

**School of Psychology and Speech Pathology**

**Wanting to be important with someone: Exploring the construction of close  
relationships, sexuality and 'intellectual disability'**

**Emily Louise Castell**

**This thesis is presented for the Degree of**

**Doctor of Philosophy**

**of**

**Curtin University**

**March 2015**

### Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Signature: ..... *ELM* .....

Date: ..... *02/03/15* .....

## Acknowledgments

I would like to thank all of the individuals who took part in this research. Thank you for welcoming me into your lives and communities and for the support you have given this project.

I want to thank my supervisory team; Associate Professor Clare Roberts, Associate Professor Brian Bishop, Dr Peta Dzidic, Associate Professor Lynne Roberts, Professor Errol Cocks, and Dr Gareth Merriman.

Clare, Errol, and Gareth, thank you for your support and guidance, particularly in the formative stages of this project. Our early discussions have directed the scope, shape, and development of the project throughout. Lynne, thank you for your support; your input, guidance and feedback has been invaluable.

Brian and Peta; thank you for your guidance, mentorship and humour; you have gifted me the ability to think, and for that I am forever grateful.

I would also like to acknowledge the staff in the School of Psychology and Speech Pathology at Curtin University for supporting me to engage in my studies.

Thank you to my PhD friends at the Hub; you are all so lovely and generous, and my life is so much lovelier for having you all in it.

Adva, thank you for being such a beautiful friend; when things became tough I often reflected back to our time in undergrad; I imagined you were sitting by my side, as you did then, encouraging me to keep at it.

Kate, I am so lucky to have had you by my side throughout this experience, to have shared many coffees, laughs and tears with you has been a delight. I look forward to sharing many more coffees, laughs and (perhaps fewer) tears with you in the years to come.

Thank you to my bears, Sarah and Karen, and to my “big bro” Matt, for your love, support and humour.

Mum and Dad, you have given me the opportunity and confidence to pursue my passion, and I am so grateful. Mum, thank you for your well-timed hugs, for watching terrible TV with me, and for everything you have done to keep me afloat. Dad, thank you for our “PhD Saturdays” - on some weekends I know that the promise of a pre-PhD coffee with you was the only thing that kept me going.

Simon, thank you for your love, support and unwavering confidence in me - knowing that you believed I could do it meant so much. Thank you for putting up with my ramblings, my rants and for challenging me. Most of all, thank you for making me laugh, and for reminding me that life happens in the moment.

**Dedication**

*For “Matt C.”*

## Abstract

The sentiment *wanting to be important, with someone* captures the centrality of social and intimate relationships to the human experience. The opportunity to engage in intimate and meaningful relationships represents a basic human right. Individuals labelled with intellectual disability appear to exist in complex socio-cultural settings that pose a challenge to this right. Discourses and rhetoric within the research literature and within the community suggest that close relationships and sexuality are fundamentally problematic. The aim of this research was to explore the close relationship experiences of individuals labelled with intellectual disability. Adopting the model of *participant-conceptualiser*, I employed a qualitative research design; embedded in principles of contextualism, inclusive, and participatory research; to explore the lived experiences of individuals labelled with intellectual disability.

I conducted 26 conversational interviews with several community members labelled with intellectual disability to reflect on their close relationship experiences. I analysed the interview transcripts via causal layered analysis, an analytical framework that allows for exploration of complex social-cultural issues at multiple levels of understanding. Findings generated from the analysis suggested that intellectual disability is constructed as an inherent quality of the individual and that so-labelled individuals are assumed to be vulnerable, incompetent and in need of protection. These myths posed challenges to so-labelled individuals engaging in relationships, sexual expression, being married, and having children. Worldviews and discourses reflected these assumptions; for example, individuals labelled with intellectual disability were expected to prove a level of competence prior to attaining independence, and engaging in intimate relationships. These assumptions appear to underpin formal and informal settings that are disability-specific and place limitations on choice, control, and autonomy. Findings suggest that the label 'intellectual disability' compromises opportunities to engage in relationships characterised by independence and choice.

An additional aim of my research was to explore participatory, action-oriented and inclusive research processes. Reflections on my role as a researcher highlight the power afforded to researchers within dominant Western culture. Reflexive processes highlighted how my engagement with the community replicated assumptions of

intellectual disability that emerged from the research findings. A key reflection to emerge from this research is the notion of *getting it right*, and the pressure that we, as researchers, experience to evaluate participatory, inclusive, and action research according to criteria which undermines the value of these approaches.

Key interpretations from this research reflect an integrated interpretation of themes emerging from the analysis and my reflections on engaging inclusive research processes. The enduring nature of logical-positivism and individualism within dominant Western culture is speculated to govern the ways in which sexuality, close relationships, and intellectual disability are understood and challenged. Contemporary discourses of normality, inclusion, participation, and empowerment are paradoxical and appear to undermine, rather than support, the right of all individuals to engage in close relationships. There seems to be a dissonance between what should be *possible* and the *reality* of the lived experiences of individuals labelled with intellectual disability. My findings provide insight into the continued marginalisation of so-labelled individuals within and beyond the context of relationships and sexuality. Future research endeavors should engage a critical stance toward the experiences under exploration, and the processes engaged to explore those experiences. Researchers must be willing to respect *disability as culture* and to re-frame the dominant Western cultural construction of researcher and, more broadly, research. This critical stance is fostered by engaging collectivist and contextualist frameworks to unsettle, challenge, and disrupt dominant cultural understandings that govern the close relationship experiences of individuals labelled with intellectual disability.

## Table of Contents

<b>Declaration</b> .....	i
<b>Acknowledgments</b> .....	ii
<b>Dedication</b> .....	iii
<b>Abstract</b> .....	iv
<b>Table of Contents</b> .....	vi
<b>List of Tables</b> .....	x
<b>List of Figures</b> .....	xi
<b>Chapter one: Introduction</b> .....	1
1.1 A note on context and language .....	6
<b>Chapter two: Ideologies of intellectual disability</b> .....	8
2.1 Paradigm shift and barometers of change.....	8
2.2 The individual model of disability.....	11
2.2.1 Criticisms of the individual model of disability.....	12
2.2.2 Locating intellectual disability within the individual model of disability.....	13
2.3 The social model of disability.....	21
2.3.1 Criticisms of the social model of disability.....	23
2.3.2 Locating intellectual disability within the social model of disability.....	26
2.3.3 Intellectual disability as an administrative construct.....	29
2.3.4 The illusion of the institution.....	29
2.4 An embodied ontology of disability.....	32
2.4.1 Criticisms of an embodied ontology or human variation models of disability. .....	34
2.4.2 Locating intellectual disability within an embodied ontology of disability....	34
2.5 A way forward.....	36
2.6 Critical disability studies.....	38
2.6.1 Political and theoretical allies.....	39
2.7 Governmentality, normalising ideologies and power.....	40
2.8 Conclusion.....	43
<b>Chapter three: Relationships and sexuality: A situated and specific context</b> .....	45
3.1 An historical context.....	45
3.2 Continuing concerns.....	50

3.3	Having a relationship.....	52
3.4	Cultural assumptions, and cultural scripts.....	54
3.5	Understandings of relationships and sexuality.....	55
3.6	Boundaries, power and regulations.....	57
3.7	Policies, guidelines and rushed sex lives.....	62
3.8	Negotiating moral, cultural and legal terrains.....	68
3.9	Close relationships as remarkable.....	72
3.10	Conclusion.....	74
<b>Chapter four: Ontology, Epistemology, Research Aim, Methodology and Methods.....</b>		<b>75</b>
4.1	Epistemological assumptions.....	75
4.1.1	Ways of knowing.....	76
4.1.2	Building a knowledge base: the role of epistemology and ontology.....	77
4.1.3	My epistemological position: A pluralist perspective.....	78
4.2	Considering a research paradigm.....	80
4.2.1	Emerging spaces for the use of “new” research paradigms.....	81
4.2.2	Contextualism and applied research.....	84
4.2.3	Inclusive research.....	85
4.2.4	Inclusive research, applied research, and contextualist principles in practice.....	86
4.2.5	Reconceptualising the researcher-participant relationship.....	88
4.3	Method.....	89
4.3.1	Research design.....	89
4.3.2	The research process.....	90
4.4	Conclusion.....	117
<b>Chapter five: Findings.....</b>		<b>118</b>
5.1	Introduction.....	118
5.2	Vignette: Presenting a complex cultural context.....	118
5.2.1	Rhiannon’s story.....	119
5.3	Thematic map.....	120
5.4	Myth Metaphor Layer.....	125
5.4.1	‘The Intellectual Disability Myth’.....	127
5.4.2	‘The Intellectual Disability Paradox’.....	133
5.4.3	‘The Ingenuine Adult’.....	136
5.4.4	Summary.....	139



5.5	Worldview Discourse Layer.....	140
5.5.1	‘The Disability Discourse’.....	143
5.5.2	‘I don’t really know, you’ll have to ask mum about that’.....	146
5.5.3	The Parent: Heavy burden of high expectation.....	152
5.5.4	Life as stasis: Future is Fantasy.....	157
5.5.5	Summary.....	161
5.6	Social Causal Layer.....	162
5.6.1	‘Just get them into groups’.....	165
5.6.2	As a carer.....	174
5.6.3	Summary.....	177
5.7	Litany Layer.....	178
5.7.1	‘To be important, with someone’.....	180
5.7.2	‘I can go out with whoever I want!’.....	183
5.7.3	Summary.....	187
5.8	Vignette: Reconstructing the issue.....	187
5.8.1	My daughter, Rhiannon.....	188
5.9	Conclusion.....	190
	<b>Chapter six: Inviting feedback from the community.....</b>	<b>193</b>
6.1	Introduction.....	193
6.2	Feedback from the community obtained via seminars, workshops, and conferences .....	193
6.3	Findings from the community obtained via circulation of key findings to key stakeholders.....	197
6.4	Integrating feedback from community with findings from interviews with participants.....	198
6.5	Conclusion.....	200
	<b>Chapter seven: Reflections on process.....</b>	<b>202</b>
7.1	Introduction.....	202
7.2	Intellectual surprises.....	202
7.3	Reflexivity.....	203
7.4	Intellectual surprise #1: Enculturation.....	204
7.5	Intellectual surprise #2: Ethics-in-practice.....	210
7.5.1	Ethically important moments.....	212
7.6	Intellectual surprise #3: Ideals versus reality.....	217

7.6.1	The participatory ideal.....	217
7.6.2	The action ideal.....	222
7.7	A key intellectual surprise: Getting it ‘right’.....	228
7.8	Conclusion.....	230
<b>Chapter eight: Discussion.....</b>		<b>232</b>
8.1	Introduction.....	232
8.2	Reconstructing the issues.....	232
8.2.1	Reflecting on the research findings.....	233
8.2.2	Identifying key dynamics, discourses, and processes.....	235
8.3	Lived realities versus myths.....	237
8.4	The enduring nature of logical-positivism: Following the party-line.....	240
8.5	Contesting the myth of intellectual disability.....	241
8.6	The Intellectual Disability Paradox.....	245
8.6.1	The pursuit of a normal life.....	246
8.6.2	Solving the problem of intellectual disability: Alternative settings.....	249
8.6.3	Paradoxes of empowerment, normality, and participation.....	252
8.7	Negotiating close relationships and sexuality within a complex socio-cultural context.....	254
8.7.1	Disability as culture.....	257
8.8	The current state of affairs: Possibilities versus realities.....	258
8.9	Parameters of the research inquiry.....	261
8.10	Implications and opportunities for further exploration.....	263
8.11	Conclusion.....	269
<b>References.....</b>		<b>271</b>
<b>Appendix A.....</b>		<b>289</b>
<b>Appendix B.....</b>		<b>290</b>
<b>Appendix C.....</b>		<b>302</b>

## List of Tables

<i>Table 1.</i> Common Principles of Applied Research.....	84
<i>Table 2.</i> Principles of Inclusive Research.....	85
<i>Table 3.</i> Gender, relationship status, and living arrangements of participants' labelled with intellectual disability.....	97
<i>Table 4.</i> Summary of Seminars, Workshops, and Conferences attended.....	108
<i>Table 5.</i> Summary of Themes Generated from Causal Layered Analysis.....	122

## List of Figures

<i>Figure 1.</i> Visual representation of research process.....	92
<i>Figure 2.</i> Thematic map of findings generated from causal layered analysis.....	121
<i>Figure 3.</i> Thematic map of findings with emphasis on Myth Metaphor layer of causal layered analysis.....	126
<i>Figure 4.</i> Thematic map of findings with emphasis on Worldview Discourse layer of causal layered analysis.....	142
<i>Figure 5.</i> Thematic map of findings with emphasis on Social Causal layer of causal layered analysis.....	164
<i>Figure 6.</i> Thematic map of findings with emphasis on Litany layer of causal layered analysis .....	179

## Chapter one: Introduction

*What it really all adds up to is love - not love as it is described with such facility in popular magazines, but the kind of love that is affection and respect, order, encouragement, and support.*

(Robert F. Kennedy, as cited by Edward 'Teddy' Kennedy, 1968, June 8)

I listened to these words, spoken aloud at the commencement of a seminar about "Disability and Sexuality". I found the quote moving and poignant for the topic about which we were collectively attempting to make sense. I was sitting, alongside fellow facilitators, facing a room full of parents, teachers and their students, sons and daughters. Having spoken these words, the man left the room, and the seminar commenced. The morning session was promoted to parents of individuals labelled with intellectual disability and was followed by an afternoon session, exclusively for individuals labelled with intellectual disability. Throughout the morning, we discussed various topics - what "sexuality" means, what is good about relationships, what is not so good about relationships, and some of the myths or assumptions of intellectual disability, which may affect opportunities to engage in relationships. I heard parents share their concerns for their son's and daughter's safety, parents' requests for advice on how to promote social engagement and for information on how to assist their son or daughter to form a close relationship. Some parents explained that their sons and daughters were single, were looking for partners, or that they were in a relationship and were looking to take the "next step" and engage in sexual activity.

During the morning tea break, parents shared their experiences, asked for advice, and expressed a collective desire for more sessions, information, and advice. I sat and listened, engaged where I felt I could, and attempted to make sense of the complexities and tensions unfolding around me. I was acutely aware of a few things. I could not help but reflect the strangeness of this situation. It is not often that parents attend workshops promoted to assist their sons and daughters with relationships and sexuality. It is simply not the "done thing" within dominant, Western, individualistic culture. I was also acutely aware that, aside from the opening address, we had not yet heard the voices of the sons and daughters; so far, the conversation had been *about*, and not *with*, the individuals for whom there was concern. Sitting, reflecting on what

I had heard in the morning sessions, and waiting for the afternoon session to begin, my attention was drawn to a young man who seemed to literally burst into the room. He walked quickly past parents gathered in discussion and strode directly up to the main facilitator, who was in conversation with a parent. The young man abruptly interrupted to ask the facilitator:

*How do I get a girlfriend?*

In that moment, everything suddenly snapped into consciousness. It might be an abstract way for me to describe the unfolding situation, but I had an acute sense that everything just “faded away”. Everything we had discussed – the misgivings, concerns and complexities – just faded away. In that moment, the young man captured what it was all about, why we had all gathered. His desire for a girlfriend could not be described as unreasonable or lofty. He expressed an aspiration to attain a human connection, to experience what was described in the opening address that morning as “love”.

The afternoon session proceeded, parents left the room, and their sons and daughters entered. A theme of the day was distinction between parents, and their adult children; there was a division, and each party was defined by this familial role or relationship. The structure of the workshop was embedded in an acknowledgement that adult sons and daughters should be afforded privacy and confidentiality to discuss their concerns about sexuality and disability. Some sons and daughters were noticeably absent. Several parents later reflected that they wished they had brought their son or daughter along; however, had not done so as they were unsure whether the workshop would have been appropriate. In the afternoon session the adult sons and daughters reflected on the difficulties of negotiating relationships, the nuances of meeting people, asking someone on a date and when to hold hands. One of the key messages conveyed to these young adults was, in order to get a girlfriend, boyfriend, or partner, you have to have friends. This session was full of practical exercises – we practiced initiating conversation, asking questions, and discussed when it might be appropriate to ask someone out on a date. At the conclusion of the session, the young adults were asked if they had any final questions. The same man as in the morning session put his hand up, and again asked:

*How do I get a girlfriend?*

Reflecting on the seminar, I tried to understand whether or not there was a sense of accomplishment, of having achieved something that day. I didn't have the sense that it was "not for nothing", but I was reminded of the real, enduring, and searing sense of unfairness that seems to emerge from discussions on relationships and sexuality in the context of intellectual disability. My sense is that there is a feeling of "reaching for something more" that often accompanies these kinds of events, gatherings and conversations. There is a sense that the primary requirements of accommodation, employment and sustenance have been achieved, and that to have a relationship, and to express one's sexuality, would constitute a bonus.

