortage or shelter), but rather as being deprived of *capabilities*. Sen (2000) identified that capability deprivation may be a major determinant of exclusion beyond financial means. Deprivation can be described as not being able to afford or acquire particular goods, services or activities that are consensually regarded as being essential for everyday living (Pate, 2009). According to Sen (2000), having income is a prominent way for living a life without deprivation, however it is not the only influence on human potential. Despite the importance of income in a society framed by Neoliberal and Capitalist ideologies, focusing on income alone overstates the role of determining wellbeing and quality of life (Australian Social Inclusion Board, 2009). This perspective is ontologically supported by Sen (2000) when he related a capabilities approach to deprivation with qualities such as wellbeing and social justice (Fraser, 1995). To this end, Nussbaum (2003) identified Sen’s approach to capabilities as a “major contribution to the theory of social justice” (p. 33). The capabilities approach is supported by epidemiological research which determined that reducing inequality through enabling capabilities was the best method to improve the quality of life of citizens across the spectrum, as well as the quality of the social environment (Wilkinson & Pickett, 2009). The capabilities approach has also been influential to many academic disciplines and movements such as economics, development studies, disability studies, political philosophy and egalitarianism (Kuklys & Robeyns, 2005; Sen, 1992; Terzi, 2009).

The basic premise of the theory of capability focuses on life “consisting of a set of interrelated ‘functionings’, consisting of beings and doings” (1992, p. 39) such as good health, happiness, participating in community life and enjoying a nutritious diet (Sen, 1992, 1993). Functionings are constitutive of wellbeing (Terzi, 2009). ‘Capability’ is closely related to Sen’s concept of functionings and encapsulates “a set of vectors of functionings [ranging from elementary to more complex functionings in nature; i.e. eating and social integration], reflecting the person’s freedom to lead one type of life or another” (p. 40). Self-determination and freedom to choose the life that one wants through enacting capabilities by achieving sets of functionings are important benefits or outcomes of Sen’s theory of capability (Alexander, 2009; Pettit, 2001; Saunders, 2003; Sen, 1992, 2000). The doings and beings are in and of themselves important to realising capabilities, as opposed to a utilitarian approach (i.e. welfare enables capability) where lives are only seen as being enriched through being granted goods or services (Sen, 1992). A person’s capability is dependent on a variety of factors which determine “[a person’s ability to] do the things that she would choose to do and has reason to choose to do” (Sen, 2001, p. 55).

Sen (Ransome, 2010; Sen, 2000) related living poorly and capability deprivation with Aristotelian philosophy of doing and living:

“...the Aristotelian account of the richness of human life was explicitly linked to the necessity to “first ascertain the function of man,” followed by exploring “life in the sense of activity.” In this Aristotelian perspective, an impoverished life is one without the freedom to undertake important activities that a person has reason to choose” (Sen, p. 3-4).

From this Aristotelian description which promotes a flourishing human life through doing and being (functionings), Sen’s capabilities approach can be directly linked to epistemological and ontological foundations of occupation-based disciplines (Phelan & Kinsella, 2009; Sellar, 2012) such as occupational science and occupational therapy which emphasise the impact of occupation on participating in a life that is purposeful and meaningful leading to health, wellbeing and quality of life outcomes (Wilcock, 1998, 2006). Philosopher Martha Nussbaum has further developed Sen’s capabilities approach through exploring Aristotle’s political philosophy and ethics, and is credited to being a contributing developer of the capabilities approach

(Alexander, 2009, 2010; Claassen, 2009). Sen has been described as defining the capabilities approach with Nussbaum adding its philosophical and theoretical credence (Alexander; Claassen).

Nussbaum depicted Aristotle's concept of a 'flourishing human life' as central to understanding different capabilities and as such developed a list of 10 'essential capabilities' to provide an objective evaluation to contribute to a good life (Alexander, 2003, 2009; Nussbaum, 2011). The list of capabilities captures capabilities that are deemed to be essential to life such as bodily health, having emotions, affiliation to others, being able to play as well as having control over an individual's environment. Nussbaum's (2011) discrete list of essential capabilities is where Nussbaum philosophically parts ways with Sen's perspective on the capabilities approach (Alexander; Nussbaum, 2003, 2011; Nussbaum as cited in Alexander; Sen, 2004). Sen promoted an open approach to "advocating a capabilities-based understanding of justice...without endorsing a definite list of capabilities" (Alexander, 2003, p. 63) whereas Nussbaum critiqued Sen for not being radical and objective enough to describe how "...functionings can be assessed for their contribution to the good human life" (Nussbaum, 1988, as cited in Alexander, 2003, p. 64).

#### Connectedness: A cross-cultural understanding.

Western theories of social inclusion across several domains only provide a limited perspective about its transformative capacity (Townsend, 2012). As previously explored, such theories commonly depicted a linear relationship between including and being included (i.e. through intersubjective relationships, or through a process or outcome). However, social inclusion from a non-Western perspective, such as incorporating a broad view of connectedness, can provide an ecological perspective into human relationships with one another as well as with the broader environment. Increasing across-cultural understanding of social inclusion not only improves considerations for respectfully situating Western policies in context, but could also lead to utilising non-Western ideas about social inclusion to ameliorate current and future policy-

making practices beyond its original scope. An example is the theory and practice of *ubuntu* across the African continent.

*Ubuntu*, interconnectedness and social inclusion.

In his landmark book on sharing a non-Westernised perspective of social inclusion concepts, Nobel Peace Prize laureate and former Anglican Archbishop of Cape Town, South Africa, Desmond Tutu (1999) captured the essence of *ubuntu* through his following description of its philosophy:

“*Ubuntu* (original emphasis) is very difficult to render into a Western language. It speaks to the very essence of being human. When you want to give high praise to someone we say, “*Yu, u nobuntu*”; “Hey, so-and-so has *ubuntu*”. Then you are generous, you are hospitable, you are friendly and caring and compassionate. You share what you have. It is to say, “My humanity is caught up, is inextricably bound up, in yours”. We belong in a bundle of life. We say, “A person is a person through other persons”. It is not, “I think therefore I am”. It says rather: “I am human because I belong. I participate, I share.” A person with *ubuntu* is open and available to others, affirming of others, does not feel threatened that others are able and good, for he or she has a proper self-assurance that comes from knowing that he or she belongs in a greater whole and is diminished when others are humiliated or diminished, when others are tortured or oppressed, or treated as if they were less than who they are” (p. 31).

*Ubuntu* speaks to social inclusion as its concepts share commonalities in how they are both considered from philosophical standpoints. For example, Tutu related *ubuntu* with belonging, participation and sharing. Understanding social inclusion as solidarity (Bach, 2002, 2005; Honneth, 1995, 2001; Saloojee, 2001) as well as Wilcock’s (1998; 2006) doing, being, becoming and belonging paradigm relate to *ubuntu* in this sense. Furthermore, *ubuntu* also relates to self-construal theory documented in social psychology, culture and leisure research which have described people from Asia, Africa, Southern Europe and Latin America as having ‘interdependent self-construals’, who value belonging, maintaining harmony, promoting others’ goals and connectedness (Walker, Deng & Dieser, 2005). This construct is contrasted to people of other cultures such as European North Americans who have ‘independent self-construals’, valuing being unique, expressing inner attributes as well as asserting oneself (Walker, Deng & Dieser).

Lewis (2010) highlighted that *ubuntu* as a construct relates to having an interdependent self-construal (Walker, Deng & Dieser, 2005) by “[emphasising] personal empowerment and limitless potential through an understanding of identity construction as an ongoing process of ‘becoming through relationship with the other’” (p. 70-71). Through *ubuntu*, being able to participate in the life of a society is beyond an ‘inclusion-as-a-right’ perspective (Lombe & Sherraden, 2008). Rather, it invites an epistemology of what it is to be human in a community of shared culture and mutual understanding, or innate interrelatedness or interconnectedness (Lombe & Sherraden). Furthermore, *ubuntu* would contest social inclusion’s ‘process’ and ‘outcome’ paradigm, preferring it to be conceptualised as never being in question in the first place due to its innateness. In this sense, *ubuntu* is an ecological approach to harmony with the environment and each other. Despite *ubuntu* being an innate concept, the symbiotic relationship between an ecological view of each other and the environment could still experience imbalance leading to ecological damage, or ‘exclusion’ in Western experience. Tutu (1999) expressed this through tribal conflict in his landmark book.

From a Western perspective, a basic understanding of *ubuntu* has the potential to transcend into Western political thought and practice through instilling a culture of inclusion as well as developing an intrinsic respect for the other through belonging, solidarity and reciprocity (Komter, 2005). Such a culture of inclusion further supports Bach’s (2002, 2005), Komter’s and Saloojee’s (2001) notion of social inclusion as solidarity as well as Lombe and Sherraden’s (2008) idea of shared understandings. If anything, *ubuntu* can widen possibility as well as support the previously expressed theories of social inclusion from a unique and nuanced perspective.

In capturing ideas that are central to an understanding of social inclusion from political, social, cultural and theoretical perspectives, the following Table (Table 1) provides an overview of the key themes discussed thus far. It also introduces some new concepts such as connectedness and solidarity which serve as a useful theoretical resource in understanding the scope of social inclusion as a guiding idea across many disciplines in the preceding three decades. In addition to the table, having *choice*, *dignity*, *equitable access* (i.e. *physical access*; *access to information*),



and *being involved in decision-making processes* are other key concepts which also compliment an 'inclusion-as-a-right' agenda within international social inclusion discourses.

Table 1: Framings of social inclusion (updated from table published in Whiteford & Pereira, 2012, pp. 194-197)

Key Elements	Key Concepts / Constructs	Key Authors
Social inclusion as <i>capability</i>	<ul style="list-style-type: none"> <li>The basic premise of the capabilities approach focuses on life “consisting of a set of interrelated ‘functionings’, consisting of beings and doings” (1992, p. 39) such as good health, happiness, participating in community life and enjoying a nutritious diet (Sen, 1992, 1993)</li> <li>Functionings are constitutive of well-being</li> <li>‘Capability’ is closely related to Sen’s concept of functionings and encapsulates “a set of vectors of functionings [ranging from elementary to more complex functionings in nature; i.e. eating and social integration], reflecting the person’s freedom to lead one type of life or another” (1992, p. 40)</li> <li>Benefits (or outcomes) can include self-determination and freedom to choose the life that one wants through enacting capabilities by achieving sets of functionings</li> <li>A person’s capability is dependent on a variety of factors which determine a person’s ability to “do the things that she would choose to do and has reason to choose to do” (Sen, 2001, p. 55)</li> </ul>	<p>Alexander (2003, 2009, 2010)  Alkire (2005)  Anand, Hunter &amp; Smith (2005)  Burchardt (2004)  Claassen (2009)  Graham &amp; Harwood (2011)  Nevile (2007)  Nussbaum (2003, 2011)  Sen (1992, 1993, 1999, 2000, 2001, 2004)  Sen &amp; Nussbaum (1993)  Srinivasan (2007)  Terzi (2009a, 2009b)</p>
Social inclusion as <i>opportunity</i>	<ul style="list-style-type: none"> <li>Broader environments and contexts facilitate or provide opportunities</li> <li>Opportunities enable individuals to use their capabilities and resources to participate as they choose</li> <li>Self-determination and choice</li> <li>There is a nexus between capabilities, opportunities and resources for social inclusion (Levitas et al., 2007; Department of Education, Employment and Workplace Relations, 2009)</li> </ul>	<p>Australian Social Inclusion Board (2010)  Department of Education, Employment and Workplace Relations (2009)  Department of the Prime Minister and Cabinet (2009a, 2009b)  Levitas, Pantazis, Fahmy, Gordon, Lloyd and Patsios (2007)  Nelms and Tsingas (2010)  Sayce (2001)  Sen (1999)</p>
Social inclusion as <i>solidarity</i>	<ul style="list-style-type: none"> <li>Social bonds between the individual and society</li> <li>Living together peacefully and constructively</li> <li>Shared system of interdependence</li> <li>Relationships can be based on cooperation</li> <li>Contributing to the common good</li> <li>Capacity of people to come together, despite their differences, in ways that are mutually beneficial (Vasta, 2010a)</li> <li>“Valuing forms of life characterised by many social differences” (Bach, 2005, p. 128)</li> <li>Reciprocity provides a foundation for the realisation of rights in relation to others (Bach, 2005)</li> </ul>	<p>Bach (2002, 2005)  Heidegren (2002)  Honneth (2001)  Komter (2005)  Saloojee (2001, 2005, 2011)  Vasta (2010a, 2010b, 2011)</p>

Social inclusion as <i>recognition</i>	<ul style="list-style-type: none"> <li>• Acknowledges the recognition, acceptance, dignity and respect of a person's or societal group's difference and diversity (Honneth, 2001; Morrison, 2010)</li> <li>• Recognition is reciprocal, incorporating reciprocal respect</li> <li>• Recognition promotes self-respect as a product of an inclusive transaction between individuals or groups that takes place in moral and practical terms (Honneth, 2001)</li> <li>• Personal integrity</li> <li>• Recognising one another as equal is a moral imperative, rather than being an exclusive human rights imperative</li> <li>• Recognition allows one to value diverse forms of knowledge</li> <li>• Recognition is central to realising human dignity and equality of worth across interpersonal, institutional, and societal levels (Bach, 2005)</li> </ul>	<p>Bach (2002, 2005) Calder (2011) Deranty (2009) Fraser (1995) Heidegren (2002) Honneth (1992, 1995, 2001) Ikäheimo (2002, 2007, 2009) Ikäheimo &amp; Laitinen (2010) Komter (2005) Morrison (2010) Shakespeare (2006) Smith &amp; Deranty (2012) Thompson &amp; Yar (2011)</p>
Social inclusion as <i>poverty reduction</i>	<ul style="list-style-type: none"> <li>• Understanding social inclusion beyond having material goods and services; inclusion is more than market involvement</li> <li>• Considers inclusion through paid employment as limited regarding the realities of other roles, responsibilities and obligations such as care-giving, volunteering and education</li> <li>• Supports poverty as being deprived of 'capabilities'</li> <li>• Enabling opportunities through sustainable community development and inclusive education for combating poverty</li> </ul>	<p>Alkire (2005) Fraser (1995, 2000, 2001) Lauckner, Krupa &amp; Paterson (2011) Levitas (1996, 1998) Lister (1998, 2004, 2010) Mitchell &amp; Shillington (2005) Morrison (2010) Saunders (2003) Saunders, Naidoo &amp; Griffiths (2007) Sen (1999, 2000) Silver (1994) van Bruggen (2010)</p>
Social inclusion as <i>citizenship</i>	<ul style="list-style-type: none"> <li>• Key elements of citizenship include having civil rights, political rights and social rights (Kim, 2010)</li> <li>• Realisation and enactment of human rights</li> <li>• Freedom to participate and contribute to society</li> <li>• Recognising the rights, obligations and institutions that play a role in developing and supporting equality of status in the community (Buckmaster &amp; Thomas, 2009, p. 16)</li> <li>• Being a valued citizen</li> <li>• Mutual sharing and upholding equality and respect</li> <li>• Enjoying a basic standard of living</li> </ul>	<p>Buckmaster &amp; Thomas (2009) Edwards (2008) Kim (2010) Lister (2010) Saloojee (2001, 2002, 2005, 2011) Sinclair, Bramley, Dobbie &amp; Gillespie (2007) Shergold (2009)</p>
Social inclusion as <i>rights</i>	<ul style="list-style-type: none"> <li>• Upholding universal rights and privileges</li> <li>• Celebrating equality, recognition and mutual respect</li> <li>• Rights-based agendas enable harmonious interaction, collaboration and participation</li> <li>• Rights enable participation in cultural, economic, political and social aspects of life</li> </ul>	<p>Edwards (2010) Frazee (2002, 2005) Honneth (1992, 1995, 2001) Government of South Australia (2009) Lombe &amp; Sherraden (2008) Morrison (2010) Nelms and Tsingas (2010)</p>

	<ul style="list-style-type: none"> <li>• Full participation across social, political, and economic processes</li> <li>• Social justice</li> <li>• Potential for active citizen engagement such as being involved in decision making at the individual, interpersonal, group, organisational, community and societal levels</li> </ul>	Rawls (1971, 1999) Reiter, (2008) Saloojee, (2001, 2005, 2011) Sayce (2001)
Social inclusion as <i>means and ends</i>	<ul style="list-style-type: none"> <li>• ‘Means’ for participating in, and contributing to, society</li> <li>• Social inclusion processes enacted by organisations, institutions or governments make them accountable for their actions</li> <li>• Lead to goals or ‘outcomes/ends’</li> <li>• Can be measured, evaluated and critiqued for the betterment of society</li> </ul>	Democratic Dialogue (1995) Levitas (1996) Lister (1998) Lombe & Sherraden (2008) Morrison (2010) Nelms & Tsingas (2010) Saloojee (2001; 2011) Saunders (2003) Smyth (2008, 2010) Ward (2009) Whiteford & Townsend (2011)
Social inclusion as <i>connectedness</i>	<ul style="list-style-type: none"> <li>• Being actively involved with another person, object, group, or environment</li> <li>• Interactions provide and promote comfort and well-being</li> <li>• Sharing bonds and understandings between people which may bring them closer</li> <li>• Culturally relative i.e. Western perspectives of connectedness (Hagerty et al., 1993; Taket et al., 2009; Townsend &amp; McWhirter, 2005) is epistemologically different to an African perspective of connectedness, or interconnectedness (i.e. <i>Ubuntu</i>; Tutu, 1999)</li> </ul>	Hagerty, Lynch-Sauer, Patusky & Bouwsema (1993) Maulana & Eckhardt (2007) Owens (2009) Taket, Crisp, Nevill, Lamaro, Graham & Barter-Godfrey (2009) Townsend & McWhirter (2005) Tutu (1999)
Social inclusion as <i>economic participation</i>	<ul style="list-style-type: none"> <li>• Social inclusion through work/employment/productivity</li> <li>• Positive feeling of self-worth through work</li> <li>• Work provides meaning</li> <li>• Economic participation is a means by which people can be integral, productive and contributing members of society</li> </ul>	Levitas (2001) Social Exclusion Task Force (2009) Social Exclusion Unit (2004) Department of the Prime Minister and Cabinet (2009a, 2009b)

## **Introducing an occupational perspective of social inclusion: Occupation, justice and participation considered**

Occupational justice discourses are salient in understanding social inclusion from a critical occupational science perspective (Hammell, 2008; Hammell & Iwama, 2012; Hocking & Whiteford, 2012; Townsend, 1993, 1997, 1998, 2003, 2012; Townsend & Whiteford, 2005; Townsend & Wilcock, 2004a, 2004b; Whiteford & Hocking, 2012; Whiteford & Townsend, 2011; Wilcock & Townsend, 2000). The underlying principles of rights, inequalities and social justice that guide social and community practice (Davis, as cited in Ward, 2009) are also central to the occupational therapy profession as well as occupational justice scholarship (Townsend & Whiteford; Whiteford & Townsend). Occupational-based disciplines (Phelan & Kinsella, 2009; Sellar, 2012) and social inclusion can be conceptualised as being philosophically aligned as 'justice' has been valued as a key pillar in occupational therapy's knowledge base (Townsend, 1997b; Townsend & Whiteford; Whiteford & Townsend) and central in the expanding critical occupational science discourse. In the practice of enabling occupation, 'justice' has also been considered as a 'client-centered, occupation-based enablement foundation' (Townsend, Beagan, Kumas-Tan, Versnel, Iwama, Landry et al., 2007). As described in the 'Canadian Model of Client-Centred Enablement' (Townsend & Polatajko, 2007), 10 key enablement skills for the occupational therapy profession have been expressed. Such enablement skills include advocacy, collaboration, coordination, education and enabling capabilities (Townsend et al., 2007). Models supporting an occupational perspective of social inclusion are examples of the rising influence of social inclusion, justice and rights discourses which are beginning to take effect in critical occupation-focused research (Cutchin & Dickie, 2013; Kronenberg, Pollard & Sakellariou, 2011; Whiteford & Townsend).

In order to provide a theoretical framework for understanding social inclusion from an occupational perspective, relevant literature on occupation was reviewed. Christiansen and Townsend (2010) described someone who investigated an 'occupational perspective' of life

and/or society as a person who was interested in raising questions and seeking answers about occupations. According to Christiansen and Townsend,

“One looks at life and society using an occupational lens to understand what people are doing, or want and need to do to survive, be healthy, and live well as valued citizens” (p. 2).

More recently, in their systematic review of occupational science and therapy literature of the common used phrase ‘an occupational perspective’, occupational scientists Njelesani, Tang, Jonsson and Polatajko (In press) defined it as “a way of looking at or thinking about human doing” (Njelesani, Tang, Jonsson & Polatajko, In press). However, this statement significantly disregards the crucial importance of ‘context’ in situating and shaping occupation, participation and inclusion (Laliberte Rudman & Huot, 2013; Whiteford, 2010). Therefore, in this thesis, ‘an occupational perspective’ will be expanded to incorporate occupation in context with the social world.

#### Definition of occupation: Key terms and concepts.

The noun ‘occupation’ originated from a derivative of the Latin verb, *occupare* which means to occupy, seize or take possession of (Christiansen & Townsend, 2010; Kidd, as cited in Wicks, 2003; Yerxa, 1993). In this context, ‘occupation’ as it is commonly understood in the Western world, has been narrowly attached to paid employment (Christiansen & Townsend; Creek, 2010). However, with the development of the occupational therapy profession over the past 100 years as well as the foundation of occupational science as an interdisciplinary science in the late 1980s supporting the philosophical base of occupational therapy, a strong body of literature exists which surmountably expands on the ‘occupation as work’ paradigm. In this thesis, occupation is conceptualised as a recognisable everyday life endeavour that a person engages or participates in (Christiansen & Townsend). It also acknowledges that occupation is a multifaceted phenomenon which “embodies time, purpose, meaning, form and context” (Wicks, 2003, p. 18). Occupations incorporate everything that we do on a day-to-day basis that brings meaning and purpose to our lives (Pereira & Stagnitti, 2008). Every day, people engage in occupations which are named,

organised and given value and meaning in personal, social, environmental, cultural and political contexts (Kronenberg & Pollard, 2006; Law, Polatajko, Baptiste & Townsend, 1997).

Occupations are socioculturally constructed and can involve “everything [that] people do to occupy themselves, including looking after themselves...enjoying life...and contributing to the social and economic fabric of their communities” (Law, Polatajko, Baptiste & Townsend, 1997, p. 34). Occupation is also more than a task or an activity, which are conducted with a specific purpose, such as writing a shopping list (Law et al.; Pierce, 2001). The main difference is that although tasks and/or activities may fulfill their inherent purpose, an occupation ascribes meaning to life (Law et al.; Pierce). In acknowledging the multifaceted and complex sociocultural phenomenon of occupation, Molineux (2010) proposed an exploration of the *nature* of occupation, or its understanding and potential, as a more appropriate consideration. Molineux suggested five characteristics or factors which constituted an occupation or occupations: (1) active engagement (as manifested in some form of doing, be it mental or physical); (2) purpose (human endeavours are purposeful and are based on having a reason for engagement or participation); (3) meaning (acknowledging the subjective experience of occupation); (4) contextual (situated in a particular type of environment, place or situation for participation purposes), and (5) human: occupation is characterised by human capacity for participation beyond survival needs or doing for doing’s sake which exists in many other animals such as primates. Other authors have suggested other features beyond mental or physical doing described by Molineux’s first characteristic of occupation, such as “physical, cognitive, psychological, social, or spiritual” (Miller Polgar & Landry, 2004, p. 198). This is consistent with other theories, such as the ‘flow’ state championed by social psychologist Csikszentmihalyi’s research into time use, activity and meaning (Csikszentmihalyi, 1990; Csikszentmihalyi, 1997; Csikszentmihalyi & Csikszentmihalyi, 1988; Emerson, 1998) which displayed active use of the mind as being imperative for an individual to participate in occupation. Other key features of occupations are that they are a basic human need (Wilcock, 1993; 1998; 2005; 2006); a determinant of health (Law et al., 1997; Wilcock, 1998; 2006); a source of choice and control; a

source of balance and satisfaction, a means to organise and make use of time, and are a source of meaning and purpose (Clark, Parham, Carlson, Frank, Jackson, Pierce et al., 1991; Law et al., 1997; Yerxa, Clark, Frank, Jackson, Parham, Pierce et al., 1990).

Occupations can therefore be understood as complex phenomena, requiring deeper investigation compared to the Eurocentric historicopolitical discourse which framed occupation as paid employment. To further scholarship on occupation, the discipline of occupational science was formally developed in the late 1980s specifically dedicated to the study of human occupation. The founders of occupational science proposed that it would be an interdisciplinary discipline and basic science concerned with studying the human as an occupational being (Yerxa et al., 1990; Yerxa, 1993), as well as the form, function and meaning of occupation through exploring what, when, why and how we ‘do’ in various contexts (Pereira, 2011). The premise of humans as ‘occupational beings’ directly refers to human engagement in, and experience of, occupations, including the need for, and capacity to engage in and orchestrate, daily occupations in various environments and contexts over the life span (Clark, 1997; Yerxa et al., 1990). Therefore, occupational science investigates human engagement with occupation in context with their environments; “not as decontextualised beings” (Yerxa et al., p. 11). Further, occupational science researchers are interested in exploring the meaning of everyday occupations (Hasselkus, 2006, 2011). Everyday occupations include the lived experiences of everyday life which are often seen but go unnoticed or are taken-for-granted (Hasselkus). They are typically reduced to ‘mundane things’ which are only noticed when they do not exist, are removed, or are not possible due to factors outside of one’s control (Wilcock, 1998; 2006; Whiteford, 2004, 2010).

This thesis acknowledges the influence that occupational science has had on broadening the scientific scope of human relations. The potential of occupational science can not only provide an impetus for a greater understanding on what influences human doing and being, but also increases the critical understanding of how doing and the influence of what we do in context affects the broader community, both at different levels in different ways. In supporting the



critical occupational science perspective adopted throughout this thesis, Lo Bartolo and Sheahan (2009), proposed that

“occupational science provides a strong foundation for political engagement in relation to...human experience...Utilizing a critical lens can enable occupational scientists to make a strong contribution to important social debates” (p. 414).

The focus of occupation thus far has introduced an occupational perspective of social inclusion, including the salience of occupational justice discourse such as supporting the right for all to participate in occupations for health, wellbeing and quality of life (Hammell, 2008). Discussion now turns to highlight the political influences on occupation and participation.

#### Empowerment in context with justice.

Social inclusion, together with being compelling (Saloojee, 2001), innovative in the policy process (Lombe & Sherraden) and a human right (Bach, 2002, 2005; Lombe & Sherraden; Saloojee), has also been related to the concept of empowerment in social and occupational science literature. Empowerment can involve caring for oneself or others, making decisions, advocacy, power sharing, controlling one's circumstances in life, feeling respected, safe, secure, having a sense of belonging as well as having a voice (Canadian Association of Occupational Therapists, 1997; Luttrell, Quiroz, Scrutton & Bird, 2009; Shergold, 2009; VicHealth, 2006; World Health Organization, 1998). However, a major assumption inherent within the concept of empowerment is that it assumes that power exists in the first place to either be shared or empower oneself or others (Layton, 2009). A significant critique of empowerment can be related to day-to-day realities of injustice in Western societies, such as poverty in Australia (ACOSS, 2012b). Due to the unequal power relations that exist in Western and non-Western democracies, some individuals have power to empower their own lives and interests, while others do not and remain entrenched in their marginality (Stadnyk, Townsend & Wilcock, 2010). Further, such citizens are often deprived of opportunities for occupational participation (Laliberte Rudman, 2010).

Empowerment from an occupational science perspective is congruent with the concept of enablement, in the sense that being empowered to do can enable an individual to be, become and belong should the right mix of external conditions (context) be in place to support the ends of occupational participation (Canadian Association of Occupational Therapists, 1997; Townsend, 1998; Wilcock, 1998, 2006). Both are also inherent in an historical view of justice as well as through a conceptual understanding of the theory of recognition (Honneth, 2001), a politics of redistribution (Fraser, 1995; Levitas, 1998; Morrison, 2010) and the capabilities approach (Nussbaum, 2003; Sen, 1999) explored earlier. Extending from such theories, a philosophical view of empowerment and enablement can also be related to Rawls' historical theory of justice (1971) and Young's concept of a 'justice of difference' (1990, as cited in Stadnyk et al., 2010). Rawls determined that justice emphasised one's freedom, rights, opportunities and responsibilities as moral principles (Rawls, 1971; 1999; Stadnyk et al.). Therefore, empowerment as justice was a *moral* duty of fairness for all to acknowledge (Rawls). A justice of fairness would therefore enable empowerment and its various elements through the equitable distribution of resources and power on moral grounds (Stadnyk et al.). Empowerment from Young's 'justice of difference' perspective, on the other hand, highlighted the importance of having 'opportunities' to engage in life. Opportunity, in Young's view, is a concept of 'enablement'; a justice to enable individuals to carry out their occupations and enjoy a life free from exploitation, violence and oppression (Stadnyk et al.). From a critical occupational science perspective, Townsend (1998) defined empowerment as "a participatory process of learning to critique and transform individual feelings, thoughts, and actions, as well as the organisation of society, so that power and resources can be shared equitably" (p. 13).

### Occupation in context.

Various conditions or factors influence everyday doing, or participation in occupations. Such factors can be categorised into three main groups: biological factors, psychological factors and contextual factors (Carlson & Clark, 1991; Christiansen & Townsend, 2010). This section

addresses the contextual factors which influence occupation in legal, legislative and political contexts (Barbara & Whiteford, 2005; Christiansen & Townsend; Stadnyk, Townsend & Wilcock, 2010; Whiteford, 2010). Societies determine certain rules and regulations which influence (or control) what people can and want to do in their lives (Christiansen & Townsend, 2010). Under these circumstances, doing is influenced by what is accepted, expected or allowable based on cultural values (Christiansen & Townsend). Doing is also influenced by governing bodies who determine specific criteria that must be met for doing to occur. From this understanding, 'doing' may not necessarily be 'free' to choose or even an option for occupational participation. Examples of this include the causational factors which stem across institutional and government policies that lead to citizens living with disability not being able to do, or participate in meaningful occupations due to physical and systemic barriers (Whiteford, 2004; 2010). According to Whiteford, Klomp and Wright-St Clair (2005), doing, or occupational participation, is always bound by social, cultural, economic, historical and political influences. Whiteford (2010a) also identified that the sociocultural context where occupation is experienced, "...is arguably the most significant contextual force that shapes occupational behaviour" (p. 141). Together with physical and systemic barriers which exclude occupational participation, the broader cultural context is also a crucial one to consider (Whiteford, 2010a). The cultural context enables citizens to

"understand and ascribe *meaning* (original emphasis) to what they do. In this respect, culture may be seen as a system of shared meanings...that enable survival in whatever environment communities of people live" (Whiteford, 2010a, p. 141).

Further, Barbara and Whiteford (2005) and Whiteford (2004; 2010) also attested that the impact of political and economic environments are less visible, inherently *more complex* (as compared to sociocultural contexts) and are no less influential on how people engage in occupations and participate in society. An example of the impact of political and economic environment was the rise of neoliberal economics (or Neoliberalism) in the 1980s originating in the United Kingdom and the United States through former Prime Minister Margaret Thatcher and former United States Ronald Reagan's policies respectively (Levitas, 1998). Neoliberalism has directly influenced globalization and Western societies through how goods and services are

distributed (Levitas, 1998). Neoliberalism and Capitalism have had major influences on the day-to-day lives of citizens living in Western societies, such as Australia (Levitas; Whiteford, 2010). Whiteford (2010) suggested that such less visible contexts continued to exist today and are directly influenced by “the degree to which the ideology of the group in power affects control of the market” (p. 145). In doing so, governments can create opportunities for participation and social inclusion depending on their political ideologies, or can subjugate such opportunities in preference for other political needs which may not necessarily be for the benefit of all. Citizens living with disability in Australia are at the forefront of power imbalances and a lack of recognition arguably as a result of the continuation of Neoliberal and Capitalist ideologies masked under third way politics (Buckmaster & Thomas, 2009). Therefore, ‘occupational deprivation’ (Whiteford, 2000) may result from such political ideologies. Whiteford (2000) defined occupational deprivation as

“...a state in which a person or group of people are unable to do what is necessary and meaningful in their lives due to external restrictions. It is a state in which the opportunity to perform those occupations that have social, cultural and personal relevance is rendered difficult if not impossible” (p. 200).

In this context, social inclusion for people with disabilities may be a utopian goal, as preclusion from meaningful and purposeful occupational participation may exist due to factors outside of one’s control (Whiteford, 2000; 2004; 2010). In relating historical conceptualisations of justice (and injustice), justice will now be explored from an occupational perspective.

#### Occupational rights and occupational justice.

Historically, sociologist T. H. Marshall’s theory of citizenship which developed in the 1950s increased knowledge generation of the three key elements of what it meant to be a full citizen in society; those being civil rights, political rights and social rights (Kim, 2010). Enabling citizenship and justice in its various forms has led to having the freedom to participate and contribute to society. However, I contend that to enable full participation, another rights-based element for social inclusion is required to compliment Marshall’s theory. As the empowering

nature of occupation and its relationship to promote health and wellbeing are understood (Wilcock, 1998, 2006, 2007), ‘occupational rights’ (Hammell, 2008; Townsend & Wilcock, 2004a, 2004b) can add to Marshall’s theory of citizenship and act as the missing link to explain and reason how we engage and participate through doing in its broadest sense to achieve social inclusion and a sense of belonging. As previously discussed, ‘doing’ from an occupational perspective is beyond its ‘objective’ connotations such as walking to the local park or cycling. ‘Doing’ includes ‘being in doing environments’ (Van’t Leven & Jonsson, 2002) leading to becoming and belonging as stipulated by Wilcock (2006). In their study of 10 residents in an aged care facility in the Netherlands, Van’t Leven and Jonsson discovered that residents described being in a doing atmosphere could as fulfilling the same or similar occupational needs and expressions compared to ‘objective’ doing. This study expanded the theoretical and real-life practical development of performance or participation in occupations as a phenomenon and further justified the statement that one does not need to be physically active to participate in occupations (Miller Polgar & Landry, 2004). Therefore, lack of occupational opportunities, resources and/or capabilities for participation could lead to being at risk of marginalisation and social exclusion (Pereira & Whiteford, 2010). Researching how occupational justice and occupational rights have a role to play in an ‘inclusion-as-a-right’ discourse (Lombe & Sherraden, 2008) is paramount to shaping crucial understandings of the experience and description of power relations and subjugations. They can also assist in exploring the issues of privilege and limited political action propagated towards disadvantaged Australian citizens such as those who experience poverty and disability. Further, occupational rights and occupational justice have the potential to enable the views and expressions of marginalised citizens to be adopted through the social policy making process. The following section of the literature review applies occupational justice in the context of social inclusion and participation.

## Occupational justice and social inclusion.

As previously mentioned, occupational science, or the study of humans as occupational beings (Wilcock, 1998, 2006), proposed that participation in ‘occupations’ is central to human existence and survival through an innate need to ‘do’ (Townsend, 2003; Wilcock, 1993). In contrast, being deprived of doing through factors outside of one’s control can be detrimental to one’s health and quality of life (termed ‘occupational deprivation’; Whiteford, 2004b). This is an example of an occupational injustice and directly impacts on an individual’s right to occupation (Hammell, 2008). Townsend has stipulated that

“enabling, participatory, client-centred approaches are the basis of empowerment for oppressed or marginalised people; therefore, we recognise and need to make public that occupational injustices occur when participation in daily life occupations is: barred, trapped, confined, segregated, restricted, prohibited, undeveloped, disrupted, alienated, imbalanced, exploited, deprived, marginalised, or segregated. In other words, if we start from an occupational perspective, and we value enabling over arrogant expert-driven approaches, we discover a new language and ideas for making injustices that occur in everyday occupations visible and conscious”.

Dr Elizabeth Townsend from Canada along with prominent Australian occupational scientist, Dr Ann Wilcock, first coined the term ‘occupational justice’ due to the need to address occupational injustices at the macro-(population) and sociopolitical levels in the hope of an ‘occupationally just’ world (Townsend & Wilcock, 2004a, 2004b).

Occupational justice principles focus on “recognizing and providing for the occupational needs of individuals and communities as part [of] a fair and empowering society” (Wilcock & Townsend, 2000, p.84). Without occupational justice, Wilcock and Townsend conceded that “...the interpersonal interactions, communities, and the world [could] experience inequalities which touch the very essence of living” (p.84). The capacity of exploring macro-level issues and how they related to doing and participation is relatively untouched territory in occupational science research requiring critical examination (Pereira, 2009).

Since the 1990s, occupation has been attributed as also being a political issue (Hammell, 2008; Law, 1991; Kronenberg & Pollard, 2005). Despite an evolving political discourse on enabling occupation, issues of poverty, marginalisation and oppression in Western democracies

such as Australia remain as major social problems. Several occupational science and therapy scholars have called for the need to critique and further develop health and social policy through an occupational lens, leading towards advocacy, change and agency spanning across individual, community and sociopolitical levels (Galvaan, Mdlokolo & Joubert, 2010; Nilsson & Townsend, 2010; Pereira, 2008, 2009; Pollard, Sakellariou & Kronenberg, 2009; Rose, Cocks & Chenoweth, 2010; van Bruggen, 2010; Wilcock, 2007; Whiteford, 2000). If social inclusion is considered from a human rights perspective (Labonte & Sherraden, 2008), so too can occupation be considered in a similarly critical light. In context, Townsend and Wilcock (2003) and Hammell (2008) have explored such critical discussions through their scholarship on occupational justice, promoting the need for occupational rights in distinct ways. Hammell defined occupational rights “as the right of all people to engage in meaningful occupations that contribute positively to their own well-being and the well-being of their communities” (p. 62). In recognising occupation and occupational rights as a political issue to drive occupational therapy’s contribution to humanity, Hammell critiqued Wilcock and Townsend’s (2004) four manifestations of occupational injustice: occupational alienation, occupational deprivation, occupational marginalization and occupational imbalance. In naming these four manifestations, Wilcock and Townsend outlined four occupational rights to combat occupational injustice: “to experience occupation as meaningful and enriching”, “to develop through participation in occupations for health and social inclusion”, “to exert individual or population autonomy through choice in occupations”, and “to benefit from fair privileges for diverse participation in occupations” (p. 80). Although Hammell acknowledged the importance of “this wealth of terms” (p. 62), she contested that they added to further confuse occupational therapists due to the common accounts of struggles with defining their role to colleagues and consumers (i.e. Wilding & Whiteford, 2008, 2009) as well as “lacking in distinct parameters” (Hammell, p. 62). Nevertheless, the theoretical principles of occupational justice and occupational rights have had a wave of epistemological and ontological development in knowledge synthesis and generation, especially in developing, non-Western communities, known as the ‘majority world’ (Kronenberg, Simó Algado & Pollard, 2005; Thibeault, 2006).

Others have also articulated that occupation was a right, not a lifestyle choice (Harrison & Sellers, 2008).

### Occupational deprivation.

A key occupational injustice that is critically explored in this thesis is occupational deprivation. Originally framed by occupational scientist Dr Ann Wilcock (1998) in context with how people are not granted equitable opportunities for participation in personally meaningful occupations, occupational deprivation was originally coined as “the influence of an external circumstance that keeps a person from acquiring, using, or enjoying something” (p. 145). Following further inquiry into such a phenomenon, Whiteford (2000) later defined occupational deprivation “a state of preclusion from engagement in occupations of necessity and/or meaning due to factors that stand outside the immediate control of the individual” (p. 201). In the second edition of her book detailing an occupational perspective of health, Wilcock (2006) expressed occupational deprivation to not only impact on individuals but also upon communities as well: “[occupational deprivation is] deprivation of occupational choice and diversity because of circumstances beyond the control of individuals or communities” (p. 343). Considering such conceptualizations, the crux of occupational deprivation is bound by “something or someone external to the individual [group or community] is doing the depriving” (Whiteford, p. 201).

An example of interest to this thesis is the occupational deprivation and social exclusion of citizens living with disability in Australia. Commissioned by the Australian Government, the ‘Shut Out’ report (National People with Disabilities and Carer Council, 2009) which detailed rich narrative accounts which uncovered some of the structural and cultural barriers which limited the participation, social inclusion, self-worth, self-esteem and a sense of belonging for hundreds of Australian citizens living with disability and other forms of disadvantage. Whiteford (2004) suggested that attitudinal barriers were a major restricting factor inhibiting citizens’ community participation and general day-to-day participation in occupations. Applying the case of people living with physical chronic illness, Whiteford suggested that “stereotyped perceptions, limited



expectations, and subtle marginalization all served to constrain people who have chronic physical illness or physical disability from accessing and fully engaging in occupations of meaning and choice” (p. 236). This premise was echoed by Farrell and Bryant (2009) with reference to social inclusion and mental health. From their perspective, for the process of social inclusion to become a seamless reality, a fundamental shift needed to occur in how society perceived disability, marginalization, deprivation and opportunity (Farrell & Bryant). Perceived negative societal attitudes precluding participation and inclusion needed to be accepted, owned, dismantled and adapted to enable participation and social inclusion as well as being a shared social responsibility (Farrell and Bryant).

#### Participation and social inclusion.

This review thus far has analysed social inclusion from political, theoretical and occupational perspectives. Politically in Australia, social inclusion is considered as a process for people to participate in the life of the society through working, being educated, engaging and having a voice (Australian Social Inclusion Board, 2010). This next explores how participation is conceptualised from occupational science, occupational therapy and disability studies literature to provide context for further discussion and appraisal of social inclusion as it has been described in Australian political discourse. Firstly, descriptions of participation and social inclusion have been used synonymously in the political arena. In this section, I challenge and critique this false dichotomy from an occupational perspective through delineating and exploring the meaning ascribed to ‘participation’ in its broadest sense beyond its common relationship with economics and work as suggested across Western policy discourses on social inclusion (Christiansen & Townsend, 2010). This section further unravels how, what, when, where and why occupations are engaged in, termed ‘enabling [or hindering] occupation’ (Canadian Association of Occupational Therapists, 1997), which is how ‘participation’ has evolved from an occupational perspective and why it is of keen critical and practical interest for the discipline of occupational science and profession of occupational therapy respectively.

Miller Polgar and Landry (2004) suggested that it was not sufficient to understand that a person or community just does something. Participation encompasses and "...explores what they are doing, why they are doing it, and what it brings to their lives, individually or collectively" (p. 198). The complexities of participation and engaging in occupations that citizens want to, need to and have to do as well as forced occupations or oppressive occupations add to how people understand human behaviour (Miller Polgar & Landry). Townsend (2003) related the concept of participation as being "at the core of occupational justice", where power was shared, people collaborated with each other, and avenues for cooperation were sought rather than being bound by power hierarchies. Such hierarchies significantly influence the occupational possibilities (Laliberte Rudman, 2010) which support or hinder participation.

In a recent critical review of occupational therapy literature on participation published between 2004 and 2006, Vessby and Kjellberg (2010) determined that there were three main categories which identified how participation was used and conceptualised theoretically and in practice: client-centredness, involvement in the environment and meaningfulness. Of the 38 papers that were chosen for content analysis, 23 of them expressed the importance of the subjective, intrinsic experience of participation (as framed under 'meaningfulness'). In this sense, participation reflected people's engagement in occupations that were valued and personally meaningful (Vessby & Kjellberg). Furthermore, the subjective experience that occurred during participation in occupations was described as being connected with the ability to do the things that one wanted to do (Vessby & Kjellberg). This included doing with others such as with friends and being involved in the community (Anaby, Miller, Eng, Jarus & Noreau, 2009, 2011; Borell, Asaba, Rosenberg, Schult & Townsend, 2006; Glass, Mendes de Leon, Marottoli & Berkman, 1999; Levasseur, Richard, Gauvin & Raymond, 2010; Pereira & Stagnitti, 2008). The final of the three categories of participation, being connected with the environment, or more specifically, involvement in the environment, was also an outcome of the critical review (Vessby & Kjellberg). The environment provides context for, and dynamically influences, participation in occupations (Desrosiers, Wanet-Defalque, Témisjjan, Gresset, Dubois, Renaud et al., 2009; Hammel, Magasi,

Heinemann, Whiteneck, Bogner & Rodriguez, 2008; Law, Cooper, Strong, Stewart, Rigby & Letts, 1996; Letts, Rigby & Stewart, 2003; Rebeiro, 2001; Strong, Rigby, Stewart, Law, Letts & Cooper, 1999; Whiteford & Wright-St Clair, 2005). Law (as cited in Chapparo & Ranka, 2005) defined the environment as including “physical, social, political, economic, institutional, cultural and situational contexts” (p. 61) that enable or hinder participation. From this perspective, environmental barriers to participation can include having little money, limited transport options, physical difficulties for access and limited social networks which may or may not contribute to other health and/or social concerns (Vessby & Kjellberg).

Some people living with mental illness for example have described similar issues such as physical limitations, lack of finances and lack of transport as their main barriers to participating in leisure occupations (Pieris & Craik, 2004). They also suggested that the main enabling factor for participation was having a network of supportive people to assist with facilitating opportunities for meaningful leisure participation (Bejerholm, 2010; Pieris & Craik). Therefore, the environment can either hinder or promote participation (Milner & Kelly, 2009). From an occupational science perspective, Townsend, Dale Stone, Angelucci, Howey, Johnston and Lawlor (2009) viewed environment as ‘place’, adding that it encompassed “a complex interplay of features such as culture, economics, geography, organization, and policies that govern occupational experiences and social inclusion” (p. 54). Similar to the framing of the ‘Person-Environment-Occupation’ (PEO) model which perceives the person, their environment(s) and occupations as dynamically interacting and transacting over time and space (Law et al., 1996; Strong et al., 1999), Townsend and colleagues also acknowledged that people and the occupations which they engage in are not separate entities to place. Rather, such engagement in occupations, or participation, is shared in context with place (symbiotic relationship; Townsend et al.). Therefore, for successful participation to occur, an enabling place requires a fair balance between governing powers for the benefit of the engager, or doer.

Vessby and Kjellberg’s (2010) timely paper demonstrated how participation can be conceptualised across personal, environmental, sociocultural and contextual levels including both

micro (personal) and macro (environmental) perspectives (Pereira, 2009; Taket et al., 2009). To date, there has been a significant lack of critical understanding of the subjective experience of participation in policy development, social science literature as well as in popular international health charters which have influenced world reform despite best practice recommendations and recent calls for action (i.e. Hemmingsson & Jonsson, 2005; Parnell & Wilding, 2010; Shergold, 2009). Further, there is a paucity of research which has explored the lived experience and participation realities of citizens living with entrenched disadvantage characterised by poverty, disability and other psychosocial issues.

In her paper on participation and occupation, Desrosiers (2005) referred to participation as

“...the accomplishment or engagement in daily activities and social roles resulting from the interaction between the individual’s characteristics (personal factors/identity such as age, gender, education) and the individual’s organic system and capabilities and the components of his/her life milieu (environmental factors) that modulate the accomplishment of valued occupations” (p. 196-197).

In this context, social roles related to activities which are carried out in society generally required for development and well-being (Fougeyrollas et al as cited in Desrosiers). According to Desrosiers, Wanet-Defalque, Témisjian, Gresset, Dubois, Renaud and colleagues (2009), “...participation goes beyond activities or roles that are done in society and includes daily activities that are required to interact well with others [encompassing what one needs, wants and has to do]” (p. 1228). Such a description of participation acknowledges its multidimensional nature and complexity incorporating both objective and subjective constructs. Importantly, subjective approaches referenced to person-perceived or intrinsic participation consider a person’s life experiences and preferences as opposed to how participation can be objectively considered from the outside or objective perspective (Desrosiers et al.). Anaby et al. (2011) further supported the importance of the meaning that participation ascribes to the engager or doer which was evident in their study of wellbeing amongst 200 Canadian older adults living with chronic conditions. Anaby et al.’s study determined that satisfaction with participation (subjective experience) was more important than the accomplishment of activities (physical, or objective doing). Anaby et al. concluded that the subjective experience (satisfaction) of participation was

the key factor that mattered most for wellbeing compared to the performance itself. Anaby et al.'s findings provided empirical support for previous studies which explored the subjective meaning of, and performance in, occupational participation for citizens living with disability and chronic illness (Levasseur, Desrosiers & Noreau, 2004; van Campen & Iedema, 2007). Therefore, participation and its importance is broader than what can be objectively viewed from an outsider's perspective.

In their comprehensive focus group study consisting of 63 people of adult age who identified themselves as living with disability across Illinois and Minnesota in the United States, Hammel, Magasi, Heinemann, Whiteneck, Bogner and Rodriguez (2008) gained insider perspectives of the lived experience of disability and how the participants characterised and conceptualised participation, including its barriers and enablers. The main theme areas as expressed by the participants in the study involved sets of participation values which included the main value of having respect and dignity followed by having choice and control, being meaningfully engaged, having personal and societal responsibility, being socially included and connected, having access and opportunity and finally having an impact and supporting others. Participation was conceptualised as a "multifaceted, transactive process" (Hammel et al., p. 1458) for a majority of the participants, involving interaction with and within the environment in context. This description was consistent with Law's definition of what constitutes an environment (as cited in Chapparo & Ranka, 2004) as well as with the 'Person-Environment Occupation (PEO)' model (Law et al., 1996; Strong et al., 1999). Finally, participants in Hammel et al.'s study not only engaged in personally meaningful occupations, but also desired to contribute to the broader community and society, emphasising participation as a human right as well as acknowledging that they also required support for participation on occasion.

Participation as a human right was also highlighted in Hammel et al.'s (2008) study as being important due to acknowledging that equity of access, respect and opportunity were enablers of social inclusion beyond participation. Together with findings from studies grounded in participatory action research on meanings of participation, this study also described participation

as a personal and societal responsibility, bound by the values of determination, advocacy and empowerment (Hammel et al.). Participants also acknowledged that participation was a means to experience social connectedness with people and their communities. Instead of showcasing particular occupations that enabled social inclusion per se, participants highlighted and ascribed value to social interdependence (doing, being and belonging with others), being a valued, productive and contributing member of society, having choice, control as well as having the freedom to pursue participation opportunities in enabling environments. One of the participants in Hammel et al.'s (2008) study poignantly stated:

“I have a problem with people that don't have disability making rules and stuff for people with disabilities...I think there is a big gap with the able-body community and the disabled community because they – the people like the politicians... they can sit up there and make rules and cut this and cut that for us, when they don't know nothing about us...I think there is a lack...where we are all working together to try to let people know what our needs are” (p. 1451).

## **Relevance of an occupational perspective of social inclusion to marginalised populations:**

### **A focus on citizens living with poverty and disability**

“The world of disability is a socially constructed domain of exclusion and reflects persisting societal bias” (United Nations, 2010). Twenty percent of Australia's population experiences a level of disability, with major disparities existing for participation outcomes within certain groups and communities nationwide (ABS, 2006, 2010a, 2010b). Such levels of disability range from requiring a hearing aid to needing significant assistance to carry out one's everyday occupations (Hasselkus, 2006, 2011), such as getting out of bed, showering, dressing and feeding (ABS). Of this group of citizens, 6.3 percent experienced profound difficulties with self-care, communication or mobility (ABS). Having a disability or chronic illness, may impact on social inclusion as well as many different life roles, participation in occupations and other life transitions. Disability is conceptualised as “the inability or limitation in performing socially defined activities and roles expected of individuals within a social and physical environment as a result of internal or external factors and their interplay” (Christiansen & Baum, 1997, p. 594). A

chronic illness, on the other hand, is defined as any health condition or disorder that persists over a long period of time and affects physical, social, emotional, intellectual or spiritual functioning (Mosby's Medical, Nursing, & Allied Health Dictionary, 2002).

Exclusion for people with disabilities and chronic illnesses is considered to be associated with limited opportunities, occupational deprivation (Whiteford, 2000) and other forms of occupational injustice (Townsend & Wilcock, 2004a, 2004b; Wilcock, 1998; 2006). Limited opportunities extend beyond labour force participation to include prejudice and discrimination, inadequate public support, greater likelihood of living alone, social rights not being realised or upheld as well as a multiplicity of other factors. Despite research which strongly promotes a positive shift towards a culture of inclusion and justice at the local, community and societal levels (Bach 2002; 2005; Lombe & Sherraden, 2008; Morrison, 2010; Saloojee, 2001; 2005; Smith, 2010), legal, legislative and political contexts continue to take effect on limited opportunities (Barbara & Whiteford, 2005; Stadnyk, Townsend & Wilcock, 2010; Whiteford, 2010). This is particularly true in Australia, as people living with disability are less likely to work in paid employment, are more likely to be a recipient of, and dependent on, income support (i.e. Disability Support Pension) and are more likely to live below the poverty line (National People with Disabilities and Carer Council, 2009; Palmer, 2011; Wilkinson-Meyers, Brown, McNeill, Patston, Dylan & Baker, 2010).

Lombe and Sheraden (2008) further exclaimed the impact of missed employment opportunities for citizens living with disability. They expressed that a common element impacting on occupational justice and the social inclusion for people who consider themselves as marginalised, oppressed, deprived and disadvantaged, “is weak or absent attachment to the labor market, which, in an income-driven society [such as in Australia and many developed nations], is a major impediment to full social, economic, and political integration” (Lombe & Sherraden, p. 202). With regards to impacts on work and social inclusion, for people of working age (15-64 years of age in Australia), many structural and sociocultural barriers exist when considering labour force participation among people with disability and/or chronic illness (ABS, 2010a,

2010b; Australian Institute of Health and Welfare, 2008). Not only are age and disability exponentially related. So too exists discrepancy between the significantly low amounts of people with disabilities in paid employment compared to people without a disability or defined chronic illness (Australian Institute of Health and Welfare; Jan, Essue & Leeder, 2012; Wilkinson-Meyers et al., 2010). As previously described, living in an income-driven, capitalist society inherently framed by neoliberal ideologies on both sides of government (left and right) undoubtedly is inhibited by the realities of Levitas' (1998) three social exclusion discourses (SID, RED, MUD).

In Australia, the General Social Survey conducted in 2006 identified that five percent of citizens aged between 18 and 64 years experienced three or more types of disadvantage, expressed by the Australian Government as 'multiple disadvantage' (Department of the Prime Minister and Cabinet, 2009a). The types of disadvantage were categorised under three broad areas: economic (i.e. no access to funds in emergency situations; living in a jobless household), personal (education attainment below Year 10 level; poor subjective wellbeing and self-assessed health status) and social (unable to seek help or additional support during a crisis) (Department of the Prime Minister and Cabinet). In the developing social inclusion political discourse, 'multiple disadvantage' was later expressed as 'entrenched disadvantage' (Australian Social Inclusion Board, 2010) to more accurately describe the interconnected, highly complex and non-discrete nature of disadvantage. Therefore, entrenched disadvantage can be described as including a complex combination of low income and assets, low skills, difficulties finding and keeping a job, housing distress, poor health and other social issues (Australian Social Inclusion Board; Department of the Prime Minister and Cabinet 2009a). Other factors can include disability, discrimination and mental illness (Australian Social Inclusion Board; Department of the Prime Minister and Cabinet). A stark reality about entrenched disadvantage in Australia, is that one in five Australians are considered to be at risk of poverty (Australian Social Inclusion Board). One in eight people also lived in households with high financial distress, despite Australia's high standard of living compared to other Western democracies (Department of the Prime Minister and Cabinet). Citizens living with disability were also considered as a marginalised



group who are more prevalent to multiple disadvantage (Department of the Prime Minister and Cabinet).

Entrenched disadvantage is salient towards an understanding of poverty in an Australian context. As previously suggested, there is a paucity of critical occupational science research which has explored the lived experience of poverty in conjunction with living with other forms of entrenched disadvantage, such as disability and other social issues. There are numerous research studies published in occupation-based disciplines (Phelan & Kinsella, 2009; Sellar, 2012) which have highlighted the occupational realities of living with disability, but have not taken into account matters of poverty commonly associated with disability and other social issues as portrayed in national statistics and government reports (i.e. Australian Social Inclusion Board, 2010; Department of the Prime Minister and Cabinet, 2009a). This thesis specifically tackles this chronic gap in social and occupational science literature by exploring the life histories of Australian citizens living with entrenched disadvantage characterised by poverty and disability.

Research conducted by the Australian Council of Social Services (ACOSS, 2010) defined poverty as

“a relative concept used to describe the people in a society that cannot afford the essentials that most people take for granted. While many Australians juggle payments of bills, people living in poverty have to make difficult choices – such as skipping a meal to pay for a child’s textbooks...‘Poverty’ refers to people living in relative poverty: those whose living standards fall below an overall community standard. People living in poverty not only have low levels of income; they also miss out on opportunities and resources...such as adequate health and dental care, housing, education, employment opportunities, food and recreation” (p. 1).

In their 2010 report on poverty in Australia, ACOSS identified five causes of poverty. They stipulated that poverty is caused by significant inequalities that are a feature of Australian society, and stem from issues with access to (1) work and income, (2) education, (3) housing, (4) health services, and (4) other social services and institutional supports. ACOSS (2012b) clarified that in Australian and international research on poverty, the *poverty line* [emphasis added] for a single adult is usually calculated as a proportion of the disposable income of a ‘middle income’ (median) household – in this case 50% and 60%” (p. 6). More recently, ACOSS produced their latest

report about poverty in Australia, which highlighted the following statistics:

- The poverty line (50% of median income) for a single adult was \$358 per week, for a couple with 2 children it was \$752;
- 2,265,000 people (12.8 percent of all people) were living below the poverty line, after taking account of their housing costs;
- 37 percent of people on social security payments lived below the poverty line including 52 percent of those on Newstart Allowance...[and] 42 percent of those on Disability Support Pension;
- 62 percent of people below the poverty line had social security as their main income and 29 percent had wages as their main income;
- The level of poverty was 12.6 percent in capital cities compared to 13.1 percent outside capital cities, and
- The proportion of people in poverty rose by approximately one third of a percent from 2003 to 2010 (p. 6).

Many who also experience disability or chronic illness have a higher probability that they will experience entrenched disadvantage and end up as a statistic (Ahern & Hendryx, 2005; Australian Bureau of Statistics, 2010; Australian Institute of Health and Welfare, 2009; Carr & Klaber Moffett, 2005; Glover, Hetzel & Tennant, 2005; Murphy, Murray, Chalmers & Marston, 2011). A study commissioned by the Melbourne Institute of Applied Economic and Social Research using data from the 'Household, Income and Labour Dynamics in Australia' (HILDA) survey demonstrated that for Australian citizens of working age, 30 to 40 percent of Australians experienced 'marginal exclusion', 4 to 6 percent were classified as 'deeply excluded' and 1 percent were considered as 'very deeply excluded' (Scutella, Wilkins & Kostenko, 2009). Such figures were calculated by the number of disadvantages citizens experienced as well as the length of time experienced in such areas of disadvantage (Scutella et al.; Smyth, 2010). Many citizens would also experience one dimension, or one type of disadvantage only, classified by Scutella et al. as

‘shallow exclusion’. As the statistics highlighted above indicate (ACOSS, 2012b), critical occupational science research is significantly required which highlights the effects of policy such as Australian social inclusion policy on the everyday realities of citizens, complimented by narrative research which provides an in-depth exploration into the existential realities of citizens living with poverty, disability and other entrenched disadvantages.

The Rudd and Gillard Labor Governments in Australia recognised living with socioeconomic disadvantage, such as being the recipient of a pension or living with low income, together with living with disability or poor health, as major disadvantages impacting on poverty risk (Department of the Prime Minister and Cabinet, 2010). Glover, Hetzel and Tennant (2004) suggested that any policy intervention that addressed the impact of disability, chronic disease and illness needed to take into account *socioeconomic inequalities* at a population level. To date, there has been a dearth of research that has attempted to investigate the needs of citizens living with entrenched disadvantage in Australia, such as the explicit link between socioeconomic disadvantage, poverty and disability (CSDH, 2008; Marmot, 2005; Sinclair, 2005; van Kippersluis, O'Donnell, van Doorslaer & Van Ourti, 2010; Wilcock, 2006; World Health Organisation [WHO], 2011). Moreover, research conducted to date has taken a macro and objective investigation into the quantity of people ‘classified’ as having ‘socioeconomic disadvantage’ and disability (i.e. Ahern & Hendrix, 2005; Glover et al., 2004; Walker, 2007; Walker & Peterson, 2003). Research exploring the entrenched disadvantage inclusive of issues related to poverty, socioeconomic disadvantage and disability is therefore of key importance to changing Australian social demographics requiring just policy for meeting citizen’s occupational needs. In addition, research uncovering potential injustices in policy from a critical occupational science perspective (Hocking & Whiteford, 2012; Whiteford & Hocking, 2012) into the experiences of entrenched disadvantage is scarce in social science literature, although similar reviews in policy analysis and critical social theory have been explored from other perspectives, such as in social work literature (i.e. Gould, 2006; Morris, Barnes & Balloch, 2009).

## Summary

This literature review has explored social inclusion from several perspectives. As it is inherently a political term, the review commenced with a focus on the socio-political history and origins of social inclusion. It then explored the various tensions and dilemmas that currently exist in attempting to define it. Social inclusion was highlighted as a multidimensional construct, involving it being conceptualised as a ‘process’ and ‘outcome’ across several different discourses including poverty, economics, rights and advocacy. Various scholars attempted to frame social inclusion from humanistic perspectives to drive policy agendas to create cultures of inclusion. This review explored the major theories that exist across political philosophy, economics and sociology to express intrinsic and political drivers for social inclusion as well as what it means to be an included and recognised citizen. It then framed social inclusion from an occupational perspective, introducing occupational science discourse and the relevance of adopting a critical occupational lens on matters of occupation, participation and inclusion. Finally the review outlined the realities of entrenched disadvantage in Australia, focusing on the needs of citizens living with poverty, disability and other complex social issues.

The literature reviewed in this chapter has guided the need for a research agenda to explore and critique the relatively new policy discourse of social inclusion in Australia from a critical occupational science perspective (Hocking & Whiteford, 2012; Whiteford & Hocking, 2012; Whiteford & Townsend, 2011). There is a need for critical analysis due to the *uncritical manner* in which social inclusion discourse has been introduced and received in Australia (Edwards, 2010). In light of this, Edwards warned that policies promoting a social inclusion agenda were “not an *automatic* good and should not be adopted *uncritically*” (original emphasis, p. 23).

There currently exists a dearth of research into social inclusion policy analysis from an occupational perspective. Together with this gap in social and occupational science research, there also exists a paucity of narrative research into the lives of people living with poverty, socioeconomic disadvantage and disability. This thesis explores both needs through reporting the

findings and the synthesis of two linked studies which respectively documented a critical discourse analysis of Australian social inclusion policy, as well as a life history study. The life history study explored the lived realities of occupation, participation and inclusion of seven citizens living with entrenched disadvantage in Western Sydney. In Chapter 3, the methodology of the research studies are outlined prior to four chapters dedicated to displaying the findings of both studies.

## Chapter Three

### Methodology

The previous chapter presented a review of the literature into the sociopolitical history and conceptual meaning of social inclusion, including how it can be viewed from an occupational perspective incorporating issues such as justice, empowerment and entrenched disadvantage. This chapter presents the methodologies and methods employed to explore the studies described in this thesis. It also introduces the purpose of the research and outlines the research questions that guided the investigation. Following a general introduction into the qualitative orientation which informed both studies, the chapter is then divided into two sections (Part 1 and Part 2 respectively) to separate and clearly describe each of the methodologies used in the studies. The theoretical approaches to the methods which guided data interpretation are elucidated, and processes related to participant recruitment and interviewing are presented in detail. Further, the data analysis processes employed relative to each distinct method are described, and the study limitations, authenticity and uniqueness are also discussed. Finally, the chapter concludes by explaining how the findings are presented, including an introduction of study participants and a reflexive statement of my stance as a researcher.

#### Purpose of the research.

As indicated in the previous chapter, this thesis had two main foci. Due to the historically recent introduction of social inclusion policy in Australia, the first purpose was to *critically* analyse the developing discourse of social inclusion and investigate how ‘participation’ was politicised and problematised by the Rudd Labour Government (November 2007 – June 2010). In this thesis, ‘critique’ does not adopt a negative connotation as it is occasionally perceived. The following passage about ‘critique’ by notable French philosopher, Michel Foucault, provided a

more challenging conceptualisation which guided the first focus of the research documented in this thesis:

“Critique is not a matter of saying that things are not right as they are. It is a matter of pointing out on what kinds of assumptions, what kinds of familiar, unchallenged, unconsidered modes of thought the practice that we accept rests” (Foucault, 1988, p. 154).

The second focus, or purpose of this research, was to explore the lived experience of entrenched disadvantage in Australia. This was pursued by investigating the experiential, in-depth perspectives and storied accounts of seven citizens who experienced the ‘entrenched disadvantage’ of *poverty* and *disability*, who lived in the socially disadvantaged local government areas (LGAs) of Blacktown and Parramatta in Western Sydney, New South Wales, Australia. This region is noted nationally as one of high deprivation (Vinson, 2007).

#### Research questions.

The literature review comprehensively highlighted the complexities of social inclusion and its direct relationship with entrenched disadvantage in Australia from occupational and demographic research perspectives. From this, several gaps within the literature became clearly evident. One gap involved the dearth of research that has critically analysed social inclusion policy in Australia from a critical occupational science perspective (Whiteford & Hocking, 2012). The other gap identified, pointed to a lack of understanding into the lived experience, occupational realities and complexities of entrenched disadvantage, characterised by poverty, disability and other social issues. The two research questions (which are explored through Part 1 and Part 2 in this chapter respectively) that were formulated provided a guide to investigate these studies through a critical lens. What was discovered through the systematic analysis of literature across several disciplinary discourses (ranging from occupational science to sociology and philosophy discourses), was clearly broader than the final questions chosen to explore through this research. However, questions formulated were chosen as they best represented an *occupational* framing able to span both policy analysis and existential issues emerging from lived realities of exclusion. In essence, such a framing provided a unique position from which to understand the

relationship between policy and lived experience, a framing often absent from numerous discourses, especially occupational science.

Both questions were distinct enough to warrant two distinct approaches: one for sourcing and analyzing formal *texts*, and the other for generating and analyzing stories. The first question addresses *texts* in the public domain which were formally adopted by the Rudd Government. As such, *texts* are discursively constructed, the question warranted a method which used specific *tools* to critically analyse the discursive constructions (Bacchi, 2009; Whiteford & Townsend, 2011). On the other hand, as personal accounts are more ‘immediate’, ‘informally’ constructed and not in the public domain, the method chosen to address the second question focused on respecting and validating the *essential holism* of their narrative complexities. Therefore, despite both questions being essentially interpretive in nature, they could not be comprehensively explored through the adoption of a single method.

The two research questions explored in these studies were:

1. How was ‘participation’ conceptualised and problematised in social inclusion policy whilst Australia’s Rudd Labor Government (November 2007-June 2010) was in power?
  - How did the policy aim to address the ‘social inclusion’ of citizens living with multiple disadvantage? What was the ‘problem’ represented to be? (Bacchi, 2009),
  - To what extent did the policy enable or constrain participation?,
2. What are the experiential perspectives of citizens living in poverty with disability? And, as a corollary to the above,
3. To what extent does social inclusion policy in Australia address everyday realities for people at risk of exclusion because of poverty and disability?



Qualitative research and its application to research into entrenched disadvantage from a critical occupational science perspective.

Several publications focused on national statistics (i.e. Australian Bureau of Statistics 2006, 2010; Australian Institute of Health and Welfare, 2009) as well as Vinson's (2007) landmark report into the demographics of geographically concentrated disadvantage in Australia, served as strong evidence which supported that entrenched disadvantage was a reality in Australia. Despite such quantitative accounts, there is a paucity of research that has addressed the impacts of entrenched disadvantage from a qualitative perspective employing critical, interpretive and non-positivist methods. Whilst quantitative research is important in developing statistical representations of entrenched disadvantage which can be used in guiding policy and funding recommendations for interventions 'on the ground', it does not allow for a comprehensive understanding of how entrenched disadvantage truly affects the lives and occupational experiences of those who make up the statistics.

Qualitative research was chosen as the overarching paradigm to guide this research as it allowed for in-depth research into experience, perception and action. Action is considered in context with *doing* and the impact of *doing* across people's lives as well as in the contexts that enabling, contrive or hinder their *doing*. In this thesis, 'paradigm' is understood as "a system of ideas, or world view, used by a community of researchers to generate knowledge. It is a set of assumptions, research strategies and criteria for rigour that are shared, even taken-for-granted, by the community" (Fossey, Harvey, McDermott & Davidson, 2002, p. 718). Occupational science researchers have identified that furthering the "...unique epistemological foundation of occupation...is best understood through naturalistic means" (Whiteford, 2004, p. 41). In other words, narrative approaches are considered central to research focusing on occupation (Josephsson, Asaba, Jonsson & Alsaker, 2006). Further, narrative approaches in qualitative research are requisite to understanding people's occupational experiences in context (Clark, Carlson & Polkinghorne, 1997). This is because occupation is highly complex in nature inseparable from the context in which it is experienced (Carlson & Clark, 1991; Whiteford, 2010).

As the overarching paradigm guiding this research, qualitative research specifically involves a naturalistic and interpretive approach to researching a particular topic or phenomenon (Denzin & Lincoln, 1994), and aims to “study things in their natural setting, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (Denzin & Lincoln, p. 2). Further, qualitative research incorporates a holistic perspective, preserving the complexities of human behaviour (Black, 1994). ‘Qualitative’ broadly describes various approaches, focusing on exploring people’s experiences and interpreting their ascribed meanings to such experiences in context (Greenhalgh & Taylor, 1997; Wicks & Whiteford, 2003). The philosophy of qualitative research is deeply rooted in the “value-laden nature of inquiry” (Wiseman & Whiteford, 2007, p. 109) to drive understanding into the meanings of life events. How phenomena are interpreted and ascribed value is further explored in the following section. The section introduces two discrete research approaches drawn from the overarching qualitative research paradigm which epistemologically guided the studies documented in this thesis.

#### Qualitative methods: An introduction to an ‘analysis of discourses’ (Bacchi, 2005) methodology.

Considering the theoretical approaches to this research as previously described, the first methodology applied to answer the first question, known as an ‘analysis of discourses’ (Bacchi, 2005), is influenced by epistemologically plural paradigms (Kinsella, 2012), such as critical social theory (Fook, 2002, 2003; Laliberte Rudman, 2013) social constructivism (Bacchi, 2005), feminism (Bacchi & Eveline, 2010) and poststructuralism (Bacchi, 2009; Foucault, 1980) among others. Being framed by critical perspectives in their own right, such frameworks provide examples about how topics such as inequity, injustice, prejudice, marginalisation and power relationships can be examined. Studies that have explored these frameworks have traditionally no more than expressed concern for such issues, rather than provide measures to ameliorate them through adopting a critical, reflexive and practical lens for justification or change (Whiteford & Townsend, 2011).

Therefore, the studies documented in this thesis utilised a combination of an analysis of

discourses (Bacchi, 2005) methodology together with exploring critical issues in social policy using the ‘Participatory Occupational Justice Framework 2010’ (POJF 2010; Whiteford & Townsend, 2011), giving a practical and occupational perspective. Briefly, the POJF has the potential to shape the analysis of political discourses specific to social inclusion through applying a “conceptual tool for doing justice...[guiding] knowledge translation and knowledge exchange about occupation, enablement, and justice” (Whiteford and Townsend, 2011, p. 65). The analysis of discourses (Bacchi, 2005) methodology was conducted through the ‘What’s the problem represented to be?’ approach (WPR approach; Bacchi, 2009), which was purposefully designed to analyse policy discourses through a critical and pragmatic lens. Data gathered from a combined analysis of social inclusion policy discourse informed by Foucauldian (Bacchi, 2009) and occupational justice approaches (Whiteford & Townsend), enabled a dense and multilayered critique of how power, privilege, marginalization and subjugation emerged through policy from multiple critical vantage points.

There were several benefits through using an analysis of discourses approach (Bacchi, 2005) in combination with the POJF 2010 (Whiteford & Townsend, 2011) in this research. One of the most important benefits was an inherent need for critical development of ‘occupation-focused methodologies’ to further occupational science epistemology and scholarship. Occupation-focused methodologies favour the exploration of occupational phenomena, human experiences and contextual influences from an occupational perspective. Occupation-focused methodologies are based on the assumption that a central goal of inquiry in occupation-based disciplines (Phelan & Kinsella, 2009; Sellar, 2012) is to understand and recognise the interpretations and meanings of occupational experiences that persons negotiate in context with socio-historic and socio-political contexts (Carlson & Clark, 1991).

The critical and in-depth study of occupation and participation from interdisciplinary perspectives through employing occupation-focused methodologies has the potential to create pathways of knowledge sharing and knowledge generation across several domains (i.e. healthcare; Metzler & Metz, 2010). Indeed, social sciences such as philosophy, sociology and politics share

epistemologies and ontologies with occupation-based disciplines (Phelan & Kinsella, 2009; Sellar, 2012) surrounding the complexities of occupation, participation and inclusion (Pereira, 2010). Taket et al (2009) provided an example of such sharing of epistemologies and ontologies by exploring social exclusion theoretically and practically, paralleling with similar occupational terminologies such as occupational justice (Townsend & Wilcock, 2004a, 2004b), occupational deprivation (Whiteford, 2000), occupational marginalization (Wilcock, 1998) and occupational rights (Hammell, 2008). Therefore, the analysis of discourses methodology through utilising a WPR approach (Bacchi 2005, 2009) framed by Foucauldian-inspired and critical occupational science perspectives using the POJF 2010 (Whiteford & Townsend, 2011) were appropriate choices due to their practical and broad application to the aforementioned themes inherent in occupational science research.

### **Part 1: Answering the first question – Methodology for policy analysis**

In pursuing a critical analysis of policy to answer both parts of the first question in this research, the WPR approach (Bacchi, 2009) as a form of critical discourse analysis (Ballinger & Cheek, 2006; Laliberte Rudman, 2013), was the most appropriate methodology to apply. Prior to exploring the functionality of discourse analysis as a methodological tool, key elements of discourse analysis are defined.

#### Discourse and discourse analysis.

There are several ways of interpreting and understanding ‘discourse’ and its respective analysis within epistemologically plural discourses which can frame critical occupational science research (Kinsella, 2012). Social scientist and critical discourse analysis scholar, Norman Fairclough (2003), defined *discourse* as “particular ways of representing aspects of the world” (p.124). Such representations affect how language is understood and given meaning in context (Fairclough). From Fairclough’s perspective, discourses are not merely passive representations in context, but are “also projective, imaginaries, representing possible worlds which are different

from the actual world, and tied to projects to change the world in particular directions” (Fairclough, 2003, p. 124). Despite his relatively simplistic definition, Fairclough’s perspective of *discourse* successfully considers how language can be perceived depending on the context in which it is interpreted, or in fact, ‘experienced’.

From another postmodern perspective, political scientist Carol Bacchi (2009) described *discourse* as

“a group of related statements, signs and practices that creates the object/s and domains it purports to describe, giving those objects and domains status as ‘truth’ or ‘knowledge’. Discourse set limits on what it is possible to say or think about the object/s they create, though they can and do contain tensions and contradictions that open up spaces for challenge and change” (p. 274).

In an earlier paper about the conceptualization of discourse, Bacchi (2000) also noted a point of caution with providing it with a formal definition. She outlined that the *idea* of discourse plays “an important part in delineating ‘knowledge’. Because definitions have these effects, they require *scrutiny* [emphasis added], not replication” (p. 46). Discourses can be identified in various forms, such as in textual (i.e. professional reports, newspaper articles) and verbal communications (i.e. announcements, media, press releases; Powers, 2007). Discourses can also be located in wider social structures (i.e. how cultures are represented and perceived as a group, such as Hispanic, African-American or Indigenous; Powers).

As discourses are socially constructed and interpreted in context, they may be taken-for-granted or utilised to privilege and/or to subjugate. Therefore, through focusing on identifying *dominant* discourses and how they are applied, enacted and problematised (Bacchi, 2009), understanding them can be a way of challenging certain assumptions and understandings about the world. At the same time, discourse analysts can also highlight some of the consequences that such understandings produce (Edmunds, 2010). Ballinger and Cheek (2006) proposed that a main task of the researcher conducting discourse analysis “is to make explicit the ways in which discourses operate within particular contexts” (p. 202). In order to situate discourses in context,

‘power’ must be acknowledged as a key factor to consider. The next section explores this complex relationship.

#### Discourse analysis and power.

Discourse analysis inherently emphasises an analysis of power characterised within social relations (Foucault, 1980; Powers, 2007). French Philosopher Michel Foucault intimately explored the nexus between power and knowledge through a critical analysis of discourses (Ballinger & Cheek, 2006; Foucault). In such a nexus, Foucault situated power/knowledge through promoting both the ‘said’ or enabling discourses, as well as the ‘unsaid’ or excluded discourses (Ballinger & Cheek). As a tool specifically designed to analyse policy discourses from a critical research paradigm perspective informed by Foucault’s power/knowledge nexus, a WPR approach (Bacchi, 2009) enabled an in-depth exploration of dominant discourses represented through Australian social inclusion policy texts to identify both the said and *unsaid* surrounding discourses which both supported and hindered participation from an occupational perspective. A WPR approach to an analysis of discourses was the chosen methodology to answer the first question of this research as opposed to other discourse analytic methods, such as traditional critical discourse analysis (Fairclough, 2003) or a pure Foucauldian discourse analysis.

The critical discourse analytic method seeks to focus more on linguistic, dialogic or textual forms of analysis, where *discourse* is interpreted literally, analyzing how power relationships between dominant and non-dominant subjects through language as ‘systematic bodies of knowledge’, shapes the discourse and its effects (Powers, 2007). This is in contrast to a Foucauldian type of discourse analysis which can be multilayered and considers how discourses and knowledge are produced and shaped epistemo-historically through what is teleologically *known* (what Foucault termed *connaissance*; Scheurich & McKenzie, 2005), and how such knowledge came to be (what Foucault termed *savoir*; Scheurich & McKenzie) in the context of power structures. Recently, Laliberte Rudman (2013) stated that discourse analysis methodologies that interrogate social phenomena from a critical lens can be collectively considered as having the

key elements necessary to be classified as ‘critical discourse analysis’ (emphasis added). In order to prevent research from being caught up in semantics of one type of discourse analysis methodology or another, critical discourse analysis can instead be

“...constituted by a diversity of methodological approaches that go beyond analysis of linguistic structure and content of discourse to examine its productive effects and the ways in which it relates to broader power relations...[and is] neither a singular methodology nor a fixed method. Rather, each methodological approach to CDA [critical discourse analysis] is grounded within a theoretical framework regarding the nature of discourse and its relationships between discourse, knowledge, and power” (Laliberte Rudman, p. 173).

As has been suggested, ‘power’ is a topical concern in political discourses which can be explored through critical discourse analysis methodologies. It is also a foundational concept within Foucault’s sequential phases of thought (Motion & Leitch, 2007; Scheurich & McKenzie, 2005). Power is often considered as carrying “negative connotations of domination” (Motion & Leitch, p. 265). However, the exercise of power according to Foucault (1980) has both positive and productive implications:

“What makes power hold good, what makes it accepted, is simply the fact that it doesn’t only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms knowledge, produces discourse” (p. 119).

Foucault’s conceptualization of power demonstrated that it can be or become an agentic way to resist hegemonic practices, or *empower* individuals, groups and other institutions (Belzile, 2008). Belzile further argued that through Foucault’s ‘power/knowledge nexus’, individuals “can have power when they possess certain types of knowledge. This knowledge allows those who have it to exercise it” (p. 17). The following section introduces and explores Bacchi’s (2009) WPR approach including its direct Foucauldian influences, as well as describing why it was the most appropriate methodology to address the first research question of the studies described in this thesis.

### **Analysis of discourses: Bacchi’s (2009) WPR approach**

It is important to uncover the meanings ascribed to policies and how their foci are problematised and represented. Otherwise, policies would be implemented without the critical

considerations of the polity, leading to less democratic and transparent governance. Critiquing such problematisations is also an important aspect of policy analysis because they are assumed to function in discrete ways for governments and policy makers to achieve ‘solutions’ to identified ‘problems’ (Bacchi, 2009; Bacchi & Eveline, 2010). Further, how problematisations are represented matters to those who gain favourable outcomes, and to those who do not. Therefore, power plays a key role in determining who is a beneficiary of policy implementation, how they become known as a beneficiary, as well as identifying those who miss out. In occupational science and social science research, an understanding of the dynamics of power representations in policy-as-discourse (Bacchi, 2000, 2005), and in policy discourses such as ‘social inclusion’ in particular, is significantly limited. Bacchi’s (2005) *analysis of discourses* conceptualization for analysing policy discourses was chosen in favour of *discourse analysis*, as *discourse analysis* implies that only one type of discourse exists. Conversely, an *analysis of discourses* (Bacchi, 2005) approach highlights the array of discourses that exist simultaneously, including dominant and subjugated ones for critical examination and scrutiny.

#### Introduction to the WPR approach.

In social science research as described thus far, there are various philosophical tenets that guide which particular discourse analysis methods are chosen to explore and uncover power dynamics inherent in systematic knowledge about particular meanings or phenomena. As a global citizen and researcher, my interests in political advocacy and emancipatory practices influencing individual, community and societal issues, directed me towards discourse analysis tools which enabled me to uncover subjugation located within policy discourses. Therefore, the combination of Bacchi’s (2009) WPR approach and Whiteford and Townsend’s (2011) POJF 2010 were purposefully utilised to meet both my personal interests in eliciting oppressed truths, as well as a need for the critical analysis of dominant and subjugated discourses inherent in policy surrounding ‘social inclusion’ and ‘participation’ problematisations. The next section examines



Bacchi's WPR approach through introducing the predominant rationale for delineating how social policies are *problematized*.

Bacchi's (2009) WPR methodological approach to policy analysis.

"A WPR agenda has an explicitly normative agenda. It presumes that some problem representations benefit the members of some groups at the expense of others. It also takes the side of those who are harmed" (Bacchi, 2009, p. 44).

Bacchi's (2009) WPR methodology is a tool that can be applied to ontologically and epistemologically expand the research potential of critical occupational science through the exploration of macro influences on occupation, participation and inclusion in context with an occupational justice lens. This is one of the aims of this thesis. As a tool designed to critique and question underlying assumptions within political discourse, Bacchi's WPR methodology aims to empower marginalised individuals and groups targeted for policy intervention through promoting political accountability. In effect, political framings such as policies and other *texts* (i.e. political speeches and public releases) become the key discourses which are critically analysed. From Bacchi's (2000) perspective, analysing 'policy-as-discourse' holds the premise that "'problems' are 'created' or 'given shape' in the very policy proposals that are offered as 'responses' (p. 48). Therefore policies are intertwined with discourse and become the focus of scrutiny. Bacchi's WPR methodology explores the impact that policies as discourses have on individuals and other marginalised and oppressed groups, as well as the processes which may subjugate and subjectify them within current modes of governance (Bacchi; Cort, 2011). As previously highlighted in this chapter, Bacchi's unique methodology embraces epistemological pluralism (Kinsella, 2012) through its influences from other critical and theoretical frameworks.

Education researcher Pia Cort (2011) positioned Bacchi's (2009) methodological approach to policy analysis as "a post-structuralist, social-constructionist contribution to policy analysis" (p. 20). Importantly, what makes Bacchi's approach methodologically different from other forms of policy analysis which may analyse a policy's contents or make-up, development or outcome, is that it focuses on how 'problems' are represented in the policy (Cort). Central to Bacchi's WPR

methodology involves an analysis of a policy's problem representations, which include how they were constructed and rationalised, as well as exploring the assumptions and political, epistemological and historical contexts which may underpin such constructions (Bacchi, Cort).

As a tool specifically designed to analyse policy-as-discourse from a critical research lens (Bacchi, 2000; 2009), Bacchi's WPR methodology (2009) enabled an in-depth analysis of policy texts in this research which assisted in identifying and deconstructing both *said* and *unsaid* discourses by uncovering and critiquing issues of power, privilege, subjugation and hegemonic discourses which they contained. One of the main tenets of Bacchi's WPR methodology focuses on how 'problems' are framed and then enacted upon within policies. Such problematisations can have several affects depending on the 'three C's'. Problematisations are important to investigate as there can be significant ramifications from how they are *considered*, by policy makers and citizens; *conducted*, through policies towards citizens (or 'top-down' influences); or *concealed*, through direct or indirect subjugatory practices, where considerations for citizen engagement in the policy- and decision-making process is minimal or non-existent ('bottom-up' considerations).

Whether it be through exploring the consideration, conduct or concealment of discourses surrounding policies, Bacchi's (2009) WPR methodology offered a unique way to understand and reflect upon policy, its formation and intended action(s) in this thesis. Bacchi considered that policies understood 'problems' as particular sorts of 'problems'. As policies transcend government principles and practices in the pursuit of certain strategic outcomes (i.e. economic, political or social; Fawcett et al., 2010; Goodwin, 2011), governments in their very nature, create (or produce) policy 'problems' in their proposals for action, intervention or change (Bacchi). I have adopted Bacchi's following analogy for problem representations to contextualise her framing of a WPR approach to policy analysis: if police officers, for example, were sent out on a Saturday night 'in response' to reports of disorderly behaviour amongst revelers at nightclubs, one can imply that the 'problem' is a matter of inadequate security measures and excessive alcohol consumption and constituting it in such a way. Bacchi argued that

“...how the ‘problem’ is represented, or constituted, matters...because the way in which the ‘problem’ is represented carries all sorts of implications for how the issue is thought about and for how the people involved are treated, and are evoked to think about themselves” (p. 1).

Therefore, if a policy can be *constituted* as a ‘problem’, this idea not only adds a novel way to think about the “social construction of ‘social problems’” (Bacchi, 1999, as cited in Bacchi, p. 2), but also highlights the creative and productive role of the State (government) in “shaping particular understandings of ‘problems’” (Bacchi, p. 2), as well as its mentality in rationalising ‘problems’ to benefit its goals and objectives (Laliberte Rudman & Huot, 2013).

#### Goals, assumptions and propositions within Bacchi’s WPR methodology.

The goals of Bacchi’s (2009) WPR methodology are to (1) *problematise* or interrogate the problematisations in selected government policies, through scrutinising their premises and effects, and (2) “to intervene to challenge problem representations that have...deleterious effects, and to suggest that issues could be thought about in ways that might avoid at least some of these effects” (p. 44). Bacchi’s WPR methodology also makes the following assumptions relative to the policy analysis process: (1) some problem representations benefit some members of some groups at the expense of others; (2) it sides with marginalised individuals, groups and populations who may have been “harmed” (p. 44), and (3) rejects the idea that Capitalism or patriarchy explains everything that we need to know about exploitation and oppression. Bacchi’s WPR methodology also has three central propositions which scrutinise policy and demonstrate its critical lens: (1) we as citizens are governed through problematisations; (2) problematisations need to be studied and scrutinised by us as citizens through analyzing the problem representations that they contain, rather than ‘problems’ which assume ‘solutions’, and (3) we need to interrogate, or *problematise* the problematisations on offer through scrutinising the premises and effects of the problem representations they contained. Bacchi considered problematisations as “how something is put forward as a problem. Since policy proposals specify what needs to change, they are forms of

problematism, containing implicit representations of the character and causes of ‘problems’” (p. 277).

#### Bacchi’s six-question model for the analysis of policy-as-discourse.

Bacchi’s (2009) WPR methodology’s goals, assumptions and propositions which highlight the need to scrutinise problematisations through the analysis of problem representations and their effects on individuals, communities and populations, is more thoroughly expanded into a six-question model for policy analysis (method). In context with a WPR approach to analysing policies as discourses (Bacchi, 2000, 2009; Cort, 2011), and considering the power relationships inherent in how problem representations are discursively framed in policies, Cheek and Porter (1997) attested, “if we understand how power operates through the knowledge embedded within certain discursive frames [such as through a WPR and critical occupational science analysis of social policies], we are better placed to resist the unquestioning authority of such knowledge” (p. 111). The six interrelated questions which form the method and application of a WPR methodology to analyse policy-as-discourse (Bacchi, 2000) are shown in Table 2.

Table 2: Bacchi's (2009, p. 2, 48) six-question model for policy-as-discourse analysis.

Question	Guiding Description
<b>Q1</b>	“What’s the ‘problem’ (i.e. of ‘problem gamblers’, ‘drug use/abuse’, domestic violence, global warming, health inequalities, terrorism, etc.) represented to be in specific policy? See what the policy proposes and ‘read off’ the implied ‘problem’ from this proposal
<b>Q2</b>	What presuppositions or assumptions underlie this representation of the ‘problem’? This question involves a form of Foucauldian <i>archaeology</i> , identifying underlying conceptual logics and political rationalities in specific policies. Identify key concepts, binaries, and categories. Think beyond national and/or cultural boundaries to answer this question
<b>Q3</b>	How has this representation of the ‘problem’ come about? This question involves a form of Foucauldian <i>genealogy</i> , focusing on the practices and processes that led to the dominance of this problem representation (or of these problem representations)
<b>Q4</b>	What is left unproblematic in this problem representation? Where are the silences? Can the ‘problem’ be thought about differently? Cross-cultural comparisons and comparisons of problem representations over time (see Question 3) will be useful here, alongside the discourse analysis conducted in Question 2
<b>Q5</b>	What effects are produced by this representation of the ‘problem’? Consider three kinds of effects: discursive effects; subjectification effects; lived effects. Include effects due to dividing practices. The following sub-questions will assist here: What is likely to change with this representation of the ‘problem’? What is likely to stay the same? Who is likely to benefit from this representation of the ‘problem’? Who is likely to be harmed? How does the attribution of responsibility for the ‘problem’ affect those so targeted and the perceptions of the rest of the community about who is to ‘blame’?
<b>Q6</b>	How/where has this representation of the ‘problem’ been produced, disseminated and defended? How could it be questioned, disrupted and replaced? Consider past and current challenges to this representation of the ‘problem’. Consider the discursive resources available for re-problematisation

As previously articulated, Bacchi's (2009) WPR approach is heavily influenced by French philosopher, Michel Foucault, and his work on considering the value-laden qualities of discourses, their epistemo-historical contexts and how the nexus between power and knowledge

influence them. In essence, Bacchi's WPR approach is similar to Mills' (2004, as cited in Belzile, 2008) tips for researchers using a Foucauldian framework for discourse analysis:

“1) Draw on archives to bring attention to areas of the discourse that would not normally be thought of as important; 2) Be sceptical and be critical of your own views and avoid value judgements of the past; 3) Don't make second order judgements based on others' theories; 4) Look for contingencies rather than causes and don't oversimplify reasons for conditions that lead to certain events or actions; 5) Investigate a problem rather than a subject by allowing the “problem” to lead the investigation, and 6) Don't overgeneralise from your findings, but make statements about the particular event rather than grand statements about the culture” (p. 111-116).

Bacchi's WPR approach was specifically designed for policy analysis as well as other political discourse analyses (i.e. Bacchi & Eveline, 2010; Edmunds, 2010). Foucault and his works are briefly introduced in the following section to highlight their discursive influence on Bacchi's (2009) WPR approach to analyse political discourses and their problematisation effects.

#### Michel Foucault's influence on Bacchi's (2009) WPR methodological approach.

The WPR approach (Bacchi, 2009) is underpinned in part by a Foucauldian perspective on the nexus between knowledge, power, and discourse. Cheek and Porter (1997) and others (Horsell, 2003; Motion & Leitch, 2007; Powers, 2007) noted that Foucault's works are notoriously complex, varied and discursively divergent, allowing for many interpretations to be considered and critiqued. Foucault's published scholarship spanned over several decades since the late 1960s to the 1980s which included three distinct periods: the first was termed the 'archaeological' period where he focused on knowledge analysis (Cheek & Porter). The second period shifted Foucault's focus towards the issue of power and its relationship to knowledge and discourse (Cheek & Porter). In the third and final phase which developed during his final years, Foucault began to explore “his universalist notion of power, differentiating specific aspects of power, such as governmentality” (Cheek & Porter, p. 109).

This thesis does not adopt a pure Foucauldian methodology towards an analysis of discourses (Bacchi, 2005) as I considered Bacchi's (2009) WPR approach as the most appropriate methodology specific to critical policy analysis. Bacchi's (2009) WPR approach enabled me to

analyse how problematisations were represented in policy directly. The WPR approach is one methodology which acknowledges Foucault's significant contribution made towards philosophical thought which influenced the social sciences in the late twentieth century. The following section highlights two key framings articulated by Foucault which assisted in grounding this chapter with the theoretical underpinnings of Bacchi's (2009) WPR approach (Ballinger & Cheek, 2006).

#### Foucault's *Archaeology* and *Geneology* in brief.

Following the naming of a particular problematisation through applying the first question of Bacchi's (2009) WPR approach as demonstrated in Table 2, the following probing question (Q2) applies Foucault's concept of *archaeology* to assist with exploring the named problematisation's epistemo-historical and epistemo-political foundations (Scheurich & McKenzie, 2005). In doing so, what is known, or the *connaissance* of a topic (i.e. social inclusion policy) is analysed in context with its foundational and historical assumptions (*savoirs*, factors of knowledge). According to Foucault, *savoirs* are influenced by the epistemo-historical context in which they exist or are encountered and considered in their development of reason (Scheurich & McKenzie, 2005).

Foucault's *genealogical* approach, on the other hand, forms the analysis for the third question (Q3, see Table 2) in Bacchi's (2009) WPR approach. Geneology is different, yet complementary, to Foucault's archaeology. While a Foucauldian archaeological exploration essentially articulates a "non-epistemological framework for the analysis of discursive elements" (Kologlugil, 2010, p. 1) represented in systems of knowledge (i.e. policy), such as the identified *problematisations* ('social inclusion' and 'participation') in this research, Foucault's *geneology* focuses on Foucault's assumption that "everything is never said" (as cited in Graham, 2008), requiring the researcher "to determine, in all the possible enunciations that could be made on a particular subject, why it is that certain statements emerged to the exclusion of all others and what functions they serve[d]" (Graham, 2008). Foucault's notions of archaeology and geneology, as well as how this thesis

presented *discourse* and *power*, demonstrated methodological considerations for utilising the WPR approach (Bacchi, 2009). In doing so, considering Foucauldian influences on an analysis of discourses (Bacchi, 2005) allowed for an examination of the epistemo-historical investigation into Australian social inclusion policy and how ‘participation’ was problematised in this thesis, to contextualise discourses both past and present and examine them through a *critical* lens. Foucault’s description of *connaissance* and *savoir* (Scheurich & McKenzie, 2005) in context with archaeology and geneology also further enabled an analysis into ‘systems of power’ which formed such epistemo-political discourses, leading to *subjectifying* actions amongst citizens living with entrenched disadvantage. Adding to the critical analysis of *subjectifying* actions of ‘systems of power’ was the use of the POJF 2010 (Whiteford & Townsend, 2011), which added an occupational justice perspective and is described in the following section.

#### An analysis of discourses from a critical occupational science perspective: Whiteford and Townsend’s (2011) ‘Participatory Occupational Justice Framework’ (POJF) 2010.

Together with considering Foucauldian discourse surrounding critique and the power/knowledge nexus within Bacchi’s (2009) WPR approach to policy analysis, I also chose to consider Australia’s developing social inclusion policy discourse through a critical occupational justice framing. Specifically, I focused on key issues such as justice and the political effects on enabling or hindering occupational possibilities (Laliberte Rudman, 2010) of citizens living with entrenched disadvantage. As previously mentioned, occupational science, or the study of humans as occupational beings (Wilcock, 1998, 2006; Yerxa et al., 1990), proposed that participation in occupations was central to being human through an innate need to ‘do’ (Townsend, 2003; Wilcock). In contrast, being deprived of occupation, or meaningful *doing* through factors outside of one’s control, could be detrimental to one’s *being* and quality of life (i.e. occupational deprivation; Whiteford, 2004). This is an example of an occupational injustice and is against one’s right to occupation (Hammell, 2008; Townsend & Wilcock, 2004a, 2004b). Townsend (2003) further supported the need for ‘occupationally just’ practices through recognising the need to



make public that occupational injustices occur when occupational participation is exploited, deprived, marginalised, or many other qualities which do not enable, or preclude occupational possibilities (Laliberte Rudman). Townsend further stipulated that by considering an occupational perspective towards enabling occupation and participation over subjugated practices (either direct or indirect), then occupational injustices and their dialogue could be exposed and considered in daily life across personal, community and sociopolitical levels.

Without occupational justice, Wilcock and Townsend (2003) conceded that “...the interpersonal interactions, communities, and the world [could] experience inequalities which touch the very essence of living” (p.84). Several scholars from occupational science and occupational therapy have called for the need to critique and further develop health and justice through an occupational lens, leading towards advocacy, change and agency spanning across individual, community and sociopolitical levels (Galvaan, Mdlokolo & Joubert, 2010; Nilsson & Townsend, 2010; Pereira, 2008; Pollard, Sakellariou & Kronenberg, 2009; Rose, Cocks & Chenoweth, 2010; van Bruggen, 2010; Wilcock, 2007; Whiteford, 2000; Whiteford & Hocking, 2012; Whiteford & Pereira, 2012). In addition, the capacity to explore macro-level issues and how they relate to doing and participation is relatively untouched territory in occupational science research (Pereira, 2009). Therefore, through exploring occupational justice and injustices at macro and sociopolitical levels, adding an occupational justice perspective towards answering the first research question was considered as part of an emancipatory agenda (Breedon, 2008, 2012; Townsend, 1997b, 2012) to critique social inclusion policy.

Stadnyk, Townsend and Wilcock (2010) revealed that when a person or group experiences justice or injustice,

“they are not fully aware of the invisible decisions about policy, ...health, economics, social welfare, education, transportation, and industry that determine possibilities for participating or not in various occupations or the function of the state in regulating or otherwise influencing what they do.” (p. 332).’

Therefore, through focusing on the diverse occupational needs, possibilities and potentiality of individuals and groups living with entrenched disadvantage, issues pertaining to rights, fairness

and empowerment were critically considered through applying the POJF 2010 (Whiteford & Townsend, 2011).

Whiteford and Townsend's (2011) POJF 2010.

Townsend and Whiteford (2005) first introduced the 'Participatory Occupational Justice Framework' (POJF) which was aimed at promoting occupational justice at the micro-(personal) and macro-(population and societal) levels. The original POJF included four processes that addressed "the environment and social change through attention to resources, naming of population injustices, and negotiation with client organizations or advocates on a justice framework" (Townsend & Whiteford, p. 113). The philosophy underlying Townsend and Whiteford's framework was interpreted as one attempt to "up our game when it comes to social, cultural, and political awareness" (Simmons Carlsson, 2009, p. 10). Whiteford and Townsend (2011) further developed their POJF framework, due to the need for a 'critical' stance to empower disadvantaged and oppressed communities and populations. Philosophically, the POJF 2010 (Whiteford and Townsend) is congruent with diverse disciplinary discourses, such as critical social theory and critical social work traditions (i.e. Fook, 2002) which challenge domination, structural, interpersonal and personal forms of oppression, as well as valuing the possibilities of emancipatory and transformative social action and change (Fook, 2003). In the process of enabling social action, Fook (2003) noted that there was a "need to develop ways of knowing which [transcended] the dominant constructed ways of knowing, including the recognition that knowledge may reflect 'empirical reality' but is also socially constructed" (p. 17).

Together with its intention to guide "individualised and population-based practice" (Whiteford & Townsend, 2011; i.e. empowering people who experience entrenched disadvantage to access the resources required to enable occupation and participation), the POJF 2010 also aimed to be "...a conceptual tool for occupational therapists and others to use in *doing justice* in everyday life – a tool to guide practice processes and prompt knowledge translation and knowledge exchange about occupation, enabling, and justice" (p. 66). The POJF 2010 endorses and is congruent with the Universal Declaration on Human Rights (United Nations, 1948),

subsequent human rights charters, the 2006 World Federation of Occupational Therapists position statement on human rights (WFOT, 2006) and the International Classification of Functional Disability and Health (ICF) (World Health Organization, 2001) which is a multidisciplinary framework that outlines participation restrictions in context.

The POJF 2010 (Whiteford & Townsend, 2011) shares the following ideas with pre-existing health and social science models and paradigms:

1. “A concern for equity of social participation in civic society as well as in personal and family life;
2. A participatory process for social inclusion of individual, community or population voices in all planning, decision making and evaluation, and
3. An explicit focus on the influences of environmental [and contextual] forces that produce injustice in everyday life” (p. 66).

These shared ideas are also congruent with Townsend and Wilcock’s (2003) four occupational rights described in Chapter 2. The POJF 2010 also acknowledged that different types of governance (i.e. policy, law, funding) which *enable* opportunities, are as important to endorse as are the enabling processes (Townsend, 2003) facilitated by advocates and healthcare professionals, such as community representatives, occupational therapists and social workers.

Although different in their approaches to policy analysis and analyzing occupational injustices respectively, both Bacchi’s (2009) WPR approach and Whiteford and Townsend’s (2011) POJF 2010 share common understandings towards *just* practices. These commonalities involved the following: (1) constantly challenging the ‘status quo’ (Hammell, 2009) as well as gaps in philosophy, ideas, theories and day-to-day realities; (2) the promotion of participatory and collaborative approaches for enabling change from a *critical* lens; (3) engaging in the negotiation of power relations to uncover and insurrect ‘subjugated knowledges’ (Foucault as cited in Hartman, 1992) such as those held by citizens living with entrenched disadvantage and other people who consider themselves as disadvantaged, marginalised or oppressed; (4) aiming for transformative change in policy governance to empower “opportunities, resources and privilege

to exert choice and control” (Whiteford & Townsend, p. X), and (5) engaging and encouraging partnerships between policies and citizens to build optimism and hope for occupational justice (Whiteford & Townsend).

Due to the extensive description of the POJF 2010 (Whiteford & Townsend, 2011) as a “conceptual tool for doing justice” capturing practice processes, reflectivity considerations and influences of power, all ‘practice processes’ were necessary to critically analyse occupational justice issues inherent in Australian social inclusion policy discourses. In doing so, the utilization of the POJF 2010 as a complementary tool to Bacchi’s (2009) WPR approach enabled an in-depth and critical occupational science analysis of ‘participation’ problematisations which were found to exist in such political discourses. The findings of this analysis are outlined in Chapter 7.

#### Rationale for the selection of social inclusion policy discourses for analysis through the application of a critical analysis of discourses methodology.

As the Rudd Labor Government introduced Australian social inclusion policy discourse at a national level beyond that which was formally introduced in Australia by the South Australian Premier in 2002 (Buckmaster & Thomas, 2009), it was fitting that certain policy documents, speeches and press releases about social inclusion policy documented and announced during its national inception would be critically analysed. Further, through her roles and responsibilities as the inaugural Minister for Social Inclusion during the Rudd Labor Government, Julia Gillard’s portfolio was responsible for many key policy documents on the government’s vision and plan for *social inclusion* during her time as Minister. Finally, as discourses also exist in various types of media beyond written forms of communication, I decided to focus on the discursive traits of social inclusion policy that were *spoken* and *communicated* by Gillard through speeches and press releases that she made during her time as Minister for Social Inclusion. Appendix B outlines the key policy documents that were chosen for discursive analysis followed by Appendix C, which outlines all of the speeches and press releases made by Gillard during the Rudd Labor Government which mentioned ‘social inclusion’ for critical discourse analysis to assist with

answering the first question described in this thesis.

The analysis of the aforementioned discourses is presented in Chapter 7. However, to grasp a more complete picture of issues impacting on citizens living with entrenched disadvantage together with an analysis of discourses (Bacchi, 2005) approach, such as exploring the realities of occupational justice, participation, subjectifying practices, capabilities, opportunities, rights amongst many others, a complementary exploration of real life stories forming 'Part 2' of this chapter was conducted to answer the second research question in this research. The methodology chosen to guide this exploration was the use of life history methodology, which is introduced and justified next.

## **Part 2: Answering the second question – Methodology for narrative inquiry**

Complimenting Bacchi's WPR approach (2009) with applying a critical occupational science lens through the POJF 2010 (Whiteford & Townsend, 2011) was an innovative combined methodology to use which critically explored both 'said' and 'unsaid' discourses, which creating a platform for an objective analysis of hegemonic practices (Wilding, 2011). According to Edwards and Wajcman (2005, p. 16), "hegemony refers to the ways in which certain sets of ideas become established as natural and in which a dominated group actively consents in and helps to reproduce its own domination". Citizens living with entrenched disadvantage have the potential of being or becoming recipients of hegemonic and subjugated practices (Hartman, 1993; Wilding). Wilding contended that dominant practices and ideas imposed on subjugated individuals led to an uncritiqued 'taken-for-grantedness' and acceptance of hegemony.

Prior to exploring whether hegemonic and subjugated practices (Hartman, 1993; Wilding, 2011) were imposed on citizens living with entrenched disadvantage, their lived experiences needed to be examined in context with social inclusion policy. Therefore, this was the second focus of the studies documented in this thesis. In qualitative research, one of the most thorough methods utilised to explore lived realities of difference and disadvantage is through narrative inquiry (i.e. Frank, 2000; Polkinghorne, 1995). The following section outlines the key aims of

narrative inquiry, including a justification for choosing 'life history methodology' to answer the second question of this research.

#### Narrative inquiry: Narrative defined.

As a form of qualitative research, narrative inquiry is based on the assumption that the complexities of human interactions with the world are not bound by a sole ultimate truth. The central goal of naturalistic inquiry is to understand the interpretations and meanings that persons negotiate in sociohistorical (Carlson & Clark, 1991), sociocultural and sociopolitical contexts. The aim of this type of research, Carlson and Clark claimed, was to understand how people make sense of their lives amongst the complexities inherent in the social world. Typically, such investigations result in rich, qualitative description. Theoretical concepts are not imposed on the data, but rather emerge from the particulars of the specific research context (Carlson & Clark). Such research is described as involving inductive reasoning, which ensures that emerging theories are grounded in research data (Nayar, 2009).

The way in which individuals make sense of their social worlds, contexts and experiences is through the sharing of personal or collective narratives, or stories (Franits, 2005; Wright-St Clair, 2003). Understanding narratives assumes that human experiences are ordered episodically (Cole & Knowles, 2001). Narratives are best understood through reconstructing the natural narrative order in which it is or was lived (Cole & Knowles). Cole and Knowles highlighted that the importance of narratives

“...is given to the personal, temporal, and contextual quality of connections and relationships that honour the complexities of a life as lived as a unified whole. The focus of narrative research is on the individual, and the fact that life might be understood through a recounting and reconstruction of the life story” (p. 19).

Together with Cole and Knowles, Polkinghorne (1995) acknowledged the importance of stories which preserved a person's complexities, in context with their temporal aspects and sequences. The subjective experience and recognition of time use and temporality played out in life stories provides a space for 'meaning-making' and 'meaning-doing' in relation to the

storyteller's sense of past, present and future (Farnworth, 2003). According to Fossey, Harvey, McDermott and Davidson (2002), narrative research involves collecting people's stories to explore their experiences, thoughts and feelings relative to the questions being asked. However, narratives are not only derived from the sharing of individuals' stories through dialogue. Narratives also include a set of words that are derived from stories as well as interviews, journals and other written documents which form the data set in naturalistic inquiry (DePoy & Gitlin, 1998).

Storytelling is essentially an example of a person's ability to understand where they have come from and where they would like to go. 'Looking back, looking forward' was an expression documented by Feldman and Howie (2009) which described older adults' narratives. The research process in Feldman and Howie's life history study highlighted the need to respect and value the older adult participants as "'experts" on their own lives and assumed some level of reflection, interest, and ability to analyze the meaning of their life" (p. 622).

#### Narrative inquiry: Life history methodology.

Narrative inquiry as an area of qualitative research does not only focus on exploring narratives in a manner which describe stories as having a beginning, middle, and end, such as stories which can be plotted and made sense of in a linear fashion, such as being combined as "a succession of incidents into a unified episode" (Polkinghorne, 1995, p. 7). Despite both narrative and life history research respectively understanding and depicting life stories and "honouring the individuality and complexity of individuals' experiences" (Cole & Knowles, 2001, p. 20), a narrative research approach to stories and their analysis is methodologically different to *life history research* in the following way. Cole and Knowles (2001) described life history methodology as a more 'complete' approach compared to narrative inquiry as it situates an individual's narrative accounts within a broader *context*.

Context thus influences the 'living' of lives, and influences the complex interplay between various factors influencing such lives. These influences on context can include various elements,

including cultural, educational, familial, political and religious spheres, as well as countless others (Cole & Knowles, 2001). However, despite the nature in which context influences the lives and therefore narrative accounts of life experiences which cannot account for the complexities of such experiences, the elements and categories which directly influence context assist in formulating questions to guide and yield rich information about lives in context (Cole & Knowles). Cole and Knowles further expressed that life history research “draws on individuals’ experiences to make broader contextual meaning...[compared to] narrative research [which] focuses on making meaning of individuals’ experiences” (p. 20). In summary, a life history, or any personal account, is a story; a representation of a life at a given moment in time rather than an account of a life in its entirety (Sandelowski, 1992). Sandelowski eloquently described a life history as a (re)construction of “lives in every act of telling for, at the very least, the outcome of any one telling is necessarily a re-telling” (p. 163) at the storyteller’s discretion.

#### Applying an occupational perspective to life history methodology.

Naturalistic inquiry and using individuals’ narratives as a qualitative research methodology through life history allows the researcher to search for meanings into their subjective accounts of life events (life stories) including their feelings, thoughts, actions and attitudes (Goodfellow, 1997, as cited in Feldman & Howie, 2009; Mattingly & Lawlor, 2000; Molineux & Rickard, 2003). According to occupational scientists Wicks and Whiteford (2006), life stories are “very appropriate for understanding a lifetime of occupational experiences and for understanding the personal, social, economic, historical, [political] and geographical influences that shape those experiences” (p. 96). Importantly, Yerxa (as cited in Wiseman & Whiteford, 2007) noted that the storytelling process is necessary and essential to viewing people not as being able to be manipulated and controllable; but rather as “unique individuals whose very humanness entitles them to choices in determining their own destiny” (p. 96).

The aim of utilising life history methodology from an occupational perspective (Wicks & Whiteford, 2003, 2006) is to explore the influences and factors that facilitated or constrained



participation in occupations over the life course through a comprehensive view over time (Wicks, 2006). To answer the second question of the studies presented in this thesis, life history methodology employing an occupational perspective (Duchek & Thessing, 1996; Larson & Fanchiang, 1996; Wicks, 2006; Wicks & Whiteford) was achieved through exploring the lives of citizens living with poverty and disability in context with their lived realities, such as injustice, systemic influences on enabling participation and social inclusion as well as day-to-day occupational experiences and shortfalls. A particular focus of the life history dimension of the research described in this thesis included the investigation of how the specific forms of disadvantage that the participants experienced, impacted upon, and influenced their, participation in occupations and their resultant inclusion in society. Hearing the participants' stories about barriers to, and enablers of, occupational participation, provided a unique insight into the realities of disadvantage as well as experiences of triumphing despite adversity. Adopting a life history approach from an occupational perspective provided for a rich source of privileged information from citizens who had experienced a plethora of life experiences replete with occupational challenges and successes.

#### Storytelling in context: Exploring the lives of citizens living with entrenched disadvantage.

Wiseman & Whiteford (2007) declared that “occupational science [and applying narrative approaches to researching occupation, such as life history methodology] has much to offer society in terms of generating new knowledge about what people as individuals and what communities do and how and why they engage in [or choose not to engage in] specific patterns of doing” (p. 113). Therefore, such type of research has the potential to significantly inform policy makers in addressing occupational challenges (Wiseman & Whiteford), such as those which arise from the developing discourse of Australian social inclusion policy which are identified throughout the findings chapters.

### Ethics, respect and sensitivity with life history methodology.

Life history methodology adopting an occupational perspective can be a sensitive process for the individual sharing their stories. For citizens living with entrenched disadvantage, the process of 'looking back' (Feldman & Howie, 2009) can be a traumatic experience. Yet the telling of such stories can be empowering and assist with 'looking forward' and planning for the future (Feldman & Howie). Too often, the stories of citizens living with entrenched disadvantage have laid dormant where individuals have been in fear of retribution or have not shared their stories as more dominant, or 'privileged' stories and discourses are more commonly shared and heard (Bacchi, 2009; Pease, 2009; Schreurich & McKenzie, 2005). Stories which highlight difference and diversity, especially those of citizens living in poverty with disability which have traditionally been unheard due to oppression are worthy of sharing. When considering policy directives to promote change (be it positive or negative), policy makers have sought the stories of citizens to ground their policies and deliver action rather than rhetoric (i.e. 'Shut Out' report; National People with Disabilities and Carer Council, 2009). However, literature has indicated that such stories do not make it into the policy making process (Shergold, 2009). One reason for this is the difference between an understanding of *consultation* versus *participation* in policy making processes (Shergold), with *participation* being a more 'bottom-up' approach.

There is a significant difference between being consulted and actually participating in the process. Consultation may not necessarily grasp the depth and breadth of experience, disadvantage, subjugation, marginalisation and oppression. A key reason why this does not happen is due to the effect of policy makers 'consulting' representational bodies, such as non-government organisations who support citizens living with entrenched disadvantage (i.e. National People with Disabilities and Carer Council, 2009). As a result, citizen engagement in decision making becomes limited as policy makers hear secondhand accounts of real lives and real stories from such organisations or representative bodies. Therefore, investigating policy responses through a critical lens is imperative to contextualising what is documented by governments in

their processes of change together with exploring the realities of citizens' experiences of policy delivery and response from their unique perspectives.

In line with a postmodern perspective, exploring multiple truths through qualitative research which explores narrative accounts of lives in context (Fossey, Harvey, McDermott & Davidson, 2002; Iwama, 2003) come with a plethora of rich stories and experiences that are often unheard in policy making, or given less priority over quantifiable results for enacting policy. There a paucity of research that has investigated entrenched disadvantage specific to poverty and disability from an occupational perspective. Consequently, there is also a dearth of qualitative research that has investigated citizens' narratives about some of the realities that exemplify entrenched disadvantage in Australia. Life history methodology, is one type of qualitative research methodology identified as being an appropriate one to uncover the narratives of entrenched disadvantage throughout one's life course. The rich data gathered from life history methodology in this research provided an exploration of individuals' in-depth perspectives of their occupational lives, including how their day-to-day existential realities directly (or indirectly) affected their occupational participation, community interactions and social inclusion.

#### Setting for study.

Choosing the location and setting for the life history study was informed by Vinson's (2007) landmark report, which was used as a guide into the most socially disadvantaged locations in Sydney, New South Wales. Blacktown local government area (LGA) located in Sydney's west was chosen as one of the locations for this study as it was considered to be the second most socially disadvantaged area in Australia (Stephens, 2008). The second setting chosen for the study was Parramatta LGA in Sydney's west as it was also highlighted as being a geographical area with a higher incidence of poverty and social disadvantage compared to more urban areas (Vinson). Both Blacktown and Parramatta LGAs were also identified as having a high prevalence of disability compared to more affluent areas in Sydney and other capital cities (Australian Institute of Health and Welfare, 2009). Disability is relative to socioeconomically disadvantaged areas

throughout Australian capital cities (Australian Institute of Health and Welfare).

Process undertaken to choosing the study's settings.

As part of the ethics application process, I required written consent from potential organisations located in the Blacktown or Parramatta LGAs to support my study. Such consent indicated organisational willingness to assist in the process of advertising my study for participant recruitment purposes. During this process, the following representative organisations were contacted:

- Policy Division, Council of Social Services of New South Wales (NCOSS);
- Community Access Division, Blacktown City Council, and
- Community Resources Network (CRN) Inc.

Following a period of advertising the study from July 2010 to October 2010 through the abovementioned organisations' networks, including several meetings with Blacktown City Council's Community Access Division, three organisations responded to my request for support in advertising the study within their organisation for participant recruitment purposes. One organisation was not chosen because their focus is on citizens who specifically live with an intellectual disability, which did not meet the inclusion criteria for the study. Furthermore, a significant amount of research has already been conducted surrounding the social inclusion of people living with intellectual disability (i.e. Hall, 2010). The two organisations which were finally selected were:

- Parramatta Mission, Parramatta LGA: Non-Government Organisation (NGO) affiliated with the Uniting Church, and
- Ability Options, Blacktown LGA: Disability Employment Service (DES) Provider.

The following section provides a brief introduction to the organisations involved.

### Ability Options.

Ability Options is a Disability Employment Service (DES) in Sydney, New South Wales, Australia. According to the Department of Education, Employment and Workplace Relations (DEEWR; 2010), DES organisations receive funding from the Australian Government to deliver employment assistance for job seekers with disability. Employment assistance can include access to tailored services that are responsive and flexible to the needs of people living with disability as well as the needs of employers (DEEWR, 2010). As a DES, Ability Option identified a mission and vision statement to guide their programs. Ability Options' (n.d.) mission was:

“To provide people with disabilities better opportunities that will enable them to enhance their lifestyles and achieve their goals”.

Ability Options' vision has four central foci: quality; growth diversity and independence; identity, and participation (n.d.). In the first focus, Ability Options identifies their commitment to providing quality services benchmarked against best practice standards. The second addresses the hope to expanding their services within Australian to increase opportunities for independence and choice, strengthen their clients' relationships and participation within the community and improve quality of life. With identity, Ability Options endeavours to be a dynamic and recognised organisation, known for being a quality service provider as well as being proactive in “shaping the future direction of disability policy and practice in Australia” (n.d.).

Ability Option assists over 2,000 people living with disability and their carers in several programs across the state of New South Wales which include:

- Housing development and home maintenance;
- Supported living;
- Respite services;
- Community access;
- Post school programs;
- Case management;
- Self-management;

- Disability employment services;
- Transition to work, and
- Supported employment.

According to the list of services that clients can benefit from, the division that was involved in this study was the DES branch of the organisation. The next section explores the vision and values of Parramatta Mission, which was the NGO involved in this study.

### Parramatta Mission.

Parramatta Mission is affiliated with Australia's Uniting Church (Parramatta Mission, 2008). Parramatta Mission began 40 years ago, arising from four Uniting Church congregations (Parramatta Mission). Parramatta Mission is a major regional provider of community services, extending its service provision throughout the Parramatta and Holroyd LGAs in Western Sydney (Parramatta Mission).

As an NGO, Parramatta Mission conducts its business with several key stakeholders in conjunction with state and local governments (Parramatta Mission, 2008). Stakeholders include business organisations within the Parramatta and Holroyd LGAs, other NGOs, community groups and local individuals (Parramatta Mission, 2008). In conjunction with the foundational values of the Uniting Church, Parramatta Mission aims to create a supportive and caring community for those in need throughout their Western Sydney catchment area. Parramatta Mission defines 'those in need' as

“...those whose needs are most acute or those most neglected, especially people experiencing crisis, people living with mental illness and people who are homeless. We seek to create community with and for those in need, based on their human dignity, rights and responsibilities. Our vision is a community where all are included, valued and enabled” (2008).

The following section introduces the research's sequence and its rationale.

### Study sequence and rationale.

The studies documented in this thesis were conducted in two phases due to having two separate research questions. I had initially planned to answer the first question employing an analysis of discourses approach (Bacchi, 2005, 2009) prior to pursuing the second question which employed life history methodology. However, due to developing strong relationships with Parramatta Mission and Ability Options prior to and throughout the ethics application process, it was logical to continue building the relationships once the ethics approval to conduct the research was granted. This enabled me to immediately proceed with the research through commencing the participant recruitment process at both organisations following the ethics approval. This led me to seek to answer the second question, and conduct the life history study, prior to performing an analysis of discourses (Bacchi) of key government documents, speeches and press releases to answer the first question. Ideally, I would have preferred to commence with conducting the analysis of discourses prior to performing the life history study. However, I did not delay with the life history study due to developing strong and successful relationships with both organisations.

### Ethics approval.

The Macquarie University Human Research Ethics Committee granted ethics approval to conduct the life history study on December 23, 2010. Ethics approval is required to be able to conduct research with human subjects, providing a commitment by the researcher to conduct safe and ethical research. A copy of the letter indicating this study's ethics approval is located at the front of this thesis.

### Participant recruitment process.

Following ethics approval to conduct the study, meetings were arranged with Parramatta Mission and Ability Options management teams respectively, to determine the best methods to recruit participants. Together with advertising the study on the organisations' noticeboards

through a participant recruitment form (See Appendix D), each organisation proposed unique participant recruitment processes utilising a ‘purposive sampling approach’. Purposive sampling is a participant recruitment method primarily used in qualitative research studies by selecting individuals, groups or institutions based on the specific purposes associated with answering a study’s research question(s) (Teddle & Yu, 2007). Maxwell (1997) further reiterated that “particular settings, persons, or events are deliberately selected for the important information they can provide that cannot be [sourced] from other choices” (p. 87). Qualitative studies which utilise purposive sampling techniques for participant recruitment typically have small sample sizes (Teddle & Yu). This allows for an in-depth exploration into the lives of such participants. One of the strategies for participant recruitment through purposive sampling techniques involves sampling unique cases. This sampling technique is “...employed when the individual case itself, or a specific group of cases, is a major focus of the investigation (rather than an issue)” (Teddle & Yu, p. 80).

As each organisation involved in this study attracted a diversity of clients relative to their mission statements, values and services offered, each recommended a different way to purposely recruit participants. As the researcher, I respected how each organisation worked with their respective clients, and acknowledged their assistance throughout the recruitment process. As each organisation worked with significantly marginalised and disadvantaged citizens, their wisdom towards attracting potential participants was vital during the recruitment process. In accordance with the ethics approval, I gave each participant a \$50 shopping voucher as an incentive to participate. I felt that this shopping voucher was culturally appropriate as well as being a practical way to acknowledge my gratitude for the participants’ involvement due to my research’s focus on citizens living with poverty and disability.

The inclusion criteria to be involved in the life history study included the following:

1. Be an Australian citizen;
2. Aged 18 to 64 years;
3. Live in the Blacktown or Parramatta Local Government Area (LGA);



4. Unemployed, recipient of a pension (i.e. Disability Support Pension, Newstart Allowance), or have low income;
5. Live with an identified disability or chronic illness;
6. Understand verbal and written English, and
7. Agreeable to up to three face-to-face interviews of approximately one hour each in a confidential location.

#### Recruitment process at Parramatta Mission.

Parramatta Mission management recommended that I participate with some activities that the organisation was involved with, such as meeting people who came in for a meal at lunchtime so that potential participants could familiarise themselves with me. Together with advertising my research on the organisation's noticeboard, I was introduced to potential participants who met the inclusion criteria by management during regular lunch meetings throughout January 2011. This enabled potential participants to become familiar with me as a researcher and the purpose of my visits. Applying Parramatta Mission's recommended strategy to meet potential participants by speaking with them at various lunches during January 2011 enabled me to recruit four participants from this organisation.

Upon the initial interest of potential participants, I generally described the purpose of the research. If they were interested in participating, we mutually arranged a time and place to meet which was in a confidential and safe environment for both parties. During this meeting, I further explained the study by giving the potential participant a Participant information form explaining the formal purpose of the study in plain English (see Appendix E). If they agreed to be interviewed, I obtained a signed consent from the individual (see Appendix E) to formally participate in the study. Each of the participants were involved in up to three interviews each, lasting between 30 minutes to two hours in duration. The majority of interviews were conducted in a private room at Parramatta Mission. Two interviews were conducted at a participant's home.

### Recruitment process at Ability Options.

Participant recruitment was significantly different with Ability Options. As a Disability Employment Service funded by the government, the organisation adopted a more formal approach to organising participants and scheduling interviews at their premises in the Blacktown LGA. Following several face-to-face meetings and email correspondence between management and I, the study was formally advertised on the organisation's noticeboard together with adopting purposive sampling techniques to approach 'customers' (people who were registered with Ability Options) directly through their pre-arranged meetings. Through this method, five participants were identified, however only three formally participated in the study. One of the five participants did not meet the inclusion criteria, and one participant had found full-time, ongoing employment and was discharged from the service prior to the interview process.

### Introducing the participants.

The participants in this research were aged between 33 and 57 years and came from culturally and linguistically diverse backgrounds. Table 3 outlines the participants' demographics. It was important to include participants across the economic and education spectrum despite all experiencing socioeconomic disadvantage together with disabling health and psychosocial conditions. These factors added a unique dimension to exploring disadvantage in context with issues of education level, work experience, housing affordability and attainability which the literature identified as being significant towards a higher susceptibility and probability of acquiring or living with entrenched disadvantage (Australian Social Inclusion Board, 2009).

Table 3: Participant demographics.