I share this experience, and my reflection on it, as I feel that it is a good place to start to consolidate and capture the findings, and processes of this project. This story is perhaps symbolic of the dynamic which can be seen to replicate across temporal and historical context with regard to sexuality and disability. My reflection on the workshop that I attended is that there was a lot of "noise", but yet the recurring core question ("*how do I get a girlfriend?*") was presented and remained unanswered. My sense is that this dynamic is reflective of historical and contemporary endeavours to explore, understand, and mitigate some of the issues surrounding intellectual disability and sexuality. The research literature in this domain is extensive and yet there is collective acknowledgement of the limitations of conceptualisations of intellectual disability and sexuality. There is a sense that a lot of work has been done and that progress has been made, yet, the question: *How do I get a girlfriend?* remains unanswered. This PhD is presented as a contemporary contribution to progressive discourse on what it means to negotiate relationships and sexuality while living with the label intellectual disability.

There is a challenge inherent to considering issues related to the nature of relationships, sexuality and intimacy in the context of intellectual disability. Developing an awareness of these challenges was a result of a personal, philosophical and reflexive process. In order to provide a rationale for the following introduction and articulation of the "problem" under inquiry, I feel it is important to share my personal attempt to navigate a research inquiry on relationships, sexuality, and intimacy for individuals labelled with intellectual disability. My interest in relationships and sexuality of individuals living with the label intellectual disability was fostered by my relationship with my brother. I was always struck by a strong

sense of inequity, and unfairness, regarding projections of his likelihood to meet a partner, get married, and have children. The assumption that my brother could not expect to engage in these aspects of the human experience because he has an intellectual disability seemed, as an understatement, unfair. To this end, I viewed the opportunity to engage in this PhD research project as a kind of social justice campaign in disguise. I wanted to find out more about these apparent inequities and conceive of ways that individuals living with the label intellectual disability could indeed pursue positive sexual expression and engage in the lightness and darkness of meaningful intimate relationships.

My initial concept for this PhD project was to create a dating agency for individuals living with the label intellectual disability. As I began exploring this idea with my supervisors, I came to the realisation that it was a naïve plan. A dating agency for individuals with intellectual disability presented several concerns, for example, there was an inherent assumption that people with intellectual disability needed something special or different to individuals living without this label in order to engage in a relationship. Perhaps of greater concern was an implication that individuals labelled with intellectual disability should be manipulated into a social setting where they would only have the option of dating other so-labelled individuals. While dating agencies for individuals with disability have been established within the community (e.g., Jones, 2009), the conclusion that a dating agency represented a solution, for me, seemed premature.

This realisation led me to reflect on what might represent an appropriate form of inquiry. My interest in this area is based on the presumption that was a problem that needed fixing. I felt very strongly that people with intellectual disability are marginalised and othered on the basis of the assumption of incompetence, which seemed to legitimise the disqualification of so-labelled individuals from various aspects of the human experience. In other words, the systems and contexts which surround so-labelled individuals, rather than individuals themselves, should form the target for change and transformation. As a result of discussions with supervisors surrounding what the project would look like, and how these issues could be considered, I came to understand that I was naïve for telling people what they needed and making assumptions about the close relationship experiences of individuals labelled with intellectual disability. I came to reflect on my epistemological position



and understood that I was initially subscribing to perhaps a more objectivist and positivist stance. I saw this epistemological approach reflected in the research literature on relationships, sexuality, and disability. Just as my own approach to this research inquiry had been informed by a series of implicit assumptions of intellectual disability, so too was most of the research literature on these intersecting topics.

I decided that an exploratory approach, informed by social constructionism, pragmatism, and the analytical framework of causal layered analysis, was suitable. The research aim became to explore what it is like to pursue close relationships, in the context of living with the label intellectual disability. Further, the specific objectives associated with this research were:

- To explore close relationships as they are experienced by adults labelled with intellectual disability, and;
- To explore inclusive processes in research with individuals labelled with intellectual disability, their relationship partners, friends, family members, support-workers<sup>1</sup>, and others.

These research aims and objectives have set the focus and scope of this research inquiry. I present eight chapters within this thesis. In broad terms, the first three chapters of the thesis provide a context and background to the research inquiry. I outline the aims, objectives, a brief rationale, terminology, and language in this introductory chapter. Following on from this chapter, in chapter two, I consider the concept of intellectual disability, and locate it within various paradigms for understanding disability. In chapter three, I present the domain of relationships and sexuality as a situated and specific context for exploring the construction of intellectual disability. Following on from these introductory chapters, I present the ontology, epistemology, research question, methods, and methodology in chapter four of the thesis. Chapter four provides a context and rationale for the study, my epistemological position as a researcher, and the methodological approach to this inquiry. Findings from the research and feedback processes are presented in chapters

---

<sup>1</sup> The term 'support-worker' or carer is used to refer to an individual whose role it is to provide some level of formal or informal support to another individual. While these terms are often used colloquially interchangeably, there is a definitional distinction between a support-worker and carer. A support-worker is an individual who is employed in their role (e.g., an individual who works for a disability service-provider), whereas a carer is an individual who provides support and care without financial gain (e.g., often a family-member, friend, or other; Spina Bifida Association of WA Inc, 2007).

five and six respectively. My reflections on the research process are presented in chapter seven. Chapter eight, the discussion chapter, represents a critical analysis of the research findings, processes, and extant research literature with regard to the core aims of the research inquiry.

### **1.1 A note on context and language**

It is important to acknowledge that this research inquiry is embedded within a particular cultural context, perhaps best described as a dominant Australian Western cultural context. This cultural context is characterised by the dominant worldviews, assumptions, and understandings which underpin Australian culture. Referring to the dominant cultural context reflects that some views and understandings are championed over others, and that some views and understandings pose a challenge to the dominant culture. Framing the inquiry in terms of a dominant Australian Western cultural context is valuable for setting the parameters and boundaries within which to understand this inquiry, and the findings generated. Throughout the thesis, I will seek to embed and understand the research findings, processes, and interpretations in this dominant Australian Western cultural context.

It is necessary to take a moment to reflect on the use of disability-specific language within this inquiry. Any language which is adopted to describe a group of people as a collective and on the basis of social category runs the risk of undermining the aims of the research inquiry, and may perpetuate the construction of disability as "other" (Opie, 1992). Language is binding, and can forge a reality which undermines the subjectivity of identity, establishing a delineated discourse for individuals who are so-labelled (Corbett, 1994). To use any kind of language which identifies individuals in terms of a social category, undermines the unique individuality of those who are so-labelled (Corbett, 1994).

Using specific terminology, or attempting to define who meets membership for the category with any precision, can only ever be arbitrary (Gallagher, 2002). No attempt has been made within this thesis to define intellectual disability, or disability. While the diversity of experiences related to the label intellectual disability are acknowledged, it is a presumption that the label itself induces characteristic experiences of marginalisation, stigma, and oppression (Fine & Asch, 1988). As such, qualitative differences, and nuances in the label intellectual disability, are not

salient for understanding and exploring intellectual disability from a social constructionist perspective.

Within Australia, the term “intellectual disability” is commonly used to identify individuals who are considered to belong to this social category (Knight, 2013). People-first organisations advocate for the use of person first language; that is, to emphasise the personhood of the individual who is ascribed the label, for example, *individual with an intellectual disability*<sup>2</sup>. While any language or terminology is inevitably inadequate, for practical purposes, it is necessary. I acknowledge that I have necessarily ascribed the label intellectual disability onto the individuals involved in this research and that this label may not capture or bear relevance for their identities. The individuals who took part in this research have not had the opportunity to set their own terms of reference (Corbett, 1994). Further, I understand that use of the reference ‘individuals labelled with intellectual disability’ undermines the multi-faceted, fluid, and sometimes contradictory nature of identity (Appleby, 1994) as this phrasing presents primary or “master” identity as disability. I use quotation marks, much like Jenkins (1998, p.1) to denote the “...*contested and problematic character...*” of the label, however, throughout this work, for ease of reading, I have removed the quotation marks, and simply refer to *individuals labelled with intellectual disability*.

---

<sup>2</sup> It is acknowledged that the language adopted to refer to individuals labelled with intellectual is geographically, locally and culturally determined. For example, the British civil rights movement prefers use of the terminology “Disabled people” to emphasise that the individual is “disabled” by social and cultural settings (Clark & Marsh, 2002). It is understood that terms of reference are informed by ideologies surrounding disability (considered in greater detail in chapter two).

## Chapter two: Ideologies of intellectual disability

Within this chapter, the concept of intellectual disability is considered and located within various paradigms for understanding disability. This exercise provides a context within which to make sense of the complexities surrounding sexuality, relationships, and intellectual disability. The social construction of intellectual disability is preferably considered in terms of historical, cultural, and social contexts spanning from prehistory and biblical constructions (Braddock & Parish, 2001) to more contemporary conceptualisations. Shifting conceptualisations of disability will be broadly understood in context of Kuhn's (2012) theory of paradigm shift, and Sarason's (1996) barometers of change theory. It is important to note that models of disability are often not presented as specific to the construct of intellectual disability; rather, the models reflect understandings of the construct of disability at a broader level. Throughout this chapter, however, deliberate attempts will be made to relate these models to intellectual disability more specifically. It would be antithetical to the contextualist approach which underpins this inquiry to suggest that one model is superior to another; instead, various models of disability are considered (including the individual model of disability, the social model of disability, an embodied ontology of disability, and critical disability studies) and are accompanied by a discussion of inherent criticisms and tensions.

### 2.1 Paradigm shift and barometers of change

The prevailing theme within the disability movement<sup>3</sup>, across various contexts, situational, temporal, and cultural, is the call for action, for further research and the call for paradigm shift. A paradigm may be understood as a framework which captures collective understandings of phenomena in terms social, cultural, historical, and political contexts (Kuhn, 2012). A paradigm may carry particular ontological and epistemological assumptions, which determine the bounds, and nature, of a particular phenomenon (Cocks & Cockram, 1995). Rhetoric within disability research on paradigm shifts refers to a progressive alteration of these ontological and epistemological assumptions which have constructed the meaning of disability. Kuhn (2012) outlines a theory of the development of scientific disciplines, suggesting that the rejection of an old paradigm, for the uptake of a new paradigm, is preceded by a

---

<sup>3</sup> A social movement aiming to promote the rights of individuals labelled with disability.

period of flux, tension, and a reluctance to disown what was previously considered truth. According to Kuhn's theory, a new paradigm is only adopted when the integrity of another is undermined, or collapses, through a process of defining new knowledge regarding a particular phenomenon, which can be collectively understood as a new truth. In this sense, Kuhn's theory highlights the fluidity, and transiency, of scientific knowledge.

An interesting feature of the disability movement is a kind of self-consciousness regarding social change. Perhaps this is evidence of what Sarason (1996, p. 31) referred to as "*...a readiness to depart from the past*" within the disability movement. The notion of paradigm shift, of having had one, or being in one, has formed a central discourse of the movement. The discourse on paradigm shift suggests that this kind of amorphous movement is something that can be enacted, willingly, and with purpose. The deliberate nature of this discourse is interesting, as Day (2007, p. 40) suggests, the notion that "*...if you travel far enough, you will eventually get to where you want to go*" is a Western illusion. He suggests that transformation reflects a continuum, and that, contrary to popular belief "*... success is not always waiting at the end of the line*" (Day, 2007, p. 40). This illusion of transformation is in contest with what is known about social change, and paradigm shift, which is, by nature, very little.

Kuhn's (2012) predictions regarding paradigm shift are played out within the field of disability research, as at various times we, as researchers, have subscribed to an individual or medical model, and more recently a social model, each of which has appealed to particular understandings on the nature of truth, knowledge, and disability. In terms of understandings of disability, paradigm shifts have taken place and will continue to take place. This notion of progression toward a perfect truth of disability is evident in discourses in disability research which suggests a reaching for a new understanding, one that will shed a new light on what it means to live with the label intellectual disability. This perpetual reference to paradigm shift implies an acknowledgement that current understandings are insufficient, but also implies a somewhat positivist or objectivist position, that a truth about disability is out there for discovery.

Seymour Sarason (1996, p. 31) , in his works on barometers of change, suggested that “... *the present is not pregnant with a future, it is pregnant with many futures*”. This sentiment is reflective of his understanding of social change as a transformational, transactional, and largely unpredictable process, wherein the pattern of change, and to an extent, the pre-conditions of change, are often only clear, if at all, in retrospect to these change processes. Sarason (1996, p. 23) refers to understanding social change as equivalent to “...*playing catch-up ball...*” In unpacking his understandings of change events in his lifetime, such as the civil rights movement in America, or the conditions surrounding world war two, Sarason highlights several common discourses associated with social change processes. For example, Sarason identified the “never again” theme, which reflects a vehement desire to move away from the past, to take up new progressive ideologies and positions. Correspondent with this theme is the collective desire to achieve “what we want in life now”, and to frame this pursuit in terms of expectations and rights. As an extension on this discourse, there is a desire to construct a better existence for future generations, to leave future generations with a world which is inherently better than the one previously inhabited.

Sarason (1996) suggests that capacity to devise barometers of change, and to reliably predict change, is limited, and that any attempt to deduce a set of criteria for determining social change would be naïve. He reflects that pervasive social change results from the coalescence of various factors, including historical, social, generational, cultural, economic, and political, and so on. Sarason suggests that a defining feature of social change is that it is the result of a relationship between multiple events, issues or circumstances. A sense that a change is occurring, derives from the ability to acknowledge that events are converging, an intuitive sense that something is happening, but what is happening, is not predictable. Sarason suggests that the sense that change is taking place stems from a recognition that explicit views, arguments, and rhetoric have progressed from those of the past, and are accompanied by changes to implicit values, assumptions, and worldviews. Perhaps these themes are represented in Blatt's (1999, p. 82) reflections on the nature of humanity:

*... as we grope toward an understanding of dehumanization, we may be led to accept the puzzle of humanity. In the process, we may learn that, while living is a paradox, life is a simple and self-revealing truth.*

It is possible to relate Sarason's (1996) understandings of barometers of change to understandings of disability and sexuality, and to the disability movement in a broader sense. A critical analysis of the literature, noting historical, and contemporary discourses, highlights a shift in the explicit ways disability and sexuality are understood. For instance, where in the past there has been a complete neglect of the sexuality of individuals labelled with intellectual disability, now there are efforts to negotiate the complex tensions associated with this label, and what it means for one's sexuality. It is also possible to recognise changes in the modes of service delivery, and service models. In broad strokes, there has been a move away from an institutional model, to a community living model, however, now questions are posed around what it really means to live in a community, and to be a community member. At the risk of oversimplifying what is a very complex and nuanced movement, these are discrete examples of what might be recognised, in retrospect, as an explicit change in rhetoric surrounding the label intellectual disability. Contemporary times seem to reflect another period of flux or tension. It seems as though currently there is another shift taking place, perhaps one that moves toward a more rhetorical or fluid understanding of disability, one that is embedded in a more subjectivist or social constructionist epistemological position. In order to give some context to this new paradigm, it is valuable to deconstruct this tension, and to consider alternative paradigms, models, and paradigm shifts.

## **2.2 The individual model of disability**

Discussions of contemporary models of disability are almost always prefaced with an acknowledgement of the individual model of disability, otherwise known as the medical model of disability. The individual model of disability appears to have derived definition retrospectively, as the individual model is considered the way disability was understood prior to the conceptualisation of the social model of disability (Oliver, 2013; Soder, 2009). Interestingly, at the time that the individual model was preeminent the language, or reflexivity, to recognise this model of understanding did not exist. In this sense, the individual model of disability serves to provide a context for the social model of disability, and vice versa (Oliver, 2013).

The individual model of disability was termed by Mike Oliver (1996b) as the paradigmatic predecessor to the social model. Oliver devised a binary distinction between two models as a way to make sense of the construction of disability in a period where a consolidated framework for understanding was not readily available (Oliver, 2013). More recently, Oliver has acknowledged the rigidity that this binary distinction engenders, and suggests that this conceptualisation of the models is a useful tool for generating critical consideration and conversation about the construction of disability (Oliver, 2013).

The individual model of disability is underpinned by the personal tragedy theory of disability, the notion that disability is caused by some random course of events, resulting in functional limitations and personal tragedy (Oliver, 1996b). There are two key features to the individual model of disability – the first is the notion that disability is an inherent quality of the individual and the second posits that functional limitations and losses are a consequence of impairments arising from disability. These assumptions are seen to be represented in diagnostic criteria employed to categorise who has a disability, and who does not (Chadwick, 1996). Disability according to the individual model is constructed as a problem of the individual, and is considered to be caused by illness, deficit, and disorder. This assumption gives rise to the medicalisation of disability (Brickman et al., 1982; Gallagher, 2002; Oliver, 1996b), the notion that individuals with disability may be treated for their disability through medical and individual intervention. The medicalisation of disability is perhaps grounded in ideologies regarding the scientific method, and enlightenment, during the early modern period through to the eighteenth century. The *age of reason* established the pre-eminence the scientific method, objectivity, and observation as the means for understanding the world. During this period, experience and reason, rather than innate ideas and divine punishment, came to represent the paradigm for understanding truth, science, and fact (Braddock & Parish, 2001).

### **2.2.1 Criticisms of the individual model of disability.**

Oliver (1996a) suggests that normalising ideologies are at the core of this understanding of disability, where there is an assumption that individuals with disability wish to return to some kind of conceptually normal state. In this sense, Oliver (1996b) argues, individuals with disability, and medical professionals alike, have been trapped in a set of social relations, where medical professionals have the



power to enforce intervention on individuals with disability, and individuals with disability are relatively disempowered to resist. According to the individual model of disability, disability is considered a naturally occurring category, and those who fit within it are deemed as inherently different, defect, and in need of intervention to become normal (Gallagher, 2002). The location of the construction of disability, historically, in purely biological terms, promoted researchers to accept disability “...*uncritically as an independent variable*” (Fine & Asch, 1988, p. 8). In these studies, disability was seen to predict social outcomes and dynamics, as opposed to being constructed by socio-cultural contexts. This view of disability produced a research literature which treated so-labelled individuals as objects of research, as opposed to active participants in research. Further, disability was often studied as a means to better understand concepts related to stigma, oppression, and prejudice, and so disability was treated as a metaphor (Fine & Asch, 1988) through which humanity could be better understood. The individual model of disability suggests that the experience of living with the label intellectual disability is based solely on biology, and does not account for the socio-cultural factors which establish the label of disability (Fine & Asch, 1988). The danger inherent to this model is the perpetuation, and legitimation, of stigma toward so-labelled individuals (McDougall, 2006). Gallagher (2002) suggests that few would now admit to subscribing to this model, however he, and others, note that the evidence of this model in practice remains widespread, for example, in the dominant models of congregate, and segregated community care (Priestley, 1999).

### **2.2.2 Locating intellectual disability within the individual model of disability.**

The prevailing means of diagnosing intellectual disability within Australia is perhaps embedded within the individual model of disability. Within Australia, intellectual disability is generally diagnosed on the basis of three criteria – on the basis of a measure of IQ, adaptive functioning, and the presence of cognitive difficulty prior to 18 years of age (Gallagher, 2002). An individual is most commonly diagnosed with intellectual disability following referral, often via one's school teacher, to a clinical psychologist, who performs various assessments and observations of the individual. One such test may be the Wechsler intelligence scale for children – fourth edition (WISC-IV; Weschler, 2003). The WISC-IV is battery of tests designed to measure various cognitive abilities of a child, the results of which

can be scored to produce an IQ score or a measure of intelligence. The Wechsler intelligence scale is an adapted version of Alfred Binet's original measure of intelligence, which was designed with an acknowledgment that intelligence could not be considered a unitary construct, and in fact was applied a means to maintain existing class structures (e.g., racist and eugenicist imperatives; Gallagher, 2002).

The IQ cut-off point for being considered "intellectually disabled" has changed over time (Gallagher, 2002), although, currently, an individual with an IQ below 70 points, or within two standard deviations of this score, is considered to have a mild intellectual disability. These IQ cut-off points are reflected in the diagnostic criteria set out by "The Diagnostic and Statistical Manual of Mental Disorders" (5th ed.; DSM-5; American Psychiatric Association, 2013, p. 33) which describes intellectual disability as "*...a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains.*" With regard to difficulties in adaptive functioning, these difficulties may be identified in numerous domains, including but not limited to; independent living, communication, and social interaction (American Psychiatric Association, 2013). Biklen and Kliever (2006) criticise the diagnostic criteria set-out by the American Psychiatric Association on the basis that these criteria construct intellectual disability as a naturally-occurring category, a set of qualities possessed by the individual. This construction is grounded in an individual model, and is perhaps not consistent with a social constructionist perspective.

Individuals in Australia are most commonly diagnosed in the period of middle childhood (Davies, 1998), and once diagnosed, are eligible to access services funded by the Disability Services Commission, a Department of the Government of Western Australia. In order to access services, and receive funding, an individual must meet the commission's eligibility criteria, including, but not limited to – having a permanent disability, requiring significant and ongoing assistance in tasks of daily functioning. The commission states that a diagnosis of disability is not alone sufficient for eligibility. The individual must also be able to prove that they experience ongoing and significant difficulty with adaptive functioning. Once registered with the Disability Services Commission, an individual and their family are eligible for various services, and funding initiatives, and are likely to be associated with the system throughout the life span of the so-labelled individual.

Gresham (1986) voices widely held concerns, when he suggests that the construct validity, and treatment validity, of intelligence tests are questionable. Gallagher suggests, once a child has met the diagnostic criteria in terms of an IQ score, it is not difficult to find difficulties in adaptive functioning to give further credit to a diagnosis of intellectual disability. Gallagher (2002) notes that the essential issue with the diagnostic criteria is the emphasis on deficits as existing within the individual, as opposed to attributing difficulties to social and cultural contexts. With regard to this criticism, Gallagher (2002, p. 206) poses the question, *“To what extent is your own performance on, say, ironing, running or hang-gliding a reflection of your skill as opposed to your motivation, confidence, anxiety, time, etc.?”*

### **2.2.2.1 Competence.**

In his reflections on the assumption of incompetence which seems to serve as the sub-text for the experiences of individuals labelled with disability, Ford (1966, p. 31) offers the following anecdote:

*‘He’s a cripple, but he’s quite intelligent.’ The speaker was a Metropolitan police officer of the old school who, during his retirement, used to take me for outings in his car. This form of words was his way of introducing me to a friend.*

Competence may be defined as the *“...capacity or potential for adequate functioning-in-context as a socialised human”* (Jenkins, 1998, p. 1). Competence, or a presumed lack of, is perhaps the key qualifying feature of the social construction of disability, and intellectual disability more specifically. The value placed on competence and intelligence has operated to disempower and discredit individuals who are labelled with disability, and are thereby assumed incompetent (Rapley, 2004). Intelligence is often presented as reflecting an objective truth. Rapley, and others who adopt a social constructionism orientation, question the ultimate ontological value of intelligence, and suggest that it is an entirely contextual construct. For example, Rapley suggests that original tests of intelligence were designed to disadvantage individuals within society who were considered of lower class. He suggests that *“... (in)competence is negotiated and constructed locally, and for local purposes, by local means”* (Rapley, 2004, p. 202). Competence is a context-dependent, negotiated, and axiomatic construct for most individuals; however, for

those labelled with intellectual disability, competence is constructed as context-independent (Jenkins, 1998). For example, Fine and Asch (1988) suggest that when an individual with intellectual disability experiences difficulty, the individual's presumed impairment is seen to be the cause. Individuals labelled with intellectual disability must "...strive to be competent- more accurately, to be seen to be competent..." (Jenkins, 1998, p. 2).

Edgerton's (1993) seminal book "The cloak of competence: Stigma in the lives of the mentally retarded", originally published in 1967, offered an early deconstruction of what it means to live with the label intellectual disability, particularly in the era post-deinstitutionalisation (Klotz, 2004). In his analysis, Edgerton suggests that individuals labelled with intellectual disability exist under a *cloak of competence* in the sense that they actively deny their incompetence, and attempt to pass as normal. In other words, Edgerton determined that so-labelled individuals were, in practice, denying their true condition (Wolpert, 1980). Accounts, such as that outlined in Edgerton's (1993) book, position medical and professional conceptualisation, and diagnosis, of intellectual disability as holding ultimate ontological value. Those definitions, and understandings, of intellectual disability subscribed by professionals are viewed as the criteria against which to judge or validate the experiences of individuals who are ascribed the label (W. M. Finlay & Lyons, 2005). Edgerton's works have come under considerable scrutiny, no less from his own subsequent reflections, his analyses were situated in an historical context where intellectual disability was not so commonly understood as a social construction (Gerber, 1990). Conversely, authors such as Bogdan and Taylor (1982), embedded in a social constructionist perspective, have since argued that individuals labelled with intellectual disability are ascribed a *cloak of incompetence*, which is impossible to discard.

#### **2.2.2.2 Risk.**

Mythology that individuals labelled with intellectual disability are dangerous, or vulnerable, engenders a range of social structures and systems to mitigate and manage risk. Some suggest that so-labelled individuals are subjected to perpetual surveillance, and may become smothered, or "overprotected" by those who surround them (Almack, Clegg, & Murphy, 2009; Perske, 1972). These dynamics are fostered

by the assumptions surrounding the competencies of individuals labelled with intellectual disability, and parents are often constructed as accountable for the behaviours, wellbeing, and the lifeworld of their so-labelled son or daughter, well into adulthood (Almack et al., 2009). Perske (1972, p. 24) notes that the concept of mental retardation invokes "...such action words as "protect", "comfort", "keep safe", "take care" and "watch"...", and alludes to the complexities in striking a balance between managing risk, and affording opportunities to engage in the full human experience.

Perske (1972) conducted a critical analysis of the ways in which risk was negotiated, managed, and approached, by individuals labelled with mental retardation in Denmark and Sweden. The author noted that so-labelled individuals were afforded greater opportunity to experience risk in these settings, than were individuals in America. Perske (1972, p. 29) referred to the "...human dignity in risk...", and suggested that "...there can be dehumanising indignity in safety". In outlining his observations, Perske touched on the concept of *dignity of risk*, the notion that all individuals, in order to fully participate in the human experience, must assume a reasonable level of risk in their daily living. Perske advocated that assuming risk, and experiencing adverse consequences, was a process necessary for personal growth and development. Overprotection, lowered expectations, and preclusion from risk-taking behaviour can undermine one's hope, and lead to lowered self-esteem, and self-efficacy (Parsons, 2008; Sanders, 2006). Perhaps, reflecting the internalisation of the qualities and assumptions associated with this stigmatised or spoiled identity (Goffman, 1963).

Perske (1972, p. 25) noted "...the clever ways in which virtually total avoidance of risk has been built into the lives of the mentally retarded by limiting their spheres of behaviour and interactions in the community, jobs, recreation, relationships with the opposite sex, etc." Here, the author is referring to the structural systems which are oriented toward keeping so-labelled individuals safe, from themselves, and perhaps, from the wider community (Wolpert, 1980). Wolpert refers to these structures as the "ghettoization" of individuals with intellectual disability, into protective zones, for the good of the wider community. These myths may form legitimating myths which serve the purpose of *defending the illusion of the institution* (as referred to by Taylor & Bogdan, 1980). Risk is further negotiated and

avoided within formal and informal systemic practices, where often individuals labelled with intellectual disability have limited choice and control over their daily lives, such as, when to go to bed, what to wear, and with whom to spend their time (Parsons, 2008). Parsons suggests that those who surround the so-labelled individual mitigate and avoid risk, out of concern that adverse consequences may reflect poorly on their own professional competencies. Dignity of risk refers to the “double standard” which operates to exclude individuals labelled as incompetent from the human experience, as individuals “... *who are not diagnosed have the ‘right’ to make risky and potentially self-defeating choices without intervention from authorities...*” whereas individuals who are so-labelled do not experience this right (Parsons, 2008, p. 28).

### **2.2.2.3 A rhetorical concept.**

The rhetorical nature of the construct of intellectual disability manifests at various levels, establishing intellectual disability as an irredeemable trait or quality of the individual (Edgerton, 1993). Individuals labelled with intellectual disability are placed in a fairly disempowered position. For example, the processes of IQ testing or of qualitative criteria may be withheld from the individual. This is perhaps the mechanism of the domestic circle, referred to by Goffman (1963), in which individuals who surround the labelled individual operate to protect them from the assumptions and values of the wider community. Research findings suggest that those who surround individuals who are so-labelled may be reluctant to talk about the label with those to whom it is ascribed (Davies, 1998; W. M. Finlay & Lyons, 2005). Often, individuals do not have access to resources which give context to the label and what it means in a qualitative or socio-cultural sense.

Ashby (2010) conducted a research study to explore the middle school experiences of five individuals labelled with intellectual disability. In her observations, Ashby (2010, p. 356) noted that questions directed at teachers from “non-disabled” students regarding the behaviours or aids of individuals labelled with intellectual disability were either ignored, or dismissed (e.g., a teacher may state “*That’s not polite*”). The author suggests that a reluctance to openly discuss diversity and disability illustrates the regulating power of normalcy. These processes, Ashby suggests, establish students labelled with disability as alien within their own

classrooms. Individuals who are ascribed the label are perhaps not afforded an opportunity to make sense of its manifestation in their lives.

Individuals who reject the label intellectual disability are often subjected to critical analysis as to why this rejection has taken place. Rejection of the label is often framed in terms of a "denial" of the label (W. M. Finlay & Lyons, 2005). While denial may be understood in neutral terms as a failure to subscribe to a belief, doctrine, within psychology, denial is commonly understood as a defence mechanism, a failure to accept some form of uncomfortable reality or truth, in order to preserve self-concept, self-esteem or avoid dissonance. Indeed, Edgerton (1993) conceptualised denial of intellectual disability as a mechanism to preserve one's self-esteem. Intellectual disability is seen as a quality of the individual "... *an unambiguous identity that individuals have, whether they confess it or not*" (Rapley, 2004, p. 196). This analysis of the rejection of the label infers that the label itself has some primary ontological status, that it reflects a truth of the individual, that it is an objective category, which cannot be undermined. This view of the label as an objective truth about the nature of the individual is consistent with the personal tragedy model, or medical model, of disability (W. M. Finlay & Lyons, 2005).

Rejection of the label intellectual disability is often understood as a failure of insight, or self-reflexivity, a lack of ability to understand the truth about oneself, and can be used as evidence of one's incompetency. Davies (1998) suggests that the *Western model of individual selfhood* may serve to undermine the personhood of the individual labelled with intellectual disability. The author suggests that a lack of competency is considered synonymous with a lack of insight and reflexivity, as such; so-labelled individuals may not be seen as thinking, feeling, individuals. For example, if an individual is presumed not to realise that they have an intellectual disability, this is attributed to a lack insight or lack of capacity for reflexivity (W. M. Finlay & Lyons, 2005). Denial of disability is seen as a maladaptive coping strategy "... *and a failure to come to terms with the "truth" about oneself*" (W. M. Finlay & Lyons, 2005, p. 122). In this way, the construction of an alternative identity, perhaps not derived from one's disability, is undermined. Often, the label is assumed to reflect a central feature of the individual's identity, a kind of master status (Fine & Asch, 1988). For example, when an individual who is so-labelled performs a task requiring competencies, the performance is seen as extraordinary, and evaluated as

remarkable (Goffman, 1963). Further, should an individual who is labelled with intellectual disability exercise independence, experience love, or desire a relationship, these ordinary experiences are placed in the realm of the remarkable, the extraordinary. The pervasive nature of the label is evidenced by the difficulty an individual may have in subverting the assumptions associate with it. It might be argued that the concept of intellectual disability is maintained not only by a subscription to assumptions of what it means to have an intellectual disability, but more broadly is maintained by the worldview that science holds an ultimate ontological value. The social construction of intellectual disability may be located more broadly within the logical-positivist paradigm which is predominant within the Western cultural context (Breen & Darlaston-Jones, 2010).

#### ***2.2.2.4 Rejecting the social category.***

Finlay and Lyons (2005) argue for a more critical analysis of what it means to reject the label of intellectual disability. The authors suggest that a denial of the label can be framed in terms of social constructionism, where the individual believes that the label is inadequate to describe their life experiences. This kind of rejection is not necessarily a blanket rejection of individual differences in skills and competencies, rather, it is a rejection of the assumptions associated with the label (W. M. Finlay & Lyons, 2005). The authors suggest that individuals often reject the label, as the assumption inherent to it do not apply, but equally, they may speak to a range of skills and competencies. The competencies and skills of individuals who live without the label of intellectual disability are constructed as context-dependent; that is, skills vary on an individual basis, and depending on task, and a range of factors. Whereas individuals labelled with intellectual disability are presumed incompetent, independent of context. Finlay and Lyons (2005, p. 121) suggest:

*...there is a difference between acknowledgement of one's particular limitations in practical or cognitive tasks and acknowledgement of a general label. It is possible to acknowledge both, deny both, or to acknowledge one and deny the other.*

Individuals labelled with intellectual disability, unlike individuals who are not ascribed this label, are not afforded this flexibility in the construction of an individual identity. In discussing the meaning of the label intellectual disability with



so-labelled individuals, the authors determined that disability was often understood as an administrative category, where boundaries are drawn on the basis of localised social contexts (e.g., the authors highlight that cross-cultural understandings of disability are variable), and is ascribed on the basis of structural systems; access to education, organisational structures, and the provision of welfare services.