Name	Age	Sex	Marital Status	Disability or Health Issue	Educational Attainment	Accommodation
Rose	50	Female	Divorced; Mother of 1	Major Depression; Chronic Low Back Pain; Lumbar Spine Degeneration; Osteoarthritis; Osteoporosis	Tertiary education certificate	Public Housing
Anthony	44	Male	Separated; Father of 5	Post-Traumatic Stress Disorder; Major Depression; Anxiety; Stage 2 Grave's Disease; Hepatitis C; Former Substance Abuse; Haemochromatosis	Did not complete Year 9	Public Housing
Leigh	57	Male	Divorced; Father of 1	Depression; Osteoporosis; Cervical and Lumbar Spine Degeneration; Former Substance Abuse	Did not complete Year 8	Public Housing
Bruce	53	Male	Single, Never Married	Major Depression; Former Substance Abuse	Completed Year 10; Pursued trade apprenticeship but did not complete	Public Housing
James	33	Male	Single, Never Married	Right Foot Drop; Depression; Former Substance Abuse	Completed Year 10	Renting Privately
Annie	52	Female	Divorced and Re-married to Richard, Mother of 2 to previous husband	Depression; Cervical Spine Injury; Left wrist injury due to long ulna; Benign Paroxysmal Positional Vertigo	Tertiary education certificate	Home Owner
Richard	57	Male	Divorced and re-married to Annie, Father of 1 to previous wife	Myocardial Infarction; Surgical complications following heart surgery and resultant infections; Depression	Tertiary degree	Home Owner

### Maintaining participant anonymity and confidentiality.

I considered hearing the complex life stories of each of the participants in this research study as a privilege. Not only did they volunteer their time to participate and freely and openly share their life stories with me, but they did so in a way that enabled in-depth exploration. This was further enhanced through rapport building with each participant (Pereira, 2007). Their stories were dealt with integrity and respect which are considered as essential elements in ethical qualitative research (Guillemin & Gillam, 2004). To maximise the confidentiality of the participants, I used pseudonyms instead of their real names. During transcription of the audio recorded data, I assigned each participant with pseudonyms (see Table 3) which were used throughout the transcription and analysis processes. As some personal information such as identifiable stories and cultural background were highly specific to some of the participants, aspects of their personal details were changed throughout the analysis and documentation of findings to preserve their identities.

### Information gathering and transcription.

Upon written consent, open-ended interviews were conducted with each participant. Fifteen interviews were conducted in total between the seven participants. Each of the participants was involved in up to three interviews each, lasting between 30 minutes to two hours in duration. I developed a broad interview guide (see Appendix G) which assisted to explore each participant's lived experiences occupational participation enablers and barriers, matters of inclusion and exclusion in context with their environments. Most of the interviews were conducted in private rooms at Parramatta Mission and Ability Options. One interview was conducted in a private room at the local Blacktown Public Library and two interviews were conducted at one of the participant's home. As previously documented in this chapter, interviews were conducted in an environment which was assessed as being safe for both the participant and researcher.

Each interview was recorded using a digital voice recorder following written consent to do so. The recorder was small and easy to use, preventing any potential distraction throughout the interviewing process. The recordings were required for in-depth analysis of the data from the interviews in line with life history methodology. The interviews did not involve the secretive use of any photography, video-recording, audio-recording or other recording method(s). In two interviews of two individual participants, the interviews were momentarily stopped due to the re-telling of traumatic events which affected the participants emotionally. As a result, and in accordance with the research's ethical approval and plan for such events, I referred the participants to their local community health service to receive psychological assessment for counseling support.

After each interview was conducted, I documented the interview experience and my initial thoughts through fieldnotes, drawing mindmaps and reflexive journaling (Breedon, 2008). Writing fieldnotes, drawing mindmaps and keeping a visual journal throughout the life of the studies, promoted my own critical reflexivity (Phelan, 2011). All of these critical reflexive techniques were especially useful during the interviewing and data analysis process (Phelan). As I consider myself a visual learner, engaging in creative mindmapping and drawing diagrams assisted me to elucidate and highlight associations between the participants' stories with my own understanding of such topics that were discussed. Examples of some fieldnotes, mindmaps and journal entries are demonstrated in Appendix F.

As the researcher, I transcribed the majority of the interviews which involved listening to the audio-recorded data and documenting each word verbatim. Each sentence was meticulously double checked for quality assurance of the data (Wicks, 2003). I also used an independent and confidential transcription service to complete some of the audio-recorded transcriptions to maximise time use for the analysis of the findings.

## Analysis of findings

Literature on qualitative research has indicated that there is no *single* method of analyzing the life stories and experiences shared by the participant with the researcher. As a result, a plethora of analysis techniques exist which are also dependent upon the most appropriate method used. Previous narrative and life history studies in occupational science have taken a more ‘non-conventional’ approach to analyzing research findings (i.e. Del Fabro Smith, Suto, Chalmers & Backman, 2011; Reynolds, 2003; Gahnstöm-Strandqvist, Josephsson & Tham, 2004; Ward, Mitchell & Price, 2007; Wicks, 2003; Wiseman & Whiteford, 2007). This is substantiated due to the added complexities of occupation (Carlson & Clark, 1991) and occupational experiences *in context* and across the life span that are described within shared life histories. However, what was consistent in most narrative and life history studies reported above was that a guiding principle did exist which provided structure to data analysis. For example, these studies involved the *iterative* analysis, meaning that information was consistently reviewed, compared and contrasted to make sense of the information in a coherent and inductive way to then develop themes to describe findings elucidated from such data analysis.

This form of analysis, consistent with narrative and life story analyses, has been described as the ‘constant comparative’ approach (Boeije, 2002) which was the method chosen to analyse the findings documented in this thesis. All kinds of aids, such as writing memos, close reading and rereading of interview transcriptions, coding, visual displays and diagrams all support the principle of comparison in the constant comparative method (Boeije). Applying a constant comparative approach to analyzing the findings in this study enabled the development of ideas and themes that were grounded in the gathered information from the participant interviews (Glaser & Strauss, as cited in Boeije, 2002). Additionally, the analysis method used in this study extended from traditional narrative analysis which specifically analyses the participants’ stories in and of themselves (Polkinghorne, 1995), to incorporate the analysis of their stories and other phenomena as they occurred within temporal, sociocultural and political contexts (Cole & Knowles, 2001).

The term *findings* is preferred to *results* as *results* implies as well as follows a positivist research doctrine. Findings therefore express a more accurate depiction of analyzing the shared life histories of the participants in this research as they are in their own right, unique, and not a result obtained from discrete parameters.

#### Analysis processes.

##### Coding, theme generation and interpretation.

Interviews were conducted with participants until data saturation was reached. Concurrently with reading and re-reading each interview transcript at least twice, the reflexive tools which I used throughout the interviewing and data gathering process, assisted me to determine when data saturation had occurred (i.e. fieldnotes written after each interview). I then proceeded to analyse the data iteratively which involved an in-depth process of analysis using coding of data sets until themes were elucidated.

Following data transcription, reading and re-reading transcripts, and memoing and notetaking ideas (Grbich, 1999; White, 1999; Wright St-Clair, 2003), I proceeded to code, interpret and analyse the data from the participant interviews together with the information gathered from the reflexive tools mentioned above (Breedon, 2008). Coding is a process whereby categories are used to classify words or phrases related to the concepts, themes and theories of the research study (White). The following data analysis technique was employed to elucidate the themes documented in this research. This technique is consistent with data analysis processes documented in qualitative research (Breedon; DePoy & Gitlin, 1998; Grbich; Lincoln & Guba, 1994):

1. Open coding;
2. Axial coding ('categorising');
3. Selective coding ('clustering');
4. Relating and refining ('integration', including making reference to memos and notes taken throughout the data collection process), and

## 5. Emerging theme.

Open coding involves line-by-line, sentence-by-sentence or paragraph-by-paragraph analysis of the data (Grbich). According to Grbich, open coding as the initial coding process “is designed to fracture the data then group them conceptually, generalising concepts that emerge from it and fit within it” (p. 176). Open coding involves identifying codes ‘in vivo’, or using the participants’ own language as codes, as well as attaching particular theoretical references which may relate to the initial code (Grbich). The next step involves naming the code and questioning what, when, how and why the code matters in context with the participant’s story(ies) (Grbich). Following this, focus is directed towards particular ideas that may seem relevant to the code. Open codes are then compared and contrasted to determine if they have accounted for all of the analysed data (Grbich).

The next step involved axial coding, where open codes were categorised. In order to develop and expand on categories which accurately represent the data in context with the broader aims of the research, a critical reflexive process occurred whereby categories were related and compared to theoretical and empirical literature and my understanding of it so that they remain objective and unique (Grbich). Axial codes or categorizations of data were then clustered into groups (selective coding) where they were validated against the literature, theories and critical reflexive processes which occurred (Grbich). Such selective codes were thus ‘refined’ (Grbich) and themes that emerged were consolidated through a constant back and forth movement between the data sets and integration of the literature and critical reflexive processes (Breen, 2008; Grbich) where final theme selection, appropriateness and relevance was determined.

In conjunction with the data analysis process, particular narrative accounts were identified which best represented the themes that were generated and finally chosen for presentation through the next three findings chapters. Therefore, themes were interpreted and contextualised together with participants’ direct narrative accounts. It was important to demonstrate some of the participants’ narrative accounts verbatim in this thesis, as they boldly exemplified the richness



of their life stories in context with existential realities of social inclusion and exclusion.

#### Authenticity and trustworthiness of the findings.

The participants, or ‘storytellers’ in this research, shared their narrative accounts to make some sense of their world, consistent with past experiences (both positive and not so positive; even traumatic), which lead to representations of self that best represented their identities and realities (Sandelowski, 1991). Sandelowski concluded that attempting to ‘verify’ findings into logical sequences, such as positivist accounts of ‘truth’ (Iwama, 2003) represented a “misplaced preoccupation with empirical rather than narrative standards of truth and a profound lack of understanding of the temporal and liminal nature and vital meaning-making functions of storytelling” (p. 165). Therefore, authenticity was maintained in this study through a verbatim account of the participants’ stories which they chose to share. Together with maintaining the authenticity of the participants’ shared stories, trustworthiness was maximised by applying strategies which addressed the credibility, dependability and confirmability of the data (Krefting, 1991) such as using critical reflexive processes throughout the data collection and analysis process, and triangulation processes which were grounded in the data (interview data, fieldnotes, visual mindmaps and reflexive journaling; Breeden, 2008; Krefting).

#### Research limitations.

As is the nature of qualitative research which uses small numbers of participants as well as employs distinct methodologies to analyse discourses in particular ways, the life history study documented in this thesis has limitations in terms of generalisability and transferability (Lincoln & Guba, 1985) to a larger population (White, 1999). However, the aim of qualitative research studies like the one documented in this thesis is to critically interpret the findings in a rigorous manner.

In terms of the limitations which relate to the critical policy analysis findings in Chapter 7, documents which were included for analysis were limited to those published during the period of

the Rudd Labor Government in Australia (November 2007 – June 2010). Therefore, any government report on social inclusion policy discourse published during the successive Gillard Labor Government (June 2010 - present) was not included. However, such reports were included throughout the body of the thesis where relevant.

With regards to the limitations of the life history study documented in this thesis which complimented the critical policy analysis, the study did not include people over the age of 64 which is the current retirement age in Australia. Nor did it include people below the age of 18. Maintaining the life history study's inclusion criteria age limit between 18 to 64 years was purposeful and deliberate. This age range coincided and was consistent with social inclusion policy directives which predominantly focused intervention strategies for citizens of working age. Further, focusing specifically on including people living with disability as a result of chronic illness was due to the expertise and research interests of the author, as well as highlighting a gap in the literature which was yet to address the participation and inclusion needs of people living in poverty with disability related to chronic illness.

### **Summary**

This chapter presented a description of the qualitative research methodologies and methods which were utilised in answering the two research questions reported in this thesis. This chapter was separated into two parts; Part 1 and Part 2 which respectively explored the methodologies and methods applicable to each of the research questions. Following justification of the research methodologies, the methods employed for data gathering and analysis processes were presented. Finally, the authenticity, trustworthiness and limitations of both aspects of the studies documented in this thesis were highlighted. The next chapter, Chapter 4, is the first of four findings chapters, which specifically focuses on presenting the findings of the first meta-theme of the life history study, entitled, 'being me' which explores issues in context with aspects of the participants' identities and how they are impacted by day-to-day experiences of participation and social inclusion.

## Chapter Four

### ***Being Me: Identity and Personhood***

The previous chapter outlined the methodologies and methods that were utilised in the studies described in this thesis. Two clear and separate methodologies were chosen to critically explore the life histories and perspectives of entrenched disadvantage as experienced by seven citizens living in Western Sydney in context with Australian social inclusion policy. This chapter is the first of four findings chapters. The accounts of the seven participants are presented in context with a chapter which explicates an analysis that I completed of Australian social inclusion policy discourse as expressed during the Rudd Labor Government.

The first three chapters explore the three meta-themes identified from rigorous thematic analysis which represent detailed accounts into entrenched disadvantaged from the participants' perspectives. The fourth findings chapter complements the life history study findings by placing them in context with the Australian social policy climate. It does so by highlighting the results of an analysis of discourses (Bacchi, 2005) that I completed of Australian social inclusion policy *texts* from both critical policy discourse and critical occupational science analyses (Bacchi, 2009; Whiteford & Townsend, 2011; Whiteford & Hocking, 2012). Presenting the findings through these four comprehensive chapters provides a cogent vehicle through which the mechanisms of social exclusion as they were experienced at an everyday level can be best understood. The findings chapters also identify factors which enabled, hindered, limited or constrained participation and inclusion from the participants' accounts of their experiences and observations.

Due to the rich nature of the participants' in-depth narrative accounts, I attempted to document the most pertinent examples that best represented their *voice* together with my critical analytic commentary of the issues that such stories highlighted, in context with relevant meta-themes and their sub-themes. I have presented the life histories of citizens living with entrenched disadvantage in a unique format across the first three findings chapters, an approach which differs from other life history studies which most often present temporally (i.e. Frank, 2000;

Wiseman, 2008). The approach that I chose through which to represent the participants' life histories is consistent with life history studies published in occupational science literature (i.e. Wicks, 2003). In context with such studies (Wicks), the first three findings chapters provide in-depth narrative examples from the seven participants' life stories in thematic context as opposed to a chronological and historical order. This enabled elucidation of the meta-themes and respective sub-themes. Accounts of life experiences and observations in context with the three meta-themes are highlighted instead of attempts to abridge life stories across the lifespan (Wiseman). These carefully-selected stories include 'interpretative commentaries' (Wicks) which aim to highlight the impacts and consequences of participation and inclusion issues as they were experienced *at an everyday level* by the seven participants. The three meta-themes and their respective sub-themes are outlined in Table 4 below.

This first findings chapter explores the participants' everyday realities of living with entrenched disadvantage relative to notions of 'the self', which include personal, social and occupational identities, autonomy, social recognition and personhood. The chapter also identifies a concept which I have framed as *occupation-as-metaphor* which describes how participants used their participation in particular occupations as metaphors to highlight both the transformative potential of occupation (Breenen, 2008; 2012; Townsend, 1997b) as well as its effects on the participants' identities, life roles and hopes for future occupational opportunities. The chapter also highlights how the life stories of the participants shaped their present framings of 'being me', as well as how their identities and actions affected the lives of those close to them. Central to the first meta-theme of 'being me' presented in this chapter are considerations for how the participants experienced occupation in the context of their life worlds (Hasselkus, 2006; Whiteford & Wright-St Clair, 2005).

The chosen stories of the participants' experiences portray salient accounts of beings and doings as they relate to the concepts of identity and personhood; key ideas in social and political recognition discourse (Honneth, 2001; Ikäheimo, 2007; Onof, 2010). From their subjective experiences, sharing such accounts also enabled the participants to reflect on both the challenges

and triumphs relative to living with entrenched disadvantage, including an understanding of their aspirations for doing and being in context with barriers encountered within their broader social worlds.

Prior to considering the participants' subjective accounts captured by the 'being me' meta-theme documented in this chapter, some key terms which frame the discussion require clarification. 'Identity' and 'personhood' are key terms which respectively describe the sub-themes of the first meta-theme. Identity, in particular, can be seen as a complex phenomenon due to its diverse sociocultural constructions. There are various schools of thought which have extensively explored identity, such as in moral philosophy surrounding theories of social recognition (Deranty, 2009; Honneth, 1995), as well as salient research by social psychologist Erik Erikson (1968) into the emergence of identity during stages of human development, especially during adolescence. In this chapter, however, identity is conceptualised in its broadest sense which considers its diverse discursive epistemology. In particular, this chapter explores how identity is considered from an 'inside-out', or insider's perspective. In so doing, participants' accounts of their own subjectivities of 'being me' are crucial in providing in-depth and personal insights into their own identities and senses of personhood. Additionally, a focus on the multidimensional nature of identity and how it relates to personhood and 'being me' is also presented through the participants' own interpretations of their identities. From a multidimensional perspective, identity can be considered as static, dynamic, socially constructed, singular, intrinsic, extrinsic, collective, multiple or occupational in nature (Phelan & Kinsella, 2009). In their comprehensive and interdisciplinary analysis of occupational identity discourse, Phelan and Kinsella attested that the construct of identity has traditionally been considered from a limited and individualised approach. They proposed that there are four theoretical assumptions embedded within a Western understanding of occupational identity: "(a) individual at the core of identity formation, (b) Choice, (c) Productivity, and (d) Social dimension" (Phelan and Kinsella, p. 86). This chapter considers these four assumptions through the participants' perspectives on identity and personhood.

The notion of ‘personhood’ also requires clarification as it is also considered as a key term in this chapter. ‘Personhood’ is complementary and closely linked to a conceptual understanding of ‘identity’. As previously described in the literature review in Chapter Two, personhood as it is used here, relates to political philosopher Axel Honneth’s (2001) theory of recognition, by enabling an understanding and organisation of one’s life and position in the order of things (Ikäheimo, 2007). From an occupational perspective of empowerment, personhood has been described as relating to an “ethic of equality” (Townsend, 1998, p. 31). Townsend considered the notion of personhood as part of *inviting* participation through an ‘ethic of equality’, which

“...underpins the commitment to confer personhood on all people regardless of difference. Equity in granting personhood entitles everyone to have equal opportunity to participate, in some way, in work, and to live decently, enjoy themselves, and belong to their communities, if they so choose” (p. 32).

Townsend’s research into the social organisation of power within systems of governance, such as the mental health system in Atlantic Canada, provided a unique lens to explore issues that conferred personhood and social recognition of individuals receiving services, or not. Social science literature into the notion of personhood has also highlighted its role in strengthening inter-subjective recognition (Morrison, 2010) and interpersonal recognition (Ikäheimo).

As previously stated, identity and personhood are important concepts in Honneth’s (1995) theory of recognition, and play a key role in understanding how cultural, political and social recognition occur at an everyday level. This chapter outlines how both the concepts of identity and personhood underpinned participant perceptions of the transactional relationships that occurred between their social ontologies, occupational choices and sociocultural contexts (Frank & Zemke, 2008). The chapter concludes by summarising the key themes explored in this chapter and contemplates how ‘being me’ and participants’ social ontologies were inextricably linked to the existential realities of living with entrenched disadvantage including poverty and disability.

The first column of Table 4 below highlights the sub-themes that are individually explored in this chapter. The meta-theme of “being me” highlights experiences of exclusionary acts that participants reported, such as the lack of recognition and dignity expressed by others. It also

provides insights into the occupations, relationships, moments and things that the participants' appreciated which led them to feel like valued human and occupational beings (Yerxa et al., 1990; Wilcock, 1998, 2006).

Table 4: Findings from the life history study.

Meta-themes		
<b>1. <i>Being me:</i></b> Identity and personhood	<b>2. <i>Being in the world:</i></b> Existential realities	<b>3. <i>Being in the system:</i></b> Experiencing exclusion and disadvantage
Sub-themes		
Wanting to do something that counts (recognition)	"Living with disability is one of the hardest things"	Being told what to do Not getting a "fair go"
Doing things to pass time; Doing things that are meaningful	I can't afford to live Feeling excluded and having little hope	Being powerless Feeling demoralised
Having and upholding values	Living in a community lacking compassion	"I don't know what to do or where to go"
Having faith	Feeling lonely and isolated	"Falling through the cracks"
Living for my family		It's too complicated
Having hopes and goals		Experiencing a lack of compassion and empathy
Being strong and resilient		

Self-value, self-worth and identifying a sense of purpose were vital aspects of the participants' subjectivities of being (Laliberte Rudman, 2005), which assisted in defining their roles within society. Some participants, such as Anthony, evaluated their capacity to 'do' as 'broken', such that their potentiality had not been realised. A longing to do more and feel more productive also resonated with participants' feelings of 'brokenness', a phenomenon consistent with Phelan and Kinsella's (2009) critique of theoretical assumptions of occupational identity relative to notions of productivity. Despite this, participants were still able to recognise that they had meaningful and purposeful identities despite feeling 'broken' (Wicks, 2001, 2003). Such intra-recognition (Morrison, 2010) appeared to function as a type of safety mechanism which was useful in combating negative sociocultural experiences, stereotypes and the prejudices of others.



### ***Wanting to do something that counts***

The first sub-theme which reflects the notion of social recognition (Honneth, 2001) and challenges a broader “ethic of equality” (Townsend, 1998, p. 31) with regards to an individual’s identity, personhood and social ontology is entitled ‘wanting to do something that counts’. This sub-theme highlights the longing to do things that are recognised by others as valuable. ‘Being able to participate’ considers both objective and subjective aspects of doing as well as satisfaction with, and accomplishment of, participation (Anaby, Miller, Eng, Jarus & Noreau, 2011; Van’t Leven & Jonsson, 2002). ‘Being able to participate’ also recognises the breadth of the notion of participation from an occupational perspective, while also acknowledging that each participant had unique needs for participation (Anaby et al.; Van’t Leven & Jonsson).

The following few paragraphs explore some positive and not so positive experiences as expressed by the participants, which provide some insight into the quest for meaningful doing *for* social recognition:

*So in the meantime, I go to the Mission, say hello to people. I actually don't have any friends. I don't have any relatives. My only next of kin is my daughter. And um, and God I suppose. God is my soul mate. And it's [a] very sad life that I am living [teary] and I don't know what to do. Many times I was thinking about committing suicide. And people told me, what about your daughter? It's bad enough that the father is gone. But I, I don't know. But if I go and find a job, people come up with excuses, oh, you don't have experience or this or that. It's too long since I have been employed. I even had a forklift licence. Driver's licence. I could do anything like delivery, things like delivering blood or urine samples, you know, lab things. They just don't put you on. They don't trust you. You are not one of them. It's very hard to assimilate here [teary].*

The first example of doing *for* recognition described through Rose’s story above identifies some implications from lacking meaningful doing which impacted on her worker identity as a productive occupational being (Gupta, 2012). Rose also highlighted her difficulty in relating to others and fitting in, where she sought solace and connection instead with ‘God’. In this example, Rose’s story exemplifies some of the effects of chronic unemployment and feeling excluded from occupational opportunities, including her negative view of finding a job despite having useful skills for employment. Chronic unemployment has been found to be associated with adverse health, social and economic effects, including deleterious effects on mental health

and wellbeing (Jin, Shah & Svoboda, 1995). From an occupational perspective, the lack of discretionary income from chronic unemployment can impede opportunities to engage in other meaningful occupations (Jakobsen, 2009; Whiteford, 2000; 2004) such as enabling social and productive occupations which would contribute towards meaning-making and identity reaffirmation through occupation.

Rose's story is further complicated by feeling 'othered' as well as experiencing acts of exclusion. Her constant use of 'they' describing 'Australian' employers indicates that inclusion into 'mainstream' Australian society through participating in the paid workforce appears to have been a significant challenge for her since migrating to Australia from her homeland 25 years ago. From her account, it appears that the constant rejection that Rose has sustained from potential employers despite her list of skills and qualifications had taken its toll on her emotional health and wellbeing. A systematic review of psychology and health science literature into the mental and physical health of unemployed individuals identified that their overall wellbeing was lower compared with employed individuals (McKee-Ryan, Song, Wanberg & Kinicki, 2005). McKee-Ryan et al. also identified some qualities which were beneficial to promote mental health amongst people who were not participating in the paid workforce. These included having a valued 'worker' role, coping resources (i.e. personal, social, financial, routine, time structure), cognitive appraisals (i.e. positive self-talk) and other coping strategies (McKee-Ryan et al.).

It is evident from Rose's story above that she appears to have experienced social issues that have broadly impacted on her mental health and subjective wellbeing, as described through her expressions of feeling excluded from 'mainstream' Australian society as well as being unemployed for several years. There is salience between Rose's experiences of exclusion and not knowing what to meaningfully and productively 'do', with research which has documented some of the effects of being unemployed. Occupational science research into unemployment has highlighted the "destabilising effect" (Aldrich, 2011b, p. 2) that can result from being unemployed, especially in context with sociocultural norms and expectations surrounding time use and participation in meaningful and purposeful occupations (Aldrich). From a psychological

perspective, the landmark systematic review conducted by McKee-Ryan et al.'s (2005) exposed some adverse health effects related to chronic unemployment. Of note, is the effect of not having *social* types of coping resources (i.e. close family and friends), structured and productive use of time, as well as having high self-esteem and a positive outlook on life (McKee-Ryan et al.). Rose's accounts, amongst many of the other participants' stories, appear to have experienced significant 'destabilising effects' (Aldrich) impacting on their general health, quality of life and valuing their own contributions to their communities.

Other participants experienced similar emotional and psychosocial issues when wanting to do something that mattered (Kuo, 2011), such as establishing a 'worker identity' through participating in paid employment (Aldrich, 2011b; Gupta, 2012). For Annie, another participant, she frequently described the loss of and yearning to regain, her 'worker identity' (Aldrich; Gupta):

*With shopping, mum will come up once a fortnight, stay at my sisters. She's got a bedroom there so we might go out shopping but I'm bored shitless [crying]. I'm so bored with my life, you know [crying]. I'm so bored [sobbing]. And my husband Richard wants me to do hobbies and interests because he can see I'm bored...I mean I'm not as bad off as a lot of people and I count my blessings a lot of the time and I think, what have I got to whinge about. But there's enough physical stuff there to be a real pain in the arse, really, you know. If someone could wave a magic wand and say, "Okay, they're all gone Annie," life would be so different. I'd have a job, I'd have an interest, I'd be working with other people, we wouldn't be in – I love my husband, I adore him, but we're with each other a lot of the time. If I go and have time with my family he's not interested in the family dramas and that's what my life has become about. It's not about helping or serving people. It's not about feeling useful in the community.*

*And I've done a lot of volunteer work over the time and I've decided that - I've just enrolled in a free TAFE [Technical and Further Education] course for the next eight weeks, because it's before my surgery, and it's an adult literacy course. Now I've always had a desire to help people who can't speak English. I was a migrant. I've had the benefits of being from England. I dealt with so many migrants at social security [Centrelink] and I've always had a heart for people who can't speak English. They come to a totally different culture, they've got to learn the language and got to try and cope in this society.*

Aldrich (2011b), Gupta (2012) and Kantartzis and Molineux (2011) have suggested that having a 'worker identity' is central to Western culture. In the story above, Annie highlighted that after several years of working for the welfare system and then for her ex-husband in an administrative capacity, she attributed not being able to work as a type of *occupational loss* primarily resulting from having chronic health issues. Living with chronic pain and depression appears to have negatively

impeded Annie's ability to participate in meaningful and productive occupations. Annie's references to boredom due to a lack of purposeful doing relate to emerging occupational science discourse on boredom and its relationship to occupational deprivation (Farnworth, 1998; Illott, 2007; Martin, 2009; Martin, Sadlo & Stew, 2012). Despite such literature recognising boredom as "the most common emotional response to lack of occupation" (Wilcock, 2006, p. 171), and calling for "a greater understanding of the social and economic consequences of boredom" (Farnworth, 1998, p. 145), it has failed to address the importance of other contextual factors that can also contribute to experiencing such a phenomenon.

Martin et al. (2012), for example suggested that "boredom arises largely from factors within the person" (p. 55), and has "many negative effects" (p. 56). The discourse is generally presented within an 'ableist' framework which appears to not fully consider how individuals and groups who consider themselves as marginalised through poverty and disability, for example, experience and contextualise boredom. In Annie's case, living with disability seems to have resulted in deprivation of paid employment which she considers as highly meaningful and valuable. It appears that the flow-on effect from not participating in meaningful paid employment, living with chronic disability as well as having too much discretionary and unproductive time, lends Annie to experience decreased occupational possibilities (Laliberte Rudman, 2010). Despite being limited in what she could do, Annie's attempts of pursuing volunteering opportunities with migrants was an occupational plan that she recognised as being one which could tackle boredom and incorporate greater control in her life. Thus, pursuing education and volunteering opportunities was an initial step that Annie could try to do in an autonomous manner (Townsend, 1998) to re-engage in occupation for social recognition (Honneth, 2001; Komter, 2005) and self-actualisation (Christiansen, 2007).

Annie's husband Richard, on the other hand, did not relate his day-to-day participation patterns with boredom. Instead, he reported that he attempted to continue participating in meaningful occupations as best as he could throughout his major life transition (Blair, 2000) from acquiring a chronic disability which resulted from surgical complications and ongoing pain

and fatigue. However, the process of transitioning from being a physically active and socially engaged professional business man, to becoming unemployed and the recipient of unemployment pension benefits, appear to have negatively affected his occupational identity (Christiansen, 1999) and wellbeing in general. The following account describes some of the meaningful passive leisure occupations that he described as being part of his new consolidated lifestyle:

*But – see, I – look, if I was going to get depressed, it’s probably – I often say to Annie I’d like to get rid of the TV, but she likes the – her relaxation is watching the TV. I tend to like to read. And when I’m here with the TV on, and I can’t sort of really read that much, I’ve got a Kindle, so I’ll tend to go somewhere else and read that. But I always feel as though when I’m sitting here, the TV’s on, I should be working and making money. I feel as though I’m wasting my life. What am I doing sitting here when I could be wheeling and dealing or doing something out there? But I’m just not physically capable of that.*  
*I really enjoy reading and looking at things, I don’t really get bored. But it’d be good if some of my activities were money-making. I look at the share market and what’s happening there and things. I don’t have the money to put into that at the moment. I couldn’t trade option CFDs or anything like that. A whole lot of things like that I can’t do. And also, I’m just not sharp enough at the moment.*

As described, Richard’s current occupational life is juxtaposed by his reflections on the types of occupations that he previously participated in, which he attributed to being ‘intellectually richer’ and more stimulating. He additionally emphasised that he used to live a type of lifestyle whereby having *choice* between doings and beings were more of an option rather than a luxury. Overt in his account is a longing to return to a life where feeling *productive* and contributing something to self, family and society mattered (Kuo, 2011). Here, it appears that Richard’s worker identity has been significantly affected, resorting to engaging in less meaningful occupations to pass time. Richard’s description of “wasting my life” is a poignant example of the psycho-emotional effects of exclusion (Thomas, 1999) and occupational deprivation from participating in productive occupations, such as paid employment (Aldrich, 2011b; Whiteford, 2000, 2004). Another burden to re-engaging in meaningful financial occupations for Richard was the newfound barrier: not having enough money. This resonated strongly with all of the participants whose entrenched disadvantage was principally focused around not having adequate money to live. This sub-theme

is further explored in the next chapter which investigates the factors which affected living with the interrelated existential realities of poverty, disability and other forms of disadvantage.

### ***Doing things to pass time; doing things that are meaningful***

Despite having significant and constant barriers that affected each participant's sense of identity and personhood in their everyday interactions with others as well as with the occupations that they participated in, the second sub-theme as entitled above identified that *occupation* could also be a transformative and grounding phenomenon (Breedon, 2008, 2012; Frank & Zemke, 2008; Townsend, 1997b; Vrkljan & Miller-Polgar, 2001). Several occupations that the participants engaged in were diverse in nature and provided opportunities to ground their personal qualities, abilities, and daily participation achievements. Thus, occupational participation was not aimed to solely pass time or engage in them for their own sake. The next section describes some of the noteworthy or meaningful occupations that participants engaged in. Following this, the transformative occupation (Breedon) of 'basketball' is analysed in-depth as a case in point, which describes how occupation in and of itself was used as a metaphor to analyse the current and future life trajectories for one of the participants.

#### Diversity of meaningful occupations.

Some of the participants engaged in a diverse range of occupations variously characterised by established routines, meaningfulness, creativity and enjoyment. Due to the lack of participation in productive occupations as the result of being chronically unemployed, the participants engaged in meaningful leisure occupations instead. Leisure occupations are those occupations not pertaining to paid employment which are meaningful, volitional and hold many qualities to the doer, such as having freedom of choice, enjoying discretionary time, experiencing relaxation, and promoting subjective wellbeing (Pereira & Stagnitti, 2008). In this study, the participants' leisure occupations were both active and passive, performed individually, or in the company of others. Pierce (2003) described the latter as 'co-occupations' as those which are

categorised under the sociocultural dimension of occupation involving interaction and active engagement of two or more people. Pickens and Pizur-Barnekow (2009) further extended dialogue on co-occupations by reconceptualising them as those occupations which occur “when two or more individuals engage in an occupation which becomes transformed by aspects of shared physicality, shared emotionality, and shared intentionality. Co-occupations produce and are embedded in shared meaning” (p. 155). Having close family enabled some participants, such as Anthony, Annie and Richard, to frequently participate in co-occupations of shared value and purpose. Other types of occupations that participants engaged in were done so to fill in time in meaningful and purposeful ways which temporarily addressed boredom and feelings of hopelessness. Appendix H provides a comprehensive list of the types of meaningful occupations that the participants engaged in.

The dynamics of leisure co-occupations were also quite unique among those shared between the participants who had children. For example, living with chronic medical conditions significantly impacted on Anthony’s energy levels and his ability to participate in meaningful leisure co-occupations with his eldest son. The following story describes Anthony’s ability to use co-occupations in an advantageous manner so that his son would learn important life skills and be rewarded with being able to spend more time with his father as a fun pay-off:

*I used to go over there [son’s boarding house] and clean it and he’d sit and play PlayStation. And then I thought to myself, that’s not good parenting. That’s actually a maid. I’m not a maid; I’m his dad. I’m here to teach him how to have self-respect and self-esteem. And so I used a little bit of manipulation. He likes to play cricket and footy, and I say, “Well, Dad’s sick, I’ve got Cancer you know that.” I said, “So I get very tired once it gets to 2 o’clock in the afternoon, so when I come to your house, the more work I have to do, the less time I have to actually do things with you like play sport, chess, cards whatever it is you want to do.” And it’s worked. It’s actually worked. I come over and he goes, “Oh, there’s not much to do, dad. We’ve just got to do a bit of vacuuming and catch up with and do bits and pieces.” And yeah, so I’m actually using coping skills. And then we can do more together.*

Anthony’s story of coping with his chronic health issues by educating his son about his occupational performance needs was an example of how participants described specific compensatory strategies that they required or had developed to engage or continue to engage in meaningful occupations. Such a framing of occupational performance, choice and emotional

benefits resulting from participation is uniquely distinct from literature which has documented the health benefits of participating in meaningful occupations, such as leisure occupations (Pereira & Stagnitti, 2008; Sellar & Boshoff, 2006). The majority of the participants did not specifically make mention of either the direct or indirect health benefits, or the subjective feelings experienced through participation as described in such studies (Pereira & Stagnitti; Sellar & Boshoff). They instead focused on compensatory strategies for participation and the positive and negative psychosocial outcomes resulting from participation. This indicates that achievement through doing appeared to be more important than how the doing made them feel, or what health benefits they related to participation in occupations.

#### Exploring the meaningful leisure occupation of basketball as an ‘occupation-as-metaphor’.

This section specifically focuses on the transformative nature of basketball for James, including the influence that basketball has on his future occupational possibilities (Laliberte Rudman, 2010). James’ complex life portrays a man’s journey from being a hardworking elite athlete, to becoming a man wishing to return to “being normal again” following a workplace injury. He considered the act of returning to playing basketball at an elite level in a metaphorical way. Through considering the skills he required to return to playing basketball following his injury, he vividly questioned his own ability to pursue other occupational possibilities (Laliberte Rudman) in the future across *all* areas of his life. I have framed this concept as ‘occupation-as-metaphor’. The following account explores this process. To provide context for this account, James commenced talking with the researcher about his return to playing basketball with a former coach and mentor, prior to commenting on his state of mind. He also shared some insights into the meaning that he ascribed to playing basketball:

*He goes, I’ll give ya the basketball...you just walk out there do what you want to do at your own pace. I’m thinkin’ about it... but yeah it’s just that reality slap I’m still not, how would you say it...still not ready to have that big reality slap of ah yeah you can’t do this. And “you can’t do this” is massive. Whereas before my ‘can’t do’ list was nothing on the court. I never had one. But we’ll get there, we’ll get there yeah, I’m feeling happier at the moment.*



*I got myself in a better frame of mind. And it's all just working at the moment, yeah. But I'm makin' it work. That's the situation. You know, like without me having the attitude and push that I have at the moment, I wouldn't be feelin' the way I am now. So, yeah but we're gettin' there, we're gettin' there. Basketball will be there soon. Trust me.*

*I think that it could be a life changing moment. And that's I think what I'm scared of. That full yes I'm getting better or no I'm not getting good enough to live a "decent" physical life again. It is very hard to sort of get to that point and go, well okay here's that decision maker now. Like the real eye opener. When I step off that court, how am I gonna be as a person? Am I gonna be distraught for the rest of my life because it feels like I'm not going to get anywhere, physically again like that? Or is it going to be awesome because I have realised, okay, I can do things again? And if I realise that, how hard am I going to push to get further on? I know I will push so hard it's not funny. To the limit of maybe doing even more damage. But, I gotta be careful of that, that's all. Yeah, bit of control. Bit of control. [Laugh]. It's just like drinkin'...have a bit of control and you know you can do it a lot longer [Laugh]. You do it too hard, and you won't do it ah for much longer.*

*...Okay, um well at the moment, I sit at home and I hold my basketball and it gives ya a smile on your face. Because I'm one of these people, you throw a basketball at me and I just grab it one hand and I just hold it there like that, like the pros do. To do that is awesome, but when I step out onto that court, I know as soon as I cross that line, it's a different world for me. How do I explain it? I can step onto the rattiest court on the world, okay..., holes in the backboard, whatever okay. Even no backboard, just the basketball ring [laugh]. Okay, um, but when you play as much as I have and you're as passionate as I am about the game in your life, you walk over that line...the rest of the world don't exist. It's just you and that ring. Nothing in between ya. I don't care how many blokes are in between ya. It's just you getting to that ring. That's a goal.*

*... It gives you drive, it gives you passion and that's what a lot of people lack. Passion. I've got a hell of a lot of it and I carry that into my lifestyle where I'm as relaxed as can be. But I've got passion to do anything that I want. And that's why I will not stop, and they will not stop me doing what I want when it comes to work. If they say to me, 'well we don't think you can do that traffic control course'...pfft, whatever. I know I can. I got the drive, I got the passion to do it. Cause there's a reward at the end. There's an income and when I say that, I don't mean cash, money. I'm talking income to improve my life. So that my life gets better. That's my reward.*

*...So, yeah it's sort of funny; the whole basketball thing will screw me or make me. But honestly, I do have the realisation that I'm never gonna be as good as I was. Okay, I understand that. I'm not silly. I just have to I suppose in a sense, in what you are trying to get at, is like not expect so much out of this. And you know what I mean. Like, not expect that I suppose I can still step on a court and beat people although not even be half as good as I used to be. And be happy with that. And just be happy that the fact that I'm out there and I'm still doin' it.*

From James' account, it appears that adapting to other ways of doing or being, or occupational adaptation (Wilcock, 1998), was not the outcome which he pursued as an adequate resolution for participating in an occupation of high personal value. This response challenges common understandings of 'adaptive strategies' (Frank, 1996) in occupational discourses (Sellar,

2012) which favour compensation over restoration (Frank). Frank defined such strategies as “sequences or chunks of action to improve life opportunities or enhance quality of life, often becom[ing] part of a repertoire or style” (p. 51). Despite being a realistic and ‘fair dinkum’ man, normality and restoration were the only goals that would suffice to maintain his occupational identity. In context, occupational identity is conceptualised as “a composite sense of who one is and wishes to become as an occupational being generated from one’s history of occupational participation. One’s volition, habituation, and experience as a lived body are all integrated into occupational identity” (Kielhofner, 2008, p. 106). It also seems that James considered his participation in basketball as a means to an end, where it could either provide some closure and therefore reality into his current life circumstance, or offer some increased hope to continue with his arduous rehabilitation journey towards a “restored self” (Smith & Sparkes, 2005, p. 1097). In both situations, his occupational identity appears to provide some assurance that ‘being through doing’ was still possible as he maintained a positive outlook towards his recovery.

This story also clearly highlighted James’ determination to recover, and the importance and centrality of using meaningful occupations throughout his rehabilitation. On several occasions, James described his rehabilitation schedule which included a gruelling and professionally supervised rehabilitation ‘repertoire’ that involved daily walking, gym work, cycling and swimming to meet his own occupational needs to fulfil his goal of complete physical restoration. Interestingly however, he did not actively include or pursue participation in basketball to assist in his rehabilitation process as this occupation held more personal meaning than repetitive gym work. Regarding his rehabilitation process, James had never interpreted his repertoire as being an adaptive strategy (Frank). From James’ perspective, incorporating adaptive and compensatory strategies (Frank) would be considered as a “half-baked” approach to doing due to his passionate and competitive ‘all-or-none’ attitude.

For James, playing basketball and considering this meaningful occupation as a metaphor for future occupational possibilities (Laliberte Rudman, 2010), echoes the construct of ‘transformative occupation’ (Breedon’s, 2008; 2012). Within a disability context, occupational

scientist Breeden (2008) contended that “some occupations are *transformative* (emphasis added), in the sense of providing an overriding meaning and purpose in the life of...individuals and their community” (p. xv). To differentiate between certain meaningful occupations and their transformative potential, Breeden’s (2008) distinction becomes clearer when she highlighted that

“The power of certain occupations...defined as transformative occupations, ...promote the cultivation and use of a set of adaptive strategies [for people with disabilities which are] designed to ensure access to an occupation that is inherently more meaningful than any other” (p. 9).

Breeden (2012) later added that transformative occupations are “most central to our sense of self and sense of well-being, to inspire the creativity and adaptiveness necessary to overcome obstacles and carve out a meaningful lifestyle” (p. S23). Therefore, in James’ case, basketball can be interpreted as a transformative occupation in his life, but also held other important qualities (i.e. as described through ‘occupation-as-metaphor’) that further enhanced, or had the potential to enhance, his wellbeing, sense of self and quality of life.

### ***Having and upholding values***

Quality of life was accorded further value by the participants through symbolic representations of self *through* occupation. Doing things that were meaningful, purposeful, creative, necessary and productive were symbolic in the sense that some occupations were clear outward expressions of their own personal identities, or subjectivities (Laliberte Rudman, 2005). Through *occupation in action*, or making the intrinsic extrinsic through occupation, some of the participants’ occupational choices (Galvaan, 2012) represented their value systems. For example, some standout, or transformative occupations (Breeden, 2008; 2012) enabled participants to fulfill some of their desires for social recognition (Honneth, 2001; Komter, 2005) as well as being recognised as a contributing member of society. Social and cultural recognition through occupation also involved the participants’ recognition of their own abilities, skills and qualities. Therefore, for social recognition to be possible, these types of occupations required involvement with other people. However, participation with others was not dependent on the delineating

factors that occupational science researchers have constituted for co-occupations in social contexts, such as active engagement, shared emotions, intentions or meaning (Pierce, 2003; Pickens & Pizur-Barnekow, 2009). Instead, doing things, or participating in transformative occupations (Breedon) that upheld the participants' life values, provided even greater meaning without requiring "aspects of shared physicality, shared emotionality, and shared intentionality" (Pickens & Pizur-Barnekow, p. 155). Participating in co-occupations for personal meaning is an example of a key social construction of identity inherent in occupational-based disciplines (Phelan & Kinsella, 2009). In their reflection of theoretical assumptions on identity discourse, Phelan and Kinsella (p. 89) recognised that *socio-cultural influences* form, shape, reshape and give value to identities through dialogical processes and interactions with others.

Examples of co-occupations involved participating with others directly (i.e. through volunteering at Parramatta Mission) or indirectly, through actions and behaviours that were situated within occupational transactions between the self and the broader environment (i.e. walking the dog; Cutchin & Dickie, 2013). Life values guided participation, especially with family, friends, strangers and pets where interaction with other people, services or animals was necessary or ideal for mutual social recognition. Table 5 lists the types of life values that the participants considered as important to living a meaningful, enjoyable and dignified life despite the adversity that they so often described. Claiming to have and uphold such values, as listed in Table 5, appears to influence the participants' notions of self in a positive manner in context with their social ontologies. These reflections on their identities and social ontological positions relative to their relationships and occupational transactions with others is consistent with McQueen's (2011) perspectives on the philosophy of social and political recognition, which highlighted that "because our identity is shaped precisely through our relations to others, our being recognised by them, feelings of self-worth, self-respect and self-esteem are possible only if we are positively recognised for who we are". On recognition and the relationship between occupational participation, occupational choice (Galvaan, 2012) and life values displayed *through* occupation, James stresses for the need for all to demonstrate and live by their life values:

*It is up to every person individually, to wake up, be a real human being and respect other human beings. How can you teach that? That's the problem. People have just got to wake up to that...Those basic values of life.*

Table 5: Participants' life values which guided occupational transactions in context.

Having, giving, gaining and maintaining respect	Having responsibility	Helping others
Doing the right thing (as a motto for life)	Gaining trust and being trustworthy	Relating to others
Humility	Doing things for others	Having a sense of Karma
Doing good for self and others	Finding enjoyment through giving	Developing and maintaining rapport
Being empathic	Supporting others	Being a Role Model
Being honest	Being reliable	Having a good reputation
Putting others first	Wanting to do something with life (being driven, determined and having will)	
Having agency	Having a chance	Having and being given a 'fair go'
Acknowledging uniqueness, equality and justice	Having self-worth	Obtaining success through patience
Being responsible	Sharing knowledge and wisdom	Helping others
Being fair	Being strong (emotionally)	Having a 'can do' attitude
Respecting difference and diversity	Acknowledging importance of family	Having choice
Being a decent person		Having and accepting support
Being tolerant	Having and believing in self-determination	Greeting others
Being and making others (feel) happy	Treating people like one would want to be treated	Realising one's potential and believing in oneself
Having hopes and goals	Committing oneself	Having passion and drive
Enjoying the reward upon successful completion of task	Being positive	Valuing rest and relaxation
Being stress-free	Advocating for others	Believing in charity
Believing in the value of work	Having pride in appearance and self-expression	Being compassionate
Not wanting to hurt others	Helping others make positive changes	Counseling others
Giving advice	Trying one's hardest	
Having fun during participation	Being a team player and team member	Having passion about what one does
Owning and recognising negative behaviour(s)	Seeking self-respect	Being a caring person
Promoting pride in others	Giving others hope	Being fair
Taking responsibility	Having dignity	Having manners
Being grateful	Having and upholding ethics in life	Expecting fairness and giving same
Treating others and being treated with respect		

## ***Having faith***

The next sub-theme highlights a unique finding of this life history study, which determined that the majority of the participants related to *having faith*, which seemed to assist in creating and maintaining a positive outlook on life (Albrecht & Devlieger, 1999; Hammell, 2001; Townsend 1997a). When considering aspects of identity and personhood relative to living with meaning and purpose despite adversity, every participant apart from one valued spiritual aspects of being. However, the participants' belief in something greater than themselves went beyond aspects of spirituality. *Having faith*, rather than being spiritual, was a more accurate fit to understand notions of faith in context. I interpret the participants' beliefs in having faith as going beyond spiritual tenets to include any set of firmly held beliefs or principles that value and guide an individual in ways which are generally positive and self-affirming.

For the participants who identified as believing in and practicing 'mainstream' Christian faith, having such faith seemed to empower them by grounding their everyday realities. Furthermore, having faith helped them to live with chronic health issues in active ways such as participating in the meaningful co-occupation of practising worship and attending Church. The NGO Parramatta Mission, who is affiliated with the Uniting Church, appeared to play a fundamental role in providing opportunities to engage participants in meaningful and diverse occupations. Such opportunities went beyond involvement with traditional Church and Mission activities to include innovative types of occupational participation, such as volunteering and being role models with Parramatta Mission's community outreach programs. One such program addressed social justice issues such as social isolation and homelessness by hosting a free daily lunch program for homeless and marginalised community members.

Other participants shared deep connections with other complex aspects of having faith beyond any affiliations to religious denominations. The following accounts explore some participants' perspectives of having faith, being mindful as well as how such beliefs had served as guiding principles to life in general. In doing so, for example, James identified himself as an Atheist. He clarified his non-religious distinction between being an Atheist and not an Agnostic.

Annie also clarified her position as previously being an avid Christian up until the time when she was involved in a motor vehicle accident which resulted in her Church congregation and her Church friends apparently abandoning her. This harrowing experience of exclusion subsequently led her to re-evaluate her faith and spiritual connection. Further, Annie's husband Richard described his very active journey into seeking spiritual meaning by trying out different Eastern mythologies and religions including visits to India and engaging in silence retreats where he practiced *mindfulness*, which he described as "only focusing on the here and now". The following account describes how Richard has used his spiritual notions of self to combat his depression:

*Well, hope is a – it's a bit of a problem, the hope issue. Because – probably because I'm interested in sort of spiritual areas I – I'm interested in the Advaita Vedanta, the Buddhist teachings on self and all that, and that constantly looking forward for a lot of people can produce a lot of suffering, because then they look forward, then they look what happened in the past. But in actual fact, if I said to anyone in this village right now, "How are you?" they'd say, "I'm okay." Well, our life – my life is just a continuation of a lot of right-nows. If I start thinking too much in the future or what happened in the past, then I get bloody depressed...Yeah. So I generally just say, look, right now. Am I okay right now? Well, yeah, I am. Am I okay just sitting here right now doing this? Yeah, I am. Even when I'm in pain, am I okay? Yeah, I am okay.*

Richard commented on his thoughts about life, happiness and having faith:

*...Once you start not being present to 'now' then what mostly occurs is suffering. As a simple test of this, try washing up the dishes at night and notice what conversation is occurring especially if it is negative such as, 'why can't the others do their own dishes etc'. Now pay full attention to washing up or being mindful whilst you wash up without thinking. You will be the most content and calm when few thoughts are occurring. Notice the space between your thoughts. As Zen monks say just do what you are doing. If you are washing up, just wash up. My understanding is that happiness is our natural state or more specifically living in a state of contentment. I have found that when I live in the present moment and do not give too much power to my thoughts especially thoughts of the past or future I have a very contented existence.*

Finally, Anthony, James and Annie shared their thoughts on particular songs which they had found as ones which epitomised their life journeys thus far, or that were salient descriptors of their own faiths and mantras for guiding their lives.

*Anthony: I walk down the street and I see a man lying on a park bench, and all these people are just walking on by. And the only people that help this bloke are the blokes like me. And I don't mean me; I'm not just praising myself. I meant other homeless people. You're more likely to get a homeless bloke come up to a homeless bloke and say, "Hey, bro, are you all right? Need something to eat? Can I help you?" than the rich. The rich are like – they almost tiptoe around you. And it reminds me of that Phil Collins song, "He called out to the man on the street, 'Sir,*



*can you help me?'. That song breaks my heart because it epitomises everything we're talking about. It actually is – that's – that would be a great song actually to play at the beginning of every meeting of what I'm talking about, these social inclusions...*

*It is a perfect song that Phil Collins wrote – that's divine intervention. That song epitomises my life. It's God. I believe that sometimes songs are written – I don't know. I believe in God really strongly.*

James: *Okay, mainly cause the main line in the song, "Easy like a Sunday morning" by Faith No More. So treat everyday like it's easy like a Sunday morning. Why get up and get stressed? And that's my whole life. The lyrics to that song are so laid back. I find if you're not laid back, okay, yes, we all have stress, we all have pressure, we... [if] you don't lay back and handle life relaxed, it makes it twice as bad; 10 times as bad. You see people dying from heart attacks because they can't relax. Um, my mum for example just did 2 weeks by herself without the boss there. First night, she rings me up, 'how the hell do you handle stress so well?'...Carrying on...I'm like just relax. Like, walk in and go, okay, instead of goin' 'Oh man I've got 15 bloody things to do blah blah blah blah', go in there and go [more relaxed tone], 'Oh okay I've got 15 things to do. I'll just do this one first and I should be able to do that, I should be able to do that no worries'... get through it.*

*Yeah, it's enjoyment in life. Um, but for me to enjoy life, I have to be relaxed. And yeah, 'Easy like a Sunday morning'...what's easier than a Sunday mornin', rolling out of bed whenever you want. Having that coffee whenever you want...nothing's easier. So yeah, Faith No More, 'Easy like a Sunday morning'.*

*...well what do you want from life? You want to be happy. Relax...it makes it easier. Yeah, no stress.*

Annie: *I think that the best song to describe my life would be "We are the Champions" by Queen because I am a fighter. I have battled with my depression and chronic pain. Some days are better than others, but I still consider myself as a champion, not a loser.*

The participants' diverse reasons for describing each song's impact on their lives reflect the diversity of the lived experience of entrenched disadvantage. Each participant's song choice and reasoning appeared to also echo their hope, faith and resilience qualities which they utilised to capacitate themselves throughout everyday moments and experiences (Blair, 2000; Galheigo, 2011).

## **Living for my family**

For four out of the seven participants, notions of *being me*, identity and personhood were centred on being a loving parent. As is described in the upcoming findings chapter entitled “being in the world” which critically explores the impacts of systems of governance on participation and social inclusion, the longing to have a child was one of the major reasons why Rose sought divorce from her abusive husband. Therefore, for Rose, being and becoming a mother to her daughter which she had with her second partner, or *living for my daughter* was a defining occupational experience for her.

Anthony shared qualities of being a loving parent which he constantly described as having a deep connection with his wife and five children. Despite, having all of his five children in foster care and his wife in long-term drug rehabilitation, not spending time with them appeared to further strengthen his bond to them. Anthony believed that his motto in life was to always “be a good dad”. The following story provides valuable insights into his pride of being a father and husband:

*I walk around every day not wanting to be on the fucking planet because the only thing I ever want to ever be is a dad and a husband. That's what I want in my life. Everyone has goals in life. Mine aren't big. I don't want to be rich, a millionaire, recognised for any great achievements. The achievements I want to be recognised for are by my kids. That I love my kids. I'm willing to give them my time. And I spent a lot of time – and even my wife will credit me this – teaching them. I taught them how to draw – we had five things we used to do. I can't remember them exactly but we wanted to teach them things to do with sport, things to do with art, things to do with music, things to do with books and things to do with computers. So that gave them a diversity. It gave them a range of things to learn. And what we found out by doing that was that each one of them were differently gifted in different areas.*

*... I have five children and I looked after them very well. Now any person that meets my children will tell you that they are polite. Well [Anthony's eldest son] he would be a classic example to show you. He is humble. He's talented. [Anthony's eldest son] plays guitar. He plays sport. He does a million things. He didn't learn them by chance. I taught him those things. I taught [Anthony's daughter] keyboard. I taught [Anthony's youngest son] football. I took them to play all the time – if I was such a dysfunctional father, how is it that they have all these trophies and awards at school? How is it they have a perfect attendance record? How is it that the school reports state that they showed no sign of neglect or abuse?*

*...I love my children to death. And the fact that I lasted so long in rehab is proof that I was willing to go to any lengths to get my kids back.*

During the interview process, Anthony constantly described how he practised his goal of being a good dad by engaging in transformative co-occupations (Breedon, 2008, 2012) with his eldest son which built on his talents and skills. His children appeared to be a major influence in maximising his hope of having them return to his care in the future. What was clearly apparent during the interview process was the pride that he had for his children, especially when he reflected on the values that he instilled in them as a father.

From Anthony's accounts and the stories of other participants who were also parents, living for one's family seemed to ground them in a manner which providing meaning, purpose, hope and pride. Being proud of one's occupational role of being a loving parent also seemed to prevent participants from constantly reflecting on their current life circumstances and realities in negative ways. Additionally, being a role model for their children and instilling positive life values appeared to promote a type of healing despite having 'broken' identities.

### ***Having hopes and goals***

The importance of being and becoming a parent appeared to be strong drivers for continuing to strive for a meaningful existence as well as be a role model for the participants' children. Together with parenthood, and also for single participants, this next sub-theme entitled 'having hopes and goals' seemed to also facilitate other types of life achievements. Emerging research in the health and social sciences has identified that narratives of hope appear to be a common phenomenon for people who experience life changes due to acquiring a disability or chronic health condition (Neuhaus, 1997; Smith & Sparkes, 2005; Spencer, Davidson & White, 1997; Tutton, Seers & Langstaff, 2012). The developing theoretical discourse on *hope* has highlighted various aspects that constitute its diversity. From a cognitive perspective, Spencer et al. determined that "imagined possibilities can lead to establishment of goals that are crafted from reconciliation of what is desired (subjectively) with what is possible (objectively)" (p. 192). In addition, hope has been described as also holding emotional qualities, such as being able to

overcome and transcend difficulties through positive ways (Elliott, Witty, Herrick & Hoffman, 1991; Smith & Sparkes; Spencer et al.).

For some participants, the hope and/or goal of wanting to be normal again, as previously described, developed as a superseding concept pertaining to this sub-theme and relate to both the cognitive and emotional aspects of hope (Smith & Sparkes; Spencer et al.). This goal of pursuing normality has salience with the suggestion proposed by Smith and Sparkes that the metanarrative of restitution and concrete hope helps to create, sustain and promote the idea of a “restored self” (p. 1097). Concrete hope, according to Smith and Sparkes, is a type of hope which is results-oriented, where hopes are targeted to “realise desirable outcomes” (Barnard, 1995 as cited in Smith & Sparkes, p. 1096). For the participants, the notion of seeking the concrete hope of regaining a type of ‘normal’ existence, appeared to be driven by both reactionary experiences of exclusion at an everyday level (i.e. discrimination by others which highlighted difference) and regaining confidence with their subjective senses of self in context with their social ontologies. For the latter explanation of pursuing this concrete goal, the process of desiring it appeared to warrant change from within, directly relating to the participants’ identities and the high value that they placed on pursuing this goal into the future (Tutton et al., 2012).

Other challenges also appear to exist which affected the process of pursuing the goal of ‘living a normal life’, such as experiencing a lack of structure and routine to carry out occupations of necessity and obligation due to living with chronic disability. These factors, which also included impairment effects (Thomas, 1999, 2004), appeared to affect the participants’ occupational participation pursuits. Participants’ narratives of hope also seemed to highlight tensions between balancing having them against realising “imagined possibilities” (Spencer et al., 1997, p. 192). Further tensions appear to exist with the existential realities of daily struggles for survival while maintaining “a positive sense of direction in life in spite of emotional acknowledgement of major losses” (Spencer et al., p. 192). These experiences provide further evidence to highlight the impact that living with entrenched disadvantage has on the participants’

abilities to achieve basic goals. Some basic goals, such as getting out of bed and doing the grocery shopping, were expressed as being taken-for-granted and perceived as mundane tasks in the past, which were now apparently fraught with difficulty and challenge.

Some participants actively sought to achieve goals aimed at personal change in positive ways. Clear examples of these included eliminating previous occupations which are socioculturally perceived as harmful and undesired in Western contexts, such as drug taking and stealing. For participants such as Anthony, Bruce and Leigh, this goal was realised when they became recognised peer mentors within their communities. Overcoming such barriers and gaining respect, recognition and positive affirmation from new occupational roles, appeared to be life changing moments for these men. The following account describes James' thoughts on having goals in life (continuing on with the theme of using basketball as an 'occupation-as-metaphor') which describes the value of having "targets in life" despite experiencing entrenched difficulties:

*I'm living my life a lot better since I've played basketball because I've realised, you have that goal in front of ya...ya aim for the goal. You never miss. Things only, they turned out good. Always turned out good no matter what. Cause you don't stop until you get to that target; that goal. Stepping out onto that court for the first time again will be..."can I still do that?" "Can I still look at a goal and have that passion?"...I know I have the passion, I know I've got the drive just to keep reaching for it. But if I can't do the simple on a basketball court, what's that say for the rest of my reaching goals? You know what I mean. Like, that's where I'm at with that conflict. Like you say, what's going to be the positive; what's going to be the negative? Well the positive could be yes I still have targets in life I wanna hit. I can still hit 'em because I can hit a shot from here. You know, like and I'm havin' no problems doin' it still. Yet, taking a run-up to do a dunk...I know I won't be able to do it....actually I lie. I'm pretty sure I can dunk it still. And I'll be happy.*

From this story, James attributed having hopes and goals with also having a positive attitude towards life despite his current situation of living with a disability, which impacts on his participation in social and recreational life. For participants such as Rose, the impacts of having chronic mental and physical health issues, together with experiencing a lifetime of overt racial discrimination, appear to have detrimentally affected her ability to find hope. They also impacted on her ability to find pathways to create opportunities so that she could realise and achieve her principal goal (Spencer et al., 1997): being a productive and contributing citizen through

participating in paid employment. Living each day at a time appeared to be a more tangible and realistic goal for the participants. In addition, finding meaning through participation in transformative occupations (Breedon, 2008, 2012) was more attainable compared to pursuing hopes such as more generalised one, such as relentlessly seeking pathways for change to little avail. Tensions also existed between having hopes and achieving goals for participants such as Anthony who lived each day battling to fight against his chronic ill-health, significant mental health issues and other social impacts. Such complex issues seem to be clustered as common realities for the participants who experienced entrenched and complex difficulties. Dealing with such realities which included health, financial, psychosocial, cultural and systemic difficulties on a daily basis, further added to the participants' challenges of having and maintaining hope as well as forming goals and achieving them.

### ***Being strong and resilient***

The previous sub-theme presented some realities of having, maintaining and achieving hopes and goals, both big and small. It also introduced the qualities of strength and resilience that each participant appeared to have, which they employed to combat the effects of living with entrenched disadvantage and their effects on occupation, participation and inclusion. This final sub-theme of the first meta-theme, 'being me', showcases the tenacity of the participants' strength, determination, resilience and survival which are key components of narratives of hope (Spencer et al., 1997). My analysis of the data identified that all of the participants appeared to be forced to make certain choices throughout their life journeys which significantly challenged their survival and resilience skills.

Forced survival and resilience skills seem to be the most accurate factors which enabled a type of daily living, which challenges notions of occupation and occupational adaptation which assume a level of competence, adaptive capacity and mastery with the 'doing' process (Schkade & Schultz, 1992; Schultz & Schkade, 1992). Therefore, it appears that occupational adaptation was not sufficient or possible for more *complete* or socially recognised types of participation due to the

absence of essential resources (i.e. money to purchase and cook a nutritious meal; being successful in attaining an apartment to live in). The fallout, therefore, appeared to result in incomplete occupational identities being forged. By ‘incomplete’, I infer that the essential constructs of *competence* and *mastery* for occupational adaptation (Schkade & Schultz; Schultz & Schkade) were not possible due to living day-to-day life through modes of survival. Thus, meaningful, purposeful and dignified participation in occupations appeared to become more challenging, which impacted on possibilities for experiencing subjective wellbeing and realising occupational identities.