### **2.3 The social model of disability**

Essentially, the individual model of disability could not be accounted for in terms of a social constructionist understanding. With mounting criticism of logical-empiricism, and a turn toward social constructionist perspectives, there was an attempt to make sense of disability as a consequence of an individual interacting with an environment, rather than as an inherent quality of the individual (McClimens, 2003). The social model of disability emerged in the spirit of social constructionism, and represented an attempt to understand how disability could be understood in terms of social, cultural, and historical contexts, rather than as an assumed truth. The social model of disability has come to dominate the landscape of the disability movement in Britain (McClimens, 2003), and perhaps globally, the model is regarded as the philosophical rationale for disability, and those individuals who live with this label (Chappell, Goodley, & Lawthorn, 2001; Tregaskis, 2002).

The formalisation of a social model of disability has its roots in the British disability movement, developed in the 1970's by activists forming the Union of the Physically Impaired Against Segregation (1976). The social model emerged as an academic paradigm through the culmination of works of various authors, including Finkelstein (1980), Barnes (1991) and Oliver (1996b). Shakespeare (2004) suggests that, around this time, various social models were taking shape, and various authors were reaching similar conclusions regarding the social construction of disability. The social model of disability, as it is understood within the British disability movement, is a framework which distinguishes between disability as a social construction, resulting from "disabling" social, economic, and environmental barriers, and "impairment" as a biological or functional limitation (Oliver, 1996b). This model shifted the responsibility of disability away from the individual, rather, re-orienting disability as a social-cultural problem (Oliver, 2013). The social model of disability undermined the fundamental principle of the individual model of disability, that

disability and impairment is a naturally-occurring category, characterised by inherent difference (Tregaskis, 2002).

This social model held various implications for the community. This model suggested that disabled people represent a socially oppressed group. As such, the pursuit of civil rights, and the removal of disabling barriers were seen as a solution to the problem of disability (Oliver, 2013; Shakespeare & Watson, 2001). The social model also had an empowering impact on the community, individuals experiencing disability were able to redefine themselves, and strive for equality and fairness, and on the basis that disability was merely a social category (Oliver, 1996b; Shakespeare, 2004). For a time, the social model of disability was considered the standard by which systems, behaviours, structures, and ideologies might be considered progressive, or inadequate (Shakespeare & Watson, 2001). The adoption of the social model of disability, is perhaps reflective of Kuhn's (2012) notion of *paradigm shift*, the paradigm of the medical model on one level had collapsed, and the social model of disability was subsequently adhered to with rigid, and fervent tenacity (Shakespeare & Watson, 2001).

Tregaskis (2002) outlines several *protective belt theories* which accompany an understanding, and application, of the social model of disability, including; a modernist materialist perspective, a materialist post-structuralist perspective, and a feminist perspective. Initial conceptualisations of the social model of disability were posed in terms of an economic-capitalist perspective (Oliver, 1996b; Tregaskis, 2002), where individuals with disability were seen to be structurally bound to the category of the "needy" and dependent as they were not able to partake in the workforce and so unable to contribute to society. Economic-capitalist conceptualisations of the social model have been criticised for failing to account for the cultural and social dimensions of prejudice surrounding disability. Materialist post-structuralist and feminist theories account for the values, attitudes, and power dynamics which construct disability as other (Tregaskis, 2002). However, these perspectives have been criticised for failing to account for systemic or structural disabling aspects of society. Herein is a tension in the conceptualisation of the social model as a way of explaining the othering of people with disability, where a purely materialist structuralist views, and equally, a purely cultural views, are seen as insufficient. The tensions outlined by Tregaskis seem to highlight a need for a more

holistic, and fluid, application of the social model of disability in conceptualising what it means to be so-labelled.

### **2.3.1 Criticisms of the social model of disability.**

At the core of the social model of disability is the distinction between impairment as a biological or functional limitation, and disability as the social form of oppression engendered by impairment (Oliver, 1996b). This binary distinction has sparked ongoing debate on the credibility, and applicability of the social model of disability. There is an argument that initial conceptualisation of the social model of disability disregard the experience of impairment, or functional limitation, on the lives of individuals with disability (Oliver, 1996a). Some would suggest that some impairment, biological differences, exist independent of social environment, and that it is inappropriate to neglect to incorporate the experience of such impairment into a social model of disability. More recently, there has been a call to re-socialise impairment, so as to account for the individual's experience of impairment, rather than ignore the experience of impairment (Tregaskis, 2002). This argument is met with some contention, as some authors suggest that impairment, likewise to disability, is also a social construction (Abberley, 1987).

Essentially, there is tension around how to conceptualise or deal with impairment from a social constructionist perspective. On the one hand, it is real; on the other hand, impairment is viewed as a social construction. Abberley (1987) draws a parallel between the social oppression of individuals with disability, and social oppression based on ethnicity, gender, sexuality, religion, and other social categories. He suggests a need to deal cautiously with the incorporation of impairment in to social theory on disability, as he identifying real biological difference may serve as a "... *qualifactory condition of a wholly ideological oppression*" (Abberley, 1987, p. 8). Abberley suggests that the social oppression of women was undermined on the basis that biological difference could not be qualified. Establishing a real biological difference for individuals with disability, perhaps could be legitimising the moral disqualification of individuals with disability from the realm of humanity (Rapley, 2004). Impairment, or biological difference, may be considered a social product, one which forms an integral part of the oppression against individuals with disability (Abberley, 1987).

Abberley (1987) suggests that a progressive discourse must be characterised by an ambivalence toward impairment. For example, rather than identifying impairment as a bad thing representing some unintended form of development, impairment may be conceptualised as a positive attribute of the individual. In a similar vein, Shakespeare and Watson (2001) advocate the value of pursuing the removal of disabling structures, while also attempting to limit the impact of the pain and functional limitation associated with the experience of impairment. Some argue that the apparent denial of the experience of impairment within the social model of disability has not been a denial at all (Oliver, 1996a; Shakespeare & Watson, 2001). Shakespeare and Watson suggest that at very strong version of the model, one which perhaps neglects mention of the experience of impairment, created a public discourse which presented the social model in a particular way. The authors suggest that no one really assumes such a strong position, and that the social model does not really propose such a strong disability-impairment dichotomy.

Oliver (1996a) reflects on the tensions surrounding the rigidity with which the model is applied, and suggests that a more flexible application is needed. He suggests the social model was not an attempt to account for the individual experience of impairment, rather, the model was intended to identify issues as social constructions, creating spaces and opportunities for collective action and advocacy (Oliver, 2013). The rationale for conceptualising disability within the social realm reflected an emancipatory strategy, an attempt to sever the causal connection between impairment and disability (Thomas, 2004). Oliver (1996a) suggests that the distinction between impairment and disability was a deliberate attempt to undermine legitimised oppression on the basis of systematic and homogenous biological difference or impairment. There seems to be a sentiment that the social model of disability in itself is valuable, and has been valuable, as a means for pursuing civil rights of individuals labelled with disability.

This tension regarding the impairment-disability dichotomy, whether real or exaggerated, has sparked ongoing debate. A further criticism of the strong social model of disability is the assumption of permanence. Discourses surrounding the application of the model appeal to a disable-non-disabled dichotomy, assuming that the "disability identity" is permanently affixed to an individual (Shakespeare & Watson, 2001). Barnartt (2010) suggests that the permanence of disability reflects

social, cultural, and historical myth. She suggests that disability, impairment, and the relationship between the two are impermanent, shifting with age, time, and culture. An emerging theme regarding a critical evaluation of the social model of disability centres on concepts of rigidity, and of forced dichotomies (e.g., with regard to disabled-non-disabled, and impairment-disability dichotomies).

A further criticism of the social model of disability is the implication that removal of disabling social barriers is achievable, and that the label disability will no longer hold relevance (Shakespeare, 2004). The argument outlined by Shakespeare, Gillespie-Sells and Davies (1996) in the text "The sexual politics of disability: Untold desires" poses a challenge to the assumption that individuals labelled with disability would choose a cure, or would eradicate the experience of disability and impairment, given the choice. The sentiment outlined by contributors labelled with disability is that they would rather see the world adapt, rather than change themselves to meet the limitations of a world which demands the standards of normality be met. Further, Shakespeare (2004) contests; *can an individual be impaired, but not disabled? Can an individual experience disability without impairment?* The social model, and the social-biological/disability-impairment binary imply simplicity in the construction of disability. In this sense, it is argued that the social model does not have the capacity to address the complexities inherent to the construction of disability (Shakespeare, 2004).

The perceived inadequacy of the social model of disability in contemporary times could be perhaps considered an inevitable outcome, alluded to in Kuhn's (2012) theory of the development of scientific revolutions. The comfort afforded by strong investment in, and adherence to, any framework for understanding, to the extent that this framework comes to represent *normative science* means that such a framework is not easily challenged. Shakespeare and Watson (2001) suggest that the social model became so powerful as a means to evaluate the adequacy of ideas disability movement that attempts to pose a challenge to this model were undermined. In this sense, the social model of disability is in itself not problematic, rather, such a strong interpretation, and application of the model is (Shakespeare, 2004). As the individual model of disability came to be understood as an inadequate way for representing the lived experience of disability in historical contexts, so too perhaps is the social model

of disability for more contemporary times. Shakespeare and Watson (2001) suggest that it perhaps time for another paradigm shift (Kuhn, 2012).

### **2.3.2 Locating intellectual disability within the social model of disability.**

We might consider how intellectual disability is conceptualised with regard to the social model of disability. To this extent, the social construction of intellectual disability might be understood as conducive to a social model understanding of intellectual disability. A key understanding within this social constructionist approach is the role of stigma in constructing, and maintaining, particular identities. Goffman (1963, p. 3) suggests that stigma “... *refers to an attribute that is deeply discrediting*”, and that use of the term stigma refers to disgrace itself, as opposed to any physical evidence of it. Stigma is a means through which social categories are organised, to determine who meets normative expectations, and who may be considered other. Individuals who fail to meet normative expectation may be stigmatised, and “...*reduced from a whole and usual person to a tainted one*” (Goffman, 1963, p. 3). The individual who is stigmatised is not quite human (Goffman, 1963). Goffman referred to the *spoiling of a social identity*, the mechanism through individuals who are stigmatised are constructed as inferior, and so are likely to experience fewer opportunities in life. Such social deviance does not reflect an objective category; rather, is constructed in the assumptions shared by the wider community (Taylor, 2000).

For example, Finlay and Lyons (2005), in their social constructionist analysis of the label intellectual disability, found that the label was often used in a derogatory or abusive sense, to imply that the individual was worth less, and inherently different. Individuals who shared their stories for the study referred to notions of “perfect”, suggesting that to individuals labelled with disability are constructed as less than perfect. One individual who shared his experiences for the study, Nathan, voices his resistance to the use of the term “Mongol” as an insult (W. M. Finlay & Lyons, 2005, p. 128):

*Mongol...but that's not nice coz' no-one's perfect are they? ... I say not even you. There's a lot of things you need help on. No one's perfect, not even Jim the manager (of the day service), he's not perfect, he has some help...*

Nathan's experience suggests that the label has a social and cultural value, which extends beyond objective criteria for intelligence and adaptive functioning. This negative value is evidenced by the appropriation of the word "retard" in some social circles as an insult, or to identify an object of ridicule, Gelb (2002, p. 55) provides an example: "*Those shoes are so retarded*". To live with the label intellectual disability, it would seem means to be the embodiment of difference, abnormality, and the other. Indeed, the processes described by Goffman (1963) in his seminal works are considered valuable for understanding how the label intellectual disability works to compromise the personhood of so-labelled individuals.

Goffman (1963) notes that individuals who experience stigma are likely to internalise the stigma as truth, and are destined to experience a life world constructed by the assumptions inherent to the label. These dynamics are evident in the lives of individuals labelled with intellectual disability, where so-labelled individuals are stigmatised such that "*being 'intellectually disabled' is an incontestable identity inherent to the individual...*" (Rapley, 2004). There are various assumptions bound up in this incontestable identity which establish individuals labelled with intellectual disability as the other. A key assumption inherent to the social construction of intellectual disability is the presumption of incompetence (Rapley, 2004). From this assumption, so too do other complementary assumptions flow, such as an assumption of vulnerability, of a need for protection, and risk-management (Fine & Asch, 1988). The assumptions inherent to the construction of intellectual disability cast so-labelled individuals, and those who surround them, into restricted roles, with ascribed identities. A key aspect of the stigmatised identity, it appears, is the often rhetorical nature of the construct. The rhetorical, or infallible, nature of the social construction of intellectual disability establishes that so-labelled individuals are inherently, and interminably, different.

### ***2.3.2.1 Social role valorisation theory.***

This difference holds socio-cultural value, where individuals labelled with intellectual disability represent a social category of lesser value, of lesser personhood (Munger, Gill, Ormond, & Kirschner, 2007). Principles of normalisation and social role valorisation provide a framework to articulate the devaluing of individuals who are ascribed stigmatised identities, such as individuals labelled with intellectual

disability. Normalisation and social role valorisation originated from movements to pursue social justice for individuals into marginalised groups, for example, the anti-racism movement and feminist movement (Walmsley & Johnson, 2003).

Normalisation, later termed social role valorisation, was popularised in North America by Wolfensberger, among others (Osburn, 2006; Wolfensberger, 2000). At a time when individuals labelled with intellectual disability were objectified and castigated into socially devalued roles, social role valorisation highlighted the arbitrary and non-permanent nature of such discrimination which had the effect of motivating those who cared to facilitate better lives and opportunities for individuals labelled with intellectual disability (Wolfensberger, 2000). Social role valorisation posits that a person's welfare is dependent on the social role/s they occupy, and that certain people are more likely to occupy socially devalued roles than others.

Individuals who occupy socially valued roles are more likely to be afforded the "good things" in life, such as education, a home, respect, and dignity (Osburn, 2006). Individuals in devalued roles, such as individuals labelled with disability, may be cast into roles such as; nonhuman, subhuman, as objects of ridicule, objects of pity, and as the "eternal child" (Osburn, 2006; Wolfensberger, 2000).

Social role valorisation posits that one's role may be *valorised*, or improved, via reframing one's image in view of the broader society, or by improving the personal competencies of the individual (Osburn, 2006). Thus, image and competency form a rhetorical mechanism, where an individual who experiences competency impairment is likely also to experience image impairment, and vice versa (Osburn, 2006). The position of individuals who exist in historically devalued roles is maintained through messages communicated through major channels (Race, Boxall, & Carson, 2005). These messages perform a kind of symbolic stigmatising of individuals who are placed within various social categories. Social role valorisation provides an "*if... then...*" framework, whereby consequences for social action and engagement are outlined (Osburn, 2006; Race et al., 2005). Social role valorisation is inherently descriptive, however, and does not perform an evaluative function. Social role valorisation provides a framework for understanding and predicting the value attached to social roles, and the likelihood of achieving the good things in life, social role valorisation does not provide a lens through which to evaluate the moral or ethical nature of interventions, programmes or actions (Osburn, 2006).