According to Anthony, key strategies which he practiced for survival focused on being “street wise” and learning the ‘ins’ and ‘outs’ of how things worked *on the street*. He described this skill as being forced upon him when he was a child growing up in a dysfunctional and abusive household in a significantly socially disadvantaged community. The following account describes Anthony’s struggle with long term survival and maintaining hope and strength:

*I can know when someone’s drunk or drugged or lying or whatever, because that’s the skill I have. And this isn’t promoting myself; I’m trying to promote anybody like me that has that ability, because I think it’s an unplugged – it’s a resource that’s not being plugged into, yeah, where you’re seeing people coming out of universities and colleges whose intentions and motives are good, but they become hardened and insensitive because they haven’t actually walked that walk. And until you actually walk that walk, you can’t comprehend. And you could never fully comprehend what it’s like to live the way we do, with incredible sadness. I mean, and that’s the best way to sum my life up, is that I am incredibly alone and sad all the time, and frustrated at – I don’t know what to do. I mean, if they’re going to tell people to do something, they’ve got to follow through from their end. You can’t – because people give up. If I didn’t meet [Anthony’s eldest son] every day, I’m telling you now, I’d be dead. I would. I would suicide. I would go to King’s Cross, I would buy as much drugs as I could get, and I would take it, and I would just go to sleep. Because that’s how frustrated I feel. But that boy motivates me each day, each day when I see that smiling face and that zest that a kid has. And it’s mind-boggling that he doesn’t show – he does show signs of distress and there’s anger and there’s all that, but he copes much better than I do, because you get to a point where you’re just broken. Does that make sense? And that’s where I’ve got to. I’ve got to that point where I’m just tired. And when you get tired, that’s a dangerous place to be, because when you get tired, you get – you give up. And I’m not at the point of giving up. I won’t give up. I told you; I’ll go down swinging. I’m resilient and I bounce back, but others don’t. Like, I would challenge anybody to walk the last 12 months of my life, and see how many of them sit here and talk the way I do now, because most of them would be dead. And if they weren’t dead, they’d be cuckoo.*

In context with Anthony's story above, formal conceptualisations of resilience as documented in the literature seem to not fully acknowledge the complexities of the personal and characteristic factors which individuals living with entrenched disadvantage, such as Anthony, hold (i.e. Christiansen, 2007). Being 'broken' after a lifetime of being brave and resilient appears to have taken a major psycho-emotional toll on Anthony. However, having his eldest son accessible to him despite not being in his custody, seemed to be a key motivator and personal factor which enabled Anthony to re-create and re-evaluate his resilience skills to live a meaningful life. In this account, Anthony also identified that he would not "give up" despite significant adversity and constant daily challenges. Such enduring attitudes which were also shared by participants like James and Bruce are consistent with other narratives of hope (Smith & Sparkes, 2005) as well as Whiteford and Townsend's (2011) critical occupational science perspectives on living with "relentless optimism [and] visions of possibility" (p. 66).

Other participants such as Leigh reflected on "living a tough life on the streets for many years" where he had to survive and support himself. Following drug addiction and undergoing a successful self-rehabilitation process, he sought refuge at a drug rehabilitation facility purely for the purposes of requiring shelter. Leigh portrayed 'surviving' as a highly stressful process which he highlighted as being greatly misunderstood and taken-for-granted within 'mainstream' society. Becoming *street wise* and self-confident also seemed to assist with his interactions with various systems of governance. "Standing up for myself" and other similar comments, was a hallmark of Leigh's resilience qualities as he described them during the interview process. In view of his advocacy skills as a volunteer peer mentor within his community, Leigh informed the researcher that he encouraged others to have "people power and help people stand up for themselves". For another participant, Bruce, however, being *street wise* was difficult due to living in the 'big city' which he described as "a rat race where I wanted to paint myself into the corner". Despite describing this experience as "treading water", Bruce stated that he "accepted" the transition period in his life and believed that living with entrenched disadvantage would not become a



permanent reality. This realisation and concrete hope (Smith & Sparkes, 2005) appears to have assisted him to feel comfortable with situating his life in the here and now.

For James, Annie and Richard, having a strong work ethic across life domains added to maintaining a positive attitude towards their lives and futures (Elliott, Witty, Herrick & Hoffman, 1991; Smith & Sparkes, 2005; Spencer et al., 1997). As a married couple, Annie and Richard indicated that they would never stop trying to regain dignity through finding work again and rebuild their ‘worker identity’ (Aldrich, 2011b; Gupta, 2012; Kantartzis & Molineux, 2011) which would lead to feeling a deeper sense of happiness. James’s ability to keep “pushing hard” enhanced his reasons to continue to improve his life and assist with returning to the ‘normal’ routines and occupations that he lamented.

## Conclusion

In this chapter, I have presented and discussed what *being me* meant for the participants in this study who lived with the entrenched disadvantage of poverty, disability, chronic unemployment and other psycho-emotional and social factors. In the process, I have highlighted some of the strategies that appear to have assisted the participants to form, re-create or consolidate their identities as people of value who deserved mutual social recognition and dignity (Honneth, 1995, 2001). This introductory findings chapter has also outlined how particular transformative occupations (Breedon, 2008, 2012) enhanced the participants’ senses of self and social ontologies in context with others. It has also identified certain factors that seem to facilitate positive notions of feeling and being strong, important, resilient and valued by others and by themselves.

The participants’ rich accounts also highlighted notions critical to theories and practices of social and political recognition (Honneth, 1995; 2001). Philosophy scholars of Honneth’s theory of recognition have suggested that people should have a duty towards others which are recognised by moral relationships, as well as having a basic level of moral status (Ikäheimo &

Laitinen, 2007; Smith & Deranty, 2012). Unfortunately, it appears that the opposite case was the reality for the participants which directly affected their senses of self resulting in under-realised identities. Consequently, the participants' identities and senses of self appeared to be affected by *not* being appreciated as having equal dignity and moral status through exclusionary acts, thus feeling *othered* and *excluded* in the process.

The following chapter further explores the existential realities of everyday life for the participants, focusing on what *being in the world* actually entailed, including an analysis of recognition theories relative to mechanisms of exclusion in context. This is presented through an analysis of the barriers and enablers which appeared to influence and impact upon the participants' occupational participation and social inclusion.

## Chapter Five

### ***Being in the world: Existential Realities***

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*Persons with disabilities experience worse socioeconomic outcomes and poverty than persons without disabilities*

- World Health Organization

*The oppression that disabled people experience operates on the 'inside' as well as on the 'outside'*

- Carol Thomas, Medical Sociologist

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The previous chapter identified key factors which both supported and constrained the participants' individual subjective experiences of 'beings' and 'doings'. Of note was an overwhelming sense of strength and resilience through occupation despite individual situations and experiences of prolonged hardship. Despite the struggles for social recognition from others, the participants highlighted specific occupations which facilitated positive self-worth and in some cases were identified as being transformative in nature (Breedon, 2008, 2012; Townsend, 1997bb). This chapter considers the second meta-theme of "being in the world" (see Table 6 below for the sub-themes) which moves from individual perspectives of beings and doings, to how the participants' accounts of their own experiences of entrenched disadvantage affected their everyday lives. This explanation of lived entrenched disadvantage in context is what I mean by 'existential realities' in this chapter. Particular focus is drawn on, but not limited to, the existential realities of living with poverty as well as disability. This chapter also uncovers some complexities inherent within experiences of disadvantage and identifies other sociocultural factors which have further enhanced feelings of exclusion and *otherness* within the fabric of Australian community life. What is drawn from the participants' accounts reflect perceptions and experiences of a seemingly marked social divide between privileged citizens and the *others* (Pease, 2009).

The latter experiences of feeling othered and excluded are explored in context with interdisciplinary perspectives of disability philosophy including how they are constructed and interpreted within Western societies (Phelan, 2011). The chapter concludes by considering the interconnectedness of the first two meta-themes as they relate to the participants' stories of entrenched disadvantage, participation realities and the outcomes of their attempts to experience greater inclusion in society. This chapter also uniquely outlines a schema of four mechanisms of social exclusion which explores and unpacks the causation of 'exclusion' experienced at an everyday level. I have labeled the four mechanisms as (1) acts of exclusion by others (cause); (2) how such acts are interpreted at a psycho-emotional level (processing of causation); (3) the impacts of feeling excluded (effects), and (4) exclusion read against social norms and expectations (contextualisation).

Finally, this chapter sets the scene for the next findings chapter which considers the major meta-theme from the life history study documented in this thesis. In particular, entrenched disadvantage is considered relative to experiences of systemic disablement which appear to have further hindered opportunities for participation and inclusion in all aspects of community life.

Table 6: Findings from the life history study.

Meta-themes		
<b>1. <i>Being me:</i></b> Identity and personhood	<b>2. <i>Being in the world:</i></b> Existential realities	<b>3. <i>Being in the system:</i></b> Experiencing exclusion and disadvantage
Sub-themes		
Wanting to do something that counts (recognition)	“Living with disability is one of the hardest things”	Being told what to do Not getting a “fair go”
Doing things to pass time; Doing things that are meaningful	I can’t afford to live Feeling excluded and having little hope	Being powerless Feeling demoralised
Having and upholding values	Living in a community lacking compassion	“I don’t know what to do or where to go”
Having faith	Feeling lonely and isolated	“Falling through the cracks”
Living for my family		It’s too complicated
Having hopes and goals		Experiencing a lack of compassion and empathy
Being strong and resilient		

***“Living with disability is one of the hardest things”***

Within this meta-theme presented in this chapter, the most prominent sub-theme which emerged from data analysis involved the stark realities of what it is to live with various types of disability. Participants expressed numerous accounts of unique experiences of how they addressed their own barriers to participation in occupations and in society more broadly. This section explores some of these stories, focusing on particularly moments which best represented their descriptive experiences in terms of detail, relevance and impact.

For all participants, ‘being in the world’ consisted of living with disability resulting from chronic illnesses in the presence of social factors which negatively impacted on situations of entrenched disadvantage. Disability, it seems, was not experienced in isolation, but rather added another negative element to the participants’ complex cycles of disadvantage (ASIB, 2010).

Accordingly, learning different ways to manage life, or compensate in physical, psychological, social and/or spiritual ways, seemed to be key strategies for dealing with loss and change. Identifying these factors reconceptualised how the participants perceived their own chronic illnesses, both from a *temporal* perspective as well as how they managed them within their social worlds.

An example of understanding chronicity in context is reflected by several participants' stories about living with pain. Participants identified that living with low income significantly affected their ability to afford a consistent treatment regime to manage their pain. Therefore, traditional pain management through pharmacological or other treatment modalities was sporadically accessed at best. As a result, participants were rarely able to obtain long-term relief due to access issues (i.e. financial, physical) which further added to the complexities of their chronic health problems.

For Leigh, living on Newstart Allowance (the standard Australian social security payment of \$35 dollars per day) meant constant debt. This led him to seek other less conservative means to attempt to control his daily pain (from having Osteoporosis and lumbar spine degeneration). Due to a distrust of the medical system following repeated experiences of discrimination and “telling them what they wanted to hear” which masked his treatment inconsistencies, Leigh engaged in less than safe self-medicating practices. The following account describes Leigh's experience of attempting to control his chronic back pain:

*I don't take pills. I've never even taken antibiotics. And someone gave me a little – a little shot of one of his tablets one day and all of a sudden I felt good. I felt like – I wasn't stoned. But I could get around and move things which was probably the wrong thing 'cause then all of a sudden I've – I became reliant on it...I'd go up the road and the bloke would give me a little shot and you're only paying \$10 a pill. And I don't take a full pill so... I stretch it out. As I said, I take it for self-medication...People that use it usually have a whole pill where if I get a pill it takes – it can last me four days. So I would use a tiny little bit – just – doesn't make any difference. I'm still having one. But in my mind it does. I'm not using it for recreational purposes. I'm using it for medication really. And that's why I boot it up me arm because that's when – I usually only take a little tiny bit and it gets rid of the pain. 'Cause I have some mornings I just cannot pull my fucking pants on. I've got to sit on me bed and pull me pants up to me knees and then stand up and pull them the rest of the way... 'Cause me back just won't – and as I said once I get in here – by the time I get here I'm right. 'Cause I've moved and everything.*

Leigh's story above highlights what can happen when a person falls out of accessing services for basic healthcare. Leigh's experience of apparent discrimination by medical practitioners has led to a generalised mistrust of the medical system. Therefore, what could have been a rather straightforward transaction between accessing a free medical service resulting in a routine prescription for pain relief at a concession rate, instead led him to seek more radical ways to access potentially similar medication. The latter option that Leigh chose for pain management developed into a consistent and accessible one over time, where his dignity was spared without being judged by his appearance. Ironically, Leigh is probably spending more money to fund this option in the end, which could further hinder meaningful, purposeful and dignified participation in occupation.

James was another participant who did not follow conventional means to manage his chronic leg pain following a workplace injury. James attested that his previous lifelong involvement in the meaningful occupation of being an elite athlete and champion basketballer resulted in a more practical and hands-on coping strategy compared to pain medication. Over a period of six years, James used returning to participate in basketball as an *occupation-as-metaphor* (described in the previous chapter) to spur his self-motivated rehabilitation with its triumphs and set-backs. James' approach to his hopeful recovery revolved around the goal of "wanting to be normal". Here are some of his insights into what it meant to live with disability:

*To be honest, when I wake up in the morning, it's because of the pain. Within an hour, I'm ready to sit down again. You know like really, actually feeling sick in the head and the stomach from the pain. You sort of sit there and you go, ok well I've gotta get through this. You can't just sit there and do nothing. You know like that's just not me anyway. You know, my background with the sport, you just keep pushing. In the end, I told them I want to work 38 hours a week. I want to be normal. I don't wanna be considered 'disabled'. Yeah, because I don't consider myself 'disabled'. I consider myself having a slightly bigger speed hump in my life at the moment than most people would have. Okay, so deal with it.*

*...I think having a disability has taught me more about myself as a person...I just don't let things get me down as much anymore. I've been through all the depression all of that and got myself out of it. Didn't touch the drugs that they give ya. You know. Obviously I don't want to live the rest of my life on drugs or pain killers. So I refuse all of that and I've done it the right way. I'm on a good track. Why let it go down?*

Both Leigh and James' accounts seem to have salience relative to the theoretical framing of chronicity proposed by Manderson and Smith-Morris (2010). They suggest that counterhegemonic discourses and pragmatic solutions are necessary in understanding chronic illness and resulting disability across the lifespan, "rather than temporally liminal illness events" (Manderson and Smith-Morris, p. 11). Manderson and Smith-Morris also highlight that conceptions of illness are bounded by temporal notions of 'acute' vis-à-vis 'chronic', without contextual consideration of the life-long nature and continuum of living with disability. The participants' stories of the impacts of having chronic health and social issues reinforce the need to dispel such acute/chronic dichotomies (as suggested by Manderson and Smith-Morris), as well as the need to re-evaluate temporality in light of disability experiences. Additionally, the participants' stories reflected how life-long manifestations of chronicity played out in everyday life, where disability management such as coping skills were paramount. Literature suggests that adjusting to disability, and adapting to occupational patterns which may be challenging, are important towards experiencing a sense of normalization (Reeve, 2004; Yerxa, 1993). Regaining a sense of normality in the rhythms and routines of everyday life was the principal goal for all of the participants. For participants such as Richard, Annie, Barry and James, they frequently told and relived how life was before they acquired their chronic illnesses which then manifested into chronic disability.

In a traditional medical model conceptualisation of disability, disability itself has generally been misrepresented as being about dysfunction at the individual level (Shakespeare, 2006). Conversely, the social model of disability which emerged in the 1970s has radically challenged individual and medical models of disability (Barnes and Mercer, as cited in Goodley, 2011, p. 11). As discussed in Chapter 2, the social model of disability conceptualises disability as being socially constructed (Goodley; Shakespeare; Watermeyer, 2009), instead of assuming that the individual is disabled by their particular impairment. The social model thus proposes that disability occurs from systemic, structural and attitudinal barriers which include various levels of discrimination (Finkelstein, 1980; Oliver, 1990, 1996; Thomas, 1999; Watermeyer, 2009; 2012). Compared with



the medical model of disability which is reductionist in nature, the social model stresses that individuals with disabilities should not be 'blamed' for their disability (Calder, 2011; Goodley; Siminski, 2003; Thomas, 1999).

There is a growing acknowledgement in fields such as disability studies which critiques the 'all-encompassing' assumptions inherent in the social model of disability (Reeve, 2002; 2008; Thomas 2004a, 2004b). Critics have proposed that the social model cannot entirely capture the externalising social nature of disability without recognising social-relational considerations of disability *as* social exclusion on the grounds of impairment (Thomas). Further, the social model ignores considerations outlined by alternative disability theories and conceptual models, such as the psycho-emotional dimensions of disability (Reeve; Thomas), the affirmative model (Cameron, 2007, 2010; McCormack & Collins, 2012) or a psychology of disability (Watermeyer, 2009; 2012). From an extensive analysis of the literature, I propose that occupational disciplines (Sellar, 2012) such as occupational science and occupational therapy have traditionally documented accounts of the personal and subjective experience of disability more so than social constructivist perspectives (Hocking, 2000). Until recently (Hammell, 2007; Kielhofner, 2005; Phelan, 2011), scholarship in such disciplines has not typically problematised, or made explicit how disability philosophy could influence theoretical and practice development. This points to a potential disconnect or undervaluing of disability theory, its utility and its influence on the day-to-day lives of individuals living with disability (Hammell; Kielhofner; Phelan).

Data analysis identified consistency with understanding the multidimensional nature of disability inclusive of social constructivist, social relational, psycho-emotional and affirmative approaches to disability. Such theories (i.e. McCormack & Collins, 2012; Reeve, 2002, 2008; Thomas 2004a; 2004b; Watermeyer, 2009, 2012) were therefore found to be relevant towards contextualising some of the lived experiences of disability from the participants' perspectives. Their stories captured the personal and psychological within the social, or the subjective and lived experiences of disabled life (Watermeyer, 2009). Thus, these findings suggest that the social

model of disability should not be considered as the dominant model in isolation of personal accounts and subjective experiences of disability and its impairment effects (Thomas).

The types of health issues experienced by the participants were diverse in nature, and included chronic illnesses, physical disability, impairment (physical and psychosocial), as well as disability resulting from mental illness which were all experienced in combination with other chronic illnesses. As previously stated, no one type of health issue was experienced in isolation from other challenges. The participants' entrenched and chronic disabilities evidenced the broad spectrum of how disability has been defined in legislation (i.e. Disability Discrimination Act 1992 and its amendments 2009) as well as how it has been described in the literature (World Health Organization, 2011). In this study, participants' own experiences of disability manifested from living with chronic illness and other complex health, psychological and social issues over time. Therefore, disability viewed in this way is distinct from other conceptualizations of disability, and should not be misinterpreted from other forms of impairment or disablement such as congenital disability or intellectual disability.

As previously discussed in this section, medical sociologists Thomas (2004a, 2004b) and Reeve (2002, 2008) joined other disability theorists such as Corker and Shakespeare (2002), Shakespeare (2006) and Watermeyer (2009; 2012) in challenging the dominant 'social model of disability' which lacks consideration for the personal experience and acknowledgment of 'impairment effects' on individuals (Thomas). Data analysis identified countless stories of the existential realities of the *personal* experience of living with disability. For Rose, living with major depression had a significant impact on her ability to feel completely 'at home' and adjust to Australian social life:

*I find out there's nothing here for me. I try to be social, by going to churches on Sunday or Saturdays and I found that I am going there and no-one wants to talk to me. My daughter didn't want to come with me either. I was standing there and crying and I was very lonely after my man died. And I felt very disappointed. I went back home [Country of origin] and I couldn't get help. I had to come here [Australia] and I got more depressed, more depressed. And I've been diagnosed with major depression. And that's what stopped me from looking for work or being interested to live in this society. I end up coming here to Parramatta Mission when they give*

*handout and they help the homeless and people with drug and alcohol problems, which is not my place to be here. But I have nowhere to go, no friends.*

Applying the schema outlining mechanisms of exclusion which was introduced at the beginning of this chapter, it is clearly evident from Rose's account that a chain of events including the loss of her partner and not relating to others in social and cultural ways, appeared to promote greater depression rather than relieving it. For Rose, the implications of feeling excluded from occupational participation by people engaging in social occupations, such as participating in church and other places, appear to be significant. Compared to particular sociocultural norms related to social occupations such as participating in community places, Rose's story highlights her yearning for meaningful participation, productivity and acceptance. Therefore, the exclusionary effects for Rose look to be more than social-relational ones alone, and seem to flow into other aspects of self, identity and psyche such as low self-worth and living a less dignified and quality life.

Annie also described unmet needs and difficulties with "juggling" her life following her involvement in a motor vehicle accident and experiencing depression. Unfortunately for Annie, being subjected to a court case at the same time as separating from her first husband further exacerbated her recovery. She described this experience as particularly traumatic:

*I was 45, two young children, facing the prospect of having to get myself retrained to go back into the workforce with an injury, and was in chronic pain all the time, trying to deal with that. I just had to plough my way through the mine.*

Following a period of time in which she met her second husband, Richard, who she attributed as being a tremendous support to her, she actively engaged with a Disability Employment Service in the hope of returning to meaningful employment. However, Annie described finding a job which she could physically and psychologically manage as being particularly troublesome, leading to daily feelings of frustration. Upon reflection, Annie believed that her health above other social factors such as living on welfare payments was her main barrier to participation. In the following account, Annie describes some of her limitations to engaging in meaningful and dignified occupations:

*I think it's my health. I really do. I think it's my health. I'm willing to go give it a shot, but I don't want to treat an employer unfairly and walk in there and say, "Well yeah, I'll give it a shot and they start to train me up and all that, and then – and I don't want to have to be explaining myself to people all the time. I don't want to have to be ringing [Disability Employment Service Case Manager] saying, "Look, I've tried this job for two days and I've got such bad headaches, or whatever." I mean, she's telling me the other day, with these care jobs, because this lady who was doing the care course said – I said, "Look, I've got these problems, am I wasting my time doing this course?" And she went, "Oh, no." She said, "It is such a growing industry, we need people who can care for people with all sorts of needs. Not necessarily – I can't physically lift someone or that sort of thing. She was going to refer me to a job where I'd be driving disabled children in the Parramatta area to school, and I thought, well okay, I can drive them to school, that's fine. And then I'm thinking – my husband said, "Do they have wheelchairs?" I said, "I don't know." He said, "How are you going to manage the wheelchairs." I thought, well I definitely can't with my wrist. I possibly could once my wrist heals and I could try it and see how my neck copes with it. He said, "Some of those weigh 20 kilos." He said, "You've got lower back pain and problems with that. How are you going to do that?" I almost thought I would have to cancel this appointment today because I vacuumed the house yesterday. Every time I move, my nerve pinched and I thought – I just eventually ended up having to get myself on the lounge suite and just lay there and thought, "I'll get up in the morning and see how it is". And I can feel it now. I'm thinking, "It's going to be fun getting off this chair to go out of the room". So I don't know. It's all a morass, perhaps you can see through.*

Describing her experiences as a “morass” was consistent with how Annie conveyed her stories of “not being able to do much”, not knowing how to manage as well as “not being in control”. Annie’s story speaks to issues pertaining to the taken-for-grantedness and systemic (mis)understandings of chronic illness and related disability. In particular, Annie recounted some effects of participating in occupations such as training, future paid employment and doing things of necessity, obligation and volition (Christiansen & Townsend, 2010; Whiteford & Townsend, 2011) such as doing the housework. In particular, her account highlighted systemic difficulties with understanding and considering the relationship between disability in context with occupation, such as the disability employment service case manager taking for granted the particular tasks and activity requirements that a future career as a caregiver would involve.

Anthony described living with chronic disability as “one of the hardest things”. However, it was not experienced in isolation. For all of the participants, several competing factors seemed to occur simultaneously, where the effects of disability were compounded by other forms of disadvantage. In most cases, the impairment effects (Thomas, 1999, 2004a) of disability were not as important as other social factors (such as those which are described in the upcoming chapter

on systemic influences on occupation, participation and inclusion). In the following account, Anthony describes some of his day-to-day realities of entrenched disadvantage:

*Alright. Well, we'll start with the living with the disability. That's the hardest one for me of all, because of – how do you say it? I'm always nervous, always scared. I always have this feeling of impending doom. I'm always afraid. Like, if I see the police, I haven't committed crime since, like, '92, but I still have this fear because of the way I look, they always target me. And – which frustrates me, because usually it's when I'm with my son. And I've actually thought a lot about what you spoke about recently, about how the government can better help. And I actually got to a point of thinking I empathise actually with the government, because you're stuck between a rock and a hard place with some things in how you can help; help people with disabilities. But I think, for me, what I find difficult is what to do with my time, and self-esteem, self-respect, feeling good about myself. And you see all these people going off to work and not – like, frustrating for me is, like, it's really tragic what's happened in Queensland, okay [2010-2011 Queensland floods]! And I empathise with their plight. Having said that, it frustrates me that the government can suddenly pull \$5 billion out of their arse to help all these people who are quite well-off anyway, and I'm seriously not taking away from a tragedy. I see it for what it is and it's great that they're doing it, but why can't that money be made available to the homeless, or to the mentally ill? I mean, for me, for example, I came out of the rehab 'straight'! 'Gung-ho'! I was really on fire to change my life! And so I turn up at Housing Commission and I have Graves' disease, which makes me feel very tired – like, up to 2 o'clock, I'm fine, then after that, I'm absolutely stuffed. My emotions can go from happy and joyous to absolutely suicidal, and that's fair dinkum! That's how I go. And what frustrated me is that Housing Commission tells me they're going to give me a home if I give up my home to go to rehab. So I do that. I come out, and then they say, "Oh, you have to go on a list." And I'm like, "Okay." I go on a list. And then they tell me I've got – I mean, I've got – you're living on the streets and you've got to accumulate all these forms. That's halfway impossible as it is. I mean, I'm battling to be able to keep one bag together and shower and shave and keep myself looking respectable. And so you – it's, I think, something that they should really take a look at is the way that when people come out of jail or when people come out of rehabs, or whatever, that they don't throw them back into the pit, back into the ring.*

Although Anthony highlights that living with disability is difficult, what strongly resonated from his story was a deeply rooted feeling of hopelessness. Together with describing the effects of living with complex chronic health conditions which resulted in having low energy and feeling anxious, Anthony also described being and feeling discriminated by systems of governance such as the Police, the Department of Housing and the Department of Community Services which have impacted on his ability to participate, regain some control of his life and belong to his community in meaningful ways (Hammell, 2004; Iwama, 2003; Wilcock, 2006; 2007). To use Anthony's analogy, being "thrown back into the pit" describes his struggle to adapt to a new life within a complex and challenging world, with little or no support. The difficulties that have

apparently resulted from this exclusionary experience seemed to develop into a major barrier towards participating in society as a *valued* and contributing member. For Anthony, such barriers included re-engaging with occupations in society without having available supportive accommodation, low finances, lacking family support and coping with the effects of chronic disability. Furthermore, data analysis revealed that the impact of not having enough money strongly resonated for all of the participants in this study. The following sub-theme entitled “I can’t afford to live”, explores the issue of material deprivation in-depth by describing how living with low income has affected the participants’ ability to live a half-decent life *for* meaningful, sustainable and dignified occupational participation (Kronenberg & Pollard, 2005).

### ***I can’t afford to live***

The participants’ stories exposed a stark reality of exclusion which they related to a marked discrepancy between the ‘rich’ and the ‘poor’. They associated themselves with the latter group when referring to material goods such as having adequate finances and essential living items such as food and shelter. This is consistent with the material aspects of poverty. Participants also perceived that there was an imbalance between the ‘haves’ and the ‘have nots’, or those who are deemed ‘in’ vis-à-vis those who are ‘outside’ the dominant cultural group (Yuval-Davis, 2006). Sociologist Yuval-Davis identified that minority group members, such as the participants in this study, are often bound by a *hegemony* whereby they are subjected to, and accept the dominant group’s order and ways of being which may disregard their abilities and contributions to society (Wilding, 2011). What follows is a process of social stratification where marginalised citizens become categorised as *other* by the dominant group and thus occupy a subordinate position (Guimond, Dambrun, Michinov & Duarte, 2003; Yuval-Davis, 2006).

One of Yuval-Davis’s (2006) major claims highlighted that one’s perceived social location determines a type of “*positionality* along an axis of *power*, higher or lower than other such categories” (emphasis added; Yuval-Davis, p. 199) which can act as direct or indirect expressions of exclusion, prejudice or privilege. For the participants, living with little money and other

essential resources directly affected their lack of empowerment to have a ‘decent’ life, and therefore led to a lower sense of positionality (Yuval-Davis) along a metaphorical social axis. This theory is also relevant to literature into public health, and specifically to research into the social determinants of health (CSDH, 2008) which related a higher sense of wellbeing, healthy outcomes and sustainable resources to do and be with a positive *social gradient*. The inverse relationship of a negative social gradient (CSDH) depicting a lower sense of wellbeing, quality of life and not having sufficient resources (both financial and essential) to do, be, become, belong and flourish (Hammell, 2004; Iwama, 2006; Iwama, Thomson & Macdonald, 2009; Seligman, 2011; Wilcock, 1998, 2006) was a more accurate description of the participants’ realities of entrenched disadvantage and exclusion.

For participants such as Anthony, being a welfare recipient and living on Newstart Allowance constantly challenged his ability to budget and find ways to ‘make ends meet’:

*Money talks, bullshit walks. It really does. We live in a society where we’ve got people with billions of dollars, I mean billions, and others that, like me, I get \$600 a fortnight. I’ve got to pay rent, food and my medical costs alone equal over \$150 a fortnight. It’s almost impossible for me to survive. Unless I come to a place like this [Parramatta Mission Food Kitchen] and eat that bread and food that they give me, which a) I don’t like, and b) I’ve got to communicate with ‘that’ [other people experiencing disadvantage]. And it’s just not right...Even I feel a disdain with some of the people that work in these places. It’s like they become hardened, like nurses. And I get that. Like, some people become desensitised.*

In the above account, living on a low income was a major determinant in Anthony’s ability, or lack thereof, to provide for himself and for his eldest son who was under the care of the state who he visited daily. This brief account highlights several issues associated with living with low income which pertain not only to occupational participation restrictions in terms of what he can and cannot afford to do, but also outlines the importance of non-government organisations (NGOs) in their role of assisting marginalised people in situations of disadvantage. This story further describes certain challenges to Anthony’s pride and how he feels he is perceived by others. In particular, the final sentences in this account allude to Anthony feeling patronised by service employees which could influence a decreased sense of belonging.

Research into the associated costs of disability (Saunders, 2006) resonates with Anthony's experience of poverty. This research reported that poverty and hardship is proportionately higher amongst people living with disability (Saunders). Anthony also recounted his experiences of attempting to prioritise how his limited income would be spent. However, he also recognised that spending money on essential items and utilities was further outweighed by attending to his financial debts. Therefore, several challenges exist for Anthony which are common realities among people living with poverty (Blanden & Gibbons, 2006). Blanden and Gibbons stated that the entrenched nature of poverty, such as a lack of resources, impacts on many life domains resulting in numerous forms of deprivation. The following account, as well as another one as told by Leigh, further explores some realities of living with disability and low income:

*Anthony*

*[Are you renting?] Yeah. I'm paying rent for that, rent for the fridge, rent for a washing machine, rent for a laptop. I'm paying off a social security debt, Housing Commission debt. I'm paying \$150 a fortnight on medical costs. And then I'm paying food, rent and electricity, phone, and then trying to eat. And then on top of that, trying to spend time with my son each day. And it – I get to the bank and I see \$750 and I think, "Oh, right, I've got to pay all my rent," so I'll pull out \$150 and I pay [person who he is sub-letting from], and I've been paying off a jumper for about four weeks, so I go and – I finally got my Australian jumper in there. And then I'm \$600 in the bank, and I start to shake. I actually start thinking, shit, all right. Let's divide that into two weeks. That's actually \$300 for this week. Now, I've got \$50 I've got to pay this week on the thyroxin. I've got to get all these medications. I get a pharmaceutical allowance, which is \$30. So my needs supersede the actual allowance that's given.*

*Leigh*

*I get – unless – different before I was put on Newstart – I take home 260 a fortnight in my dole cheque. So I've gone from getting \$800 a week to 260 a fortnight. 'Cause I got to pay everybody back. I'm paying the light back, I'm paying everyone back. Yeah. And I can't do it. And so I'm broke all the time. So what would happen if places like this, Parramatta Mission, didn't exist? I would have stuck to me life of crime. I'd have no choice.*

Both Anthony and Leigh's stories highlighted the complexities of their attempts to stay afloat with managing debts, dealing with unavoidable healthcare costs and day-to-day living expenses. They both described having needs which superseded their financial capacities as well as Leigh describing himself as "being broke all the time". These accounts seem to have salience with the challenges of surviving with rising costs of living as well as juggling other unintended expenses



such as medical management costs and paying off financial debts (Jeon, Essue, Jan, Wells & Witworth, 2009).

From an occupational perspective, ‘surviving’ seems to more accurately reflect *participation* for these men, rather than traditional perspectives of ‘doing’ and ‘being’ (i.e. Wilcock, 2006), which assume a level of mastery and control with what one does in context. For participants such as Anthony and Leigh, their ability to survive was shrouded by constant challenges with managing their finances which posed as a chronically overwhelming problem. Therefore, ‘doing’ was less efficient and constantly challenged their financial survival skills. As a result, exclusion effects for these participants resulted in a perpetual cycle of living within a level of *deep exclusion* and poverty (Hayes, Gray & Edwards, 2008). Overtime, living in chronic poverty and occupational deprivation (Wilcock, 1998; Whiteford, 2000) can have a profound effect on the expectation of living a life of value, meaning and purpose (Sen, 1999).

Population based studies have demonstrated the chronic poverty can have intergenerational impacts which in turn deprive future social and occupational possibilities (Australian Social Inclusion Board, 2011; Laliberte Rudman, 2010). Research conducted by the Australian Social Inclusion Board has recognised that chronic poverty and social exclusion is the result of “lower productivity and workforce participation, preventable health problems, long-term welfare dependence, and increased rates of crime, distrust and social isolation” (p. 3). Nevertheless, such abstract and discrete elements which describe poverty and exclusion disregard and downplay the personal and emotional toll of *experiencing* such realities. From a psycho-emotional perspective (Reeve, 2002; 2008), some of the biggest implications of experiencing material deprivation and poverty for the participants resulted from having a negative outlook towards seeking sustainable paid employment due to past experiences of being unsuccessful in gaining work. They also reported a general feeling of disenfranchisement from community and place.

What was also evident through both Anthony and Leigh’s stories was the reluctant but important acknowledgement of the role of NGOs. For these men, Parramatta Mission played an

important role with addressing essential gaps to living, such as being provided with accessible food options and other basic services. The services provided by NGOs such as Parramatta Mission have potentially assisted them from declining into deeper poverty and experiencing other psycho-emotional effects. The participants' stories into their interactions and general participation with NGOs such as Parramatta Mission were positive and enriching overall. Such outcomes affirm that NGOs can deliver services for marginalised people which promote organisational values which reflect care and compassion (Parramatta Mission, 2008).

Like Anthony and Leigh, James also battled to manage the cumbersome realities of living with low income. James expressed that budgeting for and paying back loans further added to his disdain of being chronically unemployed. In addition, the rising cost of living including his rental accommodation, led him to utilise other means to adequately pay off his debts. His account below provides valuable insights into living a life of debt despite receiving welfare payments. Additionally, James' financial challenges did not account for additional expenses such as Anthony and Leigh's ongoing health and medical management costs or Anthony's costs associated with spending time with his son. This suggests that Newstart Allowance was still inadequate to support a 'reasonable' standard of living. There appears to be salience with these men's accounts of financial hardship with NGO-orientated research into the adequacy of welfare allowances (ACOSS, 2012a). The main outcome of ACOSS' research highlighted that conservative estimations of living costs *exceeded* the amount provided to welfare recipients who received such allowances (i.e. Newstart Allowance). In the following story, James outlines his experience of financially "being in the red":

*At the moment, the income I get is ridiculous. I don't know if you know much about Newstart payments and stuff like that? But I get rent assistance everything, \$590 a fortnight. I pay \$460 a fortnight in rent and I'm a big boy. I eat a lot. You know, to go to interviews, you need money. I'm left with you know, 100 something; 50 of that goes towards bills a fortnight. What are you left with after that? After you do your shopping. You know you are left with like 10 bucks for a fortnight...You're probably in the red if anything. I owe about \$850 bucks in rent at the moment. They upped it, and I didn't actually get the letter saying that they upped it. And I was saying that why am I getting letters saying that I owe rent? You know, I'm actually tapping into my own super [superannuation] to try to do this and survive.*

Despite owing money for rental payments and needing to access his superannuation to make ends meet, James had strong opinions about having the autonomy and right to choose where he could live. The following statement describes his opinions:

*How can you have a life sharing with other people [share accommodation]. You can't have your friends over. You meet a girl; you can't bring her back. You know what I mean. Like it's hard to do that. I want to have a normal life. I want to have that chance of getting married or something you know like. You have to be able to walk normal before you can find a lot of decent women anyway. I walk through the shops and people just stare at me like you know, "what the hell's wrong with him?" It is very uncomfortable, but you get used to it. But to have that normal life, I don't want people looking at me. So it means that I've gotta be able to walk properly. It also means I've got to have my own place. I've got to be able to live strong by myself as a strong individual person. Unfortunately, you need income to do that. I'm stuck between a rock and a hard place it feels like, you know.*

This account highlights James' fight to being 'normal' again despite systemic and cultural pressure, including his feelings of how he is perceived by others, such as when he would go shopping or his interactions with systems of governance, such as Centrelink. James' longing for a sense of normality appears to be significantly influenced by being respected, having autonomy, being employed and having control to make his own decisions such as where he can live. Additionally, living on his own seems to hold crucial value to becoming normal, leading a normal life and being a "strong individual person". In context with this account, James also described occasions where meetings with Centrelink would not support his desire to live on his own due to the perceived increased financial pressure of living in a more expensive type of accommodation. As a result, he reported feeling disrespected by the manner in which he was treated. Such actions by systems of governance such as Centrelink may be interpreted as a form of occupational deprivation (Wilcock, 1998; Whiteford, 2000) where external factors or actors act in oppressive ways and dictate particular ways of doing (i.e. *forced* doing by Centrelink to reduce financial pressures), such as being told who to live with, and suggestions of living in shared accommodation with strangers.

Having stable and affordable housing also resonated with Leigh who had been searching for a more habitable option for some time. In the following statement, Leigh voiced his disappointment from being relentlessly "knocked back" by rental agencies:

*How many fucking knockbacks do you think a bloke can take before he's had enough? I don't accept or expect charity. I just want a chance and not be at the bottom of the pile all the time.*

For Leigh, constant rejection by rental agencies led him to become unremittingly disappointed. The exclusionary act of being rejected from having the opportunity to succeed in obtaining a rental property can be interpreted as strengthening his cycle of disadvantage. Leigh's account provides further insight into the intertwined causes and effects of exclusion resulting from a complex combination of systemic acts, how they are interpreted psycho-emotionally, and the sociocultural implications from experiencing reduced agency and opportunities for inclusion. Unfortunately for Leigh, the effects of not having a stable rental record further added to feeling excluded. Leigh's story provides evidence for understanding how certain ways of being and doing are shaped in pre-determined and favoured ways by dominant actors exercising their power and control. In context, Leigh's rental record did not follow *favoured* systematic procedures for successful selection by rental agencies. As a result, Leigh's chances to rent property through an agency, apart from an act of charity, could potentially never eventuate in a successful outcome. I interpret Leigh's experience as a clear example of occupational injustice where his own abilities for decision-making and exercising control over what he could and could not do were significantly invalidated (Whiteford & Townsend, 2011).

In context with the implications of experiencing financial hardship affecting the ability to choose and maintain meaningful occupational participation, Rose describes in detail her observations of the rising costs of living over the past 25 years since immigrating to Australia:

*Now they [Welfare Service] put me, because of my depression, and my back injury, they put me on the Disability Support Pension 2 years ago. I'm just 2 years on it....Um, with this money, like the rent is up now like, and if you don't live with the Department of Housing, I don't know how other people are surviving. I couldn't! It's very expensive. Everything is expensive. Like the food. I mean it's very depressing...I go to the supermarket [teary] and I don't know what to buy. You know, you are looking at 'stuff' you know and I am not interested. You know, I am so depressed that the things on the shelves just doesn't attract me [teary]. I just go and buy food for the dogs and nothing for me, you know. I'm just thankful that Parramatta Mission offers food.*

*...Once upon a time, everything was \$1. One litre of milk was \$1, or eggs, a carton of eggs, like one dozen eggs, \$1 so you could buy ten items for \$10. You know. And if you have a big family, you have to put \$100 in order to feed four children. But now, everything is more than \$2, like you buy two litres of milk, or if you buy one litre of milk, it's \$1.60. You know, it's over \$1 for*

*everything. Like cartons of eggs, like one dozen, its \$3 you know wherever you go. The cleaning products are expensive. And if you have a car, you have to pay rego [car registration] and the petrol is high. Everything is high! Like, we are advanced, and the quality of life, or the cost of life is raising every day. So we are paying the big price for it just because we want to live. ...The impact is that my rent has gone up, the water is up. The electricity is up. So I really have to cut down on things. I never go to restaurants, I never go to a movie or disco or rage party. I never go to a pub. I don't allow myself to go and have a cup of coffee with someone. And I don't want anyone to buy me anything. No, because I don't want people to spend money on me and um, I don't want to spend money which is, like a cup of coffee costs \$2.50. That costs me the bus to go to Parramatta and come back. You know what I mean. You have to calculate whatever you do. Like, where your money is going.*

Rose's accounts consider both the influence of her mental illness on perceiving the world, such as the experience of going shopping, together with the challenges of financially surviving on the Disability Support Pension. Although Rose received more money through receiving this pension compared to Anthony, Leigh and James who all received Newstart Allowance, she also experienced flow-on effects of increasing cost associated with rent, food, utility bills and other living costs. In addition, Rose also reflected on Western notions of the commodification of leisure (Neumayer & Wilding, 2005) which have led to a decline or complete exclusion from participating in meaningful social occupations which could be framed as 'leisure' or 'recreation' due to cost. Therefore, Rose favoured the option of budgeting for other more necessary occupations. These included paying for the bus ride into her local town centre to attend medical visits instead of going out for a meal at a restaurant or participate in other meaningful but neglected occupations.

Rose's account illuminates the effects that rising living costs have on being able to live a decent life, which includes the means to meaningfully engage in occupations of necessity, obligation and volition (Christiansen & Townsend, 2010; Whiteford & Townsend, 2011). It is evident from Rose's story that her participation in volitional occupations is compromised due to her financial constraints. The reality of financial hardship for participants such as Rose has led to having fewer options for participation by prioritising occupational choices (Galvaan, 2012) based on affordability and necessity. In the process, other meaningful occupations appear to be reluctantly rejected which could have otherwise acted to maximise her mental health. Rose's

experiences of financial hardship and its flow-on effects of dictating occupational choice (Galvaan) is noteworthy and challenges the notion of ‘equity of opportunity’ for participation, which foregrounds socio-political goals for the *ends* of social inclusion (Department of the Prime Minister and Cabinet, 2009a).

### ***Feeling excluded and having little hope***

Together with experiencing constant financial battles as the result of having low income and trying to live a meaningful and decent life, the participants collectively and overwhelmingly reflected negative perceptions of feeling excluded, that is, of being othered. Each participant expressed deep feelings which could be described as a type of *emotional distance* from their communities. Exclusion for the participants is interpreted as having a combined effect; both psycho-emotional and physical. With the former effect, exclusion acted as a state of mind impacting on participants’ emotional wellbeing. The physical effects of exclusion were also experienced by the participants as they expressed exclusionary acts made by other community members towards them (i.e. verbal taunts, staring and other behaviours) which further heightened their sense of being pejoratively viewed as *others*. Historical references of marginalised groups as *les exclus*, or ‘the excluded others’ (Béland, 2007) which was a cornerstone phrase represented in French social policy during the 1970s, captures aspects of the lived experience of exclusion of the participants. Abstract labeling consistent with the purposes of *les exclus* (Béland), such as ‘disabled’, ‘poor’, ‘bum’ and others, acted in exclusionary ways towards the participants which lacked considerations for individuality and uniqueness in favour of more discriminatory purposes.

Table 7 below highlights common phrases that participants boldly stated which represented some of their personal experiences of feeling excluded. In some cases, participants associated their feelings of exclusion with experiencing a sense of hopelessness as well. Common experiences which were expressed included feeling depressed, lonely, isolated, not belonging,

wanting to feel included, being unhappy, feeling disheartened as well as experiencing disrespect among several other reflections.

Table 7: Experiential labels associated with experiences of exclusion.

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Having a hard time	Feeling hopeless	Having little hope
Having no support	Not one of them	Not having hope
Being unhappy	Feeling vulnerable	Not being understood
Wanting to be left alone	Being sad	Being verbally abused
Feeling lonely	Being “broken”	Feeling ashamed
Feeling isolated	Living with “incredible sadness”	Experiencing stigma
Being disrespected	Having little hope	Not being helped
Being humiliated	Feeling insulted	Feeling stressed
Being ignored	Feeling disrespected	Not being in control
Being rejected	Feeling undervalued	Being offered false hope
Being picked on	Feeling downtrodden	Belittling one’s life’s goals
Being called names	Not fitting in	Having a grim outlook on life
Being unhappy	Not having worth	Feeling negative
Not being one of them	Being disheartened	Seeing limitations, not possibilities
Being disappointed	Being embarrassed	Not living an inspiring life
Feeling demoralised	Being scared	Being on your own
Feeling discouraged	Lacking trust	Feeling hopeless about future
Not belonging	Not feeling safe in community	Living in an unfriendly society
Not fitting in	Being negative	Being frustrated
Feeling trapped	Being devalued	
Being yelled at	Not having choice	
Feeling guilty		

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These striking and overwhelmingly negative feelings extracted from a comprehensive analysis of the data, provide valuable insights into the lived experience of being othered and the psycho-emotional toll on participants’ sense of belonging, feeling part of community, sharing cultural values and experiencing social solidarity. There appears to be a disconnect between the participants’ expressed feelings of exclusion with the aims of policies such as social inclusion policy which sought to promote a positive cultural agenda (Gillard & Stephens, 2008). The often praised Australian value espoused by politicians and the polity alike of having the right to ‘a fair go’ (Middendorp, 2012) is significantly challenged by the participants’ emotional expressions of exclusion which appear to be more aligned with a contrary view of ‘fairness’. An assumption of the value of having ‘a fair go’ implies that fairness equates to a sense of entitlement to inclusion

and therefore social solidarity. Through interpreting the participants' expressions of exclusion and considering the sub-themes presented thus far in this chapter, it appears that 'a fair go' was in reality a far cry from their experiences. Further, feeling a sense of entitlement to fairness also appears to be unattainable. In some cases, participants' experiences could warrant being considered as more of an anathema than a citizen within an inherently 'unfair' community.

Two stories which exemplified active exclusion from common community activities, such as meeting people and going to church, are expressed through Rose and Anthony's stories below. These accounts also speak to feelings of hopelessness that resulted from community and societal exclusion as a result of being subjected to otherness and subjugation:

Rose

*How to belong in society?...Well I can't belong to the people who comes to the Mission because they have drug and alcohol problems. And because I don't drink and I don't smoke, I am not one of them...We are in the century that everyone has to worry about himself. His pockets. And, no-one wants to commit. I mean even to find a friend. It's very difficult today. Especially in Australia. Because everyone suspects each other. You know, they don't know you. Unless you were in the same class. The same school. Or the same workplace. The only place that you can make a social life, if you go to work you can, or studies. You know, enable to find a good friend.*

*... [Do you have hope?] I don't think so. Maybe hope for the new generation? And my only daughter has also been spoiled with alcohol and drugs and everything else. And um, it's very bad. There is a plague of drugs here in Sydney. Especially in Sydney. Everyone can get drugs. It's just like you go to the shop and buy 1 litre of milk or a loaf of bread. That's how you get your drugs. And it's a very stressful society...It's not a good society to live in and to raise your kids. It's not a pleasant society. It's not a pleasant place especially in the Western area of Sydney. It's very difficult to live here. Very difficult to gain what you want to do in your life.*

Anthony

*What I have trouble with is actually knowing how to interact with normal people because I've grown up my whole life – my Mum being a heroin addict, my dad an alcoholic and my whole life's been in a drug inclusive environment, you know what I mean? So I've had no time where I've actually got to interact with normal people and I don't fit in. And point of proof of that is yesterday, I turned up at a church with my son to attend church because I have a – I'm feeling a connection to God. And when I got there the lady come up and she sort of blocked me from the door and she said, "We don't give out food here love." And I'm like, I'm not here for a meal, mate, I'm here to hear the Word. And she went, oh, oh okay then come in, but you'll have to put a shirt on. I said, "Oh okay." And I'm thinking - on the Sunday service they've got there. And I just felt very out of place. I thought I have as much right to go to church as anyone else but I felt like I was different. I felt – I felt that I wasn't welcome and which totally goes against the doctrine of what the Bible is and then what they're teaching. You know what I mean?*



*...And all the while I'm trying to find somewhere where I can meet somebody, people. And – and I don't know how to meet people that don't use drugs or drink or are criminals because I don't fit in. When they ask me my life or when they say, "What do you do?" I say, "Well actually I'm on a disability pension. I – I don't do anything." I'm an artist, I draw, I play guitar and I'm a dad to my kids. That's all – I've got nothing on offer to anybody, you know what I mean. And so I find myself excluded from the world.*

Through these accounts, there appears to be an underlying feeling of angst from Rose and Anthony's perceptions of being excluded. Furthermore, with respect to Anthony's story, he provided examples of a longing to meet 'normal people' in his life and break away from his hostile upbringing. Several participants also described a wish to break free from current negative circumstances which appeared to continuously perpetuate their subjective and objective experiences of disadvantage and exclusion. Such experiences seem to less favourably impact on their quality of life where occupational possibilities (Laliberte Rudman, 2010), capability enablement (Sen, 1999) and social recognition (Honneth, 2001, Komter, 2005) could be less possible in their current sociocultural environments. Interestingly, Anthony's description of his occupational persona and occupational roles through what he *did* could be interpreted as playing a vital role towards his own self-worth. His account highlights the importance and centrality of occupation for his own identity (Christiansen, 1999; Phelan & Kinsella, 2009) as a citizen and individual of worth to society through which he could feel 'normal'.

Anthony's description of what he valued as meaningful doing, however, seemed to not be sufficiently considered in his own mind for mutual social recognition and inclusion (Honneth, 2001; Komter, 2005; Morrison, 2010). This can be viewed as a reflection of what others within society valued as meaningful and purposeful above other forms of doing, or participation. Despite Anthony's legitimate attempts of participating in occupations to feel and be 'normal', his statements of *not doing anything* and *not having anything to offer* provide evidence for a type of hierarchical categorisation of participation within Australian society. Anthony's and many other participants' stories expressed similar accounts of participating in less valued occupations as compared to other more favoured and esteemed types of participation. I uniquely frame this

phenomenon as the experience of *participation hierarchy* where participating in paid employment appears to be the ultimate form of socially recognised and preferred type of occupational participation. Within such a hierarchy, other meaningful occupations are relegated as less important within a culture which highly values productive occupations such as paid work. I further explore my framing of *participation hierarchy* in context with the final findings chapter (Chapter Seven) which outlines a critical analysis of discourses (Bacchi, 2005) which I undertook of the Rudd Government's social inclusion policy texts.

### ***Living in a community lacking compassion***

For the participants, the psycho-emotional toll of not being a part of a 'normal' social life was heavily affected by their impressions of living within a culture which facilitated more exclusionary effects rather than downplayed or eradicated them. As a result, participants identified elements of a *culture of exclusion*, with an apparent lack of *compassion* towards others. Thus, such experiences resulted in a deeper sense of exclusion, where participants felt relegated to a lower status along a social axis of power (Yuval-Davis, 2006). In context with these experiences, the notion of *belonging* appeared to be more redundant.

Participants provided detailed accounts which demonstrated a limited sense of belonging. The sentiment of not belonging to one's community was substantiated by participants in several ways. For example, participants described that they experienced various forms of discrimination on a frequent basis, which resulted in feeling a diminished sense of trust and care within their community. Such feelings led participants to resort to a "survival of the fittest" mentality (Richard). In effect, this notion of survival demystified a supposed "illusion of living in a peaceful community" (Anthony), as well as appeared to unveil a deep "cultural problem" (Annie). In particular, Rose's stories of racism, exclusion and discrimination in the following accounts illuminated some complexities of what *not* belonging and living in a *culture of exclusion* meant for her:

*The Department of Housing put me into a complex like this, but with more density, like 15 houses in one place. And everyone watching what you're doing, what you don't do. They start to pick on you because you are not one of them. And you are not blond and blue eyed. So they start calling me names and ah, remark about my skin and calling me "black bitch". I had to get out of there for me and my daughter's sake.*

*...Every person that you see in Parramatta is depressed! It's very depressing to walk in the mall in Parramatta. You see all the druggies there and all the alcoholics. People spitting on the ground and coughing. It's very distressing and very depressing. The community here in Parramatta. So I just try to take my stuff [food offered at Parramatta Mission] that I need and just go.*

*...They [white Australians] look at us [immigrants] like second class citizens. And they are very abusive and insulting. Especially your neighbours. They tell you you have no character. And get fucked...They are all Australians...I feel that the Australians, they have a very cold society. And they are very rejecting. Only the ones who believe in God have compassion towards others. They are not willing to make friends. A good example is I have a neighbour that lives near me in the complex. Ten years and he has never said "hello" to me...So I just live a very depressing life, that I have wasted 25 years of my life and I wanted to contribute something to society...The government can't help me. I have to help myself. I am not expecting anyone to help me. I am living in an unfriendly society.*

*...Your neighbours pick on you. They don't want you around them. And it's also hard to find a job. And when you don't find a job, feel very demoralised and you say to yourself, what's wrong with me? Sometimes they said I am too smart for the job and they won't put me on. They are scared. Looks that they are scared of me. And because I am a multiskilled woman and I speak three languages, and I can operate machines, and I can also try and translate simultaneously...I just don't find the right way to get a job and I have had enough of begging people for a job...It's a bastard of a society and they are cruel. They are very cruel. I am very demoralised. And that's how depression comes. You think you are a good-for-nothing. And why?...It's just people don't trust each other today. We need people to be more friendly, more trusting, more welcoming.*

*...[Regarding finding a job] They don't tell you in the face they don't want you. They just don't ring you. They don't want to know about you. You are not one of them. We are the rejects. All the newcomers here with their families. They expect your children not to have an accent...And I don't think in school they teach manners. They just teach to hate each other. Racism comes from home. And I can see it. They come to the park, the Australians with their children and they don't talk to you... And it's going to get worse. Today they're only into money. Making money. Money machines. If you don't make money, you are no good. Everything is expensive. The high cost of living. The rent. The food...They are all living in charity organisations. You get sometimes fresh or second-hand food. That's how we are surviving.*

In these stories, Rose described experiences and feelings of exclusion which affected her across several social and occupational roles; such as a being a citizen, a single mother, a woman, a public housing tenant, a person living with chronic disability and unemployment and finally as an immigrant. Rose's emotive expressions in these stories highlight her longing to contribute to society in social, cultural and occupational ways. However, feeling included was compromised by

exclusionary acts by others which led her to feel undervalued. As such, the outcome for Rose's seemingly unsuccessful inclusion could instead be interpreted as living an 'othered' life in Western Sydney where denigration and misrecognition (Anna, 2012) appeared to become her norm. Misrecognition negatively impacts on the self-esteem and autonomy of a person experiencing exclusion by denying moral agency (Laitinen, 2010; Thompson & Yar, 2011). Rose's stories of exclusionary experiences which include misrecognition (Anna; Laitinen; Thompson & Yar) also revealed a sense of 'internalised oppression' (Reeve, 2004), which she frequently described as being associated with demoralisation and depression. Rose's stories provide valuable insights into some consequences which can result from living with entrenched disadvantage such as poverty and disability with respect to the psycho-emotional toll of sociocultural exclusion. Rose's experiences point to research conducted by anthropologists McDermott and Varenne (1995) into the disabling nature of Western culture, which they framed as *culture as disability*. McDermott and Varenne described critical observations of Western culture where cultural problems, such as those experienced by Rose and other participants, resulted from assumptions

“that there is [only] one way to be in culture [which] encourages the misunderstanding that those who are different from perceived norms are missing something, that it is their doing, that they are locked out for a reason, that they are in fact, in reality, disabled...A disability may be a better display board for the weaknesses of a cultural system than it is an account of real persons” (p. 326).

Cultural values considered important for inclusion, cohesion and mutual respect are therefore significantly challenged by the participants' stories, which overwhelmingly highlight more negative rather than positive representations of culture, belonging and community through the exclusionary acts that they experienced.

Other participants such as Anthony, also ascribed his feelings and experiences of exclusion to living in a community lacking compassion. Thus, McDermott and Varenne's (1995) framing of *culture as disability*, appears to also resonate with Anthony's experiences. Despite being of a white, Anglo-Saxon cultural background as well as being born and raised in Sydney, his life history is replete with traumatic moments which have significantly influenced his perspectives of Australian community life and his social position within it. Not only did he describe such trauma

and exclusionary experiences in detail, he also highlighted that even his physical appearance led to him to being judged by others. Anthony felt specifically judged and targeted by those in positions of power such as the Police. He recounted some of these stories of experiences which highlight his tainted perspectives of his social position within his community:

*And the effects of that [traumatic events of past] on me are that it's left me feeling vulnerable. It's distrusting. And I really have a distaste for authority. And I don't like that. It's really hard to be a dad and teach my son, "You know what? The police are actually needed. They're a necessary evil, if you like," and my son says, "Oh, I fucking hate coppers." And I say, "No, mate, please don't talk like that." And I don't blame him, because he sees his dad pulled over daily and we're doing nothing – I'm in a shopping centre. We're doing our grocery shopping, for fuck's sake. And all of a sudden, I get followed by these two men, and they're big, burly men, one with tattoos all down his arms. And they're not in uniform. I'm street-wise enough to know that they were detectives. But my son wasn't. My son turned around, and I could see the fear in his voice, he said, "Dad, we're being followed." I said, "Son, I know that. We've been followed for about 10 minutes. They're detectives." So finally, I confront them. I just turn around and say "Look, mate, is there some problem?" He goes, "Oh, we just want to know who you are." I said, "Why?" I said, "Why didn't you ask that Chinese lady walking by? Why didn't you ask that Indian person walking by? Why is it me?"*

*...About the actual welfare and the wellbeing of people, we give this great impression of Australia, of we do it for our mates, all in, one in, we look after each other. That's fucking shit. That's absolute shit. In every other country, most families are very family-orientated. I'll just pick one nationality; Italians. You will find with an Italian family that they have a lot of respect for their mama and their papa. They take care of them. And you'll have a large family where they – and it's a lot of love there. It's really family-orientated. In Australia, it's not like that. You hit 14 years old and it's almost like, "Mate, you're out. Fuck off." And that's how it sort of works. We get to a certain age and our kids are encouraged to go. And that's bloody sad. We need to teach people to stay connected to the families.*

From a *culture as disability* perspective (McDermott & Varenne, 1995), acts by systems of governance such as being frequently followed and targeted by the Police, appeared to influence and project Anthony's feelings of being othered, disabled and rejected. Further, his tensions with apparent sociocultural norms and expectations of promoting a type of open exclusion within families seemed to challenge his own thoughts and values of family and community.

Together with Anthony's stories, James also felt disconnected from community and place. The following accounts shed some light into James' experiences of fear, misrecognition (Anna, 2012; Calder, 2011; Thompson & Yar, 2011) and discrimination as well as hopes for a more inclusive community:

[Referring to living in a socially disadvantaged area of Western Sydney] *It is very bad in a sense you know. I want to get exercise so I can get moving more. You can't walk around the park. We get like 60, 70 year olds getting bashed for their shopping. Not for money. For their shopping bags, you know. Like, it's ridiculous. So socially you know, you can't get your exercise, you can't interact with people because people are scared in that area to talk to other people sometimes.*

*...That lack of trust where everyone's trying to rip someone off to get something because they've all got nothing. You know like. I see the classic example. I know its Western Sydney, I grew up around the area, I feel safe. But I think that's because I can take care of myself. If you're a lady, like, when I do get my exercise and walking through the park, there'll be like, I think probably now maybe a large percentage of my area are Muslims. So, you know, the women are a bit hesitant to talk to men anyway because of religion and culture. But when you are walking around in the park, I'm one of these people that will always say "hello" if the person makes eye contact with me. You know, just a general hello might put a smile on a person's face for around 5 minutes. A lot of them won't answer you back because they're scared. The men won't answer you back because they're scared that you are going to rob 'em. Don't know if that's because I'm 6 foot 4 and I've got the tattoos and I'm normally walking around in a singlet, but um...[laugh] you know, it's the negative stereotype, like you know you're stereotyped.*

*...I was brought up to work; that's all there is to it, and to respect my fellow man. And if I didn't, I'd copped an absolute hidin' for it, okay. If I didn't turn up at work even as a 6 year old, my Dad would bash me, you know. It instills that lifestyle in ya. It puts that respect for fellow man in ya. And, to treat everyone equal. It doesn't matter what you are. We all bleed the same. We are all in the same boat together. Like I said, I do not see that changing until generations of individuals teach their children better and learn better themselves. And have more compassion. And it's very disheartening to say that. But yeah I don't see it ever gettin' better. Because we have proved that already. How many generations and we are still the same, you know what I mean. I think its lack of education too. Um, that's a big part of it. With education comes tolerance.*

James' accounts reinforce his views about the need for a collective response to promote compassion, equity and peace within community and society. Feeling stereotyped appears to have impacted on his relationship to society where he felt singled out for looking different. Having features such as being tall, having tattoos and wearing casual clothes seemed to be associated by others within his community as imposing, deviant and dangerous characteristics. Therefore, instead of being able to walk freely in the park, greet others and enjoy the experience, it became a more fraught activity leading, eventually, to reluctant avoidance.