### **2.3.3 Intellectual disability as an administrative construct.**

Finlay and Lyons (2005), in their exploration of the sociocultural construction of the label intellectual disability, noted that participants tended to refer to individuals who were labelled with intellectual disability as residents, service-users, and clients, rather than using terms such as handicapped. This finding led the authors to believe that perhaps the label derives meaning as an administrative category. The authors suggest that service-providers<sup>4</sup> operate on an educational and developmental philosophy, where programs are designed to engender independence and growth, with an understanding that individuals are working toward independent living, or employment, and as such, will one day no longer require the service (W. M. Finlay & Lyons, 2005). This model implies that one can leave the social category, if one can transcend the need to exist within various administrative contexts (W. M. Finlay & Lyons, 2005). Participants appeared to subscribe to the possibility of exit from the social category, evident in the ways which they described friends and associates who were described as no longer conforming to the category, or the label. For example, participants articulated that getting married or having a job was evidence that an individual no longer had a disability, or that the label was no longer appropriate for them. As such, lack of opportunity to achieve these social markers of adulthood may render an individual in a perpetual state of suspended development, reinforce membership to the social category, necessitate engagement in service-provider contexts and may preclude their participation in various aspects of adult life (Davies, 1998)

### **2.3.4 The illusion of the institution.**

Taylor and Bogdan (1980) suggest that formal organisations, such as service-providers for individuals labelled disability, are structures which are oriented toward and maintained via particular goals. The authors suggest that in order for any organisation to survive, the organisation must operate under a series of legitimating myths. For example, the historical and contemporary disability service settings, such as custodial care, congregate and segregationist care, and welfare production, are

---

<sup>4</sup> A term used to refer to a formal system or organisation which provides a service. Disability service-providers provide services individual labelled with disability. Some disability service-providers may be government-funded, not-for-profit, private not-for-profit or private and commercial. Disability service-providers are characterised by some kind of formalised organisational structure, and may provide a range of services including, but not limited to; accommodation, personal care, social support, respite, therapeutic intervention, independent living skills development.

predicated on myths of dependency, individualism, and difference inherent to the individual model of disability (Priestley, 1999). Taylor and Bogdan recognise a dynamic where, in order to maintain function and purpose, seemingly outdated legitimating myths must be abandoned, for contemporary and culturally appropriate myths. As such, organisations undergo a kind of symbolic transformation, but may be operating under the same mythology and assumptions. The authors place their analysis in the context of institutions for individuals with intellectual disability, and suggest that in order to survive, service settings will continually shape-shift, and appeal to the prevailing rhetoric and paradigm of the time.

As such, assumptions of incompetence, vulnerability, and protection; inherent to the social construct of disability, establishes intellectual disability as an administrative construct. The logic surrounding service-use is circular, as individuals may be ascribed a label because they use a service, and use a service because they possess the label. For example, having met diagnostic criteria for intellectual disability, students may be placed into special education programs based on academic performance or cognitive profiling, however, in order to exit this setting they must prove their educability, their right to be included in "Mainstream"<sup>5</sup> school programs (Biklen & Burke, 2006). Once in the special education setting, the student experiences a range of assumptions, expectations and may fall victim to the presumption of incompetence (alluded to by Bogdan & Taylor, 1982). Kliwer, Biklen and Kasa-Hendrickson (2006, p. 164) suggest that restricted literacy, often, an assumed quality of the individual labelled with intellectual disability:

*...has become institutionalized as a presumably natural manifestation of organic defects thought to objectively exist well beyond the reach of social, cultural or historical consideration.*

A student placed into special education may not be socialised in the same way as his or her peers, and may not benefit from an inclusive environment, which may influence skills, abilities and competencies, ultimately, rendering social exit unlikely (Biklen & Burke, 2006).

---

<sup>5</sup> Mainstream is a colloquial term used to refer to schools and educational settings which do not constitute special educational schools.

Perhaps this phenomenon is similar to that identified in the famed experiment conducted by Rosenhan (1973) which exposed the socially constructed, and rhetorical, nature of diagnostic categories. In this study, Rosenhan recorded the experiences of eight pseudo-patients who achieved admission to various psychiatric hospitals. Aside from reporting initial symptoms of psychoses to achieve admission to the hospitals, pseudo-patients reported no further symptoms. Despite an absence of symptoms, and self-reporting feeling “fine” to hospital staff, Rosenhan recounts that pseudo-patients were treated as though they were insane, and various normal behaviours were pathologised by staff, as evidence of psychiatric disturbance.

Rosenhan (1973) reflected that once labelled, the label *schizophrenia* seemed to stick to pseudo-patients; that is, patients were not reclassified as sane on exit from the institutions, rather, they were diagnosed as having schizophrenia “in remission”. Rosenhan (1973, p. 257) referred to this label as “... *a mark of inadequacy forever*”. Rosenhan (1973, p. 257) found that psychiatric hospitals were settings which depersonalised, disempowered, and stigmatised patients, and posed the question:

*... How many patients might be “sane” outside the psychiatric hospital but seem insane in it – not because craziness resides in them, as it were, but because they are responding to a bizarre setting, one that may be unique to institutions...*

These observations reflect a “catch 22” scenario, where individuals in psychiatric institutions have little opportunity, or hope, of being listened to, attended to, or afforded civil and human rights (Rosenhan, 1973). Equally, Taylor (2000) notes a paradoxical dynamic –the more an individual is embedded within disability-specific contexts which aim to assist and promote development, the more the individual is ascribed the negative stigma and assumptions associated with the label. This paradox may form evidence of the legitimating myths which underpin institutional or care-settings which ensure the survival such structures, and maintain the status quo.

It is the case that this dynamic, and the function of the label as an administrative category, is perpetuated within the field of disability research. Often, in engaging individuals to participate in research we, as researchers, demand that they adopt the label, as a precondition for participation (Rapley, 2004). Further, in adopting this label, and sharing their stories, individuals may find themselves discredited, and

classed as unreliable reporters of their own experiences (e.g., see Stoffelen, Kok, Hospers, & Curfs, 2013). In this regard, the means of research production, and research relations, are designed to maintain and, in many ways, reinforce the assumptions central to the social construction of intellectual disability.

#### **2.4 An embodied ontology of disability**

Some argue that the social model of disability requires further development in order to reflect the experiences of those whom it proposes to represent. Shakespeare and Watson (2001), however, suggest that any attempt to adapt the model would be piecemeal and ineffective. They suggest that the strong social model has outlived its usefulness for the community. As a materialist conceptualisation of disability was appropriate and valuable in capitalist times, perhaps there is a need of a new way to understand what it means to live with the label disability in contemporary times (Goodley, 2013). Shakespeare and Watson (2001), suggest that it not feasible to continue to assume a biology-social binary between impairment and disability. The authors argue that a more complex model, one which extends beyond the social-biological realms, and accounts for all aspects of the experiences of individuals with disability, is required. In an earlier publication, reflecting on the adequacy of the social model of disability Shakespeare and Watson (1997, p. 298) state "*No theory comes into the world fully formed...*". It would seem that in reaching the conclusion of a need for an alternative position, the authors also engage a reflexive stance, attributing their contemporary position to personal experiences, and a changing social, cultural, historical context (Shakespeare & Watson, 2001).

Shakespeare and Watson (2001) do not presume to propose a new social theory of disability, rather, they suggest that the disability movement would benefit from a social theory which identifies an alternative ontology of disability. This new ontology is the notion that everyone is impaired (Shakespeare, 1998). To this end, the authors propose that there is no qualitative difference between individuals with disability and those without. Shakespeare and Watson (2001, p. 24) suggest that "*Impairment is not the core component of disability (as the medical model might suggest), it is the inherent nature of humanity*". Impairment is placed within a broader context of humanity, rather than in the specific context of disability. Impairment is not reserved for those who live with the label disability. Rather, all individuals are likely to experience some form of impairment throughout their

lifetime, perhaps as part of the ageing process, perhaps as a result of trauma, or perhaps as a result of specific cultural and social contexts (Davies, 1998).

Historically, and contemporarily, individuals living with the label disability have been categorised on the basis of impairment. It seems as though some impairments extend beyond the threshold for what might be accepted as part of acceptable human variability. Scotch and Schriener (1997) offer an alternative model of disability, the human variation model, which shares an ideology inherent to Shakespeare and Watson's (2001) embodied ontology of disability. The human variation model of disability represents disability as an extension of the natural variability shared by all of humanity, suggesting that individuals are disabled when particular impairment is constructed as extending beyond the capacity of social systems and structures to routinely respond. The human variation model shares features with the embodied ontological approach, however, places emphasis on the notion that disability is the outcome of inherent inadequacies social systems and structures (Scotch & Schriener, 1997). According to the human variation model, disability is not identified primarily as a handicapping condition, rather, disability is form of social oppression engendered by socio-cultural conceptualisations of impairment (Schriener, 2001).

Both the human variation and embodied ontology of disability models are presented as an alternative to the minority rights-based approach to disability. The more traditional rights-based approach aims to achieve equality for individuals labelled with disability, through the removal of social or systemic barriers. While this approach is widely acknowledged as being valuable for drawing attention to systemic and social barriers (Shakespeare, 2004), some suggest that it cannot "*...serve as the sole underpinning for disability policy*" (Scotch & Schriener, 1997, p. 152), on the basis that it is difficult to construct conditions where human rights are achieved for all. Some authors articulate this point using the principle of universal design as an analogy, highlighting that specific elements of the built environment which enhance access for some, may in fact disadvantage others (Schriener, 2001; Shakespeare, 2004). To this extent, a minority rights-based approach is considered valuable for a specific level of intervention (at the socio-political level), and the human variation or embodied ontology model at a broader level of intervention.

A key feature of both the embodied ontology of disability, and the human variation model, is an acknowledgment that not all individuals who experience impairment experience social oppression (Scotch & Schriener, 1997; Shakespeare & Watson, 2001). Only some individuals with impairment also experienced disabling barriers within society. In this sense, who is disabled or not is constructed by the perceived acceptability of impairment. Some argue for a continuum of impairment, rather than a dichotomous definition of disabled or non-disabled individuals (Barnartt, 2010). Shakespeare (2004) suggests that as are gender, race, and sexuality, impairment should also be conceptualised as a fluid, rather than distinct social category. A key feature of Shakespeare's position is ambivalence toward impairment. Similar to that outlined by Abberley (1987), Shakespeare outlines an understanding that impairment is undesirable, but should not be cured at all costs. Considering impairment in this broader context does not deny the reality of the impairment for the individual, rather, it creates a space where individuals are not defined by a perceived level of impairment.

#### **2.4.1 Criticisms of an embodied ontology or human variation models of disability.**

Likewise to various other models of disability, the embodied ontology, or human variation model, is not immune to criticisms. On one level, these approaches are criticised for their emphasis on impairment, and an implication that "all people are defective, just like people with disability". Hughes (2007) suggests that this kind of rationale is biological-reductionist, and falls victim the same issues as the individual model of disability. Hughes suggests that an embodied ontology approach presents impairment as pre-social, and runs the risk of presenting disability as "*...biological dictum that should teach us all to be humbled by our own vulnerability*" (Hughes, 2007, p. 679). There is also an argument that the dictum we are all impaired "*...leaves the concept of disability with no teeth...*" (Hughes, 2007, p. 679).

#### **2.4.2 Locating intellectual disability within an embodied ontology of disability.**

The challenge inherent to attempting to locate intellectual disability within the embodied ontology of disability is that to do so would be antithetical to the principles of the model itself. As Hughes (2007) suggests, the embodied ontology of disability undermines the very concept of disability. For example, other than reflecting that an embodied ontology on intellectual disability would recognise cognitive ability as

diverse and part of human variation, there is no means to articulate the concept of intellectual disability – the model itself undermines the value for determining intellectual disability as a distinct social category. The principles inherent to the embodied ontology of disability might be considered as posing a challenge to and highlighting the complexity associated with concepts of diversity and impairment.

Essentially, an embodied ontology of disability advocates for recognising diversity in a way which is not value-laden. It seems, however, that the rhetoric surrounding diversity and impairment so often is value-laden. What is perhaps problematic about the embodied ontology of disability, as Hughes (2007) suggests, is that it draws focus to impairment. The embodied ontology of disability is predicated on the assumption of a pluralistic culture, one which does not seek to construct binaries or social categories. This assumption is problematic as it seems to neglect the complexities and tensions which surround diversity and impairment. These tensions are well-articulated within the sporting arena, where diversity may be recognised in some settings as reflective of extraordinary talent, or extraordinary disadvantage. The tensions are further exacerbated in instances where what might be considered disability in some settings, constitutes advantage in others. For example, in the athletic arena, Oscar Pistorius' use of prosthetic limbs posed a challenge to acceptable levels of diversity within sport (van Hilvoorde & Landeweerd, 2008). Discourses surrounding Oscar Pistorius' participation in the Olympics revolved around notions of fairness, and socially acceptable levels of diversity (Jones & Wilson, 2009). The complexities surrounding Oscar Pistorius' engagement in the Paralympics and Olympics illustrates the tensions inherent to the embodied ontology model. It would seem that Oscar Pistorius is eternally objectified on the basis of the challenge he seems to pose to normalising ideologies and ableism.

The narratives surrounding Oscar Pistorius' engagement in the sporting arena parallel those narratives faced by many individuals who are seen to exist outside of the threshold for acceptable human variation. For example, McDougall (2006) outlines two competing narratives commonly faced by individuals labelled with disability, the "Ag shame" narrative (derived from a South African idiom, refers to the construction of individuals labelled with disability as pitiable or disadvantaged) and the "superhero" narrative. McDougall suggests that individuals may be constructed in terms of a superhero narrative, where individuals are seen as heroic

simply for living with the assumed effects of their constructed impairment. These narratives are evident in the social construction of intellectual disability, where individuals are often constructed as objects of pity, or alternatively, when seen as engaging in an ordinary life (e.g., having a boyfriend or girlfriend, having a job, and living out of the family home) are constructed as extraordinary and celebrated for overcoming their intellectual disability. These sentiments were expressed by the late Stella Young (writer, comedian and advocate) in her TED talk titled "I'm not your inspiration, thank you very much" (2014, April). Stella Young contested discourses of disability characterised by pity, shame and inspiration, and stated her desire to "*...live in a world where we don't have such low expectations of disabled people that we are congratulated for getting out of bed and remembering our own names in the morning.*" Narratives on inspiration, and pity, are equally harmful, as both reduce the identity of the individual to their perceived or constructed impairment, diversity or disability (McDougall, 2006). Stella Young, and others, advocated and advocate for a re-claiming of that which Goffman (1963) termed the spoiled identity, assuming a critical stance toward this discourses, and actively re-framing notions of impairment, diversity, and difference. This critical stance is evident in the "Mad Pride" and "hearing voices" movements, which advocate for the "*...active and thoughtful positioning of the self with respect to dynamic social narratives regarding mental difference and diversity*" (Schrader, Jones, & Shattell, 2013, p. 62). Advocates within these movements call for a reframing of the parameters which construct normality, and give rise to abelist, and prejudice, attitudes.

## 2.5 A way forward

Ongoing debate on the nature and adequacy of various models of disability has failed to provide any kind of unified sociological theory of disability (Priestley, 1998; Thomas, 2004). Thomas laments that the unfortunate outcome of debate surrounding various models of disability is a focus on what does or does not constitute restricted activity, impairment, and disability. This reductionist debate seems to contravene the rationale associated with a sociological understanding of disability. Goodley (2013) outlines concern within the community that disability studies have become rather introspective, existing primarily within the academic domain. There is a concern that we, as researchers, currently harbour a "*...preoccupation with theory over politics....*" (Goodley, 2013, p. 641). The field of



disability studies could be characterised by an historical, and contemporary, tension surrounding the seemingly competing goals for theoretical development, and real-world social change. In the spirit of pluralism, and as a reflection of a blended social constructionist and pragmatist approach, it would seem that there is little value in attempting to pursue a definitive sociological theory of disability which might direct this research enquiry.

Shakespeare and Watson (2001) outline several key features of an alternative, holistic approach to the conceptualisation of disability. The features of this argument seem to be echoed by Goodley's (2013, p. 641) call for "...*the development of praxis: the inter-twining of activism and theory*" via exploration of the complexity of disability. Shakespeare and Watson (2001) suggest a shift away from deterministic understandings of disability, where impairment and disability are not considered dichotomous, rather, conceptualised on a continuum as representing "... *complex dialectic of biological, psychological, cultural and socio-political factors...*" (Shakespeare & Watson, 2001, p. 22). The authors also argue the need to reflect on and distinguish between various levels of intervention. For example, at times medical or individual intervention may be required, and may be equally as valuable as intervention which aims to remove social barriers, and pursue collective aims. Shakespeare and Watson (2001, p. 23) also reflect on a shared assumption inherent to the disability movement that "...*we know who the disabled subject is.*" This assumption perhaps undermines the core aims and principles of a progressive, social justice, and human-rights oriented movement. This reflection is humbling, and is useful for ensuring that processes are consistent with, and do not undermine, aims. Progressive contributions to the disability movement should avoid generalisation, and the generation of meta-narratives, to be valuable, theoretical analyses must relate to situated and specific contexts (Shakespeare & Watson, 2001).

As Shakespeare and Watson (2001) suggest, perhaps it is appropriate to refer to various models, or approaches, for application in specific contexts, and according to specific levels of intervention. Perhaps there is a need for a re-framing of the various paradigms of disability. Where, rather than considering the models in a temporal and linear context, the models are conceptualised, as Shakespeare and Watson suggest, in terms of typological levels. This re-framing of various models of disability could mean that no one model is considered superior to another and each is recognised for

its unique epistemological and ontological qualities. This conceptualisation seems to pose a challenge to Kuhn's (2012) notion of paradigm shift as, in contrast to his theory, this typological understanding of models of disability does not necessarily reflect the rejection of any particular model, for the exclusive uptake of another. At a deeper level, it is speculated that this conceptualisation is not inconsistent with Kuhn's theory. Rather, this typological understanding does reflect a paradigm shift, not in terms of knowledge itself, but at a broader level, the ways in which knowledge is understood. This more fluid conceptualisation of the ways of understanding disability is perhaps captured by the domain of critical disability studies.

## 2.6 Critical disability studies

Critical disability studies is offered as a framework for articulating the nature of contemporary disability studies (Goodley, 2013). Critical disability studies emerged out of a range of theoretical orientations, including; post-conventionist, post-structuralist and post-modernist approaches (Goodley, 2013), and reflects a culturally contextualised, and eclectic approach to study of disability and intellectual disability (Devlin & Pothier, 2006). Meekosha and Shuttleworth (2009) suggest that critical disability studies offers an opportunity to move beyond a preoccupation with binary conceptualisations in disability studies, such as the classical pitting of the social model against the individual model. Critical disability studies does not so much reflect a "new" model of disability, or a new approach, rather, a more it is a reflexive approach, which builds upon structuralist and postmodernist underpinnings of various other models.

Critical disability offers an opportunity for a new kind of engagement with disability studies, with an understanding that "*...the struggle for social justice and diversity continues but on another plane of development – one that is not simply social, economic and political, but also psychological, discursive and carnal.*" (Meekosha & Shuttleworth, 2009, p. 50). This approach is underpinned by an understanding that disability cannot be described as a static, and is not reducible to facts; rather, disability is understood as undergoing constant transformation, a process which can only be understood within social, cultural and historical realms. Taking a critical disability studies approach offers the opportunity for social transformation, and a fluid, shifting, reimagining of the meaning of disability (Goodley, 2013; Meekosha & Shuttleworth, 2009).

Some suggest that the study of disability has come to represent the study of a range of historical, political, social, and cultural issues which are relevant to all individuals (Fine & Asch, 1988; Goodley, 2013). The study of disability creates a space within which what it means to be human, to live in the world, and to make meaning from the world can be articulated. Critical disability studies is not the study of disability; rather, it is the study of dominance, oppression, exclusion, and power dynamics at a broader socio-cultural level. These themes of fluidity, of moving away from the binary, may also be applied to the ways in which sexuality and disability may be considered, where neither construct is fixed, trans-historical or pre-determined (Rembis, 2010).

### **2.6.1 Political and theoretical allies.**

Some suggest that the focus on the construction of disability as other is misplaced, arguing that the construction of disability as other is really a construction of "the abled", or those individuals who are not ascribed with this label (Goodley, 2013). It is argued that those embedded in dominant Western culture are perpetually engaged in the process of imagining, and conceptualising identities, and that these re-imaginings are achieved via reflection on what we are not (Goodley, 2013). To this extent, the construction of disability is not a reflection of the disabled individual; rather, it is a reflection of a broader socio-cultural process of self-knowing. This dynamic of defining the self, through defining the other, may be considered analogous to other socially ascribed, and often oppressed, identities. Goodley (2013) suggests that the queer, feminist, and Marxist movements represent political and theoretical allies to the disability movement. This kind of analogy does not presume that individuals labelled as disabled or othered on the basis of ethnicity, sexuality or gender, represent a homogenous group (Corbett, 1994; Soder, 2009). Rather, the analogy is relevant to exploring the social processes which may be common to individuals who are variously othered into social categories.

Drawing parallels between the disability movement and the civil rights movement is not a novel idea (Fine & Asch, 1988). Individuals labelled as disabled have long been considered as in a similar position of social and cultural oppression to individuals who are categorised in terms of ethnicity, race, sexual identity, and gender (Abberley, 1987; Appleby, 1994; Mirza, 1998), and a minority-group model of disability has been made popular (Fine & Asch, 1988). Parallels have been drawn

between the sex-gender binary salient to the feminist movement and the impairment-disability binary which is contested within the disability movement (Barnartt, 2010; Schriener, 2001). Similarly, the demand for individuals to conform to normative expectations of ableism may be considered analogous to a demand that individuals compulsorily engage in heteronormativity (Goodley, 2013).

Perhaps the experiences of individuals who are othered on the basis of social category intersect in terms of a cultural demand for hegemonic normalcy, and a resistance to cultural diversity (Corbett, 1994; Goodley, 2013; Sherry, 2004). Corbett (1994, p. 346) suggests that there is a collective pursuit of what she terms *false normality*, where we are subjected to a "...*pervasive social pressure, to be "more normal" that we are...*". Inherent to critical disability studies is an acknowledgement that the power dynamics, oppression, and exclusion that construct disability as other, are not exclusive to disability, they are a function of a culture that defines the self, according to the other. Corbett suggests that, as do individuals who identify as gay or lesbian, individuals with disability are also subject to notions of *passing, coming out*, and social oppression. A key imperative for critical disability studies is to attempt to disentangle the power dynamics and oppressive social processes which cut across various social categories (Goodley, 2013). Looking toward an understanding of social processes of oppression and stigma, in a broader non-disability specific context, offers the opportunity to transcend historical and contemporary conceptualisations of what it means to be so-labelled. In this way, critical disability studies, and a turn toward political and theoretical allies, offers the opportunity of an alternative future through collective power, and solidarity, and the common pursuit of human and civil rights (Corbett, 1994).

### **2.7 Governmentality, normalising ideologies and power**

Perhaps in the spirit of the critical disability studies approach, it is valuable to consider how macro-level concepts such as governmentality, normalising ideologies, and power contribute to a progressive discourse in disability studies. Michel Foucault (1991) termed *governmentality* as the exercise of power and knowledge by governing structures, on the population. In defining this concept, Foucault (1991, p. 102) expressed a desire to demonstrate:

*...the deep historical link between the movement that overturns the constants of sovereignty in consequence of the problem choices of government, the movement that brings about the emergence of population as a datum, as a field of intervention and as an objective of governmental technique, and the political economy as the science and the technique of intervention of the government in that field of reality.*

Essentially, the concept of governmentality is a way of understanding how knowledge and power are legitimated, and exercised through various structural means, such as institutions, interventions, welfare, and services targeted at the population. Foucault attributes the term *government* a broad meaning, where various formal (e.g., the state) and informal (e.g., the family system) are involved in “...*shaping, channelling and guiding the conduct of others*” (Chadwick, 1996, p. 38). As such, governing bodies, including; disability service-providers, health practitioners, family units, support workers, and mass media, exist within a sphere of influence, where they may enact policies and practices foregrounded in particular ideologies (Ashby, 2010; Chadwick, 1996). An ideology which underpins dominant Western culture is the pre-eminence of science, subscription to the episteme that truths are knowable and measurable. For some, however, Science may represent no more than “...*another party line, a way of thinking no less confining than religion, and one highly suspect because it represents the cultural and gender biases of white males of European genetic heritage*” (Kauffman, 1999, p. 268). Prior to the advent of measures of intelligence, and the advent of the bell curve, intellectual disability as a social category did not exist (Jenkins, 1998).

Foucault (1991) suggests that governmentality is an inherently Western phenomenon, as the concept is grounded in dominance, where government structures exist for the purpose of reinforcing power, and strengthening legitimacy to exercise such power. Chadwick (1996) advocates for a critical examination of these power structures which surround individuals labelled with intellectual disability. Arguably, the ideologies underpinning governmentality and dominant Western culture are inherently normalising. The label given to the normalising ideologies which undermine the diversity often associated with disability is *ableism*. In her critical analysis of the experiences of five students labelled with intellectual disability in middle school, Ashby (2010, p. 350) identified a dynamic where ableist ideologies

established a right or preferred way of doing or being, sometimes, at the expense of educative opportunities:

*The hidden curriculum of education, from an ableist perspective, is to move individuals with disabilities toward more normative ways of being. The goal is to minimize the effects of the disability, to do things more the way able-bodied people do them; in fact, to make the person more normal*

Ashby (2010) related her observations to Goffman's (1963) concept of passing, or approximating normality, in an attempt to manage one's spoiled identity. These normalising ideologies, and ableist attitudes, are embedded within the dominant Western cultural context. The social construction of intellectual disability is seen as in contest to dominant Western cultural norms and expectations (Gerber, 1990). There is an assumption, perhaps embedded in the high value placed on reason, language, and intelligence, within dominant Western ideologies that individuals who are labelled with intellectual disability are not living socially meaningful lives (Klotz, 2004; Rapley, 2004). Diagnostic criteria for intellectual disability reinforces the individual as abnormal, and necessitating treatment and intervention (Biklen & Kliewer, 2006). Similarly, normalising ideologies are evident in the explicit normalising policies (Wolfensberger, 2000) widely adopted by disability service-providers within the Western context (Davies, 1998). As such, there is an assumption that so-labelled individuals should be engaged in perpetual progression toward normality, perfection, and as close an approximation of personhood as is possible. Foucault's (1991) concept of governmentality provides a framework to understand how ideologies, manifest into structural and systemic realities for individuals who are placed into social categories.

The pre-eminence of Western bio-medicine (Jenkins, 1998) establishes the ontological value of science, and fosters an assumption that "...*science leads rather than follows one into citizenship...*" (Kliewer et al., 2006). As such, there may be limited opportunities for individuals labelled with intellectual disability who are, through scientific process, deemed incompetent, to attain or redeem a valued citizenship status (Kliewer et al., 2006). Similarly, universalistic religions, particularly Christianity within the Western dominant cultural context, carry ideologies and assumptions regarding intellectual disability (e.g., the belief that

intellectual disability is a punishment of a bad-deed committed by the parent) (Jenkins, 1998). Historical, and contemporary, policies surrounding eugenics, involuntary sterilisation, and restricted marriage rights for individuals labelled with intellectual disability (as outlined by Pfeiffer, 1994) perhaps provide examples of the capacity for various ideologies to enact processes of governmentality.

## 2.8 Conclusion

Within this chapter, the concept of intellectual disability was considered and located within various paradigms for understanding disability. Typically, critical discussion pits the individual model of disability against the social model of disability. The individual model of disability constructs disability as an inherent quality of the individual. In Australia, it might be argued that Western-bio-medical conceptualisations of intellectual disability support this individual model understanding. Within the framework of the individual model of disability, it is possible to explore how intellectual disability is constructed as a stigmatised identity characterised by a presumption of incompetence. The individual model of disability establishes intellectual disability as a rhetorical construct, legitimised by the ultimate ontological value of science. The social model, arose from the emancipatory aims of the disability movement, and was an attempt to focus intervention on those social structures and systems which construct disability. For example, the social model suggests that social systems ascribe a disable identity to the individual, and construct intellectual disability as primarily an administrative category. Controversy surrounding the dichotomising of impairment and disability within the social model gave rise to alternative ways for understanding disability, namely, the embodied ontology of disability. This model is underpinned by an assumption that all individuals are impaired. The embodied ontology of disability presents challenges and highlights complexities surrounding the nature of impairment.

Kuhn's (2012) theory of paradigm shift and Sarason's (1996) barometers of change theory provide a framework for understanding the fluid nature of constructions of intellectual disability. A key criticism of the disability movement is a preoccupation with outlining theories or meta-theories of disability, at the expense of engaging real world change or social action. The various models of disability are often conceptualised in a temporal or linear fashion. Critical disability studies is presented as an approach which allows for an appreciation of disability as a fluid and

entirely contextual construct, embedded in historical, political, social and cultural understandings. Critical disability studies calls for an appreciation of macro-level constructs such as governmentality, power, and normalising ideologies to make sense of the experiences of individuals ascribed the label of disability or intellectual disability. This chapter reflects an attempt to critically consider the shifting paradigms and understandings of intellectual disability, and so provides a context and background for the next chapter, negotiating relationships and sexuality within a broader ideological context.



### **Chapter three: Relationships and sexuality: A situated and specific context**

Within this chapter, the social construction of intellectual disability is considered with regard to a specific situated context; relationships, intimacy, and sexuality<sup>6</sup>. This chapter grapples with the complexities and tensions that seem to pervade the experience of individuals labelled with intellectual disability negotiating relationships and sexuality. In this chapter, I consider critically what it means to have a relationship in the context of intellectual disability. Subsequently, I consider the ways in which systems may be complicit in the form and nature of opportunities experienced by individuals labelled with intellectual disability to engage in relationships and explore sexuality. Lastly, I discuss the complex moral, legal, and cultural tensions presented by the social construction of intellectual disability in the context of relationships and sexuality.

#### **3.1 An historical context**

Shakespeare and Watson (2001) suggest that any progressive contribution to the disability movement needs to move away from generating meta-theory and instead consider how the label of disability plays out in various situated, and specific contexts. With this in mind, I return to the quotation that opened the introductory chapter of this thesis:

*What it really all adds up to is love - not love as it is described with such facility in popular magazines, but the kind of love that is affection and respect, order, encouragement, and support.*

(Robert F. Kennedy, as cited by Edward 'Teddy' Kennedy, 1968, June 8)

If the study of disability is considered a space within which what it means to be human can be understood (Goodley, 2013), then perhaps the study of disability and sexuality provides the ultimate intersection for understanding humanity demanding a reimagined discourse of humanity and human sexuality (Rembis, 2010). This is to be balanced carefully, and thoughtfully, against Fine and Asch's (1988) reflection on the research literature as focussing on disability-as-metaphor, to the preclusion of research inquiries which would actually promote wellbeing, and understanding of the

---

<sup>6</sup> As is outlined in chapter two, Shakespeare and Watson (2001) advocate the exploration of issues pertaining to the construction of disability within situated and specific contexts.

lives of so-labelled individuals. Sexuality is defined by the World Health Organisation (2006, p.5) as:

*...a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors.*

This definition suggests that sexuality is an amorphous construct, one which encompasses what it means to be human, and to partake in the human experience. Sexuality is acknowledged as a construct embedded in socio-cultural, political, and historical contexts (Gomez, 2012; Tiefer, 1987). This contemporary conceptualisation of sexuality is all-encompassing, transcending issues of sexual health, and taking into account the symbolic, metaphorical, and cultural value of sexual expression. Relative to other domains of life for individuals labelled with disability, such as employment, and housing, the study of sexuality and relationships has received little attention (Aunos & Feldman, 2002; Servais, 2006; Shakespeare, 2000). Given the role that sexuality is ascribed in determining, reinforcing, and validating one's humanity, this lack of attention seems symbolic. In fact, the pursuit of sexual rights for individuals with intellectual disability is considered by some as the "last frontier" for cultural-acceptance of so-labelled individuals (Aunos & Feldman, 2002).

Shakespeare (2000) suggests that there are several reasons why sexuality has not featured, until relatively recently, within the disability movement. At the inception of the disability movement, priority lay with addressing pressing issues such as poverty, and enabling access to the social realm (Shakespeare, 2000; Shuttleworth, 2007). Shakespeare also highlights that the social model was embedded in an economic-materialist context, with a focus on trade unionism, and socialism. He suggests that these paradigms do not account for more feminist, humanistic, and relational accounts of the experience of disability inherent to the

study of sexuality. Sexuality is simply not viewed with the same importance as is “...*social inclusion, professional enhancement, capacity building and rehabilitation.*” (Pham, 2012, p. ix). Sexuality is also culturally constructed as a private or individual issue, as such, there is a pervasive reluctance to politicise the private, and bring sexuality, and disability into the public domain (Corbett, 1994; Shuttleworth, 2007). Others suggest that the distinction is not so much private versus public, rather, a construction of sexuality as a want, versus a need. Framing sexuality as a want undermines the rationale for attaching a human and sexual rights imperative to exploration of this field (Shildrick, 2007). The study of sexuality and intellectual disability may be situated within an historical and cultural context, as the exploration of disability and sexuality has been influenced by various myths and historical, socio-cultural, and political conditions (Brown, 1994; May & Simpson, 2003).

Early discourses surrounding disability were embedded in myths around eternal childhood, difference, and fear (Brown, 1994). People with disability were conceptualised paradoxically, as either asexual, vulnerable, eternal children in need of protection, or as over-sexed, aggression individuals who posed danger to society (Hollomotz & The Speakup Committee, 2008). May and Simpson (2003) suggest that historical service models were predicated on two related functions, protecting individuals labelled with intellectual disability from the public (the innocence model), and protecting the public from so-labelled individuals (the degenerate model). Asylums and institutions arose as structures to fulfil these protective functions (Brown, 1994). Following the industrial revolution, and a growing emphasis on distributive citizenship, the conceptualisation of individuals labelled with intellectual disability shifted to focus on the degenerative model (Brown, 1994). Individuals labelled with disability became scapegoats for the perceived deterioration of society, and became resented for the strain they posed on social, and political systems (Brown, 1994). These sentiments coincided with the eugenic movement, which legitimised the sterilisation or limitation of reproductive rights of individuals labelled with intellectual disability (Brown, 1994; M. McCarthy, 2014). These imperatives were considered a logical enterprise and institutional segregation was employed as means to prevent reproduction. In the first half of the 20<sup>th</sup> century, May and Simpson suggest that individuals labelled with intellectual disability were

considered the deserving poor, achieving rights to welfare, and protection. The authors argue, however, that these conditions were achieved at a price, as care was closely associated with control, and individuals with intellectual disability assumed highly regulated lives. It is argued that those rules, policies, and regulations established within institutional settings benefitted professionals, rather than the residents to whom they referred (Hollomotz & The Speakup Committee, 2008).