James proposed *education and awareness of others' ways of life* to directly challenge exclusionary acts which he experienced and witnessed in his local marginalised community (i.e. in his local park). James' ideas for inclusion through education and building community awareness which

embraced difference and diversity are consistent with social inclusion theory and policy directives (i.e. Department of the Prime Minister and Cabinet, 2009a; Lister, 1998). However, such theory and policy directives appear to minimise the influence that education, beyond its capacity for productivity, can have to promote a more compassionate, respectful and connected community. James' specific perspectives of education *for* inclusion were encouraged by some of his life values which were instilled in him during his childhood. Considering *context* to enable inclusive places and spaces, such as respecting cross- and inter-cultural social norms, also emerged from his stories as potentially playing a pivotal role towards understanding interethnic and intergroup discrimination and violence.

The final sub-theme presented next takes a deeper analytic look into the psycho-emotional effects of exclusion. It expands on the ideas presented in the sub-themes thus far by highlighting the *social* effects of exclusion and 'internalised oppression' (Reeve, 2004).

### ***Feeling lonely and isolated***

In this study, feeling excluded from society and being 'othered' seemed to be closely related with feelings of loneliness and isolation. Both the previous and current sub-themes complimented each other as they examine the social and emotional consequences of living with entrenched disadvantage. The complex phenomena presented thus far surrounding the mechanisms of social exclusion highlight not so positive representations and experiences of culture, society and community. This appears to be the case for participants whose stories were replete with accounts of living in a community which allegedly held a *culture as disability* mentality (McDermott & Varenne, 1995). It appears that the outcome of living in a community which upheld apparently limited forms of inclusion and exclusion impacted on the participants' social health and wellbeing. The Commission on Social Determinants of Health (2008) has identified that relational processes (at the macro and micro levels) can play a significant role in being or becoming excluded from participating in meaningful occupations in context with social and community life. One such relational process at the micro level which echoed similarities between

the participants appeared to be the difficulty or inability of having, maximising and maintaining meaningful and sustainable relationships with others. Health and social science literature strongly suggests that having such social networks leads to positive health and wellbeing, including mental health (i.e. Cattell, 2001; Cullen & Whiteford, 2001; Mental Health Coordinating Council, 2007; VicHealth, 2005). The inverse of experiencing positive influences from having meaningful social networks and supports appeared to be a major outcome for the participants. Leigh described such an experience in the following story:

*Yeah, I've been bored quite a lot lately. And I'm having – it's getting harder and harder for me to – to cope with it. Even coming in this morning I'm sort – there's been times that I just don't want to cope. Yeah. It's getting really hard, just mentally at times almost driving me crazy. 'Cause – yeah it does. It's one of the hardest things for me to handle is – I mean I like my serenity but I hate being lonely...During the day I just want the day to finish.*

Participants such as Leigh repeatedly stated that they felt lonely and isolated from not having meaningful social networks, such as family, friends and significant others. From a thorough analysis of the data, it seemed that only a few participants still shared some close ties with immediate family members. Leigh described his relationship with his daughter as distant and fragile at best. Nevertheless, he spoke of her fondly throughout the interview process and stated that he was proud of her for becoming a qualified primary school teacher.

A common flow-on effect from the impact of having little meaningful social contacts, or participation in social occupations within their communities, resulted in experiencing extensive periods of unproductive time use. Having too much discretionary and unproductive time seemed to affect the mental health and wellbeing of some participants, such as Leigh's description of having too much time as "driving me crazy". Further, Leigh's severe boredom appeared to further perpetuate his subjective experiences of being lonely. Such boredom seems closely related to experiencing the unhealthy relationship between having too much discretionary time, feeling unproductive and being unchallenged (Farnworth, 1998; Martin, Sadlo & Stew, 2012).

Rose's accounts below further highlight the psycho-emotional impacts of living with entrenched disadvantage and not having stable and meaningful social networks and relationships.



It appears that her life story in particular also holds a sense of ‘failed immigration’ to the “lucky country” where having little contact with her family and having “no friends” or “no-one to visit” has resulted in feelings of hopelessness. She boldly stated:

*No-one here for the last 25 years has invited me for a cup of coffee. No-one here. It’s very sad.*

It appears then, that her struggle for social recognition resonated in a simple yet taken-for-granted social act of friendship and reciprocity which is considered as important for mutual recognition and respect (Komter, 2005). Her statement about the occupation of having a cup of coffee with somebody speaks to a personal sense of deep loss affecting her everyday life. Despite Rose’s social interactions with others and searching for friendship, such interactions seem to have masked a profound sadness of longing to be part of and “assimilate with” her broader social world. She articulates this view further in the following statement:

*So in the meantime, I go to the Mission [NGO], say hello to people. I actually don’t have any friends. I don’t have any relatives. My only next of kin is my daughter. And um, and God I suppose. God is my soul mate. And it’s a very sad life that I am living [teary] and I don’t know what to do. Many times I was thinking about committing suicide. And people told me, “What about your daughter?” It’s bad enough that the father is gone. But I, I don’t know. But if I go and find a job, people come with excuses, “oh, you don’t have experience or this or that”. It’s too long since I have worked. I even had a forklift licence...They just don’t put you on. They don’t trust you. You are not one of them. It’s very hard to assimilate here [teary].*

This account highlights Rose’s wish to actively engage with her community and feel productive through doing despite living with complex health and psychosocial issues. Rose also shared that the Australian way of life included activities and behaviours which did not align with her sense of self to belong and ‘do with’. Her following account expresses this sentiment. In the end, what seems to have eventuated for Rose could be interpreted as missed occupational experiences rather than exploring other types of participation. As a result, Rose described a relatively bleak view of her future:

*I’m very grateful...they [Department of Housing] gave me a house, a dwelling to stay. A roof for me and my daughter so we won’t be homeless. But I mean, this is the way of life here. There is no social life for me. There is no group that I could [join]...I’m just falling between the chairs. Because I don’t have where to go. I don’t drink and I don’t smoke, like most of the society here. They need to have a pub to go to and drink and talk. And this is not my culture. So um, I just started to go like on Saturday, to go to a fellowship group. It’s a small group. I used to go to many*

*churches you know, and I couldn't find myself there. They're too busy. Everyone goes home after the fellowship. And um, you really didn't have a social life...I wanted to explore 'me'. But now that I've been here for 25 years, I really have to think. Sit down and think what to do for the rest of my life. I mean, I don't know if I want to end up being here for the rest of my life, or just to go travelling and wander around the world. It's just not me to sit at home and do nothing. I just, I can't see myself like that. It's very depressing.*

*... You know, I wish someone can come here and immigrate from there to here so that I have someone to visit. Someone to knock on the door and say hello. The only people here that I meet are in the park with their dogs and this is my social life.*

These statements identify Rose's attempts to try different socioculturally accepted co-occupations (Pierce, 2003) yet not 'fitting in' in the process. For example, Rose's assumption that most of the Australian society drinks alcohol and smokes cigarettes appears to be an expression of feeling excluded and rejected. What resonates from these accounts, ultimately, is Rose's desire to be included.

Despite her constant attempts to be included and testing her own cultural identity and values in the process (i.e. going to the pub; attending different religious congregations different to her own affiliation), Rose appears to have never discovered the right 'fit' for social participation. Rose's experiences challenge the notion of what 'isolation' can mean for individuals who are struggling for a common identity which can positively resonate with others. Although Rose chose not to physically isolate herself in her own environment, her experiences and descriptions of exclusion identified clear examples of social isolation *in place* within her own community.

Occupational disciplines' (Sellar, 2012) theories on belonging as a social and occupational construct (Iwama, 2005; Hammell, 2004; Rebeiro et al., 2001; Wilcock, 2006, 2007) seem relevant when considering Rose's and others' exclusionary effects resulting from being perceived as 'other' within their communities. When considering the importance of 'doing with' in context with social wellbeing, Wilcock (2007) highlighted the importance of 'belonging' as a necessary construct for survival and health:

*"...my theory about the health relatedness of the occupational nature and needs of people is remarkably simple. It is that doing, being, becoming and belonging are essential to survival and health...The introduction of the fourth element – belonging – might be*

surprising. It emerged strongly from my ongoing research into doing, being and becoming as the contextual element, of the connectedness of people to each other as they do and of the major place of relationships within health” (p. 5).

However, Rose’s and other participants’ experiences of inclusion attempts challenge such literature from occupational disciplines (Sellar, 2012) which generally highlight a positive view of the nexus between occupation, health and belonging in context (Iwama, 2005; Hammell, 2004; Rebeiro et al., 2001; Wilcock, 2006, 2007). Instead of experiencing belonging as a positive phenomenon, excluding aspirations to belong, participants were often greeted by exclusionary acts such as receiving verbal taunts or odd looks, which did not represent notions of connectedness with others. Such interactions with other community members and resultant experiences of being and feeling excluded appeared to target participants, rather than act in ways to promote belonging and connectedness. Rose’s accounts of her occupational experiences within her social environment appear to have acted in more detrimental ways, and not facilitated sustainable outcomes to promote her social wellbeing and sense of belonging. In particular, her constant attempts to build and maintain social relationships to connect with others never seemed to meet her hopes and expectations.

Through Rose’s life history, the reality of living with entrenched disadvantage included repeated drawbacks, such as her subjective experiences of *not* belonging to her community. Such exclusion appeared to significantly affect her mental health, exacerbating her chronic mental illness. Previous examples drawn from Rose’s life story in the other sub-themes in this chapter reinforce this.

## **Conclusion**

This chapter has presented analytic insights into the life stories of citizens living with entrenched disadvantage, with a particular focus on accounts of the everyday realities and exclusionary effects of such disadvantage. The chapter explored issues such as recounting some impairment effects (Thomas 2004a, 2004b) of disability, the effects of surviving from chronic financial and material poverty, as well as the psycho-emotional toll of experiencing exclusionary

acts. This chapter also focused on unpacking and understanding the mechanisms of social exclusion as they occurred at a ‘grass roots’ level.

What is evident in these detailed accounts was an overwhelming acknowledgement of the impossibility of interpreting various forms of disadvantage as separate and discrete phenomena. Living with disability, chronic unemployment, being alone, feeling excluded and several other effects from experiencing disadvantage were so enmeshed with each other, that they could not be explored in discrete ways without considering their complexities and interconnected qualities.

Together with considering the complex and interconnected phenomena which capture some elements of the entrenched nature of disadvantage, specific literature provided a more critical lens through which to further ‘unpack’ disadvantage. For example, literature which took counterhegemonic discourses of chronicity (Manderson & Smith-Morris (2010) into account, assisted in providing context for positioning disability within a life course perspective which dispelled limited considerations of the chronic nature of disability over time. The literature also highlighted the importance of participants’ psycho-emotional dimensions of disability (Reeve, 2002, 2004, 2008; Thomas, 2004a, 2004b) which provided evidence for critical considerations of the personal or subjective experience of disability and its impairments effects on occupation, participation and inclusion.

The participants’ stories were presented in order to shed some light into taken-for-granted notions such as participation in community life, belonging, and those cultural norms and behaviours which either promoted inclusion, wellbeing and connectedness or denigration, discrimination and misrecognition (Anna, 2012). It appears that the latter behaviours were experienced by the participants significantly more than positive notions of belonging, connectedness and inclusion.

The following chapter attempts to generate further insights into the realities of entrenched disadvantage in context with exploring how participants experienced “being in the system”. “Being in the system” was the most distinct meta-theme extrapolated from data analysis. In particular, it documents the inherent difficulties of dealing not only with the

participants' own existential realities of entrenched disadvantage, but also with the bureaucratic obstacles practiced by *systems of governance* which further hampered their endemic struggle for participation, capability enablement (Sen, 1999) and social recognition (Honneth, 1995, 2001). Following the next chapter which rounds off the findings from the life history part of this research, the concluding findings chapter entitled "being the policy" presents the outcome of an analysis of discourses (Bacchi, 2005) of key social inclusion policy *texts* from a critical policy and critical occupational science lens (Bacchi, 2009; Whiteford & Townsend, 2011). The concluding findings chapter specifically presents a critical interrogation into the taken-for-grantedness and political problematisation of 'participation' within the Rudd Labor government's social inclusion agenda.

## Chapter Six

### ***Being in the system: Experiencing disadvantage and exclusion***

The previous chapter presented some of the participants' candid accounts and insights into some realities of what living with entrenched disadvantage and exclusion meant for them at an everyday level. It appears that their experiences of poverty and disability were further compounded by an endemic culture of exclusion, prejudice and discrimination. This chapter explores these stories in context by outlining the major findings of the life history study documented in this thesis. The findings are presented under the meta-theme which I have entitled "being in the system" (See Table 8 below for the sub-themes). This chapter specifically highlights some of the participants' challenges that they experienced from their daily interactions with systems of governance.

The comprehensive inductive analysis that I conducted of the participants' life stories identified that the two meta-themes presented in the previous findings chapters were overwhelmingly mitigated by contextual factors. Some of these factors appeared to be systemic in nature where *systems of governance* inhibited participants' abilities to develop or realise their capabilities (Sen, 1999). Instead, systems of governance such as the welfare system (i.e. Centrelink) seemed to exercise power and control in manners which depersonalised participants and directly or indirectly limited their occupational possibilities for flourishing (Laliberte Rudman, 2010; 2012; Seligman, 2011). Therefore, support services presented as *systems of governance* and the hegemonic practices engendered within them, appeared to hinder rather than promote the ultimate goal of social inclusion as ends.

It is important to clarify that the *stories* of the experiences of 'being in the system' rather than observed experiences of 'being the system' are presented to exemplify inclusive or exclusionary practices by people and employees within systems of governance towards the participants. I have chosen to use the term 'systems of governance' to describe specific support

services *as* systems or institutions in a manner similar to sociologist Dorothy Smith's (as cited in Townsend, 1998, p. 11) framing of 'social institutions'. Smith defined social institutions as "organizational units that determine how we look after ourselves, attend to our health, work, play, educate our children, run businesses, help those in need, arrange transportation, and worship" which produce "the broad *social organization* of power" (original emphasis, Townsend, p. 11). I chose the term 'system of governance' instead of Smith's concept of social institutions or other terms such as 'services' to highlight the role that governance plays within such institutions to exercise or enforce power through complex processes or rules (Pillora & McKinlay, 2011). Further, systems of governance as a term more accurately captures the experiences of governance which can promote or facilitate hegemonic and subjugating practices. Framing systems of governance in such a way is also different from 'governance systems' which instead places less emphasis on the functions of rules, regulations and power *practices* imposed on people's "ways of being (subjectivities) and doing (occupations)" (Laliberte Rudman, 2005, p. 150).

Furthermore, this chapter also explores participants' accounts which reported some of the transactions that occurred between them and systems of governance at the service interaction level. Significantly, these stories highlight the tensions and difficulties that they experienced in their daily transactions and interactions with systems of governance. This chapter delves into such stories by exploring how mechanisms of systemic power originated and were practiced at an everyday level. The chapter concludes by considering how alleged systemic machinations led to a negative flow-on effect which heightened participants' sense of subjectification and otherness within a *culture of exclusion*.

Table 8: Findings from the life history study.

Meta-themes		
<b>1. Being me:</b> Identity and personhood	<b>2. Being in the world:</b> Existential realities	<b>3. Being in the system:</b> Experiencing exclusion and disadvantage
Sub-themes		
Wanting to do something that counts (recognition)	"Living with disability is one of the hardest things"	Being told what to do
Doing things to pass time; Doing things that are meaningful	I can't afford to live	Not getting a "fair go"
Having and upholding values	Feeling excluded and having little hope	Being powerless
Having faith	Living in a community lacking compassion	Feeling demoralised
Living for my family	Feeling lonely and isolated	"I don't know what to do or where to go"
Having hopes and goals		"Falling through the cracks"
Being strong and resilient		It's too complicated
		Experiencing a lack of compassion and empathy

### ***Being in the system: Systemic disablement and its effects on participation and social inclusion***

The following participant stories feature some of the struggles that they experienced through day-to-day interactions with various systems of governance. Their narratives speak to the subjective and objective effects on everyday participation in necessary, meaningful, obligatory and volitional occupations. Occupational participation in context with services *as* systems of governance, is considered here from a macro or ecological perspective. An ecological perspective considers participation and social inclusion through the various transactions which occur between the person, context and occupation (Aldrich, 2008; Dickie, Cutchin & Humphry, 2006).

The participants' stories portray exclusionary acts by systems of governance and the hegemonic practices engendered by them impacting on their participation in social and community life. These stories highlight certain occupational injustices which appear to have



occurred for the participants. From an occupational justice lens, the potential outcomes resulting from unbalanced or ineffective transactional relationships with systems, or from factors beyond one's control, are congruent with occupational and capability deprivation discourse respectively (Mitra, 2006; Sen, 2000; Whiteford, 2000). As such, opportunities to fulfil participants' capabilities to live valued and supported lives have the potential to be inherently limited or denied due to systemic disablement.

### ***Being told what to do***

The first sub-theme presented is entitled 'being told what to do'. This sub-theme was the most poignant example described by the participants as they shared their stories of experiencing systemic disablement. Anthony's rich collection of stories contain a mixture of positive and very negative experiences across his life. As explored in the previous findings chapters, Anthony's story of living with entrenched disadvantage began during his childhood. During the in-depth interviews that were conducted with Anthony, he made constant references to growing up with a father who was chronically addicted to alcohol and a mother who was addicted to heroin. Thus, Anthony never chose to live in a continuous cycle of disadvantage. Unfortunately for Anthony, his disadvantage cycle was inevitable and intergenerational in nature. Anthony's accounts feature strongly throughout this chapter due to his complex social upbringing and tensions experienced with different systems of governance which appear to have dictated his occupational choices (Galvaan, 2012). He provided context by making the following statement:

*I don't want to play the victim, and I don't want to play a violin or any of those things. I am fully aware that a lot of my problems are self-inflicted. However, if you were to delve right back to the beginning of my life, I was never really given much of a chance. I mean, with a heroin addict mother that sells her son for heroin, or a father alcoholic that's as violent as they come who went to prison for crimes against us kids, and my mother, and then get dumped into a refuge in Kings Cross, run by pedophiles<sup>1</sup>, do you know what I mean.*

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<sup>1</sup> DISCLAIMER: Any statement throughout the findings chapters which mention drug use, domestic violence, abuse, paedophilia and crime have been appropriately addressed by the criminal justice system according to the participants and further substantiated in their signed consent through to the participant agreement form.

Having the possibility to make occupational choices (Galvaan, 2012) in his life stimulated rare joyous moments, such as the births of his five children. However, the inherent and never-ending cycle of denial of choice in decision-making processes during transactions with systems of governance appeared to be consistently problematic. Such occurrences seem to have forced Anthony to live his life in ways which were necessarily characterised by an inner strength and resilience for survival. During a period of Anthony's life where he "own[ed] everything that I did" which included years of illicit drug consumption and crime (including a period of two years in jail), both Anthony and his wife experienced the sudden removal of their five children who were placed into foster care.

Following an agreement made between the state child protection service (New South Wales Department of Community Services; 'DoCS') and Anthony and his wife, they participated in an initial period of 12 months of intensive 'live in' drug rehabilitation. This involved no face-to-face contact with their children in the hope of regaining custody following their period in residence. After successfully completing his intensive rehabilitation, Anthony shared his thoughts of the alleged 'false promise' that he was given regarding the goal of actively caring for his children again:

*Okay, I own that I was a drug addict and my wife was. I own all the stuff we've done. But we did what we were told. And it still wasn't good enough...*

*My wife and I were determined to do well, but unfortunately we were put into a category, do you know what I mean?*

*When you get told your – your eldest boy's been moved 26 times. Righto. This is fair dinkum stuff. My 12 year old's been moved 11 times. My 11 year old...he had one placement and stayed there the whole time. He – he's been all right. And the littlest one's been moved four times, the four year old. So that's a lot of movement!*

*She's [Anthony's wife] ticked every box, jumped through every hoop and done every single thing asked of her. She even gave up her husband, who I know she loves, and – and now she's ringing me the last few days saying "I want to come home. I want to come home." And I said to her, "No, hang in there". I said, "You've come too far to turn back". She said, "I want you back." Selfishly – if I was selfish I would say, "Please come home". But I don't think that that's what she should do. I think that she needs to get another lawyer. We need to approach parliament and we need to take this to – we need to get other people on board and we need to take this to the media. 'Cause the media needs to see that this is actually a crime. That people are being set up,*

*being told, giving false hope to people. They – they told me that if I do this, this, this, this, this, that this, this, this, this would happen. Now we did all of what we were told but those things didn't happen!*

These accounts provide valuable insights into the use and potential abuse of power by systems of governance. Instead of being empowered by learning skills for becoming better parents and carers as well as overcoming illicit drug addiction, it appears that Anthony and his wife were powerless in the decision-making process to regain custody of their children. Anthony's supposed powerlessness appears to be further impacted by the fact that he had seemingly "did what he was told" without question. Yet, DoCS's decision not to grant him custody of his children appears to have significantly affected Anthony's capabilities of becoming a father again, regaining some sense of normality or providing a stable home for his family.

Being 'told what to do' as well as being categorised as an 'other' (Barter-Godfrey & Taket, 2009) included other exclusionary acts, such as the denial of rightful knowledge. Thus, the ethics of systems of governance is called into question. Anthony succinctly captured this notion through unveiling the story of when he was diagnosed with Graves' disease, a chronic health condition affecting the thyroid gland. In Anthony's case, his condition led to a form of thyroid cancer which he was battling at the time that the life history interviews were conducted:

*So – and then I go to the doctor and they – because I've got this Graves' Disease which that's the thing I left out in [Drug Rehabilitation Centre] – four weeks before getting out of [Drug Rehabilitation Centre] I'd been jogging. I trained every day. I was just up to 86 kilos...I was fit, really strong. And then all of a sudden I lost 10 kilos in about three or four weeks, just bang, gone. And the nurse calls me and says, "Anthony something's wrong. We're a bit worried about you. You've lost a lot of weight. You're down to 75 kilos. We want you to stop jogging." And I said, "Yeah. I get that. I think – I agree with that." "And we want you to go and see a doctor." So I go and see a doctor and they say you've got cancer. You've got Graves' disease in your thyroid and it's a 10 per cent follicular cancer. Atypical pattern or some crap like that. And I don't quite understand what that's about so I go back to [Drug Rehabilitation Centre] and I say, "Look I've got Graves' Disease. Can I please have information off the internet about what it is – so I know what it does?" Anyway she said, "Yeah I'll find out what I can get." They end up giving me five pages, 80 per cent of it's been red-lined out. And I – they'd actually blocked it out. And I said, "Why are you blocking out all this information?" She says, "I don't think mentally you can cope with reading what it's about." I said, "I think it's easier for me to understand the illness and what I'm going through if I actually can read the whole fucking thing. I know – I – I'll understand why I'm doing some of the things I'm doing." And – "The decision's been made, Anthony, that's how it is. This is all you're allowed to know." All I know is that it controls my hormones. I know a lot about it now. But then all I knew was it controlled my hormones and*

*that it made me – my moods change really easily. So I – I’m thinking you’d be a little bit more compassionate to somebody who’s just suffering that illness.*

Anthony’s experience of being denied medical information that he had been diagnosed with a serious condition by the drug rehabilitation centre, including prognosis and appropriate treatment, can be described as a type of unethical practice by staff members. From Anthony’s accounts above, it appears that such unethical practice could be considered as part of deeper entrenched ethical issues at the management level. Having a decision made on his behalf by staff members of an institutionalised environment, can be interpreted as potentially employing machinations for systemic control and subjectification. Being the ‘subject’ within a system of governance demonstrated that Anthony’s personal goals other than what the Drug Rehabilitation Centre had programmed and scheduled for him and its other residents, appeared to not be important. Determining and having control over the level of importance given to knowledge access and information transfer could have devastating consequences. This seemed to be the case in Anthony’s story regarding his receipt of censored medical information. Anthony highlighted that the apparent act of receiving important medical information in a censored format lacked compassion and duty of care consistent with service regulations and ethical systemic practice. Anthony had acknowledged that he was dealing with a lifetime of “anger bottled up” throughout the rehabilitation process. Yet, it appears that he was told what to do and what to know under the control of DoCS.

Considering Anthony’s story from an occupational justice perspective, it appears that he experienced a combination of occupational injustices consistent with being denied the occupational opportunities to realise his capabilities for meaningful and *dignified* participation (Kronenberg & Pollard, 2005). For example, being denied the opportunity to seek comprehensive information about his cancer diagnosis could be described as a form of occupational deprivation (Whiteford, 2000). As a result, it appears that Anthony’s situation affected his ability to seek appropriate and timely healthcare. Other prejudices may also relate to Anthony’s situation of alleged systemic disablement such as sociocultural factors and

characteristics which may include disability and assuming the lability of his psychological state to fully comprehend his diagnosis and prognosis. Further, being denied medical information to seek appropriate treatment appears to have directly impacted on Anthony's dignity as a citizen. According to Anthony, such a political act made by the Nurse and the general healthcare team at the drug rehabilitation centre seems to have significantly denied Anthony of his dignity which potentially jeopardised his health and future occupational possibilities (Kronenberg and Pollard; Laliberte Rudman, 2010, 2012).

Anthony's experience of the 'outside world' immediately following his sudden expulsion from the drug rehabilitation centre just three weeks prior to his scheduled 'successful completion' of the 12-month rehabilitation program, was not at all conducive to his mental health and hope for a fresh start. Anthony's experience of being told what to do and what to know in relation to the treatment of his Graves' disease did not stop once he had left the drug rehabilitation centre. Firstly, being expelled from rehabilitation immediately jeopardised the chance and re-evaluation of the decision made by DoCS to not return his five children back into his and his wife's custody. Anthony's life growing up in Kings Cross, a notorious suburb known as Sydney's 'red light district' full of a diverse cultural makeup was the location where he sought refuge following his arduous and unsuccessful attempt at rehabilitation. In the following excerpt, Anthony describes his experience of trying to seek appropriate medical treatment to battle his Graves' Disease and thyroid cancer in the Kings Cross area:

*When I go back into the – the Cross [Kings Cross] I go and see a doctor about the Graves' disease. I tell him it's really hurting me – my neck is really really hurting. Now unfortunately I've gone to a doctor that's a 'doesn't-give-a-fuck' doctor. He's just – "What do you want? What is it you want?" Sitting there with a script pad in hand. In the Cross they're used to people actually walking through the door, asking for lots of whatever. I said, "Mate what I want is to know how to treat this illness." He said, "Well I'll give you Oxycontin for the pain and I'll give you Valium to help your anxiety. I said, "Okay, thanks mate." Good – he just give me heroin in another form. It's morphine and Valium which is an addictive drug. So for two weeks I'm taking 380 milligram tablets of Oxycontin a day. Not shooting up, none of that. Just taking the way I've been told by a doctor and then I ring up [Anthony's wife] and she goes, "I hear you're on the Oxycontin?" I said, "Yeah they've been prescribed to me for my Graves' disease." She goes, "Well I can't be with a junkie" and hangs up. And I'm – fucking what?!? And so that – I go back to detox to try and get off it okay. They put me on Buprenorphine for eight days. They say, "We're going to put you on a rapid detox to come off it." Anyway so I do the eight days, then I go*

*back to [Drug Rehabilitation Centre], trying back again, here I am again back at 10 days, shattered. Now I'm saying, "Hi I'm Anthony and I'm an addict, day one. Anthony day two. Anthony day three." I get to day three and I'm bloody sick – sick as hell. And now I'm thinking I've lost my family. I've got no hope. DoCS are telling me virtually there's no point you doing what you're doing and I think fuck it. Absolutely fuck it. And I gave up. I came down to Kings Cross with the intention of dying. That was my intention. I went – I went to Chapman Steps. I wanted to – to die where I started.*

*So anyway it was divine intervention. A few things happened and I – and it didn't happen. I actually got a phone call prior to – just about to shoot up – from my son and – and that was divine intervention. Although he didn't know what I was doing he – the intervention was that I heard his voice and it gave me the realisation that hey there's somebody out there that actually loves you, mate, that's going to be really fucking devastated if you do what you're about to do. And – and that cut me. I actually remember sitting on the stairs with this stuff in my hand, crying my fucking eyes out, thinking fuck I don't want to fucking be here. You know. And – and trust me I – I struggle with that daily. It's really really hard when you don't want to be on the fucking planet because there's no point. But at the other time you don't want to hurt anybody.*

*And I haven't got it in me to go out and physically hurt people and I certainly don't want to mess my kids up emotionally.*

*My dad didn't love us enough to even stick around. He fucking knocked himself. And so I struggled with that demon for ages. And I went into really bad depression. My weight's dropping, getting worse and worse. I – I'm trying to scream out from the rafters to somebody, anybody, "I need fucking help". I don't even know what help I need. I just know I need it. I know that when I – when I – I can't sleep at night. My head won't shut up. I'm crying all the time. I can't eat. I've got no appetite. I go four or five days without eating. This is a little while back. I'm starting to get a handle on things now.*

The above account provide valuable insights into the spiral effects that can occur when transactions with systems of governance, such as seeking medical support by citizens experiencing moments of desperation and dire needs, are unsuccessful. In these striking accounts, Anthony's resilience and survival skills learnt throughout life, appeared to be at breaking point. Instead of rebuilding his life and seeking 'appropriate' and person-centred medical assistance as any other citizen has the right to pursue in Australia<sup>2</sup>, the unsuccessful transactional relationship was indicative of a spiral of failure, until he considered committing suicide. The result, however, was his realisation that he was cared for by another which was his eldest son. I interpret Anthony's description of receiving "divine intervention" as a form of social recognition (Honneth, 2001; Komter, 2005), which reflected a sense of belonging and

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<sup>2</sup> Australia is a Welfare State and has an accessible public healthcare system known as Medicare. Through Medicare, Australian citizens can have access to medical practitioners through bulk-billing system with no upfront fee.

connectedness expressed through a compassionate act. Reflecting on the suicide of his father, Anthony essentially did not want to echo such an act due to the emotional repercussions that his wife and children would endure. However, the seemingly endless cycle of helplessness and hopelessness that appeared to result from trying very hard to escape and succeed in some way, took its toll physically and emotionally.

Anthony's description of seeing a "doesn't-give-a-f... Doctor" is also poignant as it exposes the alleged lack of compassion by a medical practitioner in not exploring his story comprehensively or empathically. Anthony's emotive accounts appears to describe that what he needed the most from a healthcare professional was not provided in either a nurturing and person-centred way. The outcome of the "doesn't-give-a-f... Doctor's" (in)actions led Anthony to re-engage in previous ill-health behaviours and unhealthy occupations which had significant ramifications for his relationships with his family.

Considering occupational injustices as previously described, engaging in occupations through dignified ways appeared to be denied. Systemic denial of dignity, empathy and of occupations which support transformation and resilience, seem to be key factors at this juncture in Anthony's story. The implications on Anthony and other participants' identities and notions of personhood were explored at depth in the first findings chapter entitled 'being me'. However, the patterns of systemic denial and inherent disablement of opportunity are salient here. Such denial appeared to also continue and manifest in other areas of Anthony's life where he sought change for inclusion. In the following passage, Anthony shares his experience of "being thrown back into the pit":

*I mean, for me, for example, I came out of the rehab straight, gung-ho. I was really on fire to change my life. And so I turn up at Housing Commission and I have Graves' disease, which makes me feel very – like, up to 2 o'clock, I'm fine, then after that, I'm absolutely stuffed. My emotions can go from happy and joyous to absolutely suicidal, and that's fair dinkum. That's how I go. And what frustrated me is that Housing Commission tell me they're going to give me a home if I give up my home to go to rehab. So I do that. I come out, and then they say, "Oh, you have to go on a list." And I'm like, "Okay." I go on a list. And then they tell me I've got – I mean, I've got – you're living on the streets and you've got to accumulate all these forms. That's halfway impossible as it is. I mean, I'm battling to be able to keep one bag together and shower and shave and keep myself looking respectable. And so you – it's, I think, something that they should really*

*take a look at is the way that when people come out of jail or when people come out of rehabs, or whatever, that they don't throw them back into the pit, back into the ring. Like, for me, they put me into some sort of boarding house with other men.*

This account is multilayered in that it portrays methods to succeed within a system imposed by the Department of Housing as a system of governance (i.e. collecting forms) without considering a person's living and broader occupational contexts. For Anthony, his need to survive posed greater challenges than merely collecting forms to make it "on the housing list". Therefore, there appears to be a significant disconnect between systemic expectations for occupation and capability realisation, with people like Anthony's realities of hardship and survival. From his perspective, being thrown "back into the pit, back into the ring" further defined his role within society. From his story, it appears that Anthony knew that what he needed could not be met by systems of governance which did not understand basic needs. Therefore, his quality of life became compromised as such systems of governance took for granted the lengths required to achieve basic wants which were inevitably dismissed as irrelevant. This points to the importance of recognising the roles of context and environments to enable occupation at the personal and systemic level (Whiteford & Wright St-Clair, 2005; Whiteford, 2010). Being defined in such a seemingly derogatory way, Anthony also reflected on having committed crimes in the past which included jail time, as well as sharing some thoughts about his unsuccessful attempt at drug rehabilitation:

*...if you're going to persecute somebody for their past indiscretions, then they're forever damned.*

*And even the lady there [Drug Rehabilitation Centre] said to me, she said, "You're very articulate and you're very well spoken 'for an addict' and – and you have a good rapport with people".*

Being "forever damned" and feeling discriminated against by systems of governance was also significant for James. James' stories highlight potential violations of his rights to human agency when he talked about some of his experiences of interacting with Centrelink, the national multi-purpose delivery agency which was established as a one-stop-shop to provide services which mainly focus on the areas of social security and unemployment (Halligan, 2004). James



considered that being denied his human and occupational rights to choose what he wanted to do (Hammell, 2008), such as seeking gainful employment despite having acquired a workplace injury, was fundamentally the “biggest problem with the whole system”:

*Yeah um, and I think that's the biggest problem with the whole system. They're not giving you...how to say this right..., they're not letting you be a human being with the rights of a human being. Ah, it's like a dictatorship..., that's a full control of a population. For them [Centrelink] to have control of me and tell me what I can and can't do; that's taking away my rights as a human being. My freedom of choice; the right to think for myself; the right to act for myself, and the right to take care of myself. Well, I should have those rights as a human being. And, if it was in any other country, ah, you know, it would be called, what; you get the United Nations in... It's like a violation on human rights. But because we're the multicultural Australia, we never do anything wrong, we're such a good country, no one would look at it in that sense, you know what I mean. Like, I just don't see it in that way. I see it in the way that they're violating my human rights. And, I've actually talked to a solicitor about this seeing if I can sue. I just don't want any money. I want to make my money myself. Because I will not take something for free.*

In this account, James highlights the need for systemic accountability for allegedly practising in ways which support occupational deprivation and injustice rather than ameliorate them. James' insight into exploring his legal options for systemic recognition appears to instil his altruistic drive for change and opportunity. Nevertheless, James' story also provides further evidence of participants' lack of opportunity to be involved in decision-making processes for their own benefits which he described as “being in a dictatorship”, despite his calling to be heard.

The point of departure between James and Anthony's stories appeared to be at a prioritising needs level, where James' priority was to actively seek gainful and meaningful employment, whereas Anthony's priority was focused on securing a stable home as well as regaining the custody of his children. Despite considerations for both of these participants' health needs, such needs appeared to be much lower in priority compared to the superseding need to be heard and respected at the systemic and political level. Yet, from a relational perspective, they had both experienced various levels of deprivation from participating in meaningful, purposeful and dignified occupations due to multiple barriers encountered with systems of governance.

A major barrier identified in both participants' stories seemed to manifest from the constant battle of navigating systems of governance at the service interaction level. This mainly

included interactions with the employees who represented such systems or other individuals in culturally recognised positions of power such as medical practitioners and other professionals. From the participants' perspectives, it appears that exclusionary acts primarily occurred at the service interaction level where they encountered "gatekeeping" responses which predominantly denied or limited opportunities for participation and social inclusion. From my analysis, I consider such a barrier experienced at the service interaction level as one of the most disabling barriers encountered by the participants in their daily struggles for participation and inclusion, which consistently resulted in needs being drastically unmet and capabilities remaining unrealised. This type of 'invisible' barrier is consistent with exhibiting hegemonic practices, as well existing within critical disability studies discourse which has identified attitudinal factors as being detrimental towards fostering inclusion and social connectedness (i.e. Goodley, 2011).

In James' case, being denied of his human and occupational rights (Hammell, 2008) from his perspective, appeared to damage his identity as a "strong, independent person", adding that Centrelink was "lumping me in with the others", where 'others' were citizens living with disability. James' frustration from being "lumped in" led him to define some Disability Support Pension recipients from his local community as having "faked it" when they were assessed. Remarkably, another participant, Anthony, was also challenged by being 'associated' with others, and had gone further to describe some suburbs in Western Sydney as "Pensioner's paradise", "[being] full of dole bludgers" as well as fostering "housing [and pensioner] ghettos". This could be described as a form of identity protection and self-preservation by maintaining a level of cultural distance from those Anthony and James classified as 'others'.

When James started to consider applying for the Disability Support Pension, he described that it was always his intention to also work due to the meaning he ascribed to participating in paid employment. The occupation of 'work' appeared to hold personal meaning and value which related with the work ethic that was instilled in him during his upbringing within the context of a working class family. There were two clear moments in James' story where having rightful access to opportunities for work and appropriate supports appeared to be rejected. The following

account describes his first experience of receiving little support immediately following his workplace injury:

*The problem with that is, when you go and see the doctors, I got told you'll be back at work in two weeks. They popped it back in [right foot into socket] and said you'll be back at work in two weeks. Two weeks later, I still couldn't move my foot; couldn't lift my leg; nothing.*

*Two weeks later I went back to work like they said and I couldn't walk. The bloke on the job site said, go home. I don't want you here if you can't walk mate. So I went home and went to see a real doctor; my own doctor. Um, went and seen my own physio. They put it all down.*

*...Work sent me to a doctor. Work sent me to a place...um..., it seemed to be an absolute waste. I've put in a formal complaint about the doctor actually. And the physio; cause he said nah you're right mate, there's nothing wrong with ya. I'm like, well okay. Went and saw me own doctor. They got the ball rolling. They were quite disgusted with what had been said previously about this. Basically in the end, they diagnosed me with right drop foot.*

It appears from these accounts that duty of care was not properly adhered to by the health professionals involved at the beginning of his treatment. The apparent misdiagnosis by the occupational physician, who appeared to unrepentantly pursue an incorrect clinical treatment pathway for James' workplace injury, seemed to be the initial catalyst of negative events that had occurred throughout his life up until the time when James was interviewed. Unfortunately, James reported that he became retrenched from his workplace soon after the initial unsuccessful medical intervention. It appears that the organisational management of his healthcare and return-to-work rehabilitation process was essentially ineffective. This appeared to take a major toll on James' worker role where he had developed skills as a competent traffic management officer.

From James' perspective, his defiant resilience, inner strength and never-give-up attitude led him to undergo a self-motivated and strenuous rehabilitation journey which was initially not recommended by several medical 'experts'. James inevitably met a local physiotherapist who guided and directed him through his rigorous daily training regime at little to no cost. James also shared that he underwent experimental surgery funded by accessing his superannuation benefits which enabled him to return to some form of mobility. However, his mobility and training regime led to major episodes of chronic pain.

Together with the difficulties that James experienced from being allegedly mismanaged with his return-to-work rehabilitation process, he also described being denied the opportunity to work while also receiving a disability pension due to the apparent (in)actions of Centrelink. James' accounts of being frustrated with "the system" related to Disability Support Pension applications which he claimed were repeatedly declined by Centrelink gatekeepers. James stated that he informed his pension assessors that he could work more hours than the policy allowed for pension uptake<sup>3</sup>. Therefore, his attempts to be granted the pension to temporarily survive his chronic unemployment appeared to become a futile and demoralising process. James did not believe in "taking money from the Government" if there wasn't a legitimate reason. He highlighted his experiences of trying to navigate supposed 'authoritarian' approaches by Centrelink employees, as well as his longing to return to a 'normal' life in the following accounts:

*So, the system at the moment is not . . . okay it's good if I wanted to be on the Disability Support Pension for the rest of my life, and I wanted to live in shared accommodation. And that's what they [Centrelink] are trying to force me to do . . . I walk through the shops and people just stare at me like you know, what the hell's wrong with him. It is very uncomfortable, but you get used to it. But to have that normal life, I don't want people looking at me. So it means that I've gotta be able to walk properly. It also means I've got to have my own place. I've got to be able to live strong by myself as a strong individual person. Unfortunately, you need income to do that. Unfortunately, I'm stuck between a rock and a hard place it feels like, you know. So, the system really does not help people like me. It only helps people that want to give up and do what the doctors and others tell them. Which is, sit at home, take it easy, don't do nothing, live with others. You know.*

*. . . They [Centrelink] said that "we're not giving any more rent assistance, you're going to have to think about going into shared accommodation". This is where we can put you. I said I don't even want to see that form because I'm not going. I said I am still capable about being in the workforce as a full employee. They said no . . . why not!? What, because I've got a problem with my leg!? You're fat and lazy and you sit behind a desk . . . you probably couldn't do the work that I do! That's why you're saying it! But, even though I'm disabled, I can still do it. I know I can . . . That's just my attitude, you know. Any athlete will tell you that . . . all these other people, don't see it that way yeah . . . It's a bit nasty and a bit disheartening like I said. . . . It's like a dictatorship when you get into the system. They tell you this, this, this and you've got to abide by it. But not everyone's the same, are they? . . . And I think that's the problem. They don't take us case by case. They take us as . . . and I don't mean this in the worst way . . . actually I can say this 'cause I've lived in Western Sydney pretty much all my life. They treat me like another bum, loser that just wants to be on the Disability Support Pension . . . I'm not getting lumped in with all these losers. And that's just the way I like it. You know, but then they 'do' lump you in with the losers when they are looking at you instead of doing the case to case. They just put you in with the*

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<sup>3</sup> Up to 15 hours per week did not impact on being granted the Disability Support Pension or receiving the full pension amount.

*losers and say well you've got the same attitude as anyone else in this area. No, I just live in this area because this is all that I can afford. If I had the money, I'd be living closer to the city or something you know. Um, but I just don't like that situation being lumped in with everyone else and categorised. It's just not right. It's not fair and I've been saying it for ages. Something needs to be done about it . . . Instead of just saying, this is what everyone will do, you know. 'Cause we are not all the same.*

In this descriptive self-analysis of his transactions with Centrelink, James' statement of 'being lumped in with the others' by Centrelink speaks to the invisible attitudinal barriers experienced at the service interaction level outlined earlier (Goodley, 2011). However, in this account, James identified unspoken and value-laden assumptions about participation capacity which appeared to exist amongst some "able-bodied" employees towards citizens living with physical disabilities such as James. Despite James' longing to be employed and work to the best of his ability, he appears to have been denied of such occupational opportunities at a subjective and moral level. Not being treated "case by case" and "lumped in with the losers" has become James' lived reality due to such apparent exclusionary acts which occurred at the service interaction level.

James' story provides a common thread of systemic disablement at the service interaction level experienced by all of the participants. These exclusionary experiences appear to be based on a tacit, hegemonic stance inclusive of subjective and *ableist* assumptions of capability and capacity to work and participation in life in general by able-bodied employees in gatekeeper positions. The mechanisms of exclusion are thus played out in predominantly subjective ways which appear to have had major psycho-emotional impacts on the participants. At an everyday level, not being considered on a case-by-case basis and being "lumped in with the losers" appears to clearly demarcate James as being an 'other' amongst the 'others' as well as promote unnecessary dependent behaviours which disempowered lives.

Being 'lumped in with the losers' has labelled James as a person who has been stripped of their identity. Therefore, for systems of Governance such as Centrelink, the Department of Housing, the medical fraternity and the drug rehabilitation system, occupational roles which form a major part of the participants' identities, such as being an elite basketball player, cyclist, gym

goer, father, husband, skateboarder, cricketer and rugby player, are not important. Thus, being “disabled” and “unemployed” appears to dominate the participants’ perceptions of themselves as well as how they are perceived by others in more dominant social positions. This provides further support for my conceptualisation of a *participation hierarchy* where being relegated to a less favoured social position by people in positions of power, delimits opportunities for social transformation and capability enablement.

### ***Not getting a “fair go” and being powerless***

Participants’ stories which depicted numerous experiences of being *disempowered* from interactions with employees of systems of governance, further contextualise my premise of a participation hierarchy. Additionally, feeling othered and excluded at the service interaction level provokes a theoretical exploration into the role and cultural implications of *hegemony* when contextualising a participation hierarchy. Italian political philosopher Antonio Gramsci (1971) originally coined the exercise of hegemony as comprising

“the “spontaneous” consent given by the great masses of the population to the general direction imposed on social life by the dominant fundamental group; this consent is “historically” caused by the prestige (and consequent confidence) which the dominant group enjoys because of its position and function in the world of production” (p. 12).

From an occupational science perspective, Kronenberg, Pollard and Ramugondo (2011) interpreted Gramsci’s cultural hegemony as “the political, economic, ideological, or cultural power exerted by a dominant group over other groups, regardless of the explicit consent of the latter” (p. 3). In particular, cultural hegemony highlights the power that dominant groups have which they can impose on others relegated to subordinate social positions. In some cases, ‘othered’ citizens accept the dominant group’s social ontology which becomes established as natural, where subordinated citizens actively consent to the status quo which then reproduces hegemony (Edwards & Wajcman, 2005).

In Anthony’s case, ‘being stunted’ appeared to be a feeling which he attested to exclusionary and hegemonic acts performed by the customer service officers at the Department

of Housing office that he frequented. According to Anthony, being the recipient of such acts resulted in being denied housing despite his urgent need for accommodation due to his chronic health and psychosocial needs:

*I could not do anything more to evoke, is it, change in myself. But it's not going anywhere. I'm stunted, and it's all over housing for me. At the moment, it's just the actual inability to get a place to live, my own. Somewhere I can call my own. A fucking square... There's somewhere on this planet, surely, that they could put me and my son so we can progress. But I mean, for two years, I've been stunted because I can't get a bloody roof over my head. I either have to live with someone else that I don't even know, who's a chronic alcoholic, who I don't trust...*

*I won't lie down, you know what I mean? I've fought my whole life and I'm going to go down swinging. I am adamant I want to change my life. But I approach the Housing Commission – I did it every day. Now, I just don't bother. So I've got to a point now where nothing's going to happen because I'm not initiating it. But every time I go in there [Housing Commission Office], they're just filling me full of shit.*

*...I went into the Housing Commission, I said, "Look I want out of this fucking place." Come back this day, come back that day. All right what we need is all these doctors appointments – we need letters from doctors. Letters from doctors. So there's another six weeks – six weeks. I've got a bag this fat of letters from psychologists, doctors, counselors, all saying that this guy needs to be out of the city, up in the – away from the city and in a place that's not got drugs you know what I mean!*

These stories of experiences are reflective of Anthony's previous comments where he stated that he had done what was asked of him by systems of governance for participation and inclusion to no avail. In the case above, it appears that Anthony has been denied opportunities for basic resources in less rightful ways, such as a "having a roof over my head". This is despite his accounts of acquiring professional medical reports with great difficulty to complete policy-driven and systemically defined requirements for access (i.e. processes for accessing urgent housing). He described with great detail the story when he approached an office of the Department of Housing with specific paperwork which documented his urgency for stable accommodation. He identified that he had spent a period of time being homeless. As a result, his paperwork allegedly had some dirt on it but was still legible and presentable. According to Anthony, the customer service officer working for the Department of Housing did not accept the paperwork, as they anticipated that the dirt found on the paperwork was blood instead. The officer then proceeded to don gloves in front of him to handle the paperwork. In the end,

Anthony reported that the paperwork was not accepted due to the customer service officer's apparent judgment to not accept the paperwork.

This perpetual pattern of meeting systemic requirements but not adequately receiving due resources appears to result from *value-laden* actions by employees or other individuals in positions of power. As a consequence, the policy intentions of systems of governance for service provision became limited at the service interaction level (Townsend, 1998). Other barriers beyond attitudinal ones may also exist for such individuals which can further catalyse forms of exclusion and discrimination towards service users. An example could involve such individuals who need to satisfy minimum standards, key performance indicators or targets mandated by policies for systems of governance to meet their support requirements. From analysing the participants' stories, it appears that unsupportive and at times hostile interactions with individuals could be the by-product of their need to meet unrealistic targets mandated by 'well intentioned' policies (Townsend). Unfortunately then, participants then interpret unsuccessful service interactions as being unjust, leading to further exclusion and marginalisation. Thus, cycles of disadvantage appear to continue due to participants repeatedly receiving negative responses, which do not encourage them to access such services should they require them in the future. Such exclusionary and hegemonic acts that have resulted for Anthony and many of the other participants, could be described as unfair, unjust and discriminatory in nature due to a complex interweaving of value judgements, employee pressures and policies that appear to be out of touch with *basic* everyday occupational needs. Wellbeing appears to be significantly compromised resulting from missed opportunities for occupation, participation and inclusion due to systemic denial and/or disablement.

In the following account, Anthony had more to say about the Australian motto of a 'fair go', which is consistently depicted throughout Australian social inclusion policy discourse (Department of the Prime Minister and Cabinet, 2009a):

*...This country where we're supposed to have a fair judicial system I'm telling you it's a long way from fair...Yeah. A fair go. Australia's motto of a fair go. Well it's not a fair go. What I*



*believe and – and this might be distortion, I don't know, but what I feel is that they're catering to the rich.*

Not getting a 'fair go' was also a recurring theme for another participant: Rose. Rose shared several complex stories which exposed the direct and indirect forms of discrimination and prejudice that she claimed to experience, especially within the job seeking domain, during the past 25 years since she immigrated to Australia. She shared the following account where she described her attempts to pursue paid employment including the underlying discrimination that occurred:

*...And I have been called named such as 'black bitch' and 'wog' and you name it. Very abusing and demoralising words. And insulting. And this got me to the conclusion that I am, I don't feel like I belong here. And, by not given a chance for work, I, they don't trust 'us'. We are the foreigners here. We are the newcomers. They said to you, "Welcome to Australia", but there won't be any life for you. No future. Just because I've got an accent or doesn't look like them. Not 'B' 'n' 'B' which means 'blonde and blue eyed'. Yeah. So they don't trust you in order to give you a job. They are very much keeping to themselves and employ only locals. The Australians. They are expecting you to be with high standards. And accept too much from a simple person.*

*...So um, I just find out the last 20 years I couldn't get a job, and I went to TAFE for 7 years to update my skills and I got very down, disencouraged, and demoralised by not being able to find a job. And I got into major depression. Especially with the people here that used to pick on me and call me names because of my skin. Called me 'black bitch'. They called me Aboriginal. And ah, whatever.*

In these accounts as well as throughout her turbulent life in Australia, Rose reported that she relentlessly experienced various forms of discrimination, which included racial, cultural and systemic discrimination. Feeling "disencouraged" and "demoralised" from being chronically unemployed and feeling othered seemed to negatively reflect on her identity as a single, ethnic mother needing to financially provide for her daughter. From Rose's stories, it appears that her decreased self-esteem and self-efficacy led to a flow-on effect which exacerbated her chronic health issues. Such "high standards" that Rose referred to in the above account also appeared to reflect a deep sadness from her longing to work to make a better life for her daughter and herself. Despite completing a diploma in her home country and various other vocational education and training (VET) courses over a period of more than seven years following the death of her daughter's father, she felt discriminated against due to the actions of would-be employers.

Having completed several courses and attaining various professional licenses such as a forklift, gaming and security guard licenses, she was constantly informed that she was “over-qualified”, or she was not informed of the outcome of job applications.

### **Feeling demoralised**

The implications of some of the interactions between individuals representing systems of governance and the participants, seem to have negatively affected their personal ontologies, or ways of being at a psycho-emotional level. A focus on the impact of exclusionary acts reflected by the participants was reported through their emotive accounts of interactions with systems of governance, such as the drug rehabilitation system. As such, this sub-theme highlights the exclusionary effects experienced by some of the participants when they engaged with methadone clinics. Although feelings and emotions are exclusively highlighted in the first findings chapter entitled ‘being me’ which explored elements such as personhood, recognition and identity in context, this section addresses the shortcomings of services such as methadone clinics, which inherently have ‘good intentions’ (Townsend, 1998) at their outset for ‘successful’ participation.

Bruce and Anthony unravelled what they described as the “insensitive” nature of methadone clinics as they experienced them during their rehabilitation from heroin or other drug addictions. Examples of their detailed accounts are respectively presented in the following two statements:

*Bruce: The methadone system is ridiculous...They called methadone – they called it ‘liquid handcuffs’, because you can’t go anywhere. You can’t do anything. It’s very involved. You’ve got to go to doctors’ clinics...and it just makes – it keeps you where they can keep an eye on you, more or less, sort of thing. You’re very structured, plus it’s very demoralising to have to go to these clinics with a lot of people from lower socioeconomic and educational levels...and undesirables and things like that. And you’ve got to be like a robot and just line up and get your dose, and they don’t pay much respect and stuff in these sort of clinics and that...*

*And I believe it’s ridiculous putting you on a so-called maintenance program. As you can see, I’ve lost all my teeth through it, which is a side effect and you sort of fall into this routine. “Oh, I’ve got to go to the clinic.” And you’ve got to go every day.*

*Anthony: Yeah, and what idiot, in their right mind, says, “We’re going to put these people on methadone?” Okay, I get that methadone actually saved my life at one point, and it’s very useful if*

*done properly. But it's not about helping us; it's about maintaining and controlling us. To me, a methadone clinic is a place where they give you your dose; they're always trying to entice me to go up. They want to keep you trapped to the place so they know where you are everyday, what you're doing, monitoring you. Counseling sessions are almost laughable. It's just like – it's not actually talking about, "Hey Anthony, what can we do to change your life, to actually go forward?" It's not about that. It's more like a maintenance...You don't change people unless people want to change.*

*It's like, "How can we maintain your addiction?" Because you know why? In their belief, it lowers the crime statistic, but it doesn't. An addict is an addict. And if he wants to continue using, all is being done is giving a prop-up so that he doesn't hang out, so that he has the ability to still go out and be that person. You don't change people unless people want to change. So to me, where I'm getting to is the takeaway thing. They give people methadone to take home. Now, I'm here to tell you my wife and I, for 10 years, every day, shot up methadone. We used to get our seven a week. They gave us four of them to take home. I'm an addict. I'm sitting there and I'm thinking, I've got seven bottles of methadone, or four bottles of methadone. I'll take one. I'll take another. And I'm doing this – this is two years ago I'm talking about, when I was out of control. And that was for 10 years. And now, I actually went to the clinic many, many times, so they're negligent, and said to them, "You know what? I actually can't handle takeaways. I can't handle it." I said, "I'm an addict." It's like saying to me, "Anthony, here's seven days' worth of heroin. I want you to divide that out." I said, "Oh yeah, sure. I've been a heroin addict all my life. I'll be able to do that. No worries." Like, it defies logic. It's unrealistic. There needs to be more stringent policing around how stuff's done with doctors...There needs to be more sincerity in helping people move forward. And how I believe you do that is, one, is you have to stop having people all congregate at the same time at the methadone clinic.*

Both participants highlighted the apparent 'surveillance and control' nature of methadone clinics in detail. Their accounts documented above shed some light into the manner in which power was allegedly practiced by rehabilitation professionals towards drug users and addicts. Both Bruce and Anthony described how they believed the drug rehabilitation process had failed to combat addiction at the systemic level. Instead, they described how the drug rehabilitation system, and methadone clinics in particular, had failed to address the counselling and rehabilitation needs of drug users. From their stories, it seems that clinic workers perpetuated drug dependence through methadone provision without appropriate support for sustainable change. Further, both participants illuminated the difficulties that manifested from congregating with other drug addicts. For Anthony, he stated that he wanted to rid himself of such associations but did not have a choice to do so due to the methadone program's 'rigid' routine which included congregation in one area. Bruce described this experience as donning "liquid handcuffs" whereas Anthony attested to "being trapped...where they can monitor you".

Both participants also described their motivations to pursue positive and sustainable change in their lives, which was focused on overcoming their drug addiction at the time. However, it appears that the drug rehabilitation system, represented through the strict protocols and procedures of methadone clinic service providers, had a subjectifying effect on recipients like Anthony and Bruce who claimed to be genuine about wanting to supersede their addiction and ill-health behaviours. As a result, I argue that if systems of governance are enacted in such ways at the service interaction level, then opportunities to support flourishing (Gidley et al., 2010b; Seligman, 2011), personal choice and seeking healthier occupational possibilities (Laliberte Rudman, 2010) may be significantly hindered. It appears that for participants such as Bruce and Anthony, occupational patterns fostered by policy decisions which *maintained* ill health or static behaviours rather than enact capabilities for flourishing and social transformation (Gidley et al.; Seligman, 2011; Sen, 1999) became the preferred outcome. In the end, reactions by participants following their accounts of such experiences seemed to take a psycho-emotional toll on their sense of self, identity and relationships with broader social ontologies (i.e. feeling demoralised).

### ***“I don’t know what to do or where to go”***

Navigating complicated and convoluted systems of governance, such as the drug rehabilitation, welfare, medical, child protection, legal and justice systems seemed to be a recurring theme for all of the participants. Rose, for example, highlighted some significant problems that she experienced with the justice system during her claims for divorce from her first husband. She reported that her interactions with justice system practitioners through the divorce process were particularly traumatic. She shed some light into her dilemmas in the following accounts:

*He stayed home and things got off hand. Like in the caravan park, I was coming home from work and he expected me to wash his clothes and cook, and do the grocery. And I was the only provider. He didn’t work. And um, he went to a courier company and they send him with one envelope to the city with a truck. I said, [Ex-husband’s name], this is not a life like this. What are you bringing home? 100 dollar?*

*So he took a lump of wood and chased me with it. He start to get violent and I didn't know what was my rights [were] to get AVO [apprehended violence order protecting victims from various forms of violence] against him. And we were fighting every day, every day.*

*... I couldn't walk for like 2 weeks [following seriously injuring her back from a lifting accident]. He was very violent man. And I said that's it. I went to the doctor, I start crying. The doctor never told me to take an AVO out against him and do something. No one told me what's my rights.*

In addition, when seeking legal advice and going to court to pursue her divorce, she reported to have been treated with little respect by the judge. Rose poignantly described the experience of leaving her violent husband and her interactions with the justice system in the following account:

*I said to my husband, take everything; pillow, ah blankets, take all your tools, take all your belongings. Just leave me alone. Just go. Leave me alone. I'm getting headache. I had heart problem with him. He was chasing me with a hammer.*

*And yeah, I went to the family court in [Western Sydney] and I said, I want to apply for divorce. He said how long you not been living together? I said 6 months or 7 months not together. I've been sleeping outside. I said 12, they told me to say 12 months. So I took it [application form] to the security guard from the caravan park, and I said Michael can you fill it up for me? I gave him 25 dollars. I took it back [to the family court] and they said it's not good. You have to fill up here, you have to fill up here. I said okay.*

*... Anyhow, in the meantime, I went for divorce and I went to the judge and he said, 'oh', he was sarcastic..., "I understand you want to be single. You want to be free. You know with a husband you are not free you know". And I said, no your Honour, I wanted to be a mother [Original emphasis]. And I was crying you know because all what he did to me, all these years, I let out. And I said he's hitting me, he's belting me, you know he doesn't work and he doesn't want a family. I want to be a mother. That's all I told the judge. They said, where is he? They said the solicitor said he doesn't have to come. I went to Legal Aid. So he took the paper, he stamped it and he said, "you are free to go". I said, "Praise the Lord"!*

For Rose, the actual process of filing for divorce due to irreconcilable differences with her husband was made more difficult and sensitive due to the fact that her medical practitioner apparently did not inform her of her rights to seek legal support. Unfortunately, literature suggests that Rose's experiences of apparent discrimination and victimisation was not an isolated case. Family law research suggests that women affected by domestic violence, and mothers in particular, "are confronted with negative attitudes and ineffectual practices within convoluted bureaucratic criminal justice systems, leaving many feeling revictimised" (Letourneau, Duffy & Duffett-Leger, 2012, p. 585). This experience was heightened for Rose due to the absence of a

meaningful and sustainable social network to access for ongoing psychosocial support beyond those people who initially supported her. As stated in the previous findings chapter, lacking meaningful social supports had a negative effect on Rose's mental health and sense of belonging, thus perpetuating notions of victimization.

### ***"Falling through the cracks"***

Rose's difficulty with navigating different systems of governance did not stop with the justice system or the medical system. She also reflected on the paucity of programs that existed in her local community aimed at developing social health and connectedness with others through structured leisure activities:

*I end up coming here [Parramatta Mission]...which is not my place to be here. But I have nowhere to go, no friends...There is not much to offer people with a bit of depression but they can still function. There is not much to offer the society, the Government. There is no facilities to go, or places to [socialise]...Yeah, I'm feeling that I'm falling between the chairs; between the seats. And I am not belonging here, and not belonging there. I'm not an alcoholic and I don't smoke. I don't drink and I don't take drugs. I'm just straight...And all they offer here is for people with drug and alcohol [issues] facilities or treatment. They have [services and places to go] for lesbian and gays. I'm not lesbian and I'm not gay. So it's really sad, it's really sad that the [Government] doesn't have any social life for other people. I don't go to the pub and I don't drink. So I don't know. There is no social life here. Everyone lives his own life. If you don't know anyone, you are on your own.*

Rose's account above contrasts social inclusion ideologies adopted by the Australian government which promote opportunities for citizens to learn, work, engage and have a voice (Department of the Prime Minister and Cabinet, 2009a, 2009b). I interpret 'engage' as including participation in meaningful occupations. Rose blamed the government for the lack of resources and opportunities that people could pursue such as participating in meaningful social occupations for increased connectedness and wellbeing. Such blame was targeted at the government and the broader community's cultural assumptions about mental illness, where structured leisure activity programs only catered for people experiencing major mental illness without also incorporating the needs of those who can "still function" with mental illness. She used the metaphor of "falling between the chairs" to share her thoughts about the opportunities which existed, or more

accurately *lacked*, to meet others, form relationships and engage in meaningful leisure and other social occupations. Rose's account is another example which demonstrates a disconnect between the process of identifying and prioritising social 'problems' for intervention, policy directives, funding allocation, service provision and citizens' support needs. Rose's story highlights the diverse support needs of citizens experiencing mental illness and other disabilities which appear to be significantly unrealised resulting in limited opportunities for participation.