As the eugenics movement lost influence, in the 1950s, the segregation model of care was questioned (May & Simpson, 2003). In this phase, there was a move toward community inclusion, and individuals labelled with disability were given a chance to prove their competence, and their ability to exist within the social realm. At this stage, access to an ordinary life, primarily through employment, was contingent upon notions of competence. The 1960s was marked by a sexual revolution, in which the ties between marriage, and reproduction were severed (May & Simpson, 2003). This shift in the conceptualisation of marriage meant that such a partnership was possible, although still not probable, for individuals labelled with intellectual disability.

The bulk of exploration into disability and sexuality has occurred post-1970s, following the inception of the normalisation principle, and social role valorisation theory (previously outlined in chapter two; Aunos & Feldman, 2002; May & Simpson, 2003; Wolfensberger, 2000). This new understanding of disability formed the context for deinstitutionalisation, a movement which created new possibilities for engaging in sexual expression, parenthood, and marriage (May & Simpson, 2003). In the 1980s discourses of disability and sexuality shifted from a focus on competence, to an emphasis on rights. Within Australia, the Disability Services Act (1986), and associated localised standards established the legal right of individuals labelled with disability to engage meaningfully in a range of domains, and to protect the right to privacy, dignity, and protection. More recently, Australia has moved to ratify, and thus uphold, those principles set out by the United Nations Convention on the Rights of Persons with Disabilities (United Nations General Assembly, 2006) in which the right to, and protection from discrimination preventing, privacy, marriage, parenthood, and relationships, are explicitly stated.

With the ascendancy of the HIV/AIDS epidemic, sexual health became a lens through which to study sexuality, still, however, individuals labelled with disability were not often included within this research (Shuttleworth, 2007). More recently, the field of sexuality studies has broadened to include focus on the sexual rights, and lives, of individuals labelled with disability (Shuttleworth, 2007). Focus has turned to exploring the lived experiences of individuals labelled with disability, on enacting effective social policy, on exploring the socio-cultural impediments to sexual expression, and to seeking a broader understanding of sexuality and disability. These foci place the exploration of sexuality, relationships, and intellectual disability in context of other marginalised identities, whom also experience limitations to sexuality, on the basis of social category (Shuttleworth, 2007).

While there seems to be some attitudinal change in the way that sexuality, relationships, and intellectual disability is considered, the rules and regulations of institutional settings, and the myths and assumptions of disability, have not experienced an equivalent shift (Hollomotz & The Speakup Committee, 2008). Some suggest that this discrepancy in explicit values around sexuality and disability, which embrace a human rights and social justice perspective, and extoll the need to support, facilitate and promote sexuality amongst all individuals, may be attribute to a kind of cultural lag (Shuttleworth, 2007). This cultural lag in the enactment of social policy and pragmatic promotion of sexuality for individuals labelled with disability is perhaps a manifestation of the tension between what is assumed to be right and necessary, and implicit attitudes, and desire to continue to protect so-labelled individuals, assumptions which are governed by various myths which construct disability.

While it is tempting to develop an understanding of the history of disability and sexuality in a progressive linear fashion, Brown (1994) suggests caution, arguing that these historical myths, ideologies, and discourses are still present in contemporary explorations of disability, relationships, and sexuality. She suggests that the various ideologies surrounding sexuality, relationships, and disability are apparent in contemporary service models, where sexuality for individuals labelled with disability is repressed, suppressed, earned or supported. It is argued that ideological shifts are not equivalent to shifts in practice (Healy, McGuire, Evans, & Carley, 2009). Shakespeare (2000) also understands the issues surrounding disability and sexuality

in a socio-cultural context, arguing that the problem of disability and sexuality is not inevitable. Rather, he suggests, various social structures, and systems, have established a context in which people labelled with disability experience barriers to sexual expression. These barriers exist formally (via service models, and policy), and informally (via relational structures, and the influence of individuals in care-provider roles). Individuals labelled with intellectual disability may have been awarded legal rights to sexuality; however, they may still experience social and sexual repression on moral, cultural or social grounds (Foley, 2012). Despite the apparent progress toward more and equal sexual rights for individuals labelled with intellectual disability, the gap between desire and the lived reality remains vast.

### 3.2 Continuing concerns

While the lives of individuals labelled with intellectual disability have changed remarkably in the last 50 to 100 years, this surely offers little consolation for individuals who continue to experience sexual oppression on the basis of this label. Contemporary studies have identified the complex tensions and paradoxes inherent to the study of disability and sexuality. Brown (1994) poses an argument that individuals labelled with intellectual disability, by asserting a right to sexual expression, may increase their visibility, with the unwanted effect of perpetuating stigma and oppression on the basis of this label. Conversely, Shakespeare poses a challenge to the notion that individuals labelled with disability are striving for normality in their sexuality. He suggests that, similar to those in the queer community, the disability movement must reflect on whether they are trying to gain access to Mainstream conceptualisations of sexuality, or, aiming to “...*challenge the ways in which sex and sexuality are conceived, expressed and limited in modern societies...*” (Shakespeare, 2000, p. 163). Similarly, Healy et al. (2009) suggest that the normalisation principle may not be conducive to a progressive conceptualisation of disability and sexuality. The authors suggest that principles of normalisation may be restrictive and contribute to evaluative discourses surrounding diversity in sexuality.

These ponderings raise interesting questions surrounding contemporary attempts to contribute to a progressive discourse of disability and sexuality. In their historical review on parenting, sexuality, and disability, May and Simpson (2003, p. 37) provide the following reflection:

*A marked feature of the contemporary literature is the certitude with which the case for extending parenting rights to people with intellectual disabilities is pressed, not only on the grounds that this is a moral imperative, but one that can operate in the long term interests of people with intellectual disabilities. The tone (if not purpose) is curiously reminiscent of that once adopted by proponents of policies exactly the opposite of those now being advocated, which we now (rightly) view with such distaste. What the two share, in addition to an unquestioning belief in the rightfulness of their respective positions, is the assumption that intellectual disability in itself provides grounds for intervention. Our concern here is that, in the interests of what may prove a small number of cases, we may unwittingly legitimate the extension of surveillance and regulation to a much wider group of people who were previously managing well enough.*

This quote provides an eloquent summary of key concern associated with navigating issues of disability, and sexuality. The authors suggest that each apparently new intervention, ideology or model which is contemporarily considered as contributing to a progression, has been predicated on the notion that intellectual disability introduces a remarkable quality to the experience of sexuality and parenting.

There is a serious, and perhaps inevitable, problem with research in disability and sexuality. By nature, research enquiry is undertaken through the lens of this label. The issue this presents is that the experiences of individuals labelled with intellectual disability are interpreted as disability-specific, or as a remarkable aspect of the individual's life. To this extent, research tends to honour the label of disability as a social category, and may undermine the progressive aims of the enquiry, perpetuating the notion that individuals labelled with intellectual disability are other. The tension, of course, is that individuals who are so-labelled do experience barriers to sexual expression, on the basis of this label. As such, in considering the research literature in this field, it is important to reflect upon the historical contexts, and understand the ideologies and worldviews represented. The progression of the research literature in the domain of disability and sexuality closely contributed to, and was informed by, the historical, social, political, and cultural contexts in which it was produced. While the fear-based, eugenicist-oriented, rhetoric of historical research literature is not prevalent in contemporary times, certain ideologies, and

assumptions of intellectual disability persist. For example, while it is recognised that all individuals desire intimacy and sexuality, there remains a strong focus within the research literature on establishing that individuals who are so-labelled do, in fact, want a close relationship (e.g., Lafferty, McConkey, & Taggart, 2013). This kind of research focus does not seem to appeal to a progressive discourse surrounding disability and sexuality. As McVilly, Stancliffe, Parmenter and Burton-Smith (2006a) reflect, relationships for individuals labelled with disability are not a unique phenomenon, they are comparable to individuals who live without this label. To understand relationships had by individuals labelled with intellectual disability as extraordinary in any sense is to undermine the point of the exercise.

### **3.3 Having a relationship**

To synthesise the literature in attempt to prove that individuals labelled with disability do desire relationships and sexual expression would be antithetical to the research enquiry. Rather, issues surrounding sexuality and disability are embedded in an understanding that so-labelled individuals are subject to sexual oppression, and that this label does not compromise the innate human desire to express sexuality, and engage intimately with others. As Rushbrooke, Murray and Townsend (2014a, p. 8) suggest, “...*the most helpful way for understanding the psychology of sexuality of people with intellectual disabilities is to understand the psychology of sexuality for people in general*”. Individuals who have shared their personal experiences with relationships, in the name of research on disability and sexuality, have spoken to a diverse range of experiences and issues.

Participants in various studies reflect on friendship and close relationships as characterised by reciprocity, mutual support and trust, helping and loving one another, and sharing interests (Bane et al., 2012; Healy et al., 2009; Lafferty et al., 2013; Yacoub & Hall, 2008). Participants reflected that close relationships provided practical, physical, and emotional support, and that having a partner could boost one's self and sexual esteem (McVilly et al., 2006a; Pham, 2012). Relationships are seen to provide company, love, affection, and a sense of personal development, growth, and progression (Rushbrooke et al., 2014a). Individuals express that close relationships are characterised by intimacy and represent the possibility for maturation, individual development, and development as a couple (Knox & Hickson, 2001). Some participants reflected on their sexual identities, describing that sexual



identity is fluid, developing over time, with age, and experience (Rushbrooke et al., 2014a).

Individuals labelled with intellectual disability, in various studies, shared a range of expectations and aspirations for relationships which could be considered unexceptional. Some individuals expected intimate relationships to develop into a marriage, lead to living with a partner, and perhaps result in a family (Azzopardi-Lane & Callus, 2014; Knox & Hickson, 2001). Individuals in various studies experienced a range of issues related to relationships, including; having children, being intimate, co-habiting with a partner, identifying as heterosexual, bisexual, Gay or as a member of the lesbian, gay, bisexual, transgender, intersex, and queer (LGBTIQ) community, and negotiating relationship breakdown (Healy et al., 2009; Yacoub & Hall, 2008). Some individuals expressed an eagerness to have children and were looking forward to the challenges and responsibilities of raising children (Healy et al., 2009). Some individuals shared that they are in long-term relationships, are married or divorced. Individuals labelled with intellectual disability occupy a range of roles – friend, wife, husband, boyfriend, girlfriend, ex-partner, and so on. While some individuals were happily single, others were looking for a partner (Bane et al., 2012; Yacoub & Hall, 2008).

A theme emerging from the stories shared by individuals labelled with intellectual disability in the research literature is that a lot of people who would like to have a close relationship do not have one (Johnson, Frawley, Hillier, & Harrison, 2002; Knox & Hickson, 2001; K. R. McVilly, R. J. Stancliffe, T. R. Parmenter, & R. M. Burton-Smith, 2006b). It is true that many people will navigate life without meeting dominant Western cultural standards for relationships and personhood; that is, without having met “the one”, without having children or getting married. Many people will experience heartbreak, loneliness, and love unrequited. As Hollomotz and the Speakup Committee (2008, p. 94) suggest, this forms the spectrum of the human experience:

*...everybody has their own choices and opinions and everybody can make their own decisions. Some relationships work out, some don't. But the person with learning difficulties should be able to try and make it work*

Enquiry into intellectual disability and close relationships is not necessitated by an assumption that all people should be in a relationship, rather, this enquiry is necessitated by the assumption that all people should have the opportunity, choice and control over their sexuality, relationships, identities, and experiences. The problem is that individuals labelled with intellectual disability seem to experience difficulties, and challenges, in negotiating close relationships, on the basis of this label.

### **3.4 Cultural assumptions, and cultural scripts**

Individuals labelled with intellectual disability exist in specific systemic, social and cultural contexts as a function of the label intellectual disability. These settings are culturally constructed by socio-cultural assumptions of what it means to be so-labelled. Bernert and Ogletree (2013) use the concept of *scripts*, which construct sexual values and rules of engagement, to articulate the sexual socialisation of women labelled with intellectual disability. The authors suggest that culturally established scripts guide one's sexuality, and "rules of engagement". In speaking with several women labelled with intellectual disability, the authors identified scripts which were characterised by assumptions that one should be free to associate with whomever they wish, should experience autonomy and privacy. As has been identified in other research studies (Bernert, 2011; Healy et al., 2009; Rushbrooke et al., 2014a), participants in this study spoke explicitly to their sexual rights, and responsibilities, and expressed discontent where these rights were violated.

Bernert and Ogletree (2013) suggest that rules of engagement around intimacy for women labelled with intellectual disability are characterised by various barriers to socialisation, autonomous partner selection, and sexual expression. Individuals labelled with intellectual disability in various research studies have protested violations to their sexual and human rights. For example, some participants in Healy et al.'s (2009) study explained that they would simply not be permitted to marry, and reflected on perceived inequities between their own, and their siblings' opportunities to engage in close relationships. Other participants describe that they have been actively discouraged from having children, or engaging in sexual activity (Fitzgerald & Withers, 2013).

Discourse surrounding stories shared by individuals labelled with intellectual disability is that they are vulnerable, in need of protection, or incapable of managing their own sexuality (Bernert & Ogletree, 2013; M. McCarthy, 2014). An assumption of individuals labelled with intellectual disability is that they are not well-positioned to engage in reciprocal relationships with others, to be recipients, and providers, of care (Fine & Asch, 1988). Discourses are often reflective of traditional gender stereotypes, where women are perceived as more vulnerable and naïve, and men may be perceived as focused on sexual activity, and as having limited self-control (Gilmore & Chambers, 2010; R. Young, Gore, & McCarthy, 2012). Sexuality and relationships are also often embedded in a heteronormative context, where so-labelled individuals are assumed to be heterosexual, and diverse sexual identities are often ignored, and sometimes openly discouraged (D. Abbott, 2012; D. Abbott & Burns, 2007; D. Abbott & Howarth, 2007; Burns & Davies, 2011; C. Hamilton, 2002; Lafferty et al., 2013; L. Löfgren-Martenson, 2004; L. Löfgren-Martenson, 2009). Individuals participating in research on disability and sexuality argue for their sexual rights, and argue against the social and cultural impediments to those rights (Healy et al., 2009).

### **3.5 Understandings of relationships and sexuality**

Sexuality is understood as a social construction. It seems that the kind of sexuality that is promoted to individuals labelled with disability is characterised by a range of socio-cultural messages. Fitzgerald and Withers (2013) suggest that sex education for all people is inadequate, but that individuals labelled with intellectual disability, in particular, may experience difficulty in accessing this information. While some individuals had received formal education around sexuality (Healy et al., 2009), it is widely acknowledged that sexual education for people labelled with intellectual disability is inadequate, or simply non-existent (Johnson et al., 2002; Lafferty et al., 2013; Williams, Scott, & McKechnie, 2014). Individuals labelled with intellectual disability may not experience the same kind of informal socialisation to sexuality as their age-related peers (Brown, 1994; Fitzgerald & Withers, 2013; Shuttleworth, 2007). Individuals labelled with intellectual disability typically experience very little opportunity to engage with peers in private, or to benefit from informal peer-based education. This historical, and contemporary, absence of informal and formal education around sexuality may lower one's sexual

self-esteem (Shakespeare, 2000), and preclude exploration of one's sexual identity (Bernert & Ogletree, 2013; Eastgate, 2008; Fitzgerald & Withers, 2013).