Similarly, Anthony used several metaphors to describe systems of governance which he perceived as not adequately addressing his and others' calls for justice at the policy and service interaction level. Metaphors are considered as important discursive tools to at least partially understand what cannot be completely comprehended, such as feelings, moral practices, aesthetic experiences and spiritual awareness (Lakoff and Johnson, as cited in Shinebourne & Smith, 2010). Shinebourne and Smith suggest that metaphoric expressions enable "richly textured communication" conveying "visual and tactual imagery" (p. 60). In their research on the use of metaphors in people's accounts of living with addiction, Shinebourne and Smith discovered that metaphors were powerful tools used for communicating and sharing experiences, which could more accurately capture the quality of emotions rather than the traditional uses of adjectives or emotional labels could alone (Shinebourne & Smith). Here, Anthony describes government inactions towards building more effective social, welfare and health policies:

*I think the biggest thing I can say is that the government's got to stop looking at quick fix and start looking at long term. If you want to fix something broken, you don't quickly get sticky tape, and wrap it up quickly and pass it back; you actually put time and thought into the process so that there's a proper result at the end. Do you know what I mean? Or else there's a vicious cycle that just continues. I don't know if you've heard the expression 'chasing the dragon's tail'? Well, that's – that epitomises what I'm saying. We are going around in circles. Here, you have a bloke who's had his children taken off him and been given false hope, sent to a rehab. For me, that was a big thing, considering I've been institutionalised most of my life, and then get told I have to go into an institution. I get that, right? But then when it – they justify not giving the children back because I've been in rehab for 12 months and the kids are now stable, that's just criminal. That's criminal. What it does at this end of the scale is it leaves the person suicidal, homicidal, looking for revenge, angry, and on a path of self-destruction. And I – the stories I hear from each person, and I am one of these people that does take the time to listen to people's stories, and I do that because I feel sorry for myself a lot and I'm just being – stating a fact. I try not to. I actively say affirmations in my head to try and*

*keep upbeat. But I slowly drift sometimes back, and I'm thinking, fuck, at the end of the day, I still don't have my kids, I'm all alone, I don't have a job, I can't get a job because there's always a reason for something because of my past. And there's got to be a time – like, if you're going to – what's the word? It's sitting on my tongue and I can't get it out. But anyway, if you're going to persecute somebody for their past indiscretions, then they're forever damned.*

Anthony's reports of interactions with several different government agencies, departments and related services seemed, overall, to be more destructive than constructive. Anthony related such “destructive” interactions as failing to address or facilitate positive outcomes for him and his family spanning several life domains including general wellbeing, financial stability, social networks, family life, being a father as well as psycho-emotional support. Considering all of his experiences with transactions made with systems of governance and their impacts on his wellbeing and life satisfaction, Anthony summed up his major aspiration that provided him with hope and nurtured his survival and resilience skills by the following statement:

*...I just want a simple thing. I want to put a roof over my head and a roof over my son's head so that I can meet my obligations as a father and take care of him.*

### ***It's too complicated***

The seemingly basic solutions described by Anthony in the previous account as well as other participants regarding building occupational potential (Asaba & Wicks, 2010; Wicks, 2005), appears to fall short from becoming realised. This could result from the unnecessary complications that the participants described resulting from attempts to navigate convoluted systems, which seemed to *assume* taken-for-granted abilities and skills. In the following section, Richard describes two examples of such assumptions that he believed policy makers and systems of governance held regarding accessing services to facilitate participation:

*...It's as though you get the disability and you get on a disability pension or something and you're just sort of put in the too hard basket. You know, there's not enough emphasis on being able to help people with it.*

*...Do you know what happens now when you apply – when we went in there and I went in there to put in this med thing and the lady said, “You should be going for disability.” I said, “Oh, okay.” And she said – well I said, “Well, give us a form,” and she said, “We don't give them here. They'll be sent out to you.”*



*...See, now you look at this. This is a Disability Support Pension [Richard demonstrated an application form to the researcher]. Now that page, that's a lot of reading. Well there's 27 of those. So, for somebody who's used to maybe working in a factory and not that well educated or doesn't read that much, I mean, they must just glaze over on this...But, for a lot of people, that would be an awful lot of reading...I guarantee there'd be plenty of people going, "What?"*  
*...I think one of the biggest problems is finding the resources. Now, you have a look at – go onto any of these sites...the Australian Taxation site; the Centrelink site...You start trying to find out stuff on the Taxation site...I mean, it's a nightmare, trying to download – because I've just recently done some old tax things I've had to put in, and trying to find those forms and that. I mean, it's just very convoluted.*

Assumed levels of literacy and comprehension, especially amongst citizens experiencing entrenched disadvantage is a known phenomenon in Australia (Australian Social Inclusion Board, 2011). Paradoxically, financial stress can be the root cause of illiteracy, ill health and disability (Australian Social Inclusion Board). However, citizens living in poverty who experience entrenched disadvantage are amongst those who require financial assistance the most, such as through equitable pension uptake (i.e. Disability Support Pension). Nevertheless, systemic barriers to participation such as the assumed literacy and comprehension required to process complicated documents such as pension application forms, as described by Richard, can cause unnecessary hardship. Richard clarified that he could not understand why processes targeted to 'enable' and 'empower' marginalised citizens, such as completing a Disability Support Pension application which was 27 pages long, were so complicated, "convoluted" and assumed a relatively high level of literacy. This dilemma experienced by Richard, Annie and other participants, as well as other interactions with service employees across other systems of governance, provide valuable insights into the importance of having accessible services which adopt universal design principles (Hitch, Larkin, Watchorn & Ang, 2012) and other citizen rights; from physical accessibility to accessible and 'user friendly' documents.

### ***Experiencing a lack of compassion and empathy***

The final sub-theme explored in this chapter explicates two key examples of how compassion and empathy were predominantly relegated through participants' experiences of 'being in the system'. Matters of compassion and empathy spanned across each of the findings

chapters' meta-themes. Issues pertaining to lack of compassion featured prominently in the previous findings chapter which comprehensively explored the existential realities of entrenched disadvantage from the participants' perspectives. This sub-theme specifically addresses how participants experienced an apparent lack of compassion and empathy from direct interactions with support services as well as from political misrecognition (Honneth, 2001; Thompson & Yar, 2011). Richard shared his thoughts related to this sub-theme in the following account:

*The trouble with the political level, is it doesn't have as much oomph as carbon trading schemes, or giving more funding to farmers, or expanding allowances for capital depreciation and things like that. There's not enough bite in it and really my attitude is with 'us' [people with disability]. We're basically the bottom of the pack. Unless there's a substantial change to a more compassionate country, I think you measure a country by how well it treats the bottom of the rung. That's why you look at a so-called Christian country like America, compared to an Atheist country like Sweden. I know where I'd rather be living if I was old. Sweden. You know, they look after them better and that there.*

Through Richard's cross-cultural example above which was shared in context with the current political issues occurring at the time that the life history interviews were conducted (February 2011), he illustrated how a lack of cultural compassion led to misrecognition of people living with disability across social, political and cultural spheres (Calder, 2011). He described political misrecognition as "being at the bottom of the pack" in political discourse and funding directives. Richard inferred such lack of compassion and empathy across sociocultural and political levels as an ultimate form of neglect and occupational injustice. Leigh was another participant who reported sociocultural misrecognition. He described some of his experiences of feeling stereotyped by medical practitioners and Centrelink employees in the following stories:

*I find stereotyping very segregational, in the way when you're stereotyped...the way people view you, like make assumptions on who you are. Sometimes even probably by the way you're dressed or by the association. I find that a big barrier really. And not just a barrier, I find it very insulting...*

*One day I was talking to somebody...he was a Doctor actually and his attitude was you can't speak to me that way 'cause I'm a Doctor. And I said, my answer to him was "Just 'cause I'm standing here in a pair of jeans and tattoos doesn't need to fool you. I'm not an idiot you know." Yeah, and he actually, it was just his attitude...he was speaking to me like I was just an ignorant person that had no idea on, you know...he stereotyped me. He judged me on my appearance, you know. And I find that very insulting to be judged by appearance.*

*...And I actually said to Centrelink, "You're in a position where you cannot make a judgment on who people are by the way they're dressed or the way they present their self." I said, "Because you're working in a job where you're dealing with people that are at the most vulnerable part of their life." And some people don't choose to be there, so they're in a position where something that these people can say to them can have catastrophic effects on them, you know, to the point of even committing suicide. And you have got to be aware that you're dealing with these people, and you can't speak to people the way you speak to them. And I said to her [Centrelink employee], "If I chose to wear a suit in here," I said, "You would speak to me differently." I said, "If I was coming in here the next day wearing ripped up jeans, it's not because that's my lifestyle. It's because it's what I chose to wear that day." I said, "You cannot make a judgment on my appearance, because you cannot tell a person by their appearance." But yeah, they really, people in those positions overstep their boundaries - it's not even their authority. They overstep their boundaries and their job description. Because the point being that they work for the government. They're not a government representative.*

Leigh's stories above highlight some of the complexities that exist in carrying out professional roles within systems of governance and their implications as they occur at the service interaction level. For example, Leigh reported that he felt 'boxed in' and categorised by the way a Centrelink employee had made value-laden assumptions based on the way he was dressed. Such stories of experiences can be interpreted as being disempowering to the point where service users such as Leigh could feel even further alienated from 'mainstream' society where his needs were not met on a "case by case basis" (as claimed by James).

## **Conclusion**

This chapter concludes the findings of the life history study documented in this thesis. It has presented some narrative examples of transactions experienced at the service interaction level between participants and employees of systems of governance. One of the major findings from analyzing the participants' stories describing such encounters was that they sustained negative physical, sociocultural and psycho-emotional effects resulting from unsuccessful transactions which lead to to their needs being unmet. As a consequence, the participants' cycles of disadvantage continued, culminating in capability deprivation (Sen, 1999, 2000), occupational injustice (Stadnyk, Townsend & Wilcock, 2010; Whiteford, 2000) and systemic disablement. Through not having adequate or appropriate systemic support to *do* and *be*, participants

experienced a diminution of hope and the development of despair. Eventually, agency, identity, becoming and belonging were negatively affected, and capability development (Sen, 1999) through occupational possibilities became limited as a result (Laliberte Rudman, 2010).

Unfortunately, it appears that assumptions made by people in positions of power during transactions with participants, such as medical practitioners, Centrelink employees and drug rehabilitation workers, for example, were broadly value-laden which were then perceived and interpreted by participants as exclusionary in nature. Therefore, matters of individual importance for the participants, such as enabling their capabilities and receiving opportunities for occupation, participation and social inclusion, were not considered as important due to apparent value-laden assumptions that directed the decisions made by systemic gatekeepers. Thus, hegemonic practices ensued. This chapter, however, also considered the complexities and pressures involved in decision-making processes which seem to exist at the gatekeeper level imposed by a higher chain of command. Therefore, there does not appear to be a 'one-size-fits-all' rationale to explain the mechanisms of exclusion as they are experienced at the political or service interaction level solely based on value-laden assumptions. Mechanisms of social exclusion enacted at an everyday level are therefore much more complex, interweaved with decision making, political ideologies and policy mandates across various levels of power influencing possibilities for participation and social inclusion at the service interaction level.

The next findings chapter presents the findings of a critical analysis of discourses (Bacchi, 2005) that I conducted of Australian social inclusion policy texts published during the Rudd government which sought to answer the first research question documented in the methodology chapter. It critically examines policy-as-discourse (Bacchi, 2000) through a combined research approach involving interdisciplinary techniques derived from critical political and occupational science perspectives (Bacchi, 2009; Pereira & Whiteford, 2013; Whiteford & Townsend, 2011; Whiteford & Hocking, 2012). A critical interrogation of both findings from the life history study and the critical discourse analysis is presented in the final discussion and conclusion chapter (Chapter Eight). The discussion and conclusion chapter presents a meta-synthesis of the findings

documented in this thesis. It explores the utility of how social inclusion policy takes into consideration and meets the everyday needs of citizens living with entrenched disadvantage characterised by poverty, disability and other social issues.

## Chapter Seven

### ***Being the policy: A critical analysis of policy-as-discourse***

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*The work of an intellectual is not to mould the political will of others; it is, through the analyses that he does in his own field, to re-examine evidence and assumptions, to shake up habitual ways of working and thinking, to dissipate conventional familiarities, to re-evaluate rules and institutions and to participate in the formation of a political will (where he has his role as citizen to play)*

*The real political task in a society such as ours is to criticise the workings of institutions that appear to be both neutral and independent, to criticise and attack them in such a manner that the political violence that has always exercised itself obscurely through them will be unmasked, so that one can fight against them*

- Foucault

*Good policy is one thing. But good policy without effective program implementation is a dead letter*

- Kevin Rudd

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### **Introduction**

The previous three chapters presented the findings of the life history study documented in this thesis. A thorough analysis of the data discovered that the day-to-day participation realities for citizens living with entrenched disadvantage are challenging and highly complex. Ideas and experiences surrounding the meta-themes of ‘being me’ and ‘being in the world’ were mitigated by participants’ stories of ‘being in the system’. It appears that their experiences at the service interaction level led to systemic disablement, capability deprivation and unrealised occupational possibilities (Laliberte Rudman, 2010) due to factors beyond their control. These findings therefore extend occupational deprivation discourse through a capabilities approach lens (Nussbaum, 2011; Sen, 1999, 2000) by considering the impact of systems of governance and other contexts on an individual’s abilities and *freedoms* to do and be, or live a life that they have reason to value (Sen, 1999).

This chapter explores some of the latter findings of the life history study in context by presenting the findings of an ‘analysis of discourses’ (Bacchi, 2005; 2009) of Australian social inclusion policy texts which were introduced during the Rudd government. Two particular

analytic *tools* were applied for critical policy analysis. The first was Bacchi's (2009) 'what's the problem represented to be?' (WPR) approach to policy analysis, and the second was Whiteford & Townsend's (2011) 'Participatory Occupational Justice Framework 2010' (POJF 2010). Bacchi and Whiteford and Townsends' analytic tools were respectively chosen for their complementarity and interrogative capacities from epistemologically distinct perspectives. Bacchi's WPR approach seeks to understand how the polity as a group are governed as well as how governing takes place. This is done through critiquing how social 'problems' are manifested *as* 'problems' by people within systems of governance (i.e. the State; Bacchi). Instead of attempting to understand problems as discrete entities which are proposed to have direct solutions, a WPR approach sets out to see how such problems and their related discourses have been problematised; that is, to interrogate problematisations inherent in policy and scrutinise their premises and effects of how such problematisations are represented (Bacchi). A WPR approach therefore seeks to promote critical policy analysis in the form of questioning problems rather than 'solving' them (Bacchi). Table 9 below recaps the main premises of the six questions which form a WPR approach as first presented in the methodology chapter in Chapter Three. Whiteford and Townsend's POJF 2010, in comparison, explores issues of occupational justice and injustice which may exist in processes which support or hinder occupation, focusing on providing voice and a critical lens to address the occupational needs of marginalised groups, such as citizens living with entrenched disadvantage.

Table 9: WPR approach questions (Bacchi, 2009, p. 2, 48).

- 
- Q1.** What's the 'problem' represented to be in specific policy?
- Q2.** What presuppositions or assumptions underlie this representation of the 'problem'?
- Q3.** How has this representation of the 'problem' come about?
- Q4.** What is left unproblematic in this problem representation? Where are the silences? Can the 'problem' be thought about differently?
- Q5.** What effects are produced by this representation of the 'problem'? Consider three kinds of effects: discursive effects; subjectification effects; lived effects. Include effects due to dividing practices. The following sub-questions will assist here: What is likely to change with this representation of the 'problem'? What is likely to stay the same? Who is likely to benefit from this representation of the 'problem'? Who is likely to be harmed? How does the attribution of responsibility for the 'problem' affect those so targeted and the perceptions of the rest of the community about who is to 'blame'?
- Q6.** How/where has this representation of the 'problem' been produced, disseminated and defended? How could it be questioned, disrupted and replaced? Consider past and current challenges to this representation of the 'problem'. Consider the discursive resources available for re-problematisation
- 

Occupational science literature has highlighted the need for more critical analyses of contextual issues impacting on occupation, participation and inclusion from interdisciplinary perspectives which is currently limited (Cutchin & Dickie, 2012; Kinsella, 2012; Whiteford & Hocking, 2012; Laliberte Rudman, 2012). In support of Rudman's claim that

“Occupational scientists must consider how complex interrelations of social, economic, political and cultural forces shape both expectations and possibilities for occupation...[and in the process aim to] expose complex contextual influences on occupation” (p. 101),

I sought to analyse and address the complexities of social inclusion policy and its occupational implications for citizens living with entrenched disadvantage through both methodologies as they provided analytical depth from a critical policy and critical occupational justice lens respectively. Both methodologies and their respective questions which guided the analysis, also allowed me to interrogate social inclusion policy discourses in a manner which promoted transparency and accountability of government policies according to the polity's expectations. Policies should render governments accountable for their actions towards citizens. Therefore, performing a



comprehensive textual and discursive analysis from an epistemologically plural perspective (Kinsella) enabled such accountabilities to be appropriately critiqued.

Consequently, this chapter highlights the impacts of social inclusion policy discourse. In doing so, it directly addresses the dearth of macro-level analyses of socio-political influences, such as social policies, which enable or restrict occupational choice (Galvaan, 2012), participation and capability enablement. I have also chosen to consider policy analysis from an interdisciplinary perspective, as I concur with Kinsella's (2012) concept of 'epistemological pluralism', which enables occupational science scholarship to be "inclusive of knowledge claims informed by *different* philosophical traditions" (p. 77, original emphasis). Complementary philosophical traditions which feature prominently in both Bacchi's (2009) and Whiteford and Townsend's (2011) methodologies include social construction theory, poststructuralism, feminist theory, governmentality studies, critical social work, critical social theory and justice discourse. The rich philosophical grounding of both methodologies provided a comprehensive theoretical, practical and 'intellectual toolbox' (Motion & Leitch, 2007) to interrogate social inclusion policy. Both methodologies provided a natural fit to comprehensively explore the following research questions (as introduced in Chapter 3):

1. How was 'participation' conceptualised and problematised in social inclusion policy during the Rudd Labor Government?
2. How did the policy aim to address the 'social inclusion' of citizens living with entrenched disadvantage, such as poverty and disability? What was the 'problem' represented to be? (WPR approach; Bacchi, 2009), and
3. How did the policy enable or constrain participation?

Although these questions appear uncomplicated, they are highly complex. Due to their complexity, I chose to analyse various policy *texts* which were produced during the Rudd years which included government reports, speeches and media releases. Answering the research questions through a WPR approach (Bacchi, 2009) enabled a thorough interrogation into not only the political reasoning of 'social inclusion' as a worthy policy goal, but also allowed for a

deconstruction of the policy from a critical occupational science lens (Laliberte Rudman, 2013; Whiteford & Hocking, 2012). Further, Whiteford and Townsend's (2011) POJF 2010 complemented the WPR approach (Bacchi) by raising consciousness about occupational justice and injustices which the policy 'practiced' or appeared to practice. Even though both questions commenced as separate but related concepts, the analysis of discourses (Bacchi, 2005) demonstrated how interrelated and inseparable they were. Therefore, answering the questions did not follow a discrete 'question-answer' format. Rather, my interpretations of the policy analysis are enmeshed in a manner which is representative of applying a WPR approach (Bacchi) and documenting the analysis findings in a non-linear manner.

The findings of the policy-as-discourse analysis (Bacchi, 2005, 2009) supported by the POJF 2010 (Whiteford & Townsend, 2011) are presented under four sub-themes. The first introduces a Foucauldian genealogy by presenting a brief historico-political overview of Rudd's social inclusion policy discourse. The second theme highlights the discursive focus on 'productivity' as the most valued type of 'participation' as it was considered within the policy. In context, it also introduces my framing of a *participation hierarchy* to describe the implications of the policy on citizens' identities and occupational possibilities (Laliberte Rudman, 2010). In addition, this second theme also expands on a participation hierarchy by exploring the marginalising effects of Neoliberal policies and ideas such as *The Active Society* (Walters, 1997) which targets 'activation' interventions over 'passive' welfarist models. The third theme provides my interpretation of Rudd's social inclusion policy by challenging its credence as a policy in its own right vis-à-vis understanding it from a purely ideological perspective. The fourth and final theme examines the findings of the policy analysis from a critical occupational science perspective by considering macro implications on occupational participation through applying the POJF 2010 (Whiteford & Townsend). To facilitate data interpretation, rationale and reading flow, the analysis presented does not refer to the data references listed in Appendix B and 3 individually, but rather as a group of policy *texts*, differentiated by the type of *texts*, whether they are in reference to a government report, speech or media release.

Further, a key theme of the chapter presented in context with both analytic methods seeks to address the taken-for-grantedness and relegation of *participation* (Hasselkus, 2006) as it is represented in social inclusion policy, by expanding its potential conceptualisation from an occupational perspective. In doing so, it extends philosophers Smith and Deranty's (2012) notion of a 'politics of misrecognition' as it relates to Western conceptualisations of work and the cultural meanings ascribed to it. The chapter concludes by considering how the policy analysis could influence the entrenched disadvantages which impact upon the day-to-day lives and occupational realities for citizens living with poverty and disability in Australia. The final chapter presents a critical discussion of the corollary between the life histories and the policy analysis. It considers the occupational justice implications of social inclusion policy discourse and outlines ways forward to enable occupation, participation and inclusion for citizens who consider themselves as marginalised in a challenging and contested policy context.

***Theme One: A brief historico-political overview of Australian social inclusion policy discourse – Introducing a WPR approach (Bacchi, 2009)***

As discussed in the literature review and methodology chapters of this thesis (Chapters Two and Three respectively), the inception of social inclusion policy discourse on the national political map was made possible by the election of Prime Minister Kevin Rudd in November 2007 following 11 years of conservative rule. However, it was not until a media release published on 13<sup>th</sup> May 2008 by the inaugural Minister for Social Inclusion, Julia Gillard MP, that 'social inclusion' became a focus of social policy nationally. The media release entitled "Social inclusion through education and employment" pledged that an Australian social inclusion agenda would ensure that programs across the government would be targeted to "make a real difference for marginalised and disadvantaged Australians". From a WPR perspective (Bacchi, 2009), the funding announcements made in the media release distinctly focused on education, employment, and training over other types of occupational participation. Bacchi highlighted that "because

policies make proposals for change, by their very nature they imply what is held to be problematic” (p. 263), inferring that policies are therefore problematisations themselves. Funding allocation is therefore a clear indication of how governments address their problematisations of social issues. The media release also highlighted the government’s direct policy foci (‘problems’) which dominated the discourse inherent within social inclusion *texts*. The four foci aimed to (1) address the needs of children at risk, (2) provide improved and more targeted employment services for unemployed Australians, (3) build human capital (skills and training), and (4) address individual and family homelessness. These four foci were represented in economic terms as the following:

- \$520 million for universal access to preschool for all children in the year before formal school ;
- \$32.5 million for the home interaction program;
- Up to 238,000 new vocational training places for those outside the workforce over five years;
- \$3.7 billion to reform the employment services system focused on providing enhanced support to unemployed people, particularly those with real barriers, and
- \$150 million for 600 homes across Australia for families and individuals who are homeless.

Despite the Rudd government’s operational definition of social inclusion, which purported that to be socially included, an individual needed to have the opportunities, resources and capabilities they needed to learn, work, engage and have a voice (Department of the Prime Minister and Cabinet, 2009a, 2009b), policy directing social inclusion as demonstrated through these initial budget figures for 2008/2009 proved to significantly favour the former and more material aspects of participation of learning and working (Ward, 2009) over community engagement and advocacy through voice.

In a later government report entitled *A Stronger, Fairer Australia* which was released by Gillard at the inaugural Social Inclusion Conference in late January 2010, the four initial foci were expanded into six policy ‘problems’ (Bacchi, 2009) and were announced as the Government’s “Social Inclusion Priorities” (Department of the Prime Minister and Cabinet, 2009a, p. 17):

- Targeting jobless families with children to increase work opportunities, improve parenting and build capacity;
- Improving the life chances of children at greatest risk of long term disadvantage;
- Reducing the incidence of homelessness;
- Improving outcomes for people living with disability or mental illness and their carers;
- Closing the gap for Indigenous Australians, and
- Breaking the cycle of entrenched and multiple disadvantage in particular neighbourhoods and communities.

There is little doubt that the goal of investing in the material aspects of participation (Ward, 2009) can address matters of economic sustainability, optimising human capital and tackling disadvantage (Gillard media release, 2008). However, by the very nature of discretely proposing a participation ‘solution’ through education, skill-building or employment, many aspects of human occupation, including building occupational potential (Asaba & Wicks, 2010; Wicks, 2001, 2003) and occupational possibilities (Laliberte Rudman, 2010) through a more expansive consideration of participation, have been affected, subjugated and taken-for-granted in the policy (Hasselkus, 2006). From an occupational perspective, life roles and the diversity of occupational opportunities inclusive of, but not limited to, being engaged in meaningful employment, undergoing training or attending pre-school level education, have not been politically recognised nor given value within Rudd’s social inclusion policy which is problematic. Further, Gillard’s launch of the six priorities within a national social inclusion agenda further exemplified this point by promoting inclusion through an economic and Neoliberal-orientated model. It appears that this was proposed without broader occupational considerations through

aspirations such as: skill investment across the life cycle, empowering choice and aspiration through work and learning, education and training reform, incentivising government and employer partnerships for economic growth, stimulating ‘innovation’ for participation productivity, and supporting equitable and sustainable growth. Despite its function as an innovative and progressive social policy reform compared with the inaction of the former Conservative government which had a more limited social investment model (Fenna & Tapper, 2012; Mendes, 2009; Whiteford, 2006; Wilson, Spies-Butcher & Stebbing, 2009), the policy’s agenda questions the very focus of where the *social* fits within an apparent Neoliberal and economic rationalist discourse (Pusey, 1991).

The introduction of social inclusion policy overtly recognised that the Rudd government’s conceptualisation of ‘participation’ was essentially as *economic* participation above other commonly recognised types of participation in policy discourse, such as social and civic participation. Further, a key problematisation of ‘disadvantage’ in the policy more subtly alluded to an over reliance and/or dependency on the welfare state as expressed by the six policy ‘problems’ in the landmark *A Stronger, Fairer Australia* report which outlined the Rudd Government’s social inclusion policy direction. Therefore, ‘participating’ in the life of society through being and becoming employed through the labour market was the preferred solution to ‘tackle disadvantage’. In doing so, the policy would therefore address the economic, education and skill needs of jobless families, children at risk, homelessness, citizens living with disability and mental illness, and Indigenous disadvantage by targeting seemingly ‘underproducing’ and ‘unproductive’ individuals, neighbourhoods and communities (Dean; 1995; Walters, 1997).

In context with Rudd and Gillard’s key priority areas for social inclusion presented through a productivity lens, the Australian Social Inclusion Board (2010) identified common types of disadvantage, which usually related to low income and assets, low skills, difficulties finding and keeping a job, housing stress and poor health. Thus, finding a sustainable ‘solution’ for social inclusion to enable *opportunities*, *resources* and *capabilities* was identified through a predominant ‘work equals inclusion’ discourse. This meant that meeting citizens’ needs for social inclusion

directly involved stimulating the economic growth and prosperity of Australia through their ‘economic participation’, training and education. However, through a WPR approach (Bacchi, 2009), addressing the problematisation of disadvantage as a welfare reliance issue, signals a significant shift from traditional Labor policies towards a more Neoliberal orientation. This is consistent with the Labor government’s adoption of a *Third Way* politics agenda as outlined in Chapter Two.

Although Rose, O’Malley and Valverde (2006) clarified that the political architects of *Third Way politics* during the Blair Labour Government in the United Kingdom in the late 1990s explicitly rejected it as a Neoliberal philosophy, this premise cannot be rejected entirely. I make this suggestion as my analysis identified that *Third Way* politics appeared to be practiced and rationalised as a Neoliberal way of thinking and acting in social inclusion discourse, by heavily prioritising economic prosperity which appeared to be masked under Australian cultural values such as fairness, mateship and working together (Phillips & Smith, 2000). This is further demonstrated through the policy’s problematisations of marginalised groups (i.e. citizens living with disability) which promote ‘human flourishing’ (Seligman, 2011; Sen, 2000) through economic over other occupational possibilities (Laliberte Rudman, 2010). Consequently, considerations of *participation* beyond an economic framing were expressed in superficial and tokenistic ways such as the limited discussion of social, civic and cultural participation in the *A Fairer, Stronger Australia* government report.

In a speech entitled “Reforming Education And Skills: Challenges Of The Twenty First Century” made during a visit to London in June 2008, Gillard promoted a distinctive government approach which supported such an agenda and described Labor as practising “the new politics of the progressive centre...modernising, social democratic politics”. In this speech, Gillard expressed terminology (in bold) which became foundational in her discursive repertoire:

“...Our proposition is that Australia can sustain its **prosperity** by becoming **fairer**, so that **everybody** has a **fair go**, and **stronger**, by deliberately building **resilience** to adapt to new pressures...In essence, the politics of the progressive centre now seeks to answer... How do we ensure that **all of our citizens** are able to take part in the dynamic, wealth-creating **opportunity** that the market and society combined represent?”

As suggested in this statement, key terminology in the Labor Government's social inclusion policy discourse has a distinct focus on 'building the economy', 'having a fair go' and promoting education, employment and skill-building to foster social inclusion. Explicit descriptions of 'social inclusion' through these discursive constructions appear to promote a focus on participation and inclusion as *productivity*. The next theme expands on this proposition further by situating the policy discourse within the context of the *Active Society* (Walters, 1997).

**Theme 2: Social inclusion policy's focus on 'productivity' in context with the 'Active Society' (Walters, 1997)**

*"My portfolios cover a wide range of policy areas, and some have suggested they're a slightly unusual combination. But the reason why they've all been joined together is simple. In today's world, the areas covered by my portfolios – early childhood education and childcare, schooling, training, universities, social inclusion, employment participation and workplace cooperation – are all ultimately about the same thing: **Productivity**. So while my portfolios can be a mouthful, I'll be happy to be referred to simply as **'the Minister for Productivity'**" (Gillard).*

In one word highlighted in the preceding statement, Julia Gillard was able to capture what had been the tacit focus of national social inclusion policy during the Rudd years and which has continued since she became Prime Minister in June 2010: *productivity*. My critical discourse analysis through Bacchi's (2009) WPR approach identified that those citizens who would benefit from social inclusion policy were those engaged in occupations which promoted productivity and economic growth. In doing so, some citizens such as marginalised groups who did not fit the 'working Australian' ideal would therefore be regarded as 'unproductive' subjects and located outside of a so-called 'mainstream' society of *productive* citizens. Examples of such groups who were not mentioned within social inclusion policy discourse during the Rudd government included older people over the age of 65, immigrants, culturally and linguistically diverse (CALD) groups, refugees and asylum seekers as well as other minority groups.

Additionally, even though one of the six priority areas was to "[Improve] outcomes for people living with disability or mental illness and their carers" (Department of the Prime Minister



and Cabinet, 2009a, p. 17), the policy failed to specify an operational definition of disability, mental illness or carer, leaving policy intervention open to interpretation. Nor did the policy discourse offer any theoretical exploration into models of disability to best inform policy and address this priority area in a comprehensive manner. Such limited considerations of the multidimensional nature and potential of social inclusion and participation (as described in Chapter Two) within social inclusion policy discourse is disturbing because of its narrow focus. As previously suggested, prominent features of Gillard's consistent discursive repertoire within speeches and media releases which she made surrounding the Labor government's view of social inclusion included having a predominant focus on productivity, as well as the tacit goal of creating productive citizen-subjects. Indeed, this unidimensional framing of social inclusion is further evidenced by her statement made during the "Education, Employment and Social Inclusion Symposium" held in a socially disadvantaged Western suburb in Melbourne on August 21, 2008:

*"Social inclusion...is a social tool for economic growth and opportunities. I see its role as contributing to the broader economic and social needs of regions like this one in a positive way – giving people the qualifications they need, giving business the workforce they need, and thinking through how housing, transport and welfare programs can be linked to create more opportunities for everyone".*

The Active Society (Walters, 1997).

Fundamentally unchanged since the Rudd government then, social inclusion under the Gillard government has continued to be construed as *productivity* and integration into the labour market (Levitas, 1996). Such a framing seems synonymous with the Neoliberal ideology of the *Active Society* (Walters, 1997), a theory posited as the answer to combat an increasing reliance on the welfare state by 'non-workers' (Walters). Walters proposed the *Active Society* as an alternative view to the traditional conceptualisation of a welfare state. From an economic perspective, a welfare state was envisaged to foster equality of status and a society which was not divided by class (Walters).

Until recently, an Australian welfare state was modelled by a “welfare regime” (Langan & Ostner, as cited in Walters, 1999, p. 223) consistent with an Anglo-Saxon model of the welfare state. The Anglo-Saxon model proposed that employment of underrepresented groups in the market such as women, mothers, people with disabilities and unemployed citizens was neither encouraged nor dismissed (Walters). Neither did it actively encourage women to remain at home (Walters). Further, such a welfare state model did not facilitate employment or integration into the workforce for women or other groups (Walters). Employment was therefore assumed as an individual choice (Walters).

Feminist theorists contend that the welfare state was originally conceived around the nineteenth century idea of the male ‘breadwinner’ role, assuming that such an employee was in stable employment, gaining a regular income and providing for a household which included a ‘dependent’ wife and children (Walters, 1997). Thus, employment was masculinised and skewed towards male employability whereas women (and other marginalised citizens) assumed politically underrecognised and gendered roles and responsibilities instead of being considered as potential ‘workers’.

In stark contrast, the *Active Society* (Walters, 1997) proposed that such citizens were ‘inactive’ and not responding to the more macro political and economic goals for prosperity and growth (Dean, 1995). Being an ‘inactive other’ could also be associated with not assuming the role of the ‘tax payer’. In this light, the ‘inactive other’ could be seen by employed workers and others as not ‘contributing’ towards the wealth of the nation and economic fabric of society. Thus, the *Active Society* (Walters) invokes a preferred social ontology of ‘worker’, consistent with the value of having a worker identity (Aldrich, 2011b, Gupta, 2012; Kantartzis & Molineux, 2011) and being socially, culturally and politically recognised and valued through paid employment in Western contexts (Smith & Deranty, 2012).

Developed at the height of Neoliberalism during the mid-1980s in the United Kingdom and the United States, the policy idea of the *Active Society* was one in which participation in paid employment developed as the norm for *all* (Walters, 1997). The *Active Society* as Neoliberal

ideology therefore only recognised life participation through either being a ‘worker’ or ‘non-worker’ (Walters). Therefore, individualism was favoured instead of more collectivistic notions of community, society, social capital as well as considering occupationally diverse roles. The *Active Society* was proposed as the solution to address the ‘large-scale inactivity’ (Dean, 1995) which was attested to the problematisation and “fiscal crisis” (Rose, O’Malley & Valverde, 2006, p. 98) of the welfare state (Walters).

Governmentality theorists have contended that the *Active Society* as a Neoliberal conservative social policy reform ideology is a form of power and control which encourages a “politics of the self” (Walters, p. 224). Subjectification and relegation of groups such as women, mothers, people with disability and chronically unemployed citizens to policy through “self-government” is the intended aim of the *Active Society* (Walters). Therefore, the imperative of *inactive* groups outside of the workforce is to become employed and ‘participate’ by engaging in productive ‘activity’. Not working rendered an individual as inactive, unproductive and apparently disinterested in building the economy through labour market participation. Abberley (as cited in Levitas, 1996) further suggested that citizens living with disability under such hegemonic practices are considered less than full members of society.

#### Introducing the ‘participation hierarchy’.

From an occupational perspective, the *Active Society* ideology (Walters, 1997) proposes what I label here a “*participation hierarchy*”, i.e. one in which participation in paid employment is the ultimate and most worthy participation typology in Western contexts. This is also consistent with the broader cultural value of work and worker identities in such contexts (Aldrich, 2011a; Gupta, 2012; Jakobsen, 2004; Kantartzis & Molineux, 2011; Smith & Deranty, 2012). The reification of a participation hierarchy is consistent with Neoliberal ideology, which is considered by Gidley et al. (2010a, 2010b) as the most restrictive social inclusion ideology. The idea of the *Active Society*, Neoliberal ideologies and a participation hierarchy are also supported by Lister’s (1998) analysis of Eurocentric social inclusion policies. From Lister’s perspective, such policies inherently

proposed ‘integration’ and ‘inclusion’ into a profoundly unequal labour market reflecting a narrow economic view of social inclusion. Lister suggested that Levitas’ (1996) ‘social integrationist discourse’ (SID) in Labor policies was an accurate synthesis of an ‘inclusion through work’ paradigm masked as a broader ‘redistributive, egalitarian discourse’ (RED) which supported the political ideals of social rights and citizenship.

In addition, the presuppositions or assumptions (Bacchi, 2009) of SID and moral underclass discourses (MUD; Levitas, 1996) surrounding ‘disadvantaged’ individuals and groups such as citizens living with poverty and disability within social inclusion policy, appear to be predominantly ‘ableist’ discourses. These discourses pursue a focus on employment and workforce participation with little reflection of citizens who have different occupational needs and abilities to carry out economic forms of participation. Such needs span beyond the physical (i.e. access to a building) to include universal design principles which include considerations of equity, flexibility, simplicity, perceptibility, efficiency, consequence minimisation, comfort and appropriateness (Hitch et al., 2012). I therefore contextualise social inclusion policy within an ‘ableist’ discourse, as it demonstrates tacit and subtle forms of prejudice and disablism (Deal, 2006) through its lack of rigour and depth by not exploring theoretical models of ability and diversity, or related initiatives to assist in targeting interventions for ‘inclusion’.

As can be seen from British and ableist contexts, the creation of a participation hierarchy within a narrow, unidimensional and Neoliberal social inclusion ideology (Gidley et al., 2010b) is highly problematic for several reasons. From an occupational perspective, a participation hierarchy delimits occupational possibilities (Laliberte Rudman, 2010) by only privileging productive and finance-producing occupations and relegating all other types of participation as ‘non-work’, which are considered as not building national economic prosperity. Consequently, the depth and breadth of participation as it is considered in occupational disciplines (Phelan & Kinsella, 2009; Sellar, 2012), is significantly taken-for-granted and relegated to something which is undesirable (Hasselkus, 2006; Pereira & Whiteford, 2013).

Deconstructing Labor's social inclusion policy: Third way politics, work and ethical citizenship.

My interpretation of the evolution of a *participation hierarchy*, together with a politics of misrecognition (Smith & Deranty, 2012; Thomson & Yar, 2011), and resultant socio-politically unrecognised or under-recognised occupational roles, abilities and interests, is consistent with the Rudd government's ableist social inclusion discourse primarily through productive means. Gillard consistently framed this argument as "building human capital and productivity for (economic) prosperity". Clearly, the premise behind Rudd and Gillard's social inclusion policy discourse acknowledged the Neoliberal ideal of the 'worker' *participating in the market*, and the lesser valued 'inactive and non-worker' which were masked under a *Third Way* politics agenda.

Conceptualising citizens as workers against burdensome non-workers on the State appears to create divided societies between privileged 'insiders' and excluded 'outsiders' (Walters, 1997). Those who do not 'participate' in the labour market are therefore relegated to being less worthy and less valued citizens within a *participation hierarchy*. Labor's social inclusion principles focused on aspirations to reduce disadvantage, increase economic, social and civic participation and have a greater voice, combined with greater responsibility (Government report, 2008). The latter proposal of having greater responsibility can be related to the problematisation of 'disadvantage' in Labor's *texts* which could be proposed as being consistent with Levitas's (1996) SID and MUD discourses, thus prompting a shift towards the development of 'ethical citizens' (Macfarlane, 2010) through activation (Laliberte Rudman, 2012). Macfarlane's framing of ethical citizens resonates with Popkewitz's (2008) notion of 'dangerous populations' who threaten the productivity of a nation and happiness amongst the polity. Thus, disadvantaged groups or populations, such as citizens living in poverty with disability, "are objectified in ways that signify exclusion and situate them outside of what is normalised" (Macfarlane, p. 146). Normalisation in

this sense signifies that citizens living with entrenched disadvantage are categorised as a ‘dangerous population’, targeted for ‘intervention’ (Macfarlane).

A major assumption of social inclusion policy consistent with a *Third Way* politics agenda (particularly its more conservative rather than social traditions) is that the only route to being or becoming socially included is through paid employment. This is especially the case for ‘dangerous populations’ (Popkewitz, 2008), where said individuals would undergo ‘normalisation’ through labour market integration (Levitas, 1996). Both Rudd and Gillard valued categorising citizens as “working Australians” across a number of policy arenas, which had a dual discursive function of either including or excluding Australians depending on their economic contributions to society and to the nation (Macfarlane, 2010). From a workplace relations perspective, Rudd and Gillard’s (2007) *Forward with Fairness* report described ‘working Australians’ as ethical citizens by being

*“...hard workers [who do not ask] anybody for a free ride. They know that for this nation to make its way in a competitive, indeed, cut-throat world, they need to work hard, work fast and work smart”.*

The discursive effects of such active features of government language use, termed “intellectual technology” (Miller & Rose, 1990, p. 7), provide mechanisms for overt organisation, mobilisation, activation, direction and subjectification of the Australian way of life. I classify this assessment as promoting an *ideal* social ontology. Therefore, as a moral imperative, society within social inclusion govern-mentality has clearly been depicted as being reduced to the market where *ethical* citizens seek inclusion through economic participation (Levitas). As a result, those citizens who are not “hard workers” are consequently “taking a free ride” and are thus categorised as ‘dangerous populations’ (Popkewitz) who are seen as deviant, requiring interventions which are deficit-based (Macfarlane, 2010). Such categorisations provide further evidence for considering ‘labour market participation’ as the dominant participation typology within a *participation hierarchy*. From a governmentality perspective, the consideration of ‘work’ within social inclusion policy discourse can be interpreted and promoted as a Foucauldian ‘technology of the self’ (Rose, O’Malley & Valverde, 2006) where citizens come to understand themselves (‘subjectivities’;

Laliberte Rudman, 2005) within “certain regimes of authority and knowledge” (Rose, O’Malley & Valverde, p. 90), adopting techniques such ‘self-improvement’ or ‘self-government’ (i.e. within *The Active Society*; Walters, 1997). Consequently, the governmentality of work “was as significant as a site of subjectification as it was as a site of economic exploitation, and economic life” (Rose, O’Malley & Valverde, p. 95).

### **Theme three: Social inclusion – Policy or ideology?**

In order to contextualise the narrow discursive ideology that I consider to be inherent in Labor’s social inclusion policy, I conducted a quantitative textual analysis of all of the *texts* outlined in Appendix B and C which cover key policy documents, speeches and media releases using the website wordle.net. The results of the textual analysis are outlined in Figure 1 and 2 below. The first figure 1 outlines the key words that were used by Julia Gillard in her speeches and media releases. The second figure 2 includes a complete textual analysis of all of the social inclusion policy *texts* outlined in Appendix B and C. Figure 2 highlights that the higher the frequency of the word or phrase within the texts, the larger the word appears in both figures. Throughout key policy documents, such as *A Stronger, Fairer Australia* and *The Australian Public Service Social Inclusion Policy Design and Delivery Toolkit*, as well as Julia Gillard’s speeches and media releases, terms such as productivity, building human capital, fairness, prosperity, growth and the enablement of economic, social and civic participation are frequently reported. At face value, these commendable aspirations or ‘good intentions’ (Townsend, 1998), appear to be fundamental to creating an ‘inclusive’ Australia in the future.

Figure 1: Gillard’s key terminology used during her speeches and media releases.



Figure 2: Labor’s frequently used terminology within social inclusion texts.





Interestingly, such terms existed in the Labor political discourse prior to the formal inception of national social inclusion policy in May 2008. In a pre-election policy proposal entitled “An Australian Social Inclusion agenda” produced by Julia Gillard MP, who was Deputy Federal Labor Leader, Shadow Minister for Employment and Industrial Relations and Shadow Minister for Social Inclusion at the time, together with Senator Penny Wong, the then Shadow Minister for Workforce Participation, a proposed ‘social inclusion agenda’ was first announced prior to the November 2007 Federal Election, cementing the Labor party’s vision to address disadvantage through maximising *participation*. In context, Gillard and Wong’s (2007) report favoured workforce participation as the foundation of social inclusion. This statement was consistent with Labor’s ideology that *work*, together with family and community, provided life with meaning and purpose (Gillard & Wong). As discussed earlier, work *as* participation is consistently legitimised throughout Rudd’s social inclusion policy discourse as the most valuable type of participation which benefits individual lives and builds prosperous communities (Gillard & Wong). Gillard and Wong’s report also outlined a number of policy directives for social inclusion through workforce participation, including other ‘across government’ policy areas such as skill-building, welfare service reviews, mental health and disability employment, early childhood and parenting programs, housing, digital technology and working together with employers and the community sector (i.e. non-government organisations [NGOs]).

Gillard and Wong’s (2007) original social inclusion agenda brings into question the validity of expert opinions which were sought by the Rudd Government to facilitate its direction for identifying social inclusion policy priorities (Department of the Prime Minister and Cabinet, 2009a). The appointment of the independent ‘Australian Social Inclusion Board’ following the announcement of social inclusion policy in May 2008, was meant to “consult widely and advise the Australian Government on various aspects of social inclusion...driv[ing] a whole of government approach to furthering the Social Inclusion Agenda” (Gillard media release, 13<sup>th</sup> May 2008). Following several published reports such as those documented in Appendix B, the policy

directives that were adopted from the Board's recommendations in the *A Fairer, Stronger Australia* government report were almost identical to Gillard and Wong's initial description of the future Government's response to "tackle disadvantage". Therefore, the goals of having an independent voice to influence and direct Government policy are contradicted by the reality of predetermined government agendas such as those described in Gillard and Wong's pre-election policy proposal.

Calling social inclusion a 'policy' in and of itself, meaning being independent of political ideologies, is problematic for several reasons. Firstly, the findings of the comprehensive textual analysis of the terminology used by key Labor government figures surrounding 'social inclusion' presented in this chapter highlighted that the meaning behind such terminology seems to more accurately exhibit an extension of Labor's political ideology of workforce participation. This is further supported by the overt and continuous legitimisation of being employed as the most important type of *participation* throughout the social inclusion political discourse. Indeed, the Australian Labor Party expressed their values and fair work heritage on their website:

*"Labor's enduring values, which were born in the collective struggle for better living and working conditions are reflected in the progressive and reformist tradition which the Party embodies, and in the continuing pursuit of a society which values equality and security, fairness and compassion, environmental sustainability, enterprise, opportunity and aspiration"* (Australian Labor Party, 2012).

The second reason why framing social inclusion as policy discourse rather than ideology is evidenced by the way in which 'disadvantage' and 'multiple disadvantage' were problematised (Bacchi, 2009). Such problematisations appeared to have strikingly similar tenets to British ex Prime Minister Tony Blair's considerations of social exclusion and disadvantage. The following two examples compare and contrast an excerpt of Gillard's speech made at the ACOSS conference in November 2007 following Rudd's election, with that of Blair's definition of social exclusion published by the Social Exclusion Unit in 2004 and later by the Cabinet Office Social Exclusion Task Force in 2009:

*"Too many individuals and communities remain caught in a spiral of low school attainment, high unemployment and underemployment, poor health, high imprisonment rates and child abuse. Too many Australians are socially excluded"* (Gillard, 2007);

*“...a short-hand term for what can happen when people or areas have a combination of problems, such as unemployment, discrimination, poor skills, low incomes, poor housing, high crime and family breakdown. These problems are linked and mutually reinforcing. Social exclusion is an extreme consequence of what happens when people do not get a fair deal throughout their lives and find themselves in difficult situations. This pattern of disadvantage can be transmitted from one generation to the next”* (Social Exclusion Unit, 2004, p. 3).

What is most striking about how disadvantage and exclusion were categorised and problematised in both cases is that blame is directed towards “the role of the individual and the need for individual change” (Ward, 2009, p. 241), rather than the role of the State and its systems of governance to address or enable participation, inclusion and wellbeing. This major consideration is consistent with a narrow Neoliberal social inclusion ideology (Gidley et al., 2010b), and also fits with Levitas’ (1996) notion of a moral underclass discourse (MUD). It appears that a seemingly centrist political approach to social exclusion and disadvantage adopted by the Rudd government (i.e. *Third Way* politics approach; Buckmaster & Thomas, 2009), is weighted towards a more traditional conservative ideology which focuses on individualism. Some of the implications of favouring individual responsibility further condones and subjugates a certain type of ‘passive’ citizen-subject. Thus, social inclusion interventions to combat exclusion and disadvantage privilege a more autonomous and independent citizen-subject with less surmountable needs (Bacchi, 2009). Levitas proposed that such problematisations of disadvantage and exclusion therefore present ‘society’ as experiencing a rise in living standards “by defining those who have not done so, who have become poorer, as ‘excluded from’ society, as ‘outside’ it” (p. 7). This false dichotomy of progress echoes Labor’s stance on recognising national growth in terms of wealth creation and economic prosperity while ‘excluded’ “Australians are still being left behind”. This latter statement assumes that those ‘left behind’ are classified as ‘inactive others’ (Dean, 1995; Walters, 1997) requiring normalising interventions for activation (Laliberte Rudman, 2012; Walters). These ideas of governmentality (rule, governmentalities, power and hegemonic practices) are consistent with notions of ‘activation technologies’ (Laliberte Rudman) such as *The Active Society* (Walters), which seeks to address citizen passivity, including those who are at risk of becoming dependent on the State (i.e. Gillard

and Blair's descriptions of social exclusion and disadvantage above), by transforming them into 'active citizens' *through* employment.

#### ***Theme four: Applying an occupational justice framework to critically analyse social inclusion policy discourse***

Having aspirations for a "fair and engaged society" (Gillard speech January 2010) mainly through labour market participation significantly limits occupational possibilities (Laliberte Rudman, 2010) located within the diversity of social and community life. This evaluation seems to be the case for marginalised individuals and groups, such as citizens living with disability, who appear to have been 'targeted' for economic participation, or *activation* (Laliberte Rudman, 2012; Walters, 1997). This next section outlines the findings of a critical occupational science analysis of the concept of *participation* as it has been considered and constructed within occupational disciplines (Phelan & Kinsella, 2009; Sellar, 2012), which was explored in context with social inclusion policy discourses. In doing so, I sought to extend my critical analysis by utilising the POJF 2010 to advance the idea and practice of occupational justice (Whiteford & Townsend, 2011). Whiteford and Townsend's original construction of the POJF 2010 focused on enabling a critical analysis of occupational justice issues across personal, professional and service levels. However, I have extended its utility by considering how the POJF 2010 can be used to enable *macro* analyses of occupational justice practices from a 'top-down' approach. To date, the POJF 2010 (Whiteford & Townsend) has been primarily utilised as a framework to facilitate occupational justice enablement within services through an ethos of "collaborative partnerships informed by a vision of occupation justice" (Whiteford & Townsend, 2011, p. 72). The design of the POJF 2010 (Whiteford & Townsend) has traditionally considered implementing the six following enablement skills to assess and facilitate critical practice processes, reflexivity and approaches (Phelan, 2011) to support power sharing initiatives: (1) raise consciousness of occupational injustices, (2) engage collaboratively with partners, (3) mediate agreement on a plan,

(4) strategise resource finding, (5) support implementation and continuous evaluation of the plan, and (6) inspire advocacy for sustainability and closure (Whiteford & Townsend, p. 72).

A fundamental principle of the POJF 2010 (Whiteford & Townsend, 2011) is its overt attention to power relations between individuals, communities, agencies and other stakeholders. Townsend and Whiteford (2005) initially framed these ideas during the original development of a participatory occupational justice framework to support occupationally just benefits through the collaboration and sharing of power with decision making to enable occupation at the individual and organisational level (Canadian Association of Occupational Therapists, 1997; Townsend & Polatajko, 2007). What emerged from my analysis of social inclusion policy discourses in this research was the utility and usefulness of the POJF 2010 (Whiteford & Townsend) to explore matters of occupational justice and injustice within and practiced at the *political* level. As the POJF 2010 (Whiteford & Townsend) was designed within an ‘ethics of care’ ethos (Townsend, 1998) to support marginalised groups such as citizens living with entrenched disadvantage, a top-down, macro analysis of occupational justice within policy provided a natural fit to expose political accountabilities, rationalities and areas of concern. The POJF 2010 (Whiteford & Townsend) provided further analytic support in favour of marginalised citizens through its application of *critical occupational therapy* (Townsend & Whiteford 2005; Whiteford & Townsend 2011). Whiteford and Townsend’s original framing of critical occupational therapy is an approach that has salience in promoting equity across the policy spectrum involving its intention, delivery and potential long-term implementation. The central tenets of critical occupational therapy

“...focuses on changing the regulations, policies, laws, economic practices, media images, professional practices, and other forces that govern what people can do, want to do, and even imagine what is possible to do within the structural arrangements of society” (Whiteford & Townsend, p. 66).

In their expanded description of the POJF 2010, Whiteford and Townsend (2011) outlined key features of critical occupational therapy as those which aim to: (1) promote critical reflexivity to challenge practice and knowledge gaps, (2) be collaborative and participatory with decision making processes, (3) make goals explicit to enable occupation and social inclusion especially

amongst disadvantaged groups, (4) engage people in desired and necessary occupations, (5) emphasise social and individual change through contextual transformation and (6) work within teams and partnerships for the ‘ends’ of occupational justice. It is an essentially transformative agenda (Townsend, 1997b) in which participation through occupation is pivotal and one which, as has been suggested, should:

“...develop more equitable opportunities, resources, privilege, and enablement for all to participate to their potential and to exert choice and control over what they do every day” (Whiteford & Townsend, p. 66).

Through adopting the POJF 2010 (Whiteford & Townsend, 2011) including its six enablement skills and five key features of critical occupational therapy philosophy as a complementary analytic tool to Bacchi’s (2009) WPR approach, the predominant finding suggests that ‘social inclusion’ as it was promoted throughout the Labor government’s policy discourse, resonated with a type of *selective* occupational justice practice. The policy was also juxtaposed with more explicit occupational injustice practices consistent with a participation hierarchy and the extremely narrow framing of *participation* within a Neoliberal social inclusion ideology (Gidley et al., 2010b). Being selective of certain occupations in preference over others through outlining initiatives with a heavy productivity focus systematically deprived occupational choice and diversity (Galvaan, 2012). It appears that this type of ‘governmentality of doing’ is contrary to the ideals of critical occupational therapy (Whiteford & Townsend, 2011), critical occupational science (Hocking & Whiteford, 2012; Whiteford & Hocking, 2012) and instilling an inclusive approach towards enabling occupational justice. Instead, social inclusion discourse seems to marginalise citizens through governing them in such a way that they cannot “participate to their potential and to exert choice and control over what they do every day” (Whiteford & Townsend 2011, p. 66).

As previously proposed, a participation hierarchy appears to also promote a lack of recognition of other meaningful, purposeful and dignified occupational roles and identities that can exist from a more expanded consideration of *participation* within occupational disciplines (Phelan & Kinsella, 2009; Sellar, 2012). Citizens such as those living with poverty and disability,

as highlighted in the studies documented in this thesis, are bound by a hegemony which promotes activation (Laliberte Rudman, 2010; 2012; Walters, 1997) and Foucauldian ideas surrounding technologies of the self (Rose, O'Malley & Valverde, 2006) through self-improvement *opportunities*. Such opportunities are limited by what systems of governance are funded to offer or choose to provide under 'social inclusion' programs. Therefore, it appears that seamless service delivery for marginalised individuals and groups to benefit from participation and inclusion initiatives becomes complicated, convoluted and ad-hoc at best.

Through the process of introducing the term 'social inclusion' onto the national political map, it appears that the Rudd government's problematisation of citizens living with disability and mental illness explicitly determined what occupations were *definable* and *necessary* to meet its funding obligations for activation interventions. This was most notable through its operational definition of social inclusion: to either learn or work (with 'skill building' as a related concept; Department of the Prime Minister and Cabinet, 2009a). As previously discussed, the more discursive elements (Ward, 2009) of 'engage' a 'have a voice' (Department of the Prime Minister and Cabinet) within the operational definition provided noble occupational goals but were based on a 'trickle-down effect' within an economic rationalism framework (Pusey, 1991). This occurred instead of considering 'engaging' and 'having a voice' on a more equal standing with 'learning' and 'working' in political terms (Ward). My interpretation of Rudd's operational definition of social inclusion and preference for the productive goals of 'learning' or 'working' to become recognised as a *socially included* citizen, significantly restricted the recognition and importance of engaging in occupational experiences which are considered meaningful, purposeful and dignified beyond traditional 'work' or 'economic' domains. Such restrictions towards achieving other occupational possibilities (Laliberte Rudman, 2010) within a broader spectrum of *participation* from an occupational perspective could therefore manifest into larger social, cultural, occupational and political 'problems'. Such 'problems' could be framed as specific occupational injustices such as occupational marginalization, occupational deprivation and

occupational apartheid respectively (Kronenberg & Pollard, 2005; Stadnyk, Townsend & Wilcock, 2010; Whiteford, 2000).

In addition, the very nature of how ‘participation’ and ‘disadvantage’ were problematised throughout Rudd’s policy discourse added to system-driven occupational injustices based on assumptions within a participation hierarchy. The narrow and predominantly economic descriptors represented and preferred within a participation hierarchy by the Rudd government, together with the ‘passive’ and ‘inactive’ conceptualisations of citizens located outside of the labour market, also appeared to act in value-neutral ways by promoting ‘fairness’, a ‘fair go’, ‘opportunities’, ‘wealth sharing’ and other Australian cultural values (Phillips & Smith, 2000). However, such an assumption of value-neutrality within the policy could be interpreted as being and becoming subjectified, where individuals are moulded into ‘ethical citizens’ (Macfarlane, 2010) and therefore participate in limited types of doing, being and becoming (Wilcock, 1998; 2006).

When considering ‘active’ citizens as ‘ethical’ ones (Macfarlane, 2010) who are required to participate in ways which conform to social inclusion policy, the *intentions* and *accountabilities* of policy require a deeper critical analysis. In this case, the framing of social inclusion policy as one which supports activation in favour of an assumed citizen passivity towards labour market participation, can be interpreted as *unethical* in that it expects individual activation without providing the means to explore more diverse occupational opportunities *for* participation.

#### Occupational misrecognition.

I consider the act of promoting, recognising and legitimising certain types of occupations (i.e. related to work, education and skill building) over others, as a unique and previously unnamed type of occupational injustice. This I label here “*occupational misrecognition*”. Complementary to occupational marginalisation, occupational deprivation, and occupational apartheid, *occupational misrecognition* reflects the reality that some occupations are under recognised or taken-for-granted, whereas other occupations (consistent with policy frames) are reified. My



complementary critical policy-as-discourse and critical occupational science analysis (Bacchi, 2000, 2009; Whiteford & Townsend, 2011) identified that Australian social inclusion policy exemplifies occupational misrecognition in its essential lack of the depth, breadth and complexities of *participation*.

From an occupational perspective, the multidimensional nature and complexities of occupational phenomena are acknowledged within occupational disciplines (Phelan & Kinsella, 2009; Sellar, 2012) through their diversity, ascribed meanings and values. These complex yet informative occupational characteristics seem to be absent within Labor's social inclusion policy. Occupational disciplines (Phelan & Kinsella; Sellar) also recognise the taken-for-grantedness of everyday occupation (Hasselkus, 2006; 2011) and celebrate mundane forms of human doing, beyond narrow economic representations of doing, being and becoming (Wilcock, 1998; 2006). Using the POJF 2010 (Whiteford & Townsend, 2011) has critically framed occupational enablement through participation and occupational recognition from the perspective that power sharing, collaboration and occupational choices (Galvaan, 2012) inherent to values such as fairness need to be acknowledged within inclusion-promoting policies. Understanding participation from an occupational perspective can broaden narrow political ideologies and practices into more expanded ones. This could be achieved by considering occupational experiences as ones which are "active, purposeful, meaningful, contextualised and human" (Molineux, 2009, p. 17). Other considerations could involve understanding the transactional nature of occupation in context (Aldrich, 2011a, 2011b; Cutchin & Dickie, 2013; Whiteford, 2005, 2010) inclusive of cultural tendencies and social forces (Hasselkus, 2006). Further, considerations of the political, social and cultural recognition (Honneth, 1995, 2001) of the diversity of occupation could also assist with expanding ideologies of inclusion (Gidley et al., 2010b).

### The *taken-for-grantedness* of participation.

The reductionist and subjectifying conceptualisation of citizens living with disability, coupled with the underground narratives of citizens living with poverty (represented as ‘multiple disadvantage’ within social inclusion policy discourse), point to the *taken-for-grantedness* of participation as it is considered within occupational disciplines (Phelan & Kinsella, 2009; Sellar, 2012). Additionally, the narrow interpretation of participation as one which is captured within economically defined categories (Townsend & Whiteford, 2005) in Western contexts, and the Neoliberal tenets within Labor’s social inclusion agenda, further undermines the transformative potential of occupation and participation (Breenen, 2008, 2012; Townsend, 1997b). The policy, therefore, appears to promote *occupational misrecognition*. In doing so, it limits the recognition of occupational opportunities and the right to occupation (Hammell, 2008) beyond a learn/work paradigm. In other words, it fails to value *doing* in context beyond economic participation (Pereira & Whiteford, 2013; Whiteford, 2010).

Beyond undervaluing the diversity of participation from an occupational perspective, framing social inclusion policy under a narrow Neoliberal ideology (Gidley et al., 2010b) also has the potential to significantly limit the development of, exploration of, and sustainable participation in, transformative occupations for wellbeing (Breenen, 2008; 2012). Viewed in this way, the policy also delimits diverse engagement in participation opportunities. Furthermore, such a narrow and dichotomous categorisation of participation truncates the development for real and sustainable participation and inclusion (Pereira & Whiteford, 2013). For example, Australian social inclusion policy requires citizens living with disability, mental illness, poverty and other social issues to search for employment and participate in the labour market. Whilst economic participation is recognised as an important driver towards social inclusion, it does not address the diversity and meaning of participation in other important and “non-economic spheres of life” (Vellacott, 2011, p. 246) which remain unrecognised within the policy frame.

I contend that being an *economic* citizen rather than a social and occupational citizen is politically encouraged through policy funding regimes which support a participation hierarchy.

Such narrow and ableist perceptions of knowledge which do not consider broader occupational possibilities (Laliberte Rudman, 2010) for participation, are represented as ‘givens’ (i.e. being a ‘working Australian’) within social inclusion policy discourse. The lack of ontological critique regarding participation within social inclusion policy also result in limited subjectivities (beings and doings; Laliberte Rudman, 2006). To date, the policy does not adequately address an inclusive frame of participation diversity which, as evidenced by the analysis of the narrative data presented in this thesis, has impacts on people directly.

The occupational justice dimensions of social inclusion policy are further affected by how the role of government is actually carried out (Miller & Rose, 1990). The role of government determines who can benefit through the exercise of power over being subjugated, controlled or othered (Miller & Rose). From a governmentality perspective, the traditional conceptualisation of governing entirely from State rule is expanded, by considering how diverse groups and social forces (i.e. Government agencies; ‘systems of governance’) regulate citizens, and the conditions within particular spaces (i.e. within a Welfare agency) in the pursuit of goals through a variety of ways (Miller & Rose). Therefore, the *governance* of social inclusion in practice can result in disempowerment and restriction.

Scholarship focused on applying governmentality aimed at generating a broader understanding of occupation, participation and inclusion (especially within political contexts such as social policy, and how they can function to govern and control the types of doing that are possible or limited) is a relatively new domain within occupation-based disciplines (Laliberte Rudman, 2010, 2012; Sellar, 2012). Despite key priorities being identified in Rudd’s social inclusion agenda such as encouraging ‘inclusion’ through activation technologies (Laliberte Rudman) for citizens living with disability and mental illness (Department of the Prime Minister and Cabinet 2009a), where economic participation *as* inclusion is considered central to community life (Gillard & Wong, 2007; Australian Labor Party, 2012), a broader occupational perspective of social and community life is compromised through the policy’s tacit fiscal orientation. Therefore, by not incorporating a broader participation discourse within social

inclusion policy and its narrow ideology (Gidley et al., 2010a, 2010b), the occupational potential (Asaba & Wicks, 2010; Wicks, 2001, 2003), possibilities (Laliberte Rudman, 2010) and transformative capacities of occupation (Breedon, 2008, 2012; Townsend, 1997b) for citizens living with entrenched disadvantage remain at the taken-for-granted level of the status quo. Therefore, occupational choices (Galvaan, 2012) and possibilities (Laliberte Rudman) are reduced by funding imperatives which direct the following preferred occupational typologies within a participation hierarchy: either seeking participation in the labour market, becoming educated through traditional learning pathways *or* building new skills to develop human capital.

Rudd's social inclusion policy rhetoric which narrowly interprets participation as *productivity*, or paid employment through participation in the labour market, education or skill-building, also serves to reinforce the invisibility or *taken-for-grantedness* of participation. As Hasselkus (2006) stated, "...the everyday experiences of day-to-day life, [or participation in everyday occupation] is often 'seen but unnoticed.' Cultural tendencies and invisible social forces contribute to the obscurity of the everyday" (p. 627). Consistent with Hasselkus' latter statement, the orientation of Rudd and Gillard's social inclusion agenda has contributed to a configuration of social inclusion policy as one essentially tied to fiscal priorities masked under a 'social' façade. Therefore, social policy is argued from an economic rationalist perspective (Pusey, 1991), or 'governing at a distance' (Walters, 1997). These approaches focus on the role of the market to strengthen the national economy through labour market participation which, in the end, assumes ultimate utilitarian benefits such as material wellbeing and happiness for the majority (Pusey; Walters). Gillard further supported such a Neoliberal political rationalism, announcing that

*"...we must recognise that there is no neat divide between economic and social policies...made on the basis that together they will deliver our aspirations for a fair and engaged society. Our social...and economic performance are directly intertwined. And we will not succeed in any of these areas unless we harness the talents of all Australians"* (Gillard speech dated October 29, 2008).

## Conclusion

This final findings chapter has presented a comprehensive, interdisciplinary and critical analysis of Australian social inclusion policy discourse which emerged during the Rudd Labor Government in Australia from November 2007 until June 2010. From both a critical policy and critical occupational science analysis, the chapter explored the political rationalities and the role that government played to determine which types of occupational participation would promote the Rudd Government's social inclusion agenda. Analysis of key policy *texts* identified that the Government's interpretation of 'social inclusion' both theoretically and through its operation definition of social inclusion, favoured a limited Labor ideology of *economic participation* as the most valued type of occupational participation. Exemplified through such ideology, the policy was delivered in a manner which mirrored a more politically conservative approach to social investment. Gidley et al. (2010b) framed such a Neoliberal approach as the most narrow social inclusion ideology. In doing so, the political terminology and rhetoric which was used to push policy and funding directives became consumed by a focus on the individual, rather than the social, limiting occupational possibilities (Laliberte Rudman, 2010) to only those which fit within the Government's goal of building the market for national economic prosperity.

The latter ideas of individualism and labour market participation which were consistently presented through Labor's discursive repertoire, fit with the more conservative rather than communitarian goals of a *Third Way* politics agenda (Buckmaster & Thomas, 2009). The result of Rudd's social inclusion policy became representative of Walters' (1997) conceptualisation of the *Active Society*, where individuals who did not participate in the market would be relegated to being othered and labelled as 'passive' and 'inactive' (Dean, 1995), requiring intervention through *activation* (Macfarlane, 2010; Walters). Through this idea, labour market participation became the ideal and only valued typology within a *participation hierarchy* in the policy, leading to explicit occupational injustices such as the political misrecognition of other forms of doing and being (occupational misrecognition).

The next and final chapter of the studies documented in this thesis presents a critical discussion of the key themes. It particularly explores the effects of Australian social inclusion policy in context with the life histories of participants living with entrenched disadvantage. In doing so, the chapter represents the nexus between the outcomes of both studies by exploring the extent to which the policy addressed the everyday realities and occupational needs of citizens living with entrenched disadvantage. That is, those at risk of exclusion because of poverty, disability and other complex social issues. The thesis concludes by positing some recommendations in extending the political debate surrounding social inclusion. It also identifies some enablement- and occupation-focused strategies to build healthy public policy, and instils an inclusive ethos across institutional processes, which aim to contribute towards promoting occupational justice, participation and the *ends* of social inclusion (Whiteford, 2011).

## Chapter Eight

### Discussion and *Moving Forward*\*

This thesis has been informed by an occupational perspective (Nayar, 2009). An occupational perspective is defined as “a way of looking at or thinking about human doing” (Njelesani, Tang, Jonsson & Polatajko, In press) in context with the social world. A thorough review of the literature identified a paucity of research that has analysed social policy from a critical occupational science perspective (Whiteford & Hocking, 2012; Whiteford & Pereira, 2012). In addition, explorations into the everyday experiences and life histories of citizens who live with entrenched disadvantage characterised by poverty, disability and other complex social issues was also lacking. A critical occupational science perspective is one which requires a reflexive examination of the ontological biases and assumptions relative to matters of occupation in context by interrogating what may be taken-for-granted (Hocking & Whiteford, 2012, p. 4). Both a critical occupational science lens to policy and everyday issues impacting on occupation, as well as the related construct of *critical occupational therapy* (Whiteford & Townsend, 2011), have informed the epistemological and ontological orientations of the research presented in this thesis. As described in the methodology chapter (Chapter Three), critical occupational therapy highlights

“critical perspectives [which] typically raise ethical, moral, civic, and philosophic questions about injustice and the tensions or gaps between ideals and the reality of communities or populations living everyday with inequitable disadvantages or oppression associated with age, ability, ethnicity, gender, race, sexual orientation, or socioeconomic status” (Whiteford & Townsend, p. 66).

In this thesis, I have extended life history research documented in occupation-based disciplines (Phelan & Kinsella, 2009; Sellar, 2012) through exploring storied lives in context with the macro influences resulting from the specific introduction of Australian social inclusion policy

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\* “Moving forward” is a play on words used by current Australian Prime Minister The Hon Julia Gillard MP which was the Labor Party’s main political slogan during the 2010 Federal Election.

discourse. Consequently, two distinct research methods were employed to a) analyse policy and b) explore the life histories of individuals who were meant to be targeted by the policy to 'achieve' the *ends* of social inclusion (Pereira, 2012; Whiteford, 2011). There were two studies reported in this thesis: namely, a critical occupational science and policy analysis of Australian social inclusion policy (November 2007 – June 2010), and a life history study of seven citizens living with entrenched disadvantage. This chapter presents a meta-synthesis of the findings of both studies. Through the meta-synthesis, I draw the findings together with respect to the ways in which they 'speak to each other', as well as tensions, counterpoints and areas of confluence. A feature of the meta-synthesis of the findings is my effort to address the corollary question: "How does the Australian social inclusion policy discourse address matters of exclusion and needs for inclusion for citizens living with entrenched disadvantage?" Answering this question is at the heart of the rationale of this thesis. In responding to this question, important conceptualizations of occupation, participation, power, disability, gender and social inclusion ideologies (Gidley et al., 2010a, 2010b; Wicks, 2003; Wicks & Whiteford, 2005) are presented, which address what I argue to be the 'missing links' of the policy as considered from a critical occupational science perspective.

Such framings also assist in directing a critical interrogation of the accountability and sustainability of Australian social inclusion policy discourse in meeting the occupational needs, potential and possibilities (Asaba & Wicks, 2010; Laliberte Rudman, 2010, 2012; Wicks, 2001, 2003) of citizens in realising their capabilities to *do, be, become, belong* and *flourish* (Pereira, 2012; Seligman, 2011; Sen, 1999, 2000; Wilcock, 1998; 2006). In doing so, discussion focuses on exploring my unique framings of *participation hierarchy* and *occupational misrecognition* in detail, through a framework which I have developed, called the 'Social Inclusion Framework (SIF; Figure 3). The SIF summarises how mechanisms of exclusion occur at an everyday level during transactions with systems of governance, which may have a direct effect on capability enablement or capability deprivation in context with broader cultural norms, expectations, values and ideologies.



The meta-synthesis presented in this chapter is tentative as is the nature of interpretive research in occupational science (Wicks, 2003; Yerxa, 1993). This is always true in the paradigm of interpretive research, but particularly true in occupational science research, which in foregrounding the importance of context, makes generalisability impossible. Therefore, the aim is not to generate ‘grand theory’ but rather, present the findings in order that they may inform theoretical development, research and practice. My analytic interpretation of the findings in this chapter remains grounded by both the participants’ narratives, and the critical approach which I adopted to the policy analysis (policy-as-discourse, Bacchi, 2000, 2009). This final chapter concludes the thesis by suggesting some future research possibilities as well as providing enablement strategies for *moving forward*\* to further expand opportunities which realise the *ends* of social inclusion for marginalised individuals, groups, communities and populations.

### ***Understanding systemic disablement in context***

As illuminated through the findings chapters focused on the life history study, the meta-themes of ‘*being me*’ and ‘*being in the world*’ were mitigated by ‘*being in the system*’. Participants’ interactions and transactions with the interface of systems of governance such as Centrelink, community services, drug rehabilitation, medical services and others, seemed to generate a type of *systemic disablement*. In this sense, systemic disablement may be understood as tacit or explicit experiences of exclusion at the service interaction level which result in unrealised opportunities or underrealised capabilities (Laliberte Rudman, 2010; Sen, 1999). Thus, I contend that the participants were deprived of certain choices, many of which were occupational (Galvaan, 2012), as well as from opportunities to develop their capabilities through which to do, be, become, flourish and live a life that they had reason to value (Pereira, 2012; Seligman, 2011; Sen, 1999, 2000; Whiteford, 2000). However, some participants were able to temporarily combat the full effects of systemic disablement through employing strategies of conscious resistance as well as participating in transformative occupations (Breedon, 2008, 2012). Such strategies were unique to each individual, as shaped by their cultural identity and life stage.

It appears that exclusion was most manifest for the participants when the ‘good intentions’ (Townsend, 1998) of the policies that influenced service interaction level practices became ‘overruled’ (Townsend) by fiscal drivers. Although this thesis did not explore the everyday experiences of employees who work at the service interaction level between systems of governance and their users, Townsend suggested that a managerial approach to efficiency in service delivery is both unrealistic and undesirable from the service users’ perspective. Indeed, the participants’ experiences in everyday life, where opportunities to realise their capabilities were predominantly underrealised, were essentially accounts of exclusion being played out within a service context. Consequently, participants frequently reported a sense of marginalisation, of being “lumped in with the losers...[and] not treated on a case by case basis” (James).

Whilst marginalisation was being experienced at the everyday level, the policy itself also appeared to result in tacit marginalising impacts. The critical analysis of policy-as-discourse (Bacchi, 2000) highlighted that the way in which social policy-oriented systems of governance functioned was directed by funding allocation consistent with political ideologies and agendas for ‘inclusion’. Despite the policy overtly stating that people living with disability and mental illness would be targeted for inclusion through paid employment, it appears that this goal was addressed through the most narrow framing of social inclusion (Gidley et al., 2010a; 2010b). A major issue with such a narrow framing is that though all of the participants included in this study *wanted* to participate in the labour market, the governance of how occupational possibilities (Laliberte Rudman, 2010) were brokered was not conducive to such participation.

The reasons that the governance of opportunities and possibilities (Laliberte Rudman, 2010) were not conducive to labour market participation are complex. For example, participants identified that judgments were made about their workability based not on self-report, but health professional documentation which highlighted occupational performance limitations. A case in point was James’ experience, where during his application process for the Disability Support Pension (DSP), he indicated that he could work at least 30 hours per week. However, the physical limitations *attributed* to his disability were more consistent with current policy

requirements, i.e. that he was only able to work less than 15 hours per week. Stating that he could work more hours due to his self-belief and determination above documentary evidence to the contrary, led James to being denied the DSP. Subsequently, James was referred to a Disability Employment Service to explore work options and address barriers to work while remaining on the Newstart Allowance. Research into the Newstart Allowance has highlighted that living on \$35 per day is a major struggle in modern Australia (ACOSS, 2012a). However, for people living with disability receiving the Newstart Allowance, such as James, the burden of living with low income, disability and other complex issues is significantly problematic. According to ACOSS, one in six Newstart Allowance recipients have been assessed as having a ‘partial work capacity’, such as James, but do not qualify for the DSP. Saunders’ (2007) assessment of the costs of disability together with the incidence of poverty further highlighted that the poverty rate among people living with disability exceeds by six-fold compared to that of people without disability. Therefore, many people living with disability who do not meet the strict eligibility requirements of the DSP can be struggling to cope with the most basic needs, such as having enough money for food, accommodation, household goods, transportation and health management. Saunders also indicated that the rates of income support payments for people living with disability “has failed to take account of the extra costs associated with disability” (p. 476). Therefore, certain inconsistencies within systemic decision-making processes, such as those relating to DSP eligibility and provision, can have a profound effect on everyday participation, such as James’ missed opportunities to acquire essential resources for living.

Saunders’ (2007) suggested that the costs of living for people who experienced poverty and disability, including those who could be eligible for pensions such as the DSP, are high. Consequently, such issues are significantly underestimated and popularly misrepresented. This phenomenon of underestimation of disadvantage has been highlighted in this thesis, reinforcing the fact that a level playing field (Anna, 2012) does not exist. Therefore, further marginalisation and stigma can ensue which adds to other systemic barriers, societal attitudes and actions towards

citizens experiencing entrenched forms of disadvantage (Susman, 1994; Taket, Foster & Cook, 2009).

### ***Ideological influences on social inclusion policy: Occupational implications***

Of course, tacit attitudes and overt acts never occur in a vacuum and understanding the flow-on effects and machinations of social inclusion policy requires a serious consideration of the influences of *context* in shaping opportunities to realise capabilities as well as occupational possibilities (Laliberte Rudman, 2010; Laliberte Rudman & Huot, 2013; Galvaan, 2012; Whiteford, 2010). The overarching context in the social inclusion policy must be considered in the political context. The Rudd government drew upon a specific ideological set in order to frame the discourse as an ‘inclusion through paid employment’ agenda. Such an agenda appeared to be true to the Labor Party’s values and framed extensively around an egalitarian approach to participation, but overlaid with a narrow Neoliberal framing. As a result, such ideologies shaped and dictated very limited opportunities for occupational participation in Australian society. The focus on the occupation of paid employment as inclusion is consistent with the high value placed upon work and worker identities in Western contexts (Aldrich, 2011b; Gupta, 2012; Kantartzis & Molineux, 2011; Smith & Deranty, 2012). Further, ideologies surrounding ‘work’ were identified as actively promoting materialism, status and privilege. These factors coincided with also denigrating, devaluing and disempowering so-called ‘passive’ and ‘inactive’ citizens who did not, or could not, participate in paid employment (Dean, 1995; Rose, O'Malley & Valverde, 2006; Walters, 1997). Such ideologies appeared to directly and/or indirectly reinforce the social and economic status quo (Hammell, 2009, 2010) as well as *ableist* political and sociocultural discourses.

Such ideological frames had significant implications for the participants who took part in this life history study described in this thesis. From an occupational perspective, broad discourses such as Neoliberalism and activation technologies (Laliberte Rudman, 2012; Walters, 1997) and

their influence on constructions of social inclusion, limited the political validation and recognition of other occupational choices and possibilities that the participants engaged in (Galvaan, 2012; Laliberte Rudman, 2010). Based on the research documented in this thesis, then, occupational choice is indeed best understood as “a complex, socio-culturally situated matter” (Galvaan, p. 152), influenced by individual and extrapersonal factors (Galvaan). My assessment of ideological influences on limited occupational choices and possibilities supports Galvaan’s and Laliberte Rudman’s contentions that political contexts, including their ideologies which support governance decisions, dynamically influence occupational choice, occupational possibilities and the enactment of occupational justice. These, in turn, have both a positive (or enabling) and negative (or constraining) influence on occupational and societal participation (Galvaan; Laliberte Rudman, 2010). Therefore, instead of feeling empowered to participate in meaningful, purposely, dignified and diverse occupations, the research participants felt occupationally disempowered as a direct result of the ideological and discursive framing of the policy. The impact of this seemed to further enhance experiences of marginalisation.

Whilst disempowerment and exclusion were predominantly experienced at the service interaction level, disempowerment and exclusion were also experienced by the participants in other settings outside State-funded systems of governance, such as a medical practitioner’s office, or in the local shopping centre. The origins of these exclusionary experiences were described as being more ‘grass roots’, i.e. where value-laden assumptions of ability and difference were acted out more directly. Several participants such as Leigh, Rose, James and Barry explicitly described how they were discriminated against due to their disability, appearance, gender or ethnic background. These experiences speak to a cultural ethos of exclusion, or *culture as disability* (McDermott & Varenne, 1995). Consistent with these participants’ stories, Australian social inclusion policy appears to further perpetuate a cultural ethos of exclusion by holding a potentially destructive dual function. The paradoxical framing of social inclusion policy in Australia, i.e. one in which the *ideal* of full participation in society is promulgated but the means

through which this can be achieved are circumscribed, contributes to such an exclusionary milieu.

### ***Challenging Australian values and constructions of normalcy: Providing context to denied occupational alternatives***

Together with the political ideologies that have influenced social inclusion policy discourse and its effects on citizens living with entrenched disadvantage, other contextual influences were identified as playing major roles in capability enablement, social transformation and occupational possibilities; or capability deprivation and occupational injustice (Frank & Zemke, 2009; Laliberte Rudman, 2010; Sen, 2000; Townsend, 1997b). For example, another key finding in this thesis involved considering participants' occupational needs and successes. This was demonstrated through the themes of 'living for my family', 'doing things for recognition', 'having hope and faith' as well as the importance of being with others, in the context of their sociocultural environments. Their narratives of hope (Spencer et al., 1997) appeared to be shared within a highly contradictory sociocultural environment, where tensions became evident between their stories and the broader cultural norms, expectations and values specific to the 'Australian' way of life. Considering the political context's Neoliberal influences first (Gidley et al., 2010a, 2010b), a lack of political recognition of participation diversity and possibilities as understood from an occupational perspective, appeared to promote a 'responsibilisation' effect, or self-governance (Henderson & Fuller, 2011). Thus, broader occupational participation was delimited. Such an effect is described as one where "personal autonomy is incorporated into the process of governance through encouraging individuals to take responsibility for making socially responsible choices" (Henderson & Fuller, p. 195).

In promoting 'responsibilisation' (Henderson & Fuller, 2011), the social inclusion policy discourse appeared to encourage responsible, ethical, productive and 'active' citizens through paid employment, the most valued and recognised participation typology within a participation

hierarchy. Despite wanting desperately to participate in paid employment, the participants described situations where they did not have the supportive mechanisms or resources (personal, social or those provided by systems of governance) to accomplish this highly valued occupational goal. The fallout of not participating in paid employment and being engaged in meaningful work occupations, appeared to have major ramifications for the participants in terms of their social recognition and dignity. *Doing* or *not doing*, therefore, became a political construct, leading to unnecessary judgment and prejudice within a broader ‘responsibilisation’ (Henderson & Fuller) and ableist context. Therefore, despite finding meaningful occupational alternatives including transformative occupations which provided each participant with meaning, purpose and a sense of subjective wellbeing, such types of occupational participation held less cultural value and political status according to the policy. What is evident then, is that significant limitations and narrow assumptions about accepted forms of occupational participation clearly underpin the national policy which claims to promote ‘social inclusion’. This is the paradox identified earlier and one which impacts on the participants’ lives on a daily basis.

#### Cultural tensions and the influence of Western ideologies on inclusion.

When considering the participants’ narratives in context with cultural norms, expectations and values, typical ‘Australian’ values and other Western ideologies require analysis to determine their relevance to diverse populations. Indeed, such critiques are evaluated in context with timely considerations within occupational science, informed by critical disability and feminist perspectives (Phelan, 2011). Phelan contends that reductionistic, oppressive and marginalised discourses underpinning constructions of disability, difference and impairment should be refocused to emphasise critiques of the “construction of normalcy” (p. 167) and its hegemonic impacts. Interrogating such constructions is important work, as evidenced by the participants’ longing to be “normal again” and conform to a ‘normal way of life’.

Applying Phelan’s (2011) critical lens, commonly held Australian values of fairness and mateship (Phillips & Smith, 2000) are juxtaposed with other values which became apparent from

a critical interrogation of policies and cultural practices. For example, Western-framed policies uphold the cultural values of independence, self-sufficiency and individualism. As a result, less prioritisation is given to other cultural values which were equally esteemed by the participants, as well as by the majority world (Hammell, 2010), such as “interdependence, valuing social relationships, belonging, reciprocity and perceptions of value” (Hammell, p. 44). Therefore, it appears that not only were occupational participation typologies located within a dichotomous hierarchy; so too were cultural and political values. In this case, it appears that values which supported productivity, development and activation were accorded higher status and worth with greater ‘buy-in’ to “build the economic prosperity of the nation” (Gillard speech, 2008). Therefore, the practices and values that the participants cherished which promoted quality, meaning and dignity in their everyday occupational pursuits, were further under recognised politically and culturally. As a result, the operational definition of social inclusion proposed by the Rudd government in 2009 where individuals would have the ‘opportunities’, ‘resources’ and ‘capabilities’ they needed to *learn, work, engage* and *have a voice*, may not accurately depict the broader values held by marginalised and oppressed citizens, such as the research participants.

All of the participants reflected that they were not adequately supported by other community members from a values perspective. Participants, such as James and Anthony, also commented on the lack of life value practices in general, such as trust, honesty, helping others and treating others with respect. Furthermore, gender ideologies also appear to influence Australian social inclusion policy discourse in more tacit ways. From an occupational perspective, gender ideologies impact upon occupational choices (Galvaan, 2012), as well as the broader political climate, which dictate occupational classifications for participation and inclusion (Wicks & Whiteford, 2005). I contend that Australian social inclusion policy, in context with gender ideologies, is *patriarchal* and *androcentric*, especially with respect to how the concept of ‘work’ is constructed. For example, common occupational classifications, or discrete participation categories within the policy, were typically named as ‘work’, ‘volunteering’ and ‘caring’. From a feminist perspective, such categories can be considered as reflecting patriarchal and androcentric



values, embracing discursive undertones consistent with male dominated constructions of 'work'. These constructions have implications for the viability of these three occupational classifications, as 'volunteering' and 'caring' have historically been attributed to women's morality and ethics of care (Karniol, Grosz & Schorr, 2003). Volunteering and caring occupations have therefore been inherently misrepresented as gender- and value-neutral participation categories for predominantly female participants. Consequently, androcentric constructions of work, together with *ableist* discourses within social inclusion policy, could be described as 'hegemony in action', influencing how systems of governance are structured and operationalised. Considerations of gender and other political ideologies are consistent with gendered processes of exclusion and the reality of the 'feminisation of poverty' (Morrison, 2008). Morrison attributed particular groups of women as being overrepresented among citizens living in poverty and social exclusion in Australia, such as sole female parents and low wage earners like Rose and Annie.

### ***Models of disability: Missing links and implications***

Other tensions beyond cultural influences and contested ideologies also exist which impact upon Australian social inclusion policy in regards to constructions of participation and ability. Although one of the six priority areas within the policy included the aim of enabling people living with disability and mental illness to 'participate' in work (Department of the Prime Minister and Cabinet, 2009a), an analysis of discourses (Bacchi, 2005) revealed that there was no mention of any influence of theoretical models of disability to guide its planning, implementation or evaluation. Therefore, it appears that models of disability were omitted, perhaps due to the overarching Neoliberal ideology which directed the policy's 'inclusion through paid employment' agenda. Accordingly, my major critique of Rudd's social inclusion policy is that it was strategically aligned with narrow economic and ableist ideologies focused on individualism to strengthen labour market participation by targeting "the most 'able of the disabled', thus further entrenching narrow notions of social participation to the economic realm" (Soldatic & Pini, 2012, p. 191).

Such political ideology appears to have continued unchanged since Julia Gillard took over from Rudd to become the Prime Minister in June 2010.

It is important to note that the influence of the “growing orthodoxy” of Neoliberalism (Soldatic & Pini, 2012, p. 186) on disability policy more broadly, stemmed back to the Keating Labor Government in the early 1990s (Soldatic & Pini). Such a historico-political influence of Neoliberal and economic rationalist ideology (Pusey, 1991) on disability politics adds further evidence to support the emergence of a participation hierarchy being reified across both Labor and Liberal governments over the past three decades. Consequently, despite being considered as the most narrow social inclusion ideology (Gidley et al., 2010a, 2010b), the *cost* of the influence of Neoliberalism in ‘growing National economic prosperity’, has led to political misrecognition of participation across “non-economic spheres of life” (Vellacott, 2011, p. 246). This outcome, therefore, can be viewed as being shaped by a more conservative agenda that pre-dates the *Third Way* politics approach to social policy reform adopted by Rudd specific to disability politics (Buckmaster & Thomas, 2009). In terms of considering occupational participation beyond the significantly limited classification of paid employment, the adoption of theoretical models of disability to guide discourses on disability within social inclusion policy could be articulated as being ‘tokenistic’ at best.

From a Canadian perspective, Vellacott’s (2011) research which documented a critical analysis of disability employment policy, highlighted that the “tactical use of language” (p. 240) within the policy did not accurately reflect the central ideas proposed in any theoretical model of disability. Vellacott further noted that “the ad hoc use of language and constructs from various models of disability offers ample opportunity for confusion, misinterpretation or open conflict over policies lacking a firm and justifiable theoretical base” (p. 243). Comparing the Australian social inclusion policy discourse with Vellacott’s example, it seems that the apparent lack of direct consideration of any theoretical model of disability within the policy is significantly more problematic beyond a lack of disability nomenclature. My critique points to the disempowerment of ‘disabled’ (Hammell, 2004) and other marginalised voices within policies which are proposed

to assist them through systemic inclusion. From an institutional perspective, Townsend's (1998) critique of power brokers within systems of governance is also salient here. The power of language within policy-making as well as in interventions which follow activation rationalities and governmentalities (Laliberte Rudman, 2012; Walters, 1997) can result in potentially exclusionary outcomes for individuals living with poverty, disability and social exclusion. Thus, the lack of theoretical and advocacy-led disability discourses which challenge discriminatory and status quo practices result in systemic hegemonic practices by the State that promulgates the political rhetoric of "citizenship, participation and inclusion" (Soldatic & Pini, 2012, p. 192).

### ***The salience of the capabilities approach***

Both models of disability and other interdisciplinary theoretical frameworks can help situate and critique the reported and tacit discourses exemplified through lived experiences and policy. The two major theories that were considered in this thesis in context with justice discourses were the capabilities approach from economic theory (Sen, 1999) and political philosophy (Nussbaum, 2011; Sen & Nussbaum, 1993), and theories of recognition (Fraser, 1995, 2000, 2001, 2008; Honneth, 1992, 1995, 2001) respectively. This section focuses on considering the findings of both studies through the perspective of the former theoretical framework. The participants in the life history study strongly articulated that they sought to live a life with meaning, purpose and dignity. Dignified participation at home and in their communities was paramount in gaining social and political recognition. However, it became clear from the policy analysis and from interpreting their occupational and life contexts that being denied the capabilities, or opportunities, resources and choices, to engage in dignified participation had a negative effect on their wellbeing and status within their communities. From an 'inclusion through paid employment' agenda, social inclusion policy appeared to inadequately address ways to politically respect, recognise or dignify their diverse and meaningful types of occupational participation that were not classified as a work, or finance-producing domain. Consequently, typologies of participation within a hierarchy directed narrow opportunities for politically

recognised occupational participation. Yet, even when the participants sought such opportunities to participate in paid employment, or receive systemic support to address the root causes of their entrenched disadvantage, institutional mechanisms within systems of governance limited or denied their capabilities for occupational participation.

The capabilities approach (Nussbaum, 2011; Sen, 1999) was a major theoretical framework in this thesis which proved to be salient in situating the participants' denied opportunities, realities and occupational possibilities (Laliberte Rudman, 2010). From a Nussbaumian perspective, capabilities are ways of realising a life with human dignity (Nussbaum, 2011). I concur with critics such as Sen (1999) and Barclay (2012) who argued against a definitive list of capabilities such as that which was suggested by Nussbaum which could be mandated by the State without considering broader contextual influences. Despite this, I also support Nussbaum's proposal of a justice ideal which is relevant and applicable to an occupational perspective of justice, rights and dignity:

“Developing policies that are truly pertinent to a wide range of human situations means attending to diverse factors that affect the quality of a human life – asking, in each area, “What are people (and what is each person) actually able to do and to be?”” (p. 14).

Nussbaum further added that this key question would directly assess and compare societies “for their basic decency or justice” (p. 18). Consistent with this perspective, I therefore argue that occupation can play a central role in context with human rights and justice discourses to enable dignified participation. Furthering her claims of attending to factors affecting quality of life and wellbeing, Nussbaum considered that the capabilities approach had the potential to view a person as an *end*, where their wellbeing would be gauged through the opportunities that they had available to them. Together with Sen, Nussbaum considered *choice* and/or *freedom* as “holding that the crucial good societies should be promoting for their people is a set of opportunities, or substantial freedoms, which people then may or may not exercise in action: the choice is theirs” (p. 18). With regards to the occupational choices that the participants were granted through their own initiatives, compared with those that were afforded to them by systems of governance, it was evident that there was a distinct disconnect between wants, needs and outcomes. Therefore,

occupational choices for sometimes basic needs were impacted by contextual factors which were outside of the participants' control. Not only does this finding question the policy's operational definition of social inclusion which identified 'capabilities' to *learn, work, engage* and *have a voice* as a key guiding principle (Department of the Prime Minister and Cabinet, 2009a, 2009b), but it also highlights that the policy was out of touch with everyday realities of disadvantage. It is also inherently contrary to the capabilities approach's philosophy which commits to respecting an individual's "powers of self-determination" (Nussbaum, p. 18).

Originating from economic and human development approaches to addressing poverty through a capabilities approach (Sen, 1999, 2000; United Nations Development Programme, 2010), Nussbaum's (2011) conception of dignity, and influences from Aristotelian philosophy which considers human flourishing (Seligman, 2011; Sen, 2000), have theoretically guided the capabilities approach as one which is "resolutely *pluralist about value* [and] is *concerned with entrenched social injustice and inequality*, especially capability failures that are the result of discrimination or marginalization" (Nussbaum, p. 18-19; original emphasis). This statement supports the unique histories, needs and occupational potential (Asaba & Wicks, 2010; Wicks, 2001, 2003) of marginalised individuals from a politically liberal perspective (Nussbaum). As such, Nussbaum's claims could hold true for citizens living with entrenched disadvantage, suggesting that they should have *just* opportunities to enable wellbeing which supersede discrimination and other forms of prejudice. Although this is a noble claim which highlights the responsibilities and accountabilities of the State to support capability enablement, the dearth of theoretical or practical implications within social inclusion policy about how the actual mechanics of capability enablement would occur, appeared to further marginalise the participants within an ideologically Neoliberal context. Such lack of theoretical and practical application of the capabilities approach could answer for some "capability failures" (Nussbaum, p. 19) and exclusionary acts experienced by the participants at the service interaction level, or interface of systems of governance. With sporadic and inconsistent support offered to the participants by systems of governance, making opportunities for participation realistic seemed to become a utopian goal for them.

From a Sennian perspective, the capabilities approach enables an alternative view of the “means of good living” (Sen, 1999, p. 73) by focusing on “the *actual living* that people manage to achieve (or going beyond that, on the *freedom* to achieve actual livings that one can have reason to value)” (Sen, p. 73). In this description, Sen contextualises capabilities as the opportunities, choices, rights and freedoms to *do*. Freedom is defined by Sen as being “concerned with *processes of decision making* as well as *opportunities to achieve valued outcomes*” (original emphasis, p. 291). Therefore, the functionings, or occupations that result from capability enablement, or ‘flourishing’ (Nussbaum, 2011; Sen, 1999), are examples of justice in action.

Based on my research, I am in agreement with the crux of Sen’s (1999) synthesis of the capabilities approach. This is because it provides a framework for exploring the occupational realities and potential of narratives of disadvantage in context with those macro-level structures which influence experiences of inclusion or exclusion. Despite the major findings which highlighted real life examples of exclusion, the participants’ narratives also exemplified remarkable acts of resistance through survival, hope and resilience which ‘kept them going’. Such narratives of hope (Spencer et al., 1997) to some extent substantiated a Kantian view of self-determination and human agency which suggests that “the will and drive to act, lies in individuals” (Stadnyk, Townsend & Wilcock, 2010, p. 341). Such acts of resistance and resilience were mainly demonstrated through engaging in transformative occupations (Breedon, 2008, 2012).

#### Occupation as justice.

In applying Sen (1999) and Nussbaum’s (2011) capabilities approaches respectively, as well as Barclay’s timely considerations of capabilities and functionings in context with disability, respect, justice and rights (2010, 2011, 2012a, 2012b), I propose that *occupation-as-ends* (Gray, 1998), together with its enablement (Curtin, Molineux & Supyk-Mellson, 2010; Townsend & Polatajko, 2007), can be a *direct* form of justice. Occupation *as* justice is a nuanced approach to justice and rights within occupational justice discourse. But the distinction between justice and

rights for occupational participation with ‘occupation as justice’ is important to clarify. Occupation *as* justice situates functionings (Sen), or occupation-as-ends (Gray), at the core of justice in context with mechanisms which support, or guide the enactment of justice, rights and capabilities. It also refocuses the importance of not only the capabilities, opportunities and substantive freedoms (Nussbaum; Sen) to lead a valued and dignified life, but also the *value of actually being able to do*, or engage in dignified and politically recognised occupations.

Promoters and critics of the capabilities approach alike (i.e. Barclay, 2012b; Moss, 2012) have argued that recognising the *need* for capabilities alone cannot be considered without a concurrent focus on ‘functionings’, or what individuals are actually able to *do* and *be* which result from realising capabilities. This refocus within the capabilities approach itself on functionings is of significant value as it lends to theoretical and practical input from occupation-based disciplines (Phelan & Kinsella, 2009; Sellar, 2012). From an occupational perspective, occupation is applicable here as a meaningful phenomenon which can describe the functionings, or *ends* of realising capabilities. In doing so, the capabilities approach to justice, rights and dignity can be directly disseminated into occupation-based practices, disciplines and discourses. The role that occupational science can play in extending the capabilities discourse as well as gleaning insights from it, is mutually beneficial for the ongoing development of the field. The research reported in this thesis has demonstrated that there is a critical need for valuing and politically recognising the rights, opportunities freedoms and resources needed (capabilities) to participate in occupation, as well as the actual doing process (functionings) through occupation that brings meaning, purpose and dignity to life. Consequently, ‘occupation *as* justice’ can be a measure of just, equitable and dignified participation with planning, implementation and evaluation processes within social inclusion policy which encourages participation diversity more broadly. Thus, intersecting the capabilities approach with occupational science principles is valuable for operationalising a broader vision and enactment of inclusive policy.

### ***The salience of theories of recognition: Contextualising occupational misrecognition***

Together with the capabilities approach to justice articulated by Sen (1999) and Nussbaum (2011), theories of recognition expressed by political philosophers Axel Honneth, Nancy Fraser and others (i.e. Smith & Deranty, 2012; Thompson & Yar, 2011; Zurn, 2003) also have salience in expanding the discussion by considering such theories in context with transactional perspectives between the participants, what they were able to do and be, and how their occupational experiences occurred within sociocultural and socio-political environments (Cutchin & Dickie, 2013).

The research documented in this thesis presents a unique occupational perspective of poverty, disability and social exclusion realities which provides empirical evidence to support interdisciplinary theories, such as the capabilities approach and theories of recognition. Previously, such studies that have explored disability through applying theories of recognition, have done so predominantly through explorations of the subjective, or personal accounts of disability, without a cross-examination or critique of how social policies impart strategies for interpersonal, social or political recognition. This section recaps theories of recognition that were presented in the literature review in Chapter Two, prior to exploring the connection between the related concept of ‘misrecognition’ with the key findings of both the life history study and critical policy analysis.

Honneth’s (1995) theory of recognition proposed that there were three domains, or spheres, which constituted recognition: love, rights and solidarity. Love is expressed through meeting emotional needs (Honneth). Such needs evolve from primary relationships such as partners, carers, family and friends (Danermark & Coniavitis Gellerstedt, 2004; Reeve, 2012). The second sphere promotes self-respect through being recognised as a rightful citizen who enjoys and is able to realise civic, social, legal and political rights (Reeve). Finally, the third sphere, and most pertinent to the findings of this thesis, is solidarity, characterised by “freedom from denigration and being recognised as valuable to society. Having one’s unique talents or capabilities recognised in this way promotes self esteem” (Reeve, p. 228).



All three spheres in Honneth's (2005) theory of recognition need to be recognised so that self-esteem, self-respect, self-confidence and self-realisation can be achieved (Danermark & Coniavitis Gellerstedt, 2004; Reeve, 2012). Misrecognition and disrespect would thus be the result of lacking or not receiving inter-personal recognition (Honneth, 1992; Morrison, 2010; Reeve). Misrecognition, expressed as 'harm' and 'disrespect' (Honneth), takes on many shapes and forms, such as being on the receiving end of insults, feeling denigrated and humiliated amongst many others (Anna, 2012; Reeve). Misrecognition is therefore the opposite and negative effect of not receiving recognition from others, such that an individual is not able to pursue their life in freely-chosen and unforced ways (Reeve).

In broadening Honneth's (1992, 1995) moral view of recognition, other leading recognition theorists such as Charles Taylor and Nancy Fraser are also considered when contextualising misrecognition with aspects of social exclusion (Calder, 2011; Thompson & Yar, 2011). This is exemplified in Calder's timely consideration of misrecognition and disability, whose perspective is further extended through this meta-synthesis of the findings documented in this thesis. Calder highlighted that the rise of political awareness of disability issues over the past 40 years has placed matters of misrecognition at the heart of its ongoing discourse. The *social model of disability* highlighted what Calder labelled as "systematic misrecognition" (p. 106) resulting from disabling institutional structures and processes as well as other cultural barriers which framed disability within the social environment. Calder related misrecognition as being predominantly regarded as 'disablism' within the social model, characterised by "presumptions, negligences, barriers deliberate or otherwise, prejudices, lack of forethought, and default assumptions about 'normality' which exclude those with impairments" (p. 109). In context with theories of recognition, disablism *as* misrecognition is particularly relevant with regards to the participants' narratives of exclusion. I contend that the findings in this thesis extend Calder's considerations of misrecognition and disability by taking into account other important social factors which affected and impeded on the participants' occupational potential (Asaba & Wicks, 2010; Wicks, 2001, 2003). Disablism *as* misrecognition as expressed through the participants accounts, and

demonstrated through narrow social policy ideologies which perpetuated such misrecognition, could be framed as ‘entrenched disablism’ not specific to disability alone. Entrenched disablism as an extension to prejudice types, appears to have resonated for the participants as they not only experienced disablism resulting from living with disability, but also from living with low income, having low self-esteem, and experiencing disrespect, ongoing marginalisation and occupational injustices through systemic and interpersonal acts of exclusion.

The findings also uniquely highlight the complexities of considering occupational possibilities (Laliberte Rudman, 2010) in context with the politics of disability and the politics of misrecognition (Calder, 2011; Danermark & Coniavitis Gellerstedt, 2004; Thompson & Yar, 2011). The findings justify a broad view of recognition and misrecognition by considering theoretical and practical applications of moral philosophy (Danermark & Coniavitis Gellerstedt; Honneth, 1992, 1995, 2001), political philosophy (Calder; Nussbaum, 2011; Sen, 1999), social justice (Calder; Danermark & Coniavitis Gellerstedt; Fraser, 1995, 2000, 2001, 2008) and occupational justice (Stadnyk, Townsend & Wilcock, 2010) to disability and entrenched disablism (Calder; Danermark & Coniavitis Gellerstedt). In affirming disability identities (Thomas, 1999), Calder proposed a shift from medical and social constructions of disability to specifically recognise the relationship between social barriers and “the *embodied* experience of disability” (original emphasis, p. 114). In doing so, Calder proposed that “disability politics is thus altogether a politics of *recognition*” (original emphasis, p. 114) which considers Danermark and Coniavitis Gellerstedt’s analytical levels in disability research. Danermark and Coniavitis Gellerstedt’s framework includes socio-economic and cultural levels consistent with both Honneth’s (1995) and Fraser’s (1995) perspectives on recognition and redistribution respectively. It also considers other mechanisms (i.e. feelings of shame) and contexts (i.e. political, labour market) which provide an holistic framework to consider the complexities of disability (Danermark and Coniavitis Gellerstedt). Danermark and Coniavitis Gellerstedt’s analytical framework emphasises “the importance of context” and avoiding “the mistake of ‘context stripping’” (p. 351) while also recognising the impairment effects or embodied nature of disability (Calder; Thomas).

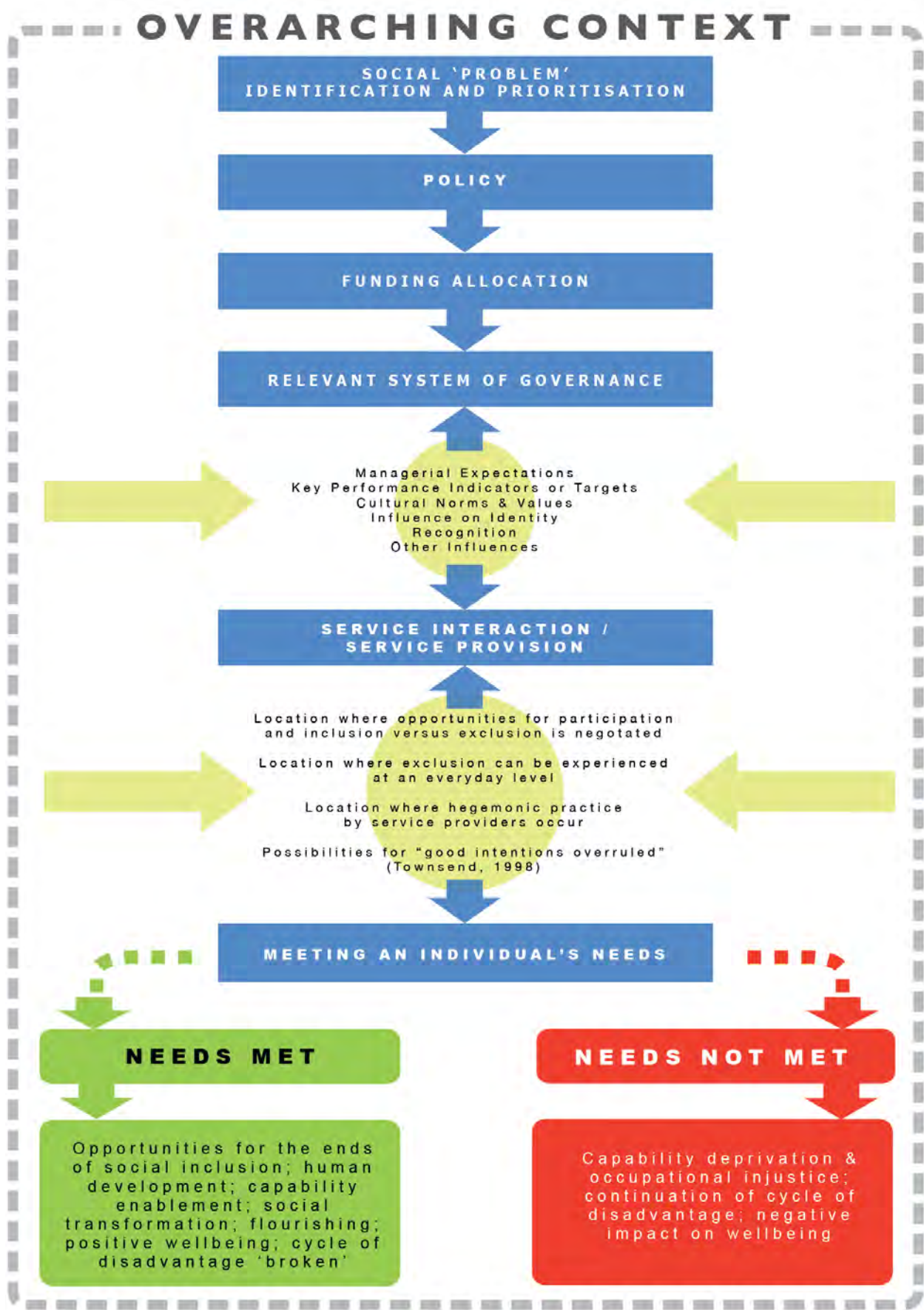
The findings of this thesis successfully identify some of the complexities of disability together with other aspects of entrenched disadvantage in context, i.e. within the political arena that appeared to govern and dictate possibilities for occupation, participation and inclusion. Data analysis findings have also exposed some realities of exclusion, capability deprivation and misrecognition consistent with those interdisciplinary theories focused on sociocultural constructions of identity, personhood, autonomy, self-determination and notions of normalcy (Phelan, 2011; Phelan & Kinsella, 2009).

### ***The Social Inclusion Framework (SIF): Introducing a visual meta-synthesis of the findings***

This section introduces a visual meta-synthesis of the findings which I name the ‘Social Inclusion Framework’ (SIF; See Figure 3). Grounded in the research findings, the SIF is a unique diagrammatic representation of the findings and the dynamic relations between them. In doing so, it extends constructs within critical occupational science, such as Laliberte Rudman’s (2010) ‘occupational possibilities’, by highlighting the specific locations where mechanisms of exclusion and inclusion are negotiated within sociocultural, political and institutional processes. It particularly emphasises the dynamic interactions between Australian social inclusion policy, systems of governance and their tacit and/or explicit influences on individuals’ possibilities for occupation, participation and inclusion in context with political and sociocultural ideologies, values and norms.

A significant feature of the SIF is that it outlines the institutional processes which occur within systems of governance, which I propose as being one of the major sites where occupational possibilities for inclusion are brokered (Laliberte Rudman, 2010). The SIF has seven processes displayed in a top-down fashion, starting out with the macro factors such as identifying and prioritising ‘problems’ for policy intervention, and the identification of them of course being shaped by specific political ideologies, and funneling down to consider an individual’s needs for inclusion through occupational participation.

Figure 3: Social Inclusion Framework (SIF).



However, the most important consideration that is highlighted in the SIF is the ‘overarching political, economic and ideological context’ (represented by “overarching context” in the SIF) which incorporates the ideologies, frames and fiscal determinants of occupational possibilities (Laliberte Rudman), occupational outcomes (Stadnyk et al., 2010) capability enablement and recognition. The overarching context which ultimately influences the effects of social inclusion policy on an individual’s possibilities to realise their capabilities to do, be, belong, become and flourish (Iwama, 2006; Iwama et al., 2009; Pereira, 2012; Rebeiro et al., 2001; Seligman, 2011; Wilcock, 1998, 2006) also includes, inter alia, the structural arrangements which “contribute to conditions of occupational justice or injustice” (Stadnyk et al., 2010, p. 336).

From a critical occupational science perspective, the findings documented in this thesis as demonstrated through the SIF empirically support and justify the emerging theory of occupational justice initially proposed by Townsend and Wilcock (2004a) and further explicated by Stadnyk, Townsend and Wilcock (2010), Nilsson and Townsend (2010), and Townsend (2012). In doing so, my research provides further evidence to demonstrate the salience of the theory of occupational justice (Stadnyk, Townsend & Wilcock) and other related frameworks (i.e. Restall, 2010; Whiteford & Townsend, 2011). The meta-synthesis of the findings presented in this chapter also support Stadnyk et al.’s theoretical proposal that *factors* such as the narrow social inclusion ideology of Neoliberalism (Gidley et al., 2010a, 2010b), cultural values such as independence and self-sufficiency (Hammell, 2010), ‘occupational forms’ which reify a *participation hierarchy*, and *value-laden assumptions* surrounding the inclusion of people living with poverty and disability, hold a significant bearing on occupational outcomes (Stadnyk et al.). The outcomes are those which enable or hinder capability enablement, occupation-as-ends and wellbeing (Gray, 1998; Sen, 1999; Wilcock).

As exemplified by the findings, two levels in the SIF where *occupational outcomes* (Stadnyk et al., 2010) are brokered and negotiated occur within institutional processes of systems of governance (i.e. between managers and service employees) such as Centrelink. Townsend’s (1998) research into the role of power within the mental health system of governance and

practice in Atlantic Canada, detailed that *occupational determinants* (Stadnyk et al., 2010) within institutional processes can be expressed through the following: unrealistic managerial expectations; high key performance indicators or targets imposed on service employees to meet, which could have a dehumanising effect at the service interaction level leading to being “treated as a number”, and value-laden assumptions being expressed in tacit and/or explicit ways which could be interpreted as misrecognition such as entrenched disablism and other prejudices.

Together with the institutional processes which occur within systems of governance, the other major site where opportunities for participation and inclusion are brokered and negotiated is at the service interaction level. It was at this level where all of the participants gave detailed accounts of predominantly negative experiences of exclusion, where the good intentions of social inclusion policy (i.e. operational definition of social inclusion and priority areas; Department of the Prime Minister and Cabinet, 2009a) were overruled (Townsend, 1998) by exclusionary acts such as experiencing tacit forms of misrecognition (i.e. social distancing; Yuval-Davis, 2006; 2010), or not meeting the requirements for the Disability Support Pension or other income supports, not being given opportunities to participate in paid work due to value-laden assumptions about workability resulting in missed occupational possibilities (Laliberte Rudman, 2010).

#### The flow-on effect of needs not being met.

A concern with missed occupational opportunities and possibilities (Laliberte Rudman, 2010) is a key feature of occupational justice. The theory of occupational justice (Stadnyk et al., 2010) proposes that occupational outcomes could promote occupational justice or occupational injustice. For certain ‘ideal’ citizens who hold agency within an environment where *ability* is standardised and privileged, social inclusion policy could be interpreted as successful in its implementation of strategies which politically recognise, and lead to, the positive *occupational outcome* (Stadnyk et al.) of participating in paid work, or receiving skills education and training to be able to work. I have framed such forms of ‘active/productive participation’ as being the

*ultimate* participation typology that is both politically and culturally recognised. However, I have also demonstrated through the findings presented in this thesis that the occupational participation realities appear to be quite different for the participants in the research compared to the ‘ideal’ citizen, i.e. one who contributes to the economic prosperity of the nation (Department of the Prime Minister and Cabinet, 2009a). Policy-as-discourse analysis (Bacchi, 2000; 2009) highlighted that such participants were deemed as ‘passive/inactive participants’ who required activation interventions (Dean, 1995; Laliberte Rudman, 2012; Walters, 1997).

Indeed, there appears to be a direct correlation with activation technologies of the self (Laliberte Rudman, 2012) and moving from being a ‘passive’ welfare recipient, to ‘actively’ participating in the labour market and becoming a tax payer. As previously discussed, there seems to be an irony in such a quest for activation through paid work where all of the participants desperately sought participation in work, yet were inherently denied due to a lack of systemic support. In context with these missed occupational outcomes (Stadnyk et al., 2010), I argue that experiencing misrecognition and being judged by an *ableist mentality* of what the participants couldn’t do rather than what they could do, could have been a major contributing factor which affected their workability. As a corollary, the participants’ occupational needs beyond economic participation were unmet. Thus, the flow-on effect (as expressed through the participants’ accounts), were replete with stories of cycles of entrenched disadvantage, as well as experiences of capability deprivation, occupational injustice and negative wellbeing. Finally, the participants’ experiences of exclusion and misrecognition seemed to have had negative repercussions on their senses of self, and an overall devaluation of the diverse occupations in which they did participate and from which they gained satisfaction.

### ***Summary of the discussion***

The discussion which has presented a meta-synthesis of the findings in this chapter has provided context and evidence to answer the corollary question reiterated at the beginning of this chapter which was, “How does the Australian social inclusion policy discourse ‘speak to’ the

everyday realities of citizens living with entrenched disadvantage? In what ways does it enable or constrain?” The meta-synthesis overwhelmingly suggests that the Australian social inclusion policy under the Rudd Government did impact upon the lives of citizens living with entrenched disadvantage in both enabling and constraining ways. In terms of its more positive and enabling qualities, being introduced into the National political discourse as an overarching agenda to guide social policy delivery was an essentially positive and transformational change in the way social policy became enacted and prioritised. This was starkly different in comparison with the lack of focus on *social* policies in favour of more economically rationalist policies (Pusey, 1991) held by the previous conservative government. Further, the introduction of social inclusion policy at National level demonstrated the *ideal* vision of promoting a socially inclusive society, where locations of disadvantage and identifying priority areas for intervention became a focus of the policy’s agenda. Consequently, the policy also aimed to mobilise resources in ways which promoted inter-agency collaboration and stakeholder involvement such as developing compacts with NGOs and other organisations.

However, the Australian social inclusion discourse also acted in ways which constrained dignified occupational participation and inclusion. Ways in which such constraints manifested occurred through the privileging of *ableist* discourses, supported by narrow ideologies with an inherent Neoliberal orientation towards productivity and labour market participation. Additionally, occupation, participation and inclusion were further constrained through the tacit promulgation of the *ideal citizen* as one who is an employed tax payer. Finally, the meta-synthesis of the findings documented in this thesis highlighted the operationalisation of a *participation hierarchy* resulting in new forms of occupational injustice which I framed as *occupational misrecognition*.

From addressing the corollary questions, the SIF also provided a diagrammatic representation of the findings which highlighted the policy implementation process, clearly demarcating where the policy’s good intentions were overruled (Townsend, 1998) by an array of complex structural and contextual factors where occupational outcomes, or possibilities for



occupation, participation and inclusion, were brokered and negotiated. The SIF presents a visual representation of where two major sites of exclusion occurred; both through explicit everyday experiences at the interface of systems of governance, as well as in more tacit ways through structural and institutional processes. As a result, occupational injustices, misrecognition and capability deprivation ensued for the participants which had a negative flow-on effect on their wellbeing, sense of self, autonomy and self-determination.

The next section concludes this thesis by outlining ‘ways forward’ through recommendations for theoretical, policy and practice development as well as future research possibilities. In doing so, it addresses the need for inclusive and occupation-focused practices across policy domains and institutional processes, as well as community initiatives to drive social transformation and human potential ideologies (Gidley et al., 2010a, 2010b) to enable the *ends* of social inclusion (Whiteford, 2011).

## Conclusion: *Moving Forward\**

Gidley's (Gidley et al., 2010a, 2010b) model depicting narrow to more expansive ideologies of inclusion is a salient example of the potential of achieving the ends of inclusion across micro, meso and macro levels. The SIF (Figure 3) above incorporated the ideals of Gidley's model by highlighting sustainable occupational possibilities (Laliberte Rudman, 2010) if *needs are met for the individual*. Throughout this thesis, I have demonstrated that social policy has a direct and profound effect on the participants' occupational outcomes, possibilities and potential (Laliberte Rudman, 2010; Stadnyk et al., 2010; Wicks, 2001, 2003), which had a significant effect on their wellbeing. To combat such missed occupational outcomes (Stadnyk et al., 2010), I propose that the ultimate *end* of social inclusion is, and must be, human flourishing through social transformation (Breedon, 2008, 2012; Frank & Zemke, 2009; Nussbaum, 2011; Pereira, 2012; Seligman, 2011; Sen, 2000; Townsend, 1997b, 2012). There are various ways in which human flourishing can be viewed and interpreted. From a social and positive psychology perspective (Seligman), Seligman determined that human flourishing is the ultimate goal of *wellbeing* which is nurtured through one or more of the following five elements, collectively known as 'PERMA': positive emotion, engagement, relationships, meaning and purpose and accomplishment. From an occupational perspective, Seligman's PERMA paradigm is consistent with the nature of occupation (Molineux, 2009), as well as collectively advocating for the promotion of health (Wilcock, 2006) and wellbeing (Aldrich, 2011a). Promoting human flourishing and living a flourishing human life where an individual can access support, enable their capabilities through occupation-as-ends (Gray, 1998) and receive mutual recognition (Fraser, 1995; Honneth, 1995, 2001; Komter, 2005; Morrison, 2010) *must* be the 'gold standard' for inclusive policy, practice and support. The following section outlines ways in which the *ends* of social inclusion (Whiteford, 2011) can be supported through highlighting the implications of the studies documented in this thesis on theoretical, practice and policy development. It then concludes this thesis by providing some recommendations to support *an individual's needs being met* (see SIF, Figure 3) through social

transformation possibilities specifically targeted for marginalised individuals, such as the participants in this research.

### ***Implications of the research for theoretical development***

Both the research documented in this thesis and discussion of the meta-synthesis of its findings acknowledged earlier in this chapter, have promoted the use of epistemologically plural perspectives (Kinsella, 2012) which both guided the thesis and assisted with situating *social inclusion* within its interdisciplinary discourses. The principal theoretical framework was from occupational science theory viewed through a critical lens. This thesis aims to expand theoretical development within occupational science discourse, as well as ontologically support the premise that humans as occupational beings can transform themselves in moral, social, healthful, cultural and political ways (Breedon, 2008, 2012; Frank & Zemke, 2009; Kronenberg & Pollard, 2005; Townsend, 1997b; Venkatapuram, 2011; Whiteford & Townsend, 2011; Wilcock, 1998, 2006; Yerxa et al., 1990). The findings empirically support the theory of occupational justice (Stadnyk et al., 2010) as well as lend support to interdisciplinary models which promote social transformation as a realistic and attainable outcome which expands doing, or participation in society (Frank & Zemke; Gidley, 2010; Gidley et al., 2010a, 2010b).

Additionally, this thesis has aimed to expand the evolving occupational justice discourse promoted within occupation-based disciplines (Phelan & Kinsella, 2009; Sellar, 2012) by using the Whiteford & Townsend's (2011) POJF 2010. It has done so by using the POJF 2010 framework (Whiteford & Townsend) as a tool for analysis from a macro, or 'top-down' perspective. As a result, this thesis has demonstrated how the POJF 2010 (Whiteford & Townsend) and other occupation- and justice-focused advocacy tools can be used in innovative and proactive ways to enable an occupationally just society (Townsend & Wilcock, 2004a, 2004b; Wilcock & Townsend, 2000) through critical analyses of social policies and others issues influencing possibilities for human flourishing and social inclusion.

### ***Implications of the research for inclusive practice and policy***

“Proper scrutiny and spirit count as much if not more than action. Successful implementation and protection of occupational rights rely obviously on the awareness and recognition of such rights, but they also depend on a vision that goes beyond the purely political into the realms of the philosophical and the ethical” (Thibeault, 2013, p. 247).

In Thibeault’s (2013) words, matters of occupational justice and occupational rights can be enacted in several ways. This thesis urges governments, policymakers, service providers, professionals and citizens to act and work together in various ways to promote morally conscious (Wilding & Whiteford, 2009; Wright-St Clair & Seedhouse, 2005) and inclusive practices which stimulate and promote recognition and dignified occupational participation. Such inclusive practices could be achieved through adopting both a capabilities and occupational lens (Sen, 1999) towards offering and achieving diverse occupational possibilities (Laliberte Rudman, 2010). The meta-synthesis of the findings documented earlier in this final chapter promotes and supports Thibeault’s broad vision of recognising and enacting occupational rights in political, philosophical and *ethical* ways. Implications for inclusive practice and policy processes must be based under a *moral* imperative (Wilding & Whiteford, 2009). Both inclusive practice and policy must also be informed by and based under an ‘ethic of care’ (Townsend, 1998) which move beyond narrow social inclusion ideologies towards supporting individuals to flourish and transform themselves. Consequently then, sociocultural, political and systemic enablement (not disablement) could be possible and attainable.

This thesis identified that occupational injustices continue to evolve as communities and sociopolitical systems continue to promote individualism and materialism. Consequently, occupational injustices, such as my framing of *occupational misrecognition* which result from what I have labeled a *participation hierarchy* develop, which can be challenged through dispelling myths about marginalised and oppressed *others’* qualities and expanding an understanding of the depth, breadth and potential of *participation*. Too often, participation in everyday occupations is taken-for-granted and relegated to narrow forms of doing (i.e. economic participation) as demonstrated through the findings of the critical policy-as-discourse analysis of Australian social inclusion

policy documented in this thesis.

This thesis also promotes principles which protect the occupational rights of individuals which can lay foundations for enabling inclusive opportunities leading to *sustainable participation*. Such principles, as suggested by Thibeault (2013, p. 250-251) include (1) examining the values, motives and attitudes of individuals; (2) adopting an occupational lens and (3) establishing fair and sustainable partnerships with communities. Each of these principles highlight a level of moral consciousness where capabilities, *occupation-as-justice* and avenues for recognition can be enacted and established in partnership with community members, social institutions, policymakers, government officials and others in positions of power.

Viewing doing and being, or ‘occupation’ *as* a form of justice in and of itself, can be the starting point for ethical, moral, social and informed action influencing meaningful, purposeful and dignified participation at the everyday level. Therefore, considering occupation and its potential, as well as adopting a morally conscious and inclusive ethic of care, *must* be on each stakeholder’s agenda for sustainable participation solutions. Ultimately, therefore, the *ends* of social inclusion could be less of an ideal. I interpret Whiteford’s (2011) notion of ‘*ends* of social inclusion’ in this context as: *all* people, including traditionally marginalised and oppressed individuals, having the opportunities, resources, capabilities (Sen, 1999), choices and political recognition (Honneth, 1995) to achieve their human and occupational potential (Asaba & Wicks; Gidley, 2010; Gidley et al., 2010a, 2010b; Wicks) leading to social transformation (Frank & Zemke, 2009; Gidley et al., 2010a, 2010b), positive wellbeing and living a flourishing life that they have reason to value (Aldrich, 2011a; Nussbaum, 2011; Venkatapuram, 2011). Some *ends* of social inclusion are depicted in the SIF (Figure 3) which include human development (United Nations Development Programme, 2010), positive wellbeing (Aldrich), capability enablement and cycles of disadvantage being ‘broken’, or eradicated.

As a critical occupational science perspective has informed this thesis, implications exist for practices which are occupation-based. Indeed, occupational scientists and occupational therapists can benefit from putting *occupation* front and centre in all forms of person-, family-,

organisational-, community- and population-centred practices, analyses, critiques and solutions (Molineux, 2011). Considering both the social and occupational determinants of health and wellbeing (CSDH, 2008; Stadnyk et al., 2010; Wilcock, 1998, 2006) are imperative in promoting sustainable, holistic, occupation-focused and inclusive solutions for every person or institution who is involved in collaborative interventions with occupational scientists and occupational therapists. Such practices are commensurate with an inclusive, non-reductionist (Saloojee, 2011), morally conscious (Wright-St Clair, 2005) and justice-centred (Pereira, 2012; Townsend & Polatajko, 2007) approach to wellbeing, social transformation and human flourishing.

### ***Research limitations, strengths and future research possibilities***

The methodology chapter (Chapter Three) highlighted some of the limitations of the research documented in this thesis. Nevertheless, this thesis highlighted a comprehensive way of exploring the situated nature of everyday occupation in context with broader sociopolitical issues influencing occupational possibilities. This was done through using complementary and epistemologically plural methodologies and perspectives. Limited research in occupation-based disciplines has explored similar studies which document macro influences on occupation, participation and inclusion on marginalised individuals, such as people living with poverty, disability and other social issues. Future critical occupational science research of such complex issues impacting across many communities can be enriched through adopting epistemological pluralism. As this research was situated in Australia, it can only be interpreted in an Australian context (and to some extent other Western European and North American contexts which have also introduced political discourse on social inclusion).

Therefore, it is hoped that the research documented in this thesis can stimulate further projects focusing on matters of occupational justice and injustice amongst other marginalised and oppressed individuals. This thesis aims to extend discourse through its empirical research which documented some of the occupational implications that can result from living with poverty, disability and other forms of entrenched disadvantage. This is a particular strength of the thesis,

especially with regards to exploring everyday realities of poverty which is largely under-examined and requires urgent attention from a critical and occupational perspective. There is an inherent need to expand discourse into the complexities of social inclusion and social exclusion from an occupational perspective within occupation-based disciplines (Phelan & Kinsella, 2009; Sellar, 2012). Current research has attempted to explore some complexities, especially in the area of mental illness and social exclusion (i.e. Diamant & Waterhouse, 2010; Farrell & Bryant, 2009; Fieldhouse & Onyett, 2012; Harrison & Sellers, 2008; Le Boutillier & Croucher, 2010; Smyth, Harries & Dorer, 2011). However, more critical and empirical studies are required.

Furthermore, the research illustrated in this thesis has presented a unique deconstruction of the occupational domain of 'work' through a critical occupational science analysis of participation problematisations which are located within Australian social policy discourse. Further research is required within occupational-based disciplines (Phelan & Kinsella, 2009; Sellar, 2012) and other interdisciplinary discourses which considers other deconstructions of social, economic and health policies and practices through a critical lens, which focuses on how sociocultural and political ideologies of occupation, gender, ethnicity, sexuality, socioeconomic status, ability and other factors are problematised. Another feature of future research could also explore the value and provision of 'self-defining opportunities' (Suleman & Whiteford, 2013), including policy considerations, perceptions and influence on 'the self' in context with occupational participation (Suleman & Whiteford).

### ***Recommendations to move forward\****

In this final section which concludes this thesis, I recommend that the following 16 'points of action' be considered as a matter of urgency in order that sustainable and inclusive solutions for marginalised and oppressed individuals, such as the participants in this thesis, can lead to social transformation possibilities and the *ends* of social inclusion:

### Policy makers:

- Enable occupation from the macro to the micro. This considers the political recognition of the depth, breadth and potential of occupational participation within policies. Through recognising participation from an occupational lens, everyday occupational needs can be taken more seriously at the political level;
- Empower *all* citizens to have and pursue equitable and accessible opportunities to be involved in all facets of the policymaking process (Restall, 2010). Recognising the key elements of social inclusion (e.g. Table 1) is vital throughout this process, as they highlight some of the political accountabilities of the State to empower citizenship, occupational rights and inclusion;
- Develop and implement person-centred and person-first policies which adopt an inclusive ethos and ethic of care (Townsend, 1998) so that service providers and other social institutions can enable meaningful, purposeful, dignified and transformative occupation and participation for citizens;
- Take occupational injustice seriously to prevent new forms of occupational injustice from developing and affecting lives (i.e. *occupational misrecognition* within the context of a *participation hierarchy*). This will require investing in time and resources to consider the value of a critical occupational science lens towards policies which impact on human doing, or participation across institutional and community levels;
- Consider the diversity of participation beyond narrow ways of doing which currently exist in Western contexts (i.e. economic participation) and adjust/improve policies and practices accordingly;
- Acknowledge that poverty is a real and relentless problem in Australia which requires a less reductionistic and more inclusive, ethical and equitable approach to policy;
- Raise the Newstart Allowance by \$50 dollars per week as recommended by the Australian Council of Social Services (ACOSS, 2012a), and



- Create policies which promote single points of entry as well as eradicate ‘red tape’ by encouraging all service providers to have accessible information, including forms that are easy to read and interpret.

Service providers and practitioners:

- Enable individuals to realise their capabilities to do, be, become, belong and prosper (Wilcock, 1998, 2006) through proactive and person-centred services that promote a morally conscious ethos. This could significantly challenge hegemonic practices at the service interaction level, leading to breaking cycles of disadvantage;
- Promote sustainable participation and inclusion through community-led processes and collaborative action with key stakeholders which always involve the direct participation of citizens. This has the potential to recognise citizens’ skills, talents and contribution potential;
- Consider the diversity of disability and acknowledge that living with disability is unique to the person with disability and can be both enriching and difficult. It is also important to consider the service provider’s or practitioner’s own value-laden assumptions and biases towards ability and diversity to eradicate exclusionary and hegemonic practices;
- Act in ways to dispel myths about people living with entrenched forms of disadvantage, promote difference and diversity, and provide them with equitable opportunities so that they can achieve occupation-as-ends (Gray, 1998) which can be interpreted as forms of *justice in action*. There is scope within this recommendation to take a leadership and mentoring role, educating others on how to be proactive in supporting inclusion and taking a stand discrimination and misrecognition by putting people first, and
- Incorporate complementary *life skills programs* to capacitate individuals with the basic skills and capabilities to meet their everyday needs with *dignity*. Such programs could complement government activity programs and other capacity building initiatives such as

learning how to cook an affordable and nutritious meal; budgeting and money management programs; digital literacy (Hamilton, In press); providing opportunities for accessible leisure and recreation; cultural diversity and awareness education; literacy and numeracy skills and countless other ways to create, innovate and empower.

Broader community:

- Recognise that there is no place for misrecognition, disablism and other forms of discrimination within Australia;
- Invoke a morally conscious culture of inclusion through holding and practising positive life values towards other community members which can support connectedness and a sense of belonging, and
- Recognise, respect, and promote diversity and an ethic of care within one's community, inclusive of members living in poverty with disability or other forms of adversity.

*He who has a why to live for can bear almost any how*

- Friedrich Nietzsche

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Appendix A: Definitions of social inclusion or exclusion.

Levitas et al. (2007, p. 21)	Taket et al. (2009, p. 7-8)
... a shorthand term for what can happen when people or areas suffer from a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health and family breakdown (SEU, 1997)	Original French definition ('exclusion sociale'), as a 'rupture of social bonds' (European Foundation, 1995, cited in de Haan, 1998, p. 12)
Social exclusion occurs where different factors combine to trap individuals and areas in a spiral of disadvantage (DSS, 1999, p. 23)	'A shorthand term for what can happen when people or areas suffer from a combination of problems, such as unemployment, poor skills, low income, bad housing, high crime, poor health or lack of transport' (Social Exclusion Unit & Cabinet Office, 2001, p. 2)
Social exclusion is a process, which causes individuals or groups, who are geographically resident in a society, not to participate in the normal activities of citizens in that society (Scottish Executive, nd)	'Inability to participate effectively in economic, social, political and cultural life, alienation and distance from the mainstream society' (Duffy, 1995, p. 17)
The notion of poverty that has guided the development of this report is where people lack many of the opportunities that are available to the average citizen.... This broad concept of poverty coincides with the emerging concept of social exclusion (NPI, Howarth et al., 1998)	'Sense of social isolation and segregation from the formal structures and institutions of the economy, society and the state' (Somerville, 1998, p. 762)
The processes by which individuals and their communities become polarised, socially differentiated and unequal (ESRC, 2004)	'an individual is socially excluded if (a) he or she is geographically resident in a society but (b) for reasons beyond his or her control he or she cannot participate in the normal activities of citizens in that society and (c) he or she would like to participate' (Burchardt et al., 1999, p. 229)
The dynamic process of being shut out...from any of the social, economic, political and cultural systems which determine the social integration of a person in society (Walker and Walker, 1997, p. 8)	ESRC Centre for Analysis of Social Exclusion (Hills et al, 2002), suggest four dimensions: consumption – capacity to buy (now and future); production – participation in economically or socially valuable activities; political engagement – in local or national decision-making; social interaction with family, friends and community
A lack or denial of access to the kinds of social relations, social customs and activities in which the great majority of people in British society engage. In current usage, social exclusion is often regarded as a 'process' rather than a 'state' and this helps in being constructively precise in deciding its relationship to poverty (Gordon et al., 2000, p. 73)	'The continuous and gradual exclusion from full participation in the social, including material as well as symbolic, resources produced, supplied and exploited in a society for making a living, organizing a life and taking part in the development of a (hopefully better) future' (Steinert, 2007, p. 5)
An individual is socially excluded if (a) he or she is geographically resident in a society but (b) for	'Social exclusion is a complex and multi-dimensional process. It involves the lack of

reasons beyond his or her control, he or she cannot participate in the normal activities of citizens in that society, and (c) he or she would like to so participate (Burchardt et al., 2002, pp 30, 32)	denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in society, whether in economic, social, cultural, or political arenas. It affects both the quality of life of individual and the equity and cohesion of society as a whole' (Levitas et al., 2007, p. 9)
An accumulation of confluent processes with successive ruptures arising from the heart of the economy, politics and society, which gradually distances and places persons, groups, communities and territories in a position of inferiority in relation to centres of power, resources and prevailing values (Estivill, 2003, p. 19)	'Exclusion consists of dynamic, multi-dimensional processes driven by unequal power relationships interacting across four main dimensions – economics, political, social and cultural – and at different levels including individual, household, group, community, country and global levels. It results in a continuum of inclusion/exclusion characterised by unequal access to resources, capabilities and rights which leads to health inequalities' (Popay et al., 2008, p. 2).
Social exclusion is a broader concept than poverty, encompassing not only low material means but the inability to participate effectively in economic, social, political and cultural life and in some characterisations alienation and distance from mainstream society (Duffy, 1995)	
(Social Inclusion) The development of capacity and opportunity to play a full role, not only in economic terms, but also in social, psychological and political terms (EU Employment and Social Affairs Directorate)	
Inadequate social participation, lack of social integration and lack of power (Room, 1995)	

Appendix B: Key Rudd Labor Government publications on social inclusion.

Year	Documents
2008	<p>Australian Social Inclusion Board. (2008). <i>National mental health and disability consultation findings</i>. Retrieved January 15, 2010 from <a href="http://www.socialinclusion.gov.au/Partnerships/Board/Documents/FindingsNov08.pdf">http://www.socialinclusion.gov.au/Partnerships/Board/Documents/FindingsNov08.pdf</a></p> <p>Australian Social Inclusion Board. (2008). <i>Principles for social inclusion – everyone’s job</i>. Retrieved January 15, 2010 from <a href="http://www.socialinclusion.gov.au/Partnerships/Board/Documents/SocialInclusionPrinciples.pdf">http://www.socialinclusion.gov.au/Partnerships/Board/Documents/SocialInclusionPrinciples.pdf</a></p> <p>Hayes, A., Gray, M. &amp; Edwards, B. (2008). <i>Social inclusion: Origins, concepts and key themes</i>. Barton, ACT: Department of the Prime Minister and Cabinet. Available: <a href="http://www.socialinclusion.gov.au/Documents/PMC%20AIFS%20report.pdf">http://www.socialinclusion.gov.au/Documents/PMC%20AIFS%20report.pdf</a></p>
2009	<p>Department of the Prime Minister and Cabinet. (2009). <i>A stronger, fairer Australia: National statement on social inclusion</i>. Barton, ACT: Department of the Prime Minister and Cabinet. Available: <a href="http://www.socialinclusion.gov.au/Resources/Documents/BrochureAStrongerFairerAustralia.pdf">http://www.socialinclusion.gov.au/Resources/Documents/BrochureAStrongerFairerAustralia.pdf</a> (Brochure, 24 pages), and <a href="http://www.socialinclusion.gov.au/Resources/Documents/ReportAStrongerFairerAustralia.pdf">http://www.socialinclusion.gov.au/Resources/Documents/ReportAStrongerFairerAustralia.pdf</a> (Full Report, 92 pages)</p> <p>Australian Social Inclusion Board. (2009). <i>A compendium of social inclusion indicators: How’s Australia faring?</i> Barton, ACT: Department of the Prime Minister and Cabinet. Available: <a href="http://www.socialinclusion.gov.au/Partnerships/Board/Documents/Compendium.pdf">http://www.socialinclusion.gov.au/Partnerships/Board/Documents/Compendium.pdf</a></p> <p>Department of Education, Employment and Workplace Relations. (2009). <i>The Australian Public Service social inclusion policy design and delivery toolkit framework</i>. Canberra, ACT: Department of the Prime Minister and Cabinet. Available: <a href="http://www.socialinclusion.gov.au/Documents/SIToolKit.pdf">http://www.socialinclusion.gov.au/Documents/SIToolKit.pdf</a></p>
2010	<p>Australian Social Inclusion Board. (2010). <i>Social inclusion in Australia: How Australia is faring</i>. Canberra, ACT: Department of the Prime Minister and Cabinet. Available <a href="http://www.socialinclusion.gov.au/Resources/Pages/Resources.aspx">http://www.socialinclusion.gov.au/Resources/Pages/Resources.aspx</a></p>



Appendix C: Speeches and press releases made by The Hon Julia Gillard on social inclusion during the Rudd Labor Government.

Speeches:

Gillard, J. & Wong, P. (2007). *An Australian Social Inclusion agenda*. Retrieved February 3, 2012

from

<http://dare2dream.westernsydneyinstitute.wikispaces.net/file/view/ALP+Social+Inclusion+Agenda+2007.pdf>

Gillard, J. (2007). *An Australian Social Inclusion Agenda: Speech ACOSS National Annual Conference, 22<sup>nd</sup> November 2007*. Retrieved January 23, 2012 from **Error! Hyperlink reference not valid.**

Gillard, J. (2008). *Social Innovation, Social Impact: A New Australian Agenda – Thursday 28 February 2008 Speech*. Retrieved January 23, 2012 from <http://ministers.deewr.gov.au/gillard/social-innovation-social-impact-new-australian-agenda>

Gillard, J. (2008). *ACOSS National Conference – Thursday 10 April 2008 Speech*. Retrieved 23 01 2012 from <http://ministers.deewr.gov.au/gillard/acoss-national-conference>

Gillard, J. (2008). *Priorities For The New Australian Government – Friday 13 June 2008 Speech*.

Retrieved January 23, 2012 from <http://ministers.deewr.gov.au/gillard/priorities-new-australian-government>

Gillard, J. (2008). *Reforming Education And Skills: Challenges Of The Twenty First Century – Friday 18 July 2008 Speech*. Retrieved January 23, 2012 from <http://ministers.deewr.gov.au/gillard/reforming-education-and-skills-challenges-twenty-first-century>

Gillard, J. (2008). *Education, Employment and Social Inclusion Symposium – Thursday 21 August 2008 Speech*. Retrieved January 23, 2012 from <http://ministers.deewr.gov.au/gillard/education-employment-and-social-inclusion-symposium>

Gillard, J. (2008). *Address to the Western Chance Breakfast – Thursday 21 August 2008 Speech*. Retrieved January 23, 2012 from <http://ministers.deewr.gov.au/gillard/address-western-chance-breakfast>

- Gillard, J. (2008). *Launch of Anti-Poverty Week – Sunday 12 October 2008 Speech*. Retrieved January 23, 2012 from <http://ministers.deewr.gov.au/gillard/launch-anti-poverty-week>
- Gillard, J. (2008). *Making the most of our people: facing new global challenges with confidence – Wednesday 29 October 2008 Speech*. Retrieved January 23, 2012 from <http://ministers.deewr.gov.au/gillard/making-most-our-people-facing-new-global-challenges-confidence>
- Gillard, J. (2009). *A Resilient Australia – Address to the Sydney Institute – 19 February 2009 – Thursday 19 February 2009 Speech*. Retrieved January 23, 2012 from <http://ministers.deewr.gov.au/gillard/resilient-australia-address-sydney-institute-19-february-2009>
- Gillard, J. (2009). *POST BUDGET SPEECH – Investing in education and innovation to create the jobs of the future – Thursday 21 May 2009 Speech*. Retrieved January 23, 2012 from <http://ministers.deewr.gov.au/gillard/post-budget-speech-investing-education-and-innovation-create-jobs-future>
- Gillard, J. (2009). *Address To Business Observers – ALP National Conference – Friday 31 July 2009 Speech*. Retrieved 23 01 2012 from <http://ministers.deewr.gov.au/gillard/address-business-observers-alp-national-conference>
- Gillard, J. (2009). *Transcript – First social inclusion ministers meeting – Adelaide – Friday 18 September 2009 Transcript*. Retrieved January 23, 2012 from <http://ministers.deewr.gov.au/gillard/transcript-first-social-inclusion-ministers-meeting-adelaide>
- Gillard, J. (2010). *Speech at the Melbourne Convention and Exhibition Centre for Social Inclusion – Thursday 28 January 2010*. Retrieved January 23, 2012 from <http://ministers.deewr.gov.au/gillard/speech-melbourne-convention-and-exhibition-centre-social-inclusion>
- Gillard, J. (2010). *Address to Skills Australia – Friday 5 March 2010 Speech*. Retrieved January 23, 2012 from <http://ministers.deewr.gov.au/gillard/address-skills-australia>

Media Releases:

Gillard, J. (2008). *Social inclusion through education and employment – Tuesday 13 May 2008 Media*

*Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/social-inclusion-through-education-and-employment>

Gillard, J. (2008). *Closing the Gap between Indigenous and Non-Indigenous Australians – Tuesday 13 May*

*2008 Media Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/closing-gap-between-indigenous-and-non-indigenous-australians>

Gillard, J. (2008). *Australian Social Inclusion Board – Wednesday 21 May 2008 Media Release*. Retrieved

January 24, 2011 from <http://ministers.deewr.gov.au/gillard/australian-social-inclusion-board>

Gillard, J. (2008). *Students with a disability to benefit from Digital Education Revolution – Thursday 18*

*September 2008 Media Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/students-disability-benefit-digital-education-revolution>

Gillard, J. (2008). *Building an Australian Social Inclusion Agenda – Monday 13 October 2008 Media*

*Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/building-australian-social-inclusion-agenda>

Gillard, J. (2008). *Government welcomes 'How Young People Are Faring' Report – Wednesday 15 October*

*2008 Media Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/government-welcomes-how-young-people-are-faring-report>

Gillard, J. (2009). *Positive Progress in Closing the Gap Welcomed – Tuesday 17 March 2009 Media Release*.

Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/positive-progress-closing-gap-welcomed>

Gillard, J. (2009). *Survey confirms education can overcome disadvantage – Tuesday 5 May 2009 Media*

*Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/survey-confirms-education-can-overcome-disadvantage>

- Gillard, J. (2009). *More places for vulnerable job seekers – Friday 8 May 2009 Media Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/more-places-vulnerable-job-seekers>
- Gillard, J. (2009). *BUDGET 2009-10: Reaching out to help more students from disadvantaged backgrounds into higher education – Tuesday 12 May 2009 Media Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/budget-2009-10-reaching-out-help-more-students-disadvantaged-backgrounds-higher-education>
- Gillard, J. (2009). *BUDGET 2009-10: \$1 billion to address Indigenous disadvantage – Tuesday 12 May 2009 Media Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/budget-2009-10-1-billion-address-indigenous-disadvantage>
- Gillard, J. (2009). *Changes to Ministry – Saturday 6 June 2009 Media Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/changes-ministry>
- Gillard, J. & Macklin, J. (2009). *Australian Government to develop national statement on Social Inclusion – Wednesday 8 July 2009 Joint Media Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/australian-government-develop-national-statement-social-inclusion>
- Gillard, J. (2009). *Communique – Social Inclusion Ministers Meeting – Adelaide – Friday 18 September 2009 Media Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/communique-social-inclusion-ministers-meeting-adelaide>
- Gillard, J. (2010). *A stronger, fairer Australia – statement on social inclusion – Thursday 28 January 2010 Media Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/stronger-fairer-australia-%E2%80%93-statement-social-inclusion>

Gillard, J. & Arbib, M. (2010). *Assisting job seekers and people with disability return to work – Thursday 11 May 2010 Joint Media Release*. Retrieved January 24, 2011 from <http://ministers.deewr.gov.au/gillard/assisting-jobseekers-and-people-disability-return-work>



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## **Living with Chronic Illness**

### **Information for Participants**

Greetings

- 
- **Are you aged between 18 and 64?**
  - **Do you experience chronic illness?**
  - **Do you live in the Blacktown or Parramatta City Council Catchment Area?**
  - **Are you homeless or do you live in public housing or rent privately?**
  - **Would you like to have your say, share your story and have the opportunity to feed back to the Government?**
- 

My name is Robert Pereira and I am from Macquarie University's Centre for Research on Social Inclusion. I am currently studying a Doctor of Philosophy (PhD) looking into the experiences of what it is like to live with a chronic illness.

The aim is to explore how living with chronic illness impacts on your participation and inclusion in society over your life course. This research will also aim to inform government policy on social inclusion. So this is a chance for your voice to be heard at a national policy level.

This study is being conducted under the supervision of Professor Gail Whiteford, Pro-Vice Chancellor (Social Inclusion) at Macquarie University (Phone Number).

If you decide to participate, you will be asked to participate in 1 to 3 interviews which will be audio-recorded for information gathering purposes. For your time, a \$50 shopping voucher will be given to you as a thank you.

Thank you very much for your time and I look forward to hearing from you if you are interested to participate.

Yours sincerely,

Robert Pereira



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Appendix E: Participant information form and consent form.

**Research Project: Social Inclusion Policy, Participation and the Perspectives of Citizens living with Socioeconomic Disadvantage and Chronic Illness**

**Information for Participants**

Greetings

You are invited to participate in a study which aims to explore the experience of what it is like to live with socioeconomic disadvantage and chronic illness. The purpose of the study is to explore national social inclusion policy and how it relates to people who the policy is meant to assist. The study aims to discover peoples' lived realities of participating in society across one's life course, including what promotes participation in day-to-day life (from getting up in the morning, going to the shopping centre, enjoying one's preferred leisure activity and so on) and what impacts or has impacted on such participation and inclusion in society. It is very important that policy is focused on assisting the real needs of people who experience various types of disadvantages. This study will give the opportunity to share your story.

The study is being conducted by Robert Pereira from Macquarie University's Centre for Research on Social Inclusion, Phone Number, Email Address. This study is being conducted to meet the requirements of a Doctor of Philosophy (PhD) under the supervision of Professor Gail Whiteford, Phone Number, Email Address, Pro-Vice Chancellor (Social Inclusion) for Macquarie University and affiliated with the Centre for Research on Social Inclusion, Macquarie University, and Associate Professor Ellie Vasta, Phone Number, Email Address, Researcher, Centre for Research on Social Inclusion, Macquarie University.

If you decide to participate, you will be asked to participate in 3 interviews of approximately 1-hour duration each which will be audio-recorded for information gathering purposes. Your involvement in this study and the audio-recordings will be kept confidential and you will not be able to be identified. There are no identified risks or discomforts foreseen to occur during the interviews. If at any point you feel at risk, uncomfortable or experience any emotional impacts, please let Robert Pereira know. For your comfort, Robert Pereira is a qualified occupational therapist, therefore he is capable of assisting you immediately if such experiences occur. The interviews would be immediately put on hold until the potential experience had passed. This is your opportunity to share your story and have your say about your experiences of participation and social inclusion to inform government through the outcome of the PhD thesis.

Any information or personal details gathered in the course of the study are confidential (except as required by law i.e. mandatory reporting of any unlawful activities, past or present). No individual will be identified in any publication of the results. The people who will have access to the data will be Robert Pereira and Professor Gail Whiteford only. A summary of the results of the data can be made available to you on request. This can be done by contacting Robert Pereira via Phone or Email at the end of June 2012 (projected study completion date).

Participation in this study is entirely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. If you are interested in participating please contact Robert Pereira (see below). You will be asked to sign a consent form and given time to consider your decision before proceeding.

Thank you very much for your time and I look forward to hearing from you if you are interested to participate.

Yours sincerely,

Robert Pereira

## Research Project

**Social Inclusion Policy, Participation and the Perspectives of Citizens  
living with Socioeconomic Disadvantage and Chronic Illness**

### Participation Consent Form



I, \_\_\_\_\_ (Block Letters) have read (or, where appropriate, have had read to me) and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw from further participation in the research at any time without consequence. I have been given a copy of this form to keep.

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

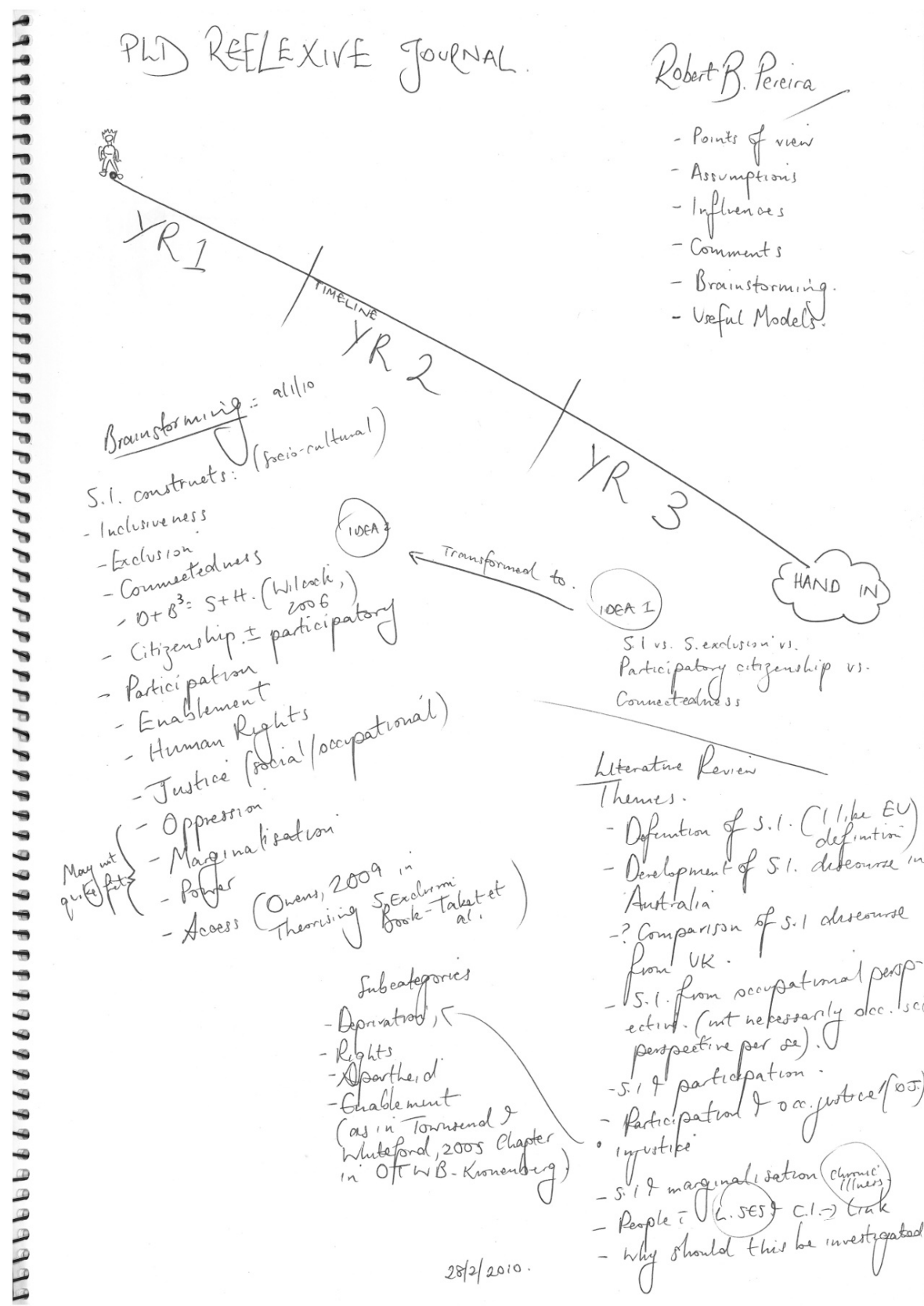
Investigator's Name: **ROBERT PEREIRA**

Investigator's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone (02) 9850 7854; email [ethics@mq.edu.au](mailto:ethics@mq.edu.au)). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome. *This research does not seek information about any unlawful activities, past or present. While we will take every measure possible to protect your identity, you should be aware that if you choose to disclose information about any illegal acts, involving yourself or others as victims, perpetrators and/or witnesses, that information may be subject to subpoena as required by law. Although this is extremely unlikely, it is important that you understand that it is a possibility.*

**PARTICIPANT      OR      INVESTIGATOR      COPY [Circle Appropriate]**





# Discourse Analysis

25/12/2010.  
11:30am

Q1.

How is social inclusion problematised?  
citizens living  
S.E.D + DISAB or CH.

What's 'social inclusion' represented to be?

- Impact of citizens experiencing multiple disadvantage on the Welfare State.
- expensive/burdensome for govt./on govt. spending
- economic solution (like any good.
- "developed" country; to get people to work)

What about an occupational perspective of social inclusion?

POJF 2010

Impact on this on occupational justice?  
What about importance of everyday occupation & wellbeing perspective on participation?

NB:

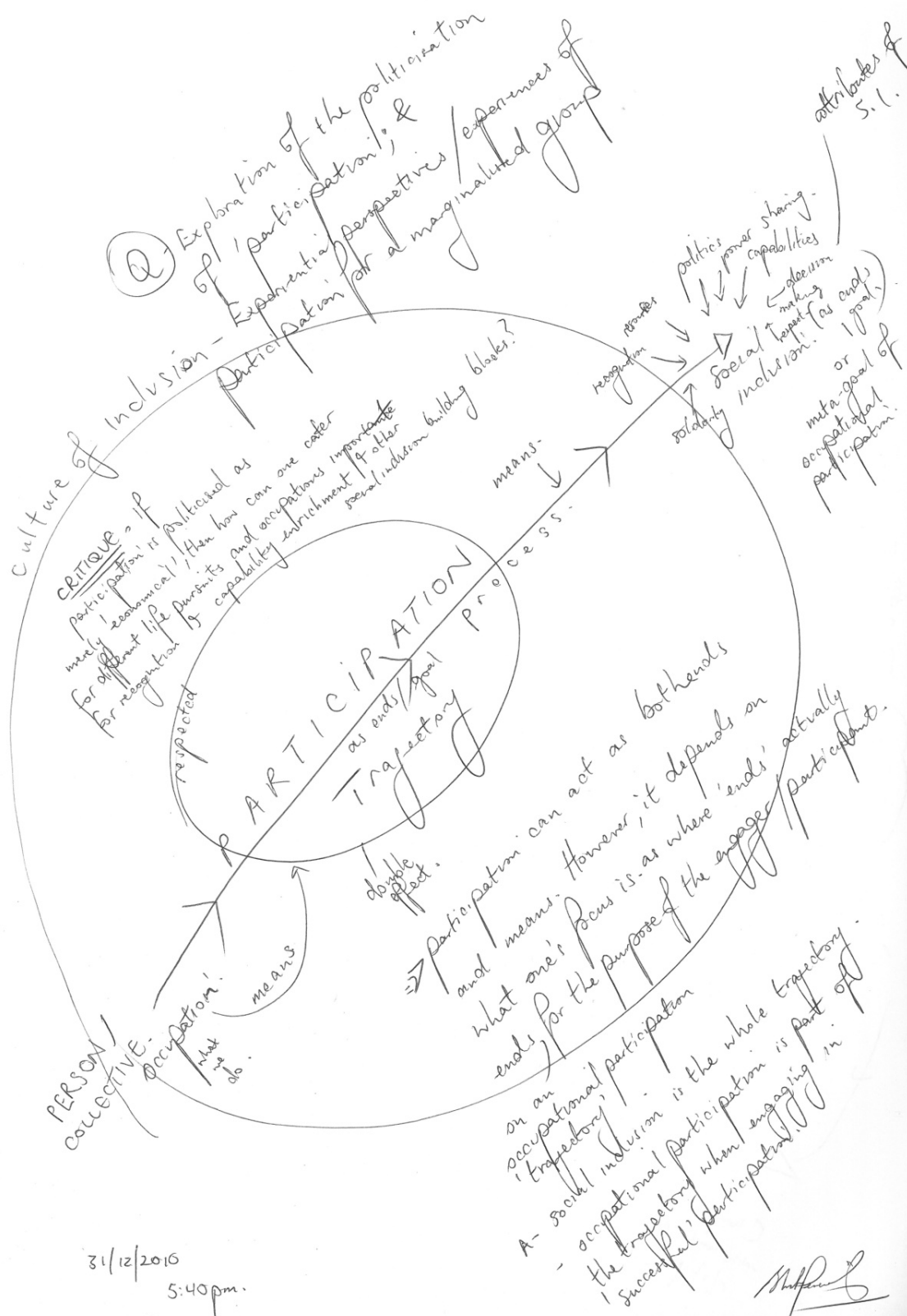
- Not only is this option naive of the broader issues, it is not new & existing policy // just the same tag only dressed differently

The Politics of participation: Social inclusion policy & its (un)effects on citizens living with multiple disadvantage.

How participation has been politicised & hence conceptualised in policy for particular effects or subjectifications. - What are the key drivers of this? Why? Economic vs. social vs systemic influences.

POUCH - AS-DISCOURSE  
(how language works with underlying power / ships & assumptions)

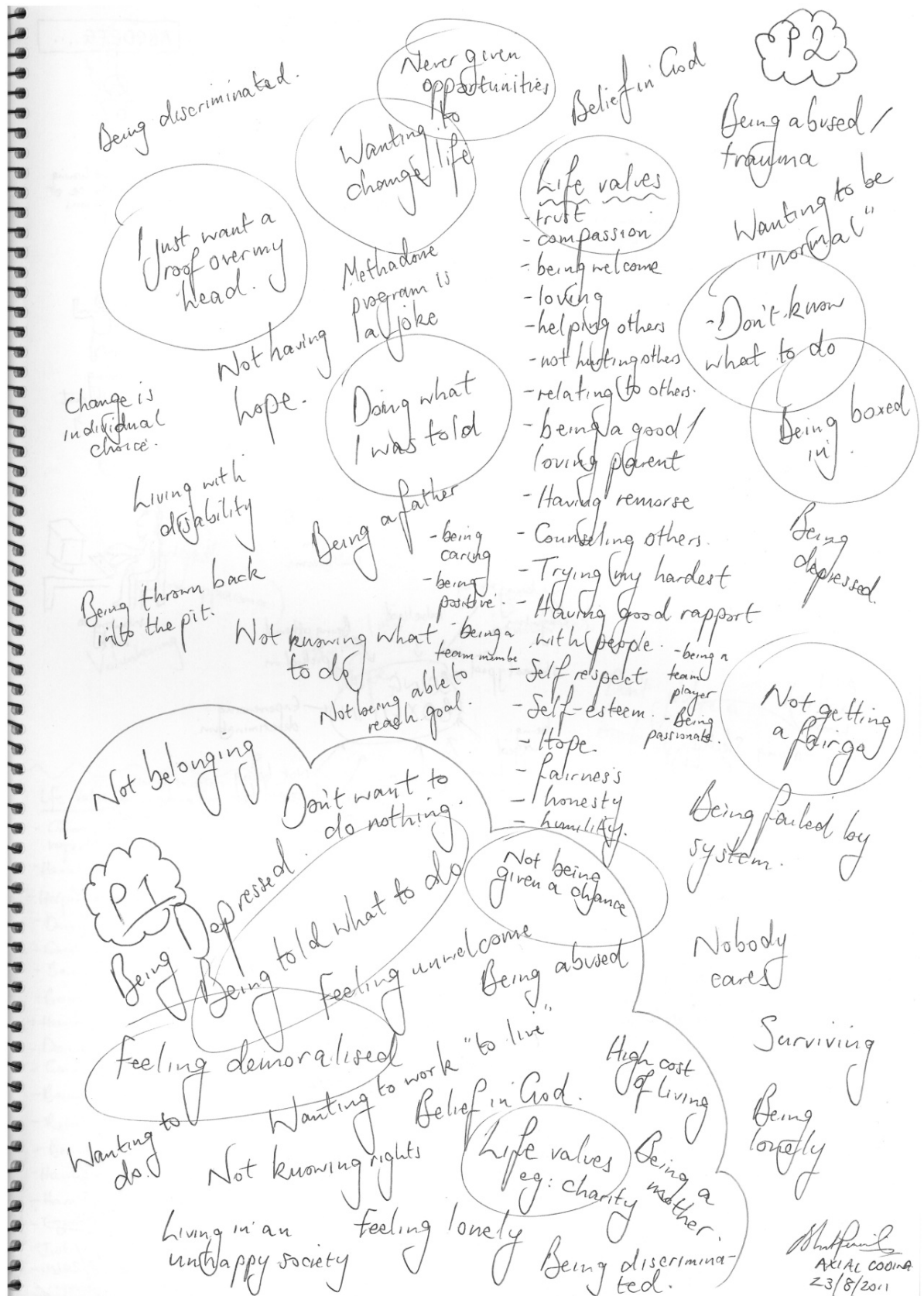
HOW DOES THIS FEED INTO SOCIAL INCLUSION POLICY?  
ACTION VS. RHETORIC.  
actual information just 'talk' for 'talk' sake.



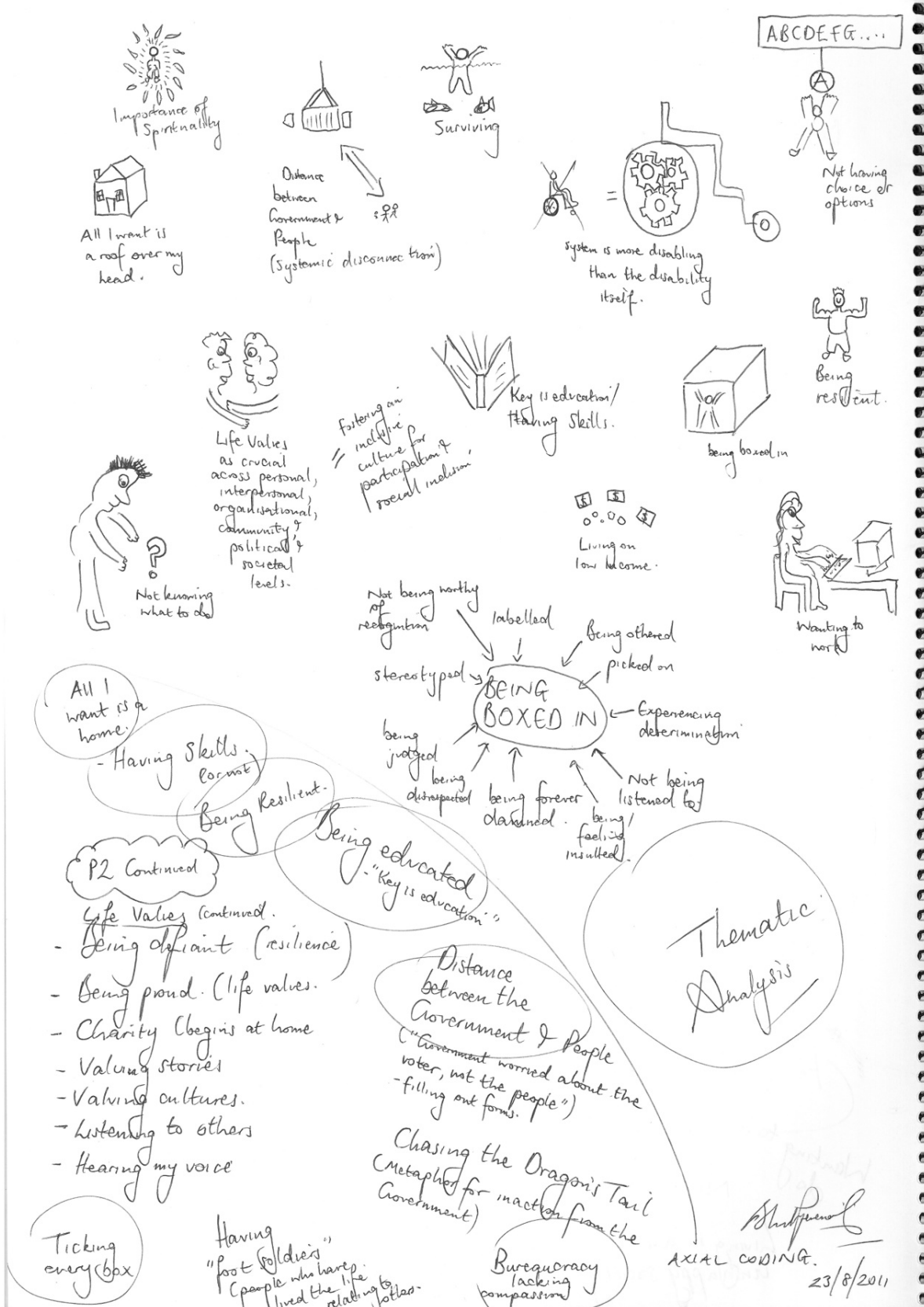
21/4/2010

### Social Position:

- Middle class, Australian-born to Chilean parents.  
- Grew up first 13 years in Corio, one of the most disadvantaged suburbs in Geelong & in Victoria - 3214 postcode. I consider myself a son, brother, brother-in-law & occupational scientist & occupational therapist. My past 4.5 years of working as an OT have opened my eyes to real need, disadvantage & need for advocacy. I consider myself a people-person & want to do good for & with my community. I highly value & regard my cultural heritage & know what it is like to live within a minority group inside a broader community. My volunteer work in southern rural Chile also has influenced me by seeing the faces of people living in poverty. Politically, I am a labour voter but consider myself a "centrist" which means doing things for the greater good of the community but also valuing hard work where people deserve to reap their hard-fought benefits. My research interests include people living with chronic illness, health promotion, policy analysis, meaningful engagement & justice & cultural relativism.



## Appendix F continued.





final theme:

BEING IN THE WORLD:

EXISTENTIAL REALITIES

LIVING WITH DISABILITY IS ONE OF THE HARDEST THINGS.  
① P1, P2, P5.

I CAN'T AFFORD TO LIVE!  
② P1, P2, P3, P5, P6.  
P3, Int 1 p. 35 - I don't accept charity.  
" p. 41 - Re: Housing - "How many fucking knockbatteries do you think a bloke can take before he's had enough?"  
P. 46. I've gone from getting \$800 a week to \$260 a fortnight. I've gone from getting a fortnight's pay to getting a fortnight's pay back.

LIVING IN A COMMUNITY THAT LACKS COMPASSION  
③

FEELING EXCLUDED AND HAVING LITTLE HOPE.  
④ P1, P5.  
Can't do things. Family doctor is expensive. Can't get away.

FEELING LONELY AND ISOLATED  
⑤ P1, P5, P6, P7.  
I never had any support for 25 years.  
having little friends.  
Friends left me. How taken to social media.

Plan.  
1. Go over Cluster Coding.  
2. Review transcripts for quotes which best exemplify meta-themes.

① - P1 - Impact of Depression on life in Australia.  
- Suicidal Ideation

P2 - Depression (Int 2, p. 16) "But this is me. Take it or leave it."

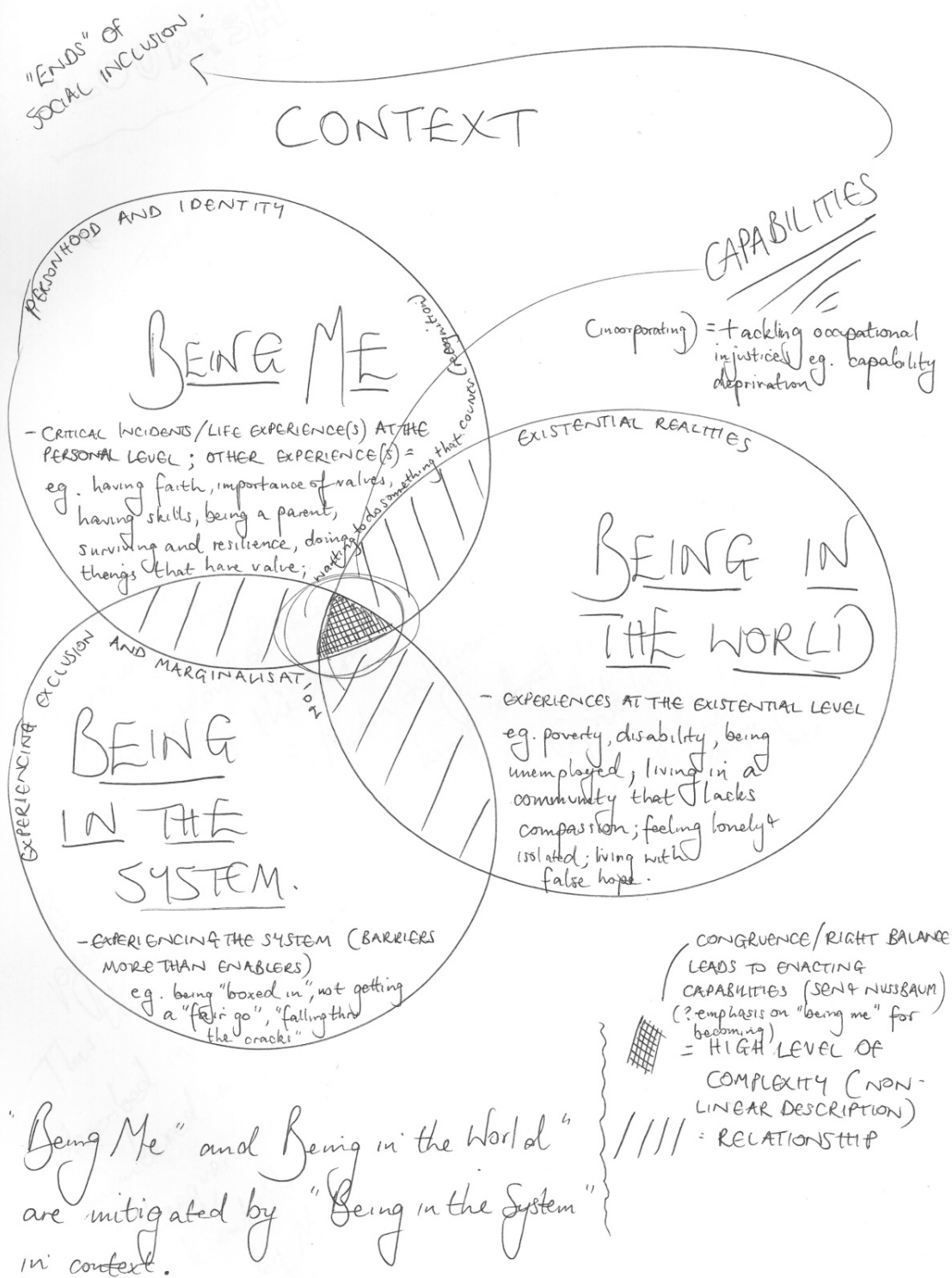
P2 (P2, Int 2 p. 42) - energy levels.

(P2, Int 2, p. 1) - Adjusting to life - nervousness, complex med & stx.

P3 - Int 1 - emphysema; bad back; pain & pain mgt (through drugs).  
Int 1, p. 314 - poor health mgt.

24/5/12

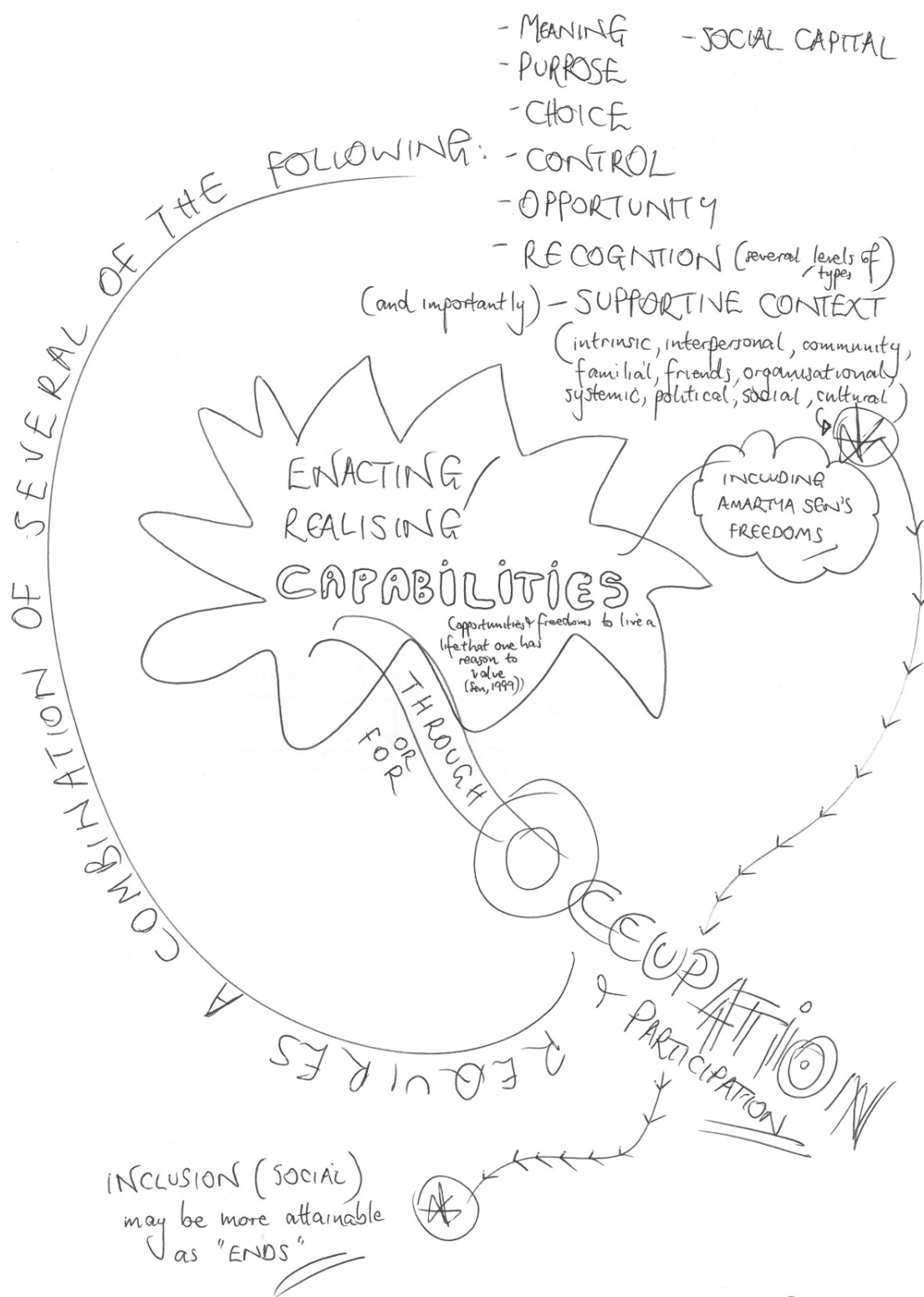
Phil Paul



ROBERT PEREIRA  
29/9/2011 *Shuffernall*







# REFLECTIONS FROM READING:

IKÄHEIMO, H. & LATINEN, A. (2007).  
DIMENSIONS OF PERSONHOOD: EDITORS' INTRODUCTION.  
JOURNAL OF CONSCIOUSNESS STUDIES, 14 (5-6), 6-16.

Self-respect  
is essential to  
personhood.

Lack of Interpersonal Recognition Respect:  
A person (or group) does not appreciate one  
as having dignity and moral status

A RIGHT TO COMMUNITY;  
RIGHT TO CAPABILITIES  
BEYOND OCCUPATION.  
This does not negate the transformative  
potential of occupation. Capabilities en-  
hance personhood, identity and being re-  
cognised as a person who is able to  
participate in the life of that they wish to  
choose! It is a moral imperative to enact  
one's others' capabilities from a 'mutual  
recognition' perspective. To enact one's  
capabilities is to be a complete person,  
capturing what participation in life &  
ultimately social inclusion (through  
social & political recognition) should  
be about as meaningful ends.  
Occupational and other forms  
of justice can be realized through  
providing opportunities  
for occupational flourishing  
and overall flourishing!

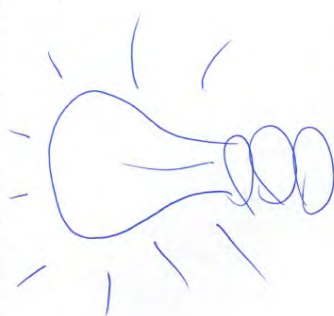
= Similar properties  
to some extent  
to personhood  
= overall flourishing  
and overall flourishing!

=> conclusion from  
my PhD study

Having a duty  
towards others  
as well as towards persons!  
= MORAL RELATIONSHIPS.

"Having some basic moral status...  
is certainly one possible way of  
defining what being a person is:  
having a moral status such as  
a right to life... it is more or less  
unanimously accepted by philosophers,  
and supported by common sense, that  
our being rational creatures gives us,  
or makes us deserving of, a special  
moral status or statuses with regard to  
each other" (p. 10).

I Agree! This was  
But Reject definitely  
not the  
that being  
deserving of  
a special  
moral  
status is  
'common  
sense'.  
moral grounds  
by 'mainstream'  
society.



while travelling  
to uni on the  
518 bus.  
from Drummoyne  
-> Macquarie  
University,  
NSW

17/1/2012



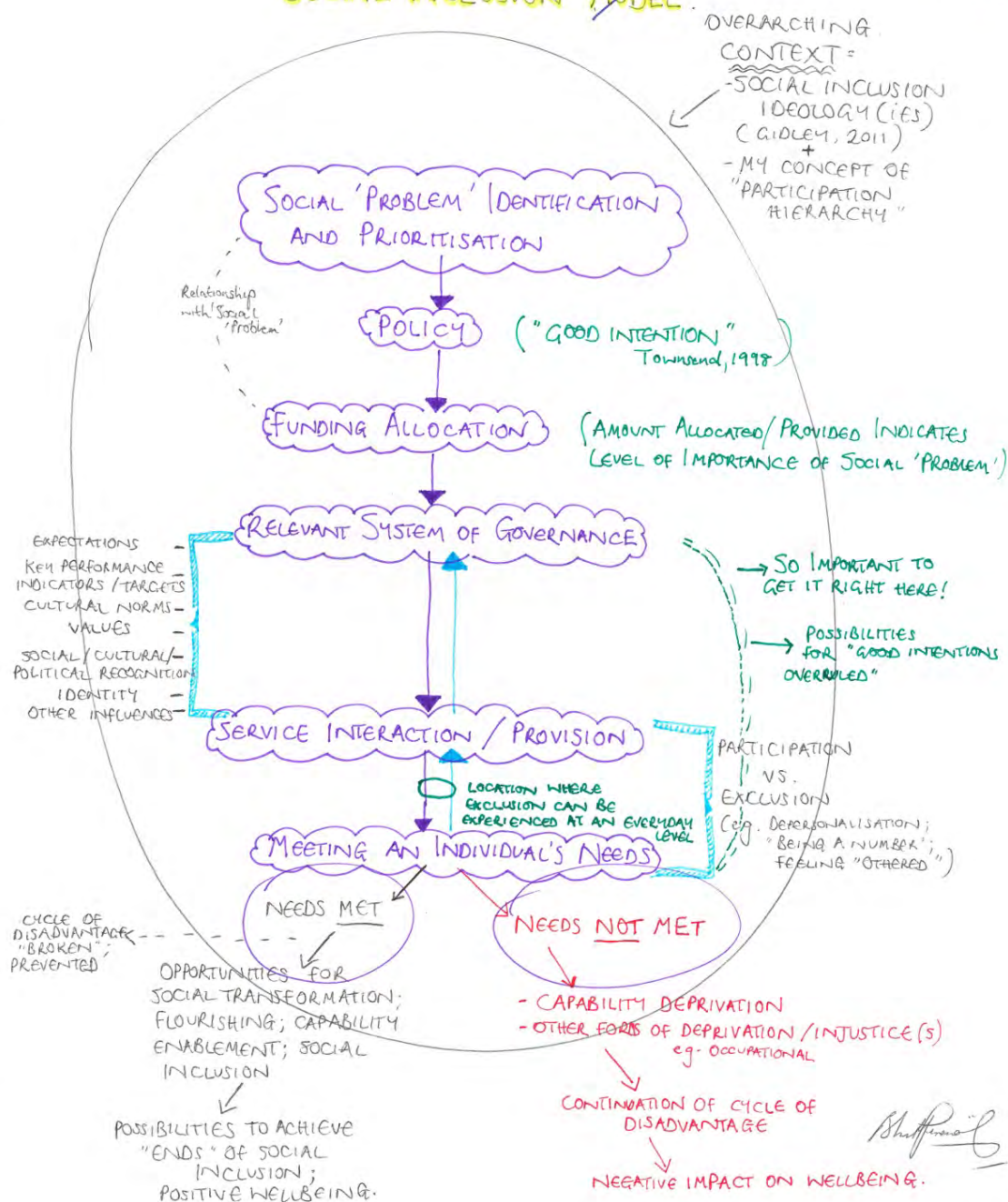
# BRAINSTORMING FOR DISCUSSION CHAPTER.

27/8/2012

ROBERT B. PEREIRA.

## SOCIAL INCLUSION MODEL

FRAMEWORK - Nov. 2012. RP



**Robert Pereira**  
**Research Project**

**Social Inclusion Policy, Participation and the Perspectives of Citizens  
living with Socioeconomic Disadvantage and Disability or Chronic Illness**

**Robert Pereira, PhD Candidate**



**MACQUARIE  
UNIVERSITY**

Applying life history methodology, interview questions will have a micro-meso-macro format beginning with a focus on individual issues pertaining to how the multiple disadvantage of socioeconomic disadvantage and disability or chronic illness has impacted upon the participant's occupational participation and social inclusion over their life course (micro), to one's involvement in the community (meso), and finally ending with questions surrounding general participation and social inclusion in society from a political context perspective (macro). There will be up to 3 interviews with each participant to obtain rich narratives through this interview guiding format.

**Guiding questions concerning the individual (micro):**

1. What disability or chronic illness do you experience? Tell me what it was like when you discovered that you had a chronic illness?
2. What impact did this immediately have on your life?
3. How has living with socioeconomic disadvantage and chronic illness impacted on your quality of life?
4. On the lead up to your diagnosis of your disability or chronic illness, what difficulties did you experience with your day-to-day activities? How did this affect your participation within the community?
5. On days where you have exacerbations or flare ups of your disability or chronic illness, how does it impact on your day-to-day activities?
6. What do you like to do? What would you like to do in the future?
7. [If the participant has a family] How has living with socioeconomic disadvantage and disability chronic illness impacted on your family life and life roles, such as being a father, brother, mother etc?
8. What do you need to participate more effectively? How can the government help you with this?
9. Do you get enough assistance from the government financially to meet your participation needs, such as accessing services in the community, or to go shopping, or to use transport to get to places? How does it meet your needs? If no, how does it affect your participation in day-to-day life?

**Guiding questions concerning community participation (meso):**

1. What enables you to participate in your community?
2. Tell me about any time that you have experienced barriers to participating in a community or social event or even during an activity at home.
3. What types of places or services do you find difficult to access in the community? Why?
4. Do you have a support network such as friends or family that you can call upon if you need any assistance? If yes, how do they support you? If no, are you aware of places, services or organisations that can help you with exploring social networks?

**Guiding questions concerning issues pertaining to policy and government (macro; as explored in the Australian government's 'Shut Out' report:** Australian Government. (2009). Shut out: The experience of people with disabilities and their families in Australia (Online). Retrieved July 31 2010 from [http://www.fahcsia.gov.au/sa/disability/pubs/policy/community\\_consult/Pages/default.aspx](http://www.fahcsia.gov.au/sa/disability/pubs/policy/community_consult/Pages/default.aspx) ):

1. What are the greatest barriers that you face to participating fully within the community?
2. What local action has made a positive difference to your life to promote your participation and inclusion in society?
3. What specific local or national actions could be taken to overcome these barriers?

4. From your own perspective, what do you see as the short falls of the government that has affected your ability to participate and be involved in your community and society in general?
5. If you had a magic wand and could inform government of your needs to participate in your life and in society more effectively, what would you say or do?

## Appendix H: Examples of participants' meaningful occupations

<b>Participant</b>	<b>Meaningful occupations</b>
Rose	Mothers Club (when daughter was younger) Walking the dogs Reading books
Anthony	Breakdancing Skateboarding (by himself and with son) Playing guitar Art Athletics (before cancer diagnosis) Cricket (with son) Football (Rugby; with son) Video games (by himself and with son) Listening to music Being a mentor to others
Leigh	Walking Volunteering at Parramatta Mission and Church
Bruce	Volunteering at Parramatta Mission and Church Art Drawing Playing Guitar Writing poetry Keeping up to date with current affairs; reading newspaper and watching news and documentaries on television Being a mentor to others
James	Basketball Cycling Reading Listening to music Socialising and 'hanging out' with family and friends Being a mentor to young basketball players
Annie	Watching television Reading Using computer and internet Using social networking websites i.e. Facebook and Skype to connect with friends and family online Bird watching (with husband Richard) Going to free courses run by local library (with husband Richard) Volunteering
Richard	Reading, especially about philosophy and spirituality Socialising with friends Bird watching (with wife Annie) Watching television Going to free courses run by local library (with wife Annie) Using the Internet Doing small or odd jobs around the house Volunteering