Traditionally sex education for individuals labelled with intellectual disability focussed on biology, rather than socio-cultural, or relational, aspects of sexuality (Bane et al., 2012; Dupras & Dionne, 2013; Knox & Hickson, 2001). Sex education has also been traditionally embedded in a heteronormative, and familial context, where sex is promoted as an activity for married couples and for reproductive purposes (Brown, 1994; Fitzgerald & Withers, 2013). This discourse ignores the socio-emotional dimensions of close relationships, and “...*tends to segment and compartmentalize the universal human experience of caring about and being cared for*” (Knox & Hickson, 2001, p. 288). Sex education tends to neglect issues related to masturbation, pap smears, breast screening, anal sex, oral sex, and diverse sexualities (Dotson, Stinson, & Christian, 2003). Sexual expression by individuals labelled with disability may also be pathologised, for example, masturbation has been previously considered by support-staff as “problem behaviour”, and contraception may be provided to women with no context or information regarding its purpose (Dotson et al., 2003). Dotson et al. suggest that in this scenario women are not afforded their reproductive rights, and that this reflects a socially-acceptable, modern-day, form of sterilisation of women labelled with intellectual disability. Various authors suggest that, without adequate sex education and information on their sexual rights, individuals labelled with intellectual disability may, in fact, become vulnerable to sexual abuse, and exploitation (Bernert, 2011; Hollomotz & The Speakup Committee, 2008; Pham, 2012).

Fitzgerald and Withers (2013) spoke with women labelled with intellectual disability to explore how they understood themselves as sexual beings. The women who shared their stories expressed that they had little or no concept of themselves as sexual beings. The authors suggest that the women spoke of “...*sex and sexuality as if having sexuality was simply not a viable option for them*” (Fitzgerald & Withers, 2013, p. 7). The women shared the opinion that sex was something nice for other people, but was not necessarily for them. Sex, and sexuality, for the women in this study was characterised as a pleasure-less, painful, dirty, disease-inducing activity. Bernert and Ogletree (2013) conducted research of a similar nature, engaging in an ethnographic exploration of sexuality in the lives of 14 women labelled with

intellectual disability. Participants in this study tended to focus on potential negative outcomes of engaging in sex, such as acquiring a disease, experiencing pain, or unwanted pregnancy. Discourses surrounding sex tended to focus on the conditions or criteria which might warrant sexual activity, for example, engaging in protected and monogamous sex within a marriage, having sex with a loving partner, and having sex for reproductive purposes. For the women in this study, abstinence from sex was a popular choice. The authors expressed concerns that the women in their study seemed to be avoiding sexual activity for the sole purpose of evading negative consequences. The authors suggest that abstinence can reflect a positive and proactive choice, but emphasise that it should reflect an informed choice.

Bernert and Ogletree (2013) note that discourses surrounding sexuality and intellectual disability revolve around sexual suppression, rather than sexual expression. Women labelled with intellectual disability may avoid having sex altogether perhaps due to lack of, or mis-, information (Johnson et al., 2002) and may be denied their sexual rights, and identities as women and mothers (Dotson et al., 2003). Fitzgerald and Withers (2013) suggest that women labelled with intellectual disability may hold negative views toward sex, and sexuality, as a cumulative effect of the socio-cultural context which constructs the sexuality of so-labelled individuals. Some individuals participating in Rushbrooke's (2014a) study viewed sexual expression as problematic, the authors suggest, because individuals are often reprimanded for acts of intimacy, such as hand-holding. Bernert and Ogletree question why women labelled with intellectual disability would have a positive perception of sexuality, potentially never having had a positive experience, or receiving any positive messages about sexuality. Individuals labelled with intellectual disability are primarily subjected to restrictive scripts surrounding sexuality, which emphasise disease, abstinence, and promote the idea of sex after marriage (Bernert & Ogletree, 2013; F. Sullivan, Bowden, McKenzie, & Quayle, 2013). Brown (1994, p. 141) suggests that individuals labelled with intellectual disability who live ordinary sexual lives should be supported in what is, effectively, an act of rebellion for their "kind".

### **3.6 Boundaries, power and regulations**

In recent years, there has been a shift in service philosophy, and ideology, a movement to shift decision-making power from service-providers to individuals

accessing services (S. Abbott & McConkey, 2006; Healy et al., 2009). This ideological shift is embedded in the shift in service-provision from institutional settings to deinstitutionalised settings. Despite these policy and philosophy shifts, it is argued that individuals labelled with intellectual disability are still embedded within contexts in which negative, or less supportive, attitudes toward disability and sexuality tend to prevail (Healy et al., 2009). Contemporary models of service-provision aim to promote community inclusion and social relationships for individuals labelled with intellectual disability. While goals such as “making friends” are often included in individual’s person-centred plans, the attainment of these kinds of goals is extremely variable (S. Abbott & McConkey, 2006). Emerson and McVilly (2004) suggest that intervention at a systems level, rather than individual or skill-based level, is required in order to foster community inclusion and social engagement for individuals labelled with intellectual disability.

There is an acknowledgment that the increased community presence associated with deinstitutionalisation, does not equate to community inclusion or meaningful social contact with others (S. Abbott & McConkey, 2006). Individuals taking part in a participatory action research project in New Zealand, exploring community inclusion and participation, described that their lives centred around segregated disability-specific settings, and that participation tended to be organised and moderated by service-providers (Milner & Kelly, 2009). Individuals in Abbott and McConkey’s (2006, p. 281) study, in which the barriers to social inclusion were explored, explained that social inclusion for them represented “... *meeting people in ordinary settings and being treated similarly.*” It seems as though current service models strive to construct a normal existence for individuals who are labelled with intellectual disability. In striving for normality, however, perhaps it is possible to create settings which perpetuate stigma around disability, and further remove opportunities for choice, control, and engaging in the full spectrum of human experiences.

There are various tensions inherent to service settings that are designated on the basis of the label intellectual disability. These tensions are represented in the research literature, and relate to issues of power, privacy, choice, control, autonomy, surveillance, and protection. Researchers in the Living Safer Sexual Lives study (LSSL; Johnson et al., 2002) uncovered what they term a culture of caution and

prohibition within service-settings for individuals labelled with intellectual disability. This collaborative action research project took place over a three year period, in two distinct stages. In the first stage of the project, 25 individuals contributed their life histories with an emphasis on sexuality and relationships. These life histories were discussed amongst a reference group, service-providers, generating several key themes, such as, feelings of social rejection and loneliness, support-staff and family members discouraging intimate relationships and, the enactment of relationships in a secretive manner. The next stage of the LSSL project involved developing, implementing, and evaluating a range of resources (e.g., workshop modules, information resources) to address the themes of the stories. A concern expressed by individuals labelled with intellectual disability in the research literature is the role that service-settings may play in creating boundaries for close and intimate relationships (McVilly et al., 2006a). Individuals labelled with intellectual disability in various studies who live in residential and family home settings and who access services for social purposes have described concerns surrounding privacy and the ability to exercise control and choice (Lafferty et al., 2013; Rushbrooke et al., 2014a; F. Sullivan et al., 2013; Yacoub & Hall, 2008).

Participants across various studies have spoken of limitations to their privacy within the family home, or residential services. For example, some individuals explained that they resided in a shared bedroom, others explained that their bedroom had no lock on the door (Hollomotz & The Speakup Committee, 2008), or that they were not permitted to keep their bedroom door closed while a friend visited (Yacoub & Hall, 2008). Other individuals described that they had no space other than a bedroom in which to entertain a friend, as their residence was otherwise communal space, and they were not permitted to go out alone (Knox & Hickson, 2001). Common to the experiences of individuals across various studies is a culture of surveillance, and restriction, on personal relationships and social activity (Lafferty et al., 2013). Some individuals explained that services restricted their ability to have a romantic relationship, for example, one participant commented "*They don't want us on our own in case something might happen*" (Healy et al., 2009, p. 908). Hollomotz and the Speakup Committee note that privacy is not just about the opportunity have sex, it is important to spend private time with someone, to get to know about that person, and to be able to communicate in private.

Other individuals described funding limitations, staff availability, and service scheduling inhibited autonomy and spontaneity in their social lives, and relationships (McVilly et al., 2006a). Transport was also identified as a common barrier to engaging in close relationships and being able to socialise independently of family or service-provider involvement (McVilly et al., 2006a). It seems that individuals labelled with intellectual disability are limited in their autonomy as they often have to rely on family, friends or service-providers to travel to and from venues. If a family member, service-provider or friend does not think it is appropriate, the individual may simply not be transported. For example, a participant in Rushbrooke et al.'s (2014a) study explained that he was not permitted to go to "clubs" because his support-worker did not feel it was safe.

For some individuals, service-settings may form the primary setting for socialisation, and opportunities to meet a romantic partner. For example, many of the participants in Healy et al.'s (2009) study explained that they had met their boyfriend or girlfriend through their service provider, and that social settings provided by the service-provider had mitigated feelings of social isolation. These service-settings tend to reflect a congregative care model, where individuals labelled with intellectual disability may be restricted to socialising only with other so-labelled individuals. Opportunities for spontaneity, variability, and personal choice to extend beyond one's immediate social contacts may be somewhat limited (McVilly et al., 2006a). Often, in these formalised service settings intimate behaviours are prohibited, which can pose challenges for couples who only get to see one another at work or at activities hosted by the service-provider (Bernert, 2011).

Sullivan (2013) notes the high level of external control, supervision, regulations, and restrictions which seem to dominate the intimate relationships of individuals labelled with intellectual disability. There is a discourse within the literature of individuals being permitted or allowed to engage in close relationships, and everyday activity. Many of the women participating in Fitzgerald and Withers (2013) study suggested that they were not allowed to have sex, for fear of getting caught, and of the associated consequences, for example, no longer being permitted to see one's boyfriend. Another woman described that staff at her service provider allowed she and her boyfriend to be in a relationship, that she was permitted to kiss and hug him, but she did not think they would be permitted to have sex. Similarly, women sharing



their stories for other research studies note that they are not allowed to have a partner spend the night, and that they are often accompanied on dates (Bernert, 2011). One woman explained that her family, unbeknownst to her, had her marriage legally dissolved (Bernert, 2011). Fitzgerald and Withers (2013, p. 9) offer the following reflection, “...it seems that women with learning disabilities are expected to relinquish to others even the most practical details of the management of their own bodies within intimate relationships”.

Fitzgerald and Withers (2013) elude to a dominant discourse within the literature that family members, support-workers, and service-providers seem to inhabit a kind of “gatekeeper role” in the lives of adults labelled with intellectual disability. For example, family members or support-workers may play an integral role in organising for a couple to meet up and spend time together (Bernert, 2011). The influence of support-workers, family members and service-providers on intimate relationships of adults could be considered inordinate (S. Abbott & Mcconkey, 2006), for example, a woman in Bernert’s (2011, p. 136) study shared that “...if she acted ‘just right’, I can go to his ‘partment alone. I can be there for a little bit.” This participant believed that time with her boyfriend could be earned through appropriate behaviour, and access would be granted on the good will of staff. Similarly, individuals attending a particular service-provider explained that they had to gain approval from a family member or guardian to socialise alone with friends in their bedroom (Bernert, 2011). Other researchers have also noted this dynamic, where time spent with one’s partner might depend on the goodwill of staff who may choose to overlook written or unwritten rules (Hollomotz & The Speakup Committee, 2008; E. Rushbrooke, C. D. Murray, & S. Townsend, 2014b). These rules of engagement take are particularly significant given that they apply to and govern the close relationship experiences of adult individuals.

It seems as though service settings, and discourses around protection, and gatekeeping, establish contexts where individuals labelled with intellectual disability are disempowered. A theme within the research literature is a sense expressed by individuals labelled with intellectual disability that they are looked down upon, and treated like children (Fitzgerald & Withers, 2013; Hollomotz & The Speakup Committee, 2008). Individuals participating in Fitzgerald and Wither’s study did not identify as women, rather, they self-identified as girls or “grown teenagers”.

Individuals labelled with intellectual disability may be kept in a suspended state of adolescence, which may be considered a form of social constraint (Hollomotz & The Speakup Committee, 2008). Individuals in various studies reflect that their caregivers or support-workers are overprotective, and feel that they should be less restrictive, and more supportive and tolerant of their relationship needs (Bane et al., 2012; Healy et al., 2009). Some individuals described caregivers' actions as unhelpful, or posing challenges to their intimate relationships (Rushbrooke et al., 2014a). Participants reflected that caregiver actions were motivated by avoiding risk, and were based in fear, which meant that support provided was often experienced as intrusive or threatening. In a study exploring how families negotiate decisions surrounding transition planning across the lifespan, Pilnick, Clegg, Murphy and Almack (2011) identified that, where conflict in views was apparent, the views of parents or carers tended to prevail over those of their son or daughter labelled with intellectual disability.

Participants across various studies argue that they should have access to sexual rights, they should be able to have children, and to get married if they wish (Bane et al., 2012). Individuals participating in Bane et al.'s study suggest that there is a need for individuals labelled with intellectual disability to be treated as adults with rights. Some participants felt strongly about these rights, and rejected the notion that resistance to "being told what to do all the time" did not reflect an attitude problem, as was perceived by staff (Bernert, 2011). Rushbrooke et al. (2014a, p. 9) suggest:

*Caregivers should expect people to want relationships and be prepared for a negative impact if they do not have the opportunity to form relationships or express their sexuality.*

A dominant discourse within the literature with regard to intellectual disability and relationships is that so-labelled individuals require protection, and family members, support-workers, and service-providers exist to carry out this function. It seems that it is a given that the intimate relationships of individuals labelled with intellectual disability should and will be managed by some external party.

### **3.7 Policies, guidelines and rushed sex lives**

A strong theme within the research literature is the acknowledgement that individuals labelled with intellectual disability tend to exist in settings (such as

formal service-settings, residential group homes, and informal familial systems) in which opportunities to engage in intimacy, sexuality, and close relationships are limited. Cambridge and McCarthy (1997) suggest that sexuality is often considered by service-providers, family members, and those in the network surrounding the individual as a problem to be solved. An assumption which is evident within the literature is that those who surround individuals labelled with intellectual disability (such as family, friends, support-workers, and agencies) have a role to play in supporting, intervening or moderating intimacy, and close relationships. This assumption is perhaps underpinned by a paternalistic, or protectionist, attitude toward individuals labelled with intellectual disability. For example, Lafferty et al. (2013) suggest that parents, family members, and support workers need to recognise that it is in part their role to facilitate relationships. This reasoning seems reflective of that which May and Simpson (2003, p. 37) caution against, the authors suggest that there is still a widely-held “...*assumption that intellectual disability in itself provides grounds for intervention.*” Mindful of this assumption, perhaps Lafferty et al.’s point could be re-framed, to suggest that family members, parents, and carers need to recognise the level of power they may exercise over the close relationship opportunities of individuals labelled with intellectual disability. This re-framing shifts the responsibility from facilitating relationships, to exercising mindfulness over the inordinate level of power one may exercise over someone else’s relationship.

The approach of formal service-providers, of family members, and support-workers to sexuality and close relationships represented in the literature was variable. Policies adopted by formal service-providers toward intimacy, relationships, and sexuality tend to be characterised as vague and restrictive (Bernert, 2011; Healy et al., 2009; Johnson et al., 2002; Wings-Yanez, 2014). There seems to be a tension represented in the literature – the notion that service-providers have a responsibility to enact some policy and guidelines, yet there was a danger that these policies could become restrictive. This paradox is perhaps reflective of an internal conflict experienced by support-workers, and family members, who perceive that it is their role to protect and ensure the safety of individuals labelled with intellectual disability, but who also feel a responsibility to support positive sexuality and close relationships (Fitzgerald & Withers, 2013). These imperatives seem to be posited as

competing goals. Some individuals noted that their support-workers had provided some psycho-sexual advice, however, that support-workers generally seemed afraid to talk about it (Healy et al., 2009).

This discourse may be underpinned by a range of issues, including, administrative concerns of formal service-providers, attitudes or values toward sex, concerns for risk management, and a paternalistic and protectionist stance toward individuals labelled with intellectual disability. Culture and religion may play in establishing the nature of the settings inhabited by individuals living with disability (Azzopardi-Lane & Callus, 2014; Brown, 1994; Saxe & Flanagan, 2014). Healy et al. (2009) reflect that many of the formal service-providers in Ireland are embedded in religious organisation, and education often occurs according to a Catholic doctrine. Religious ideology may inform policy and lead to restrictions on personal choice in relationships. For example, women in Bernert's (2011) study explained that they were not allowed to cohabit with a partner in a residential setting, have sex or attend dates independently, until they were married. The authors suggest this is a kind of oxymoron, as the women were also not likely to be permitted to get married.

For service-providers, family, and support-workers, there was some concern that they may face legal consequences for providing opportunity for sexual expression (Healy et al., 2009). Others had been "warned" of the consequences of allowing sexual activity to take place within the service, for example, one support-worker was informed "*All you need to know is that if they're caught having sex on your shift, you're fired.*" (Winges-Yanez, 2014, p. 107). One support-worker reflected that policies were not only seen as protective for individuals labelled with intellectual disability, but also for the agency itself, she noted that "*I think places are so afraid that if something happens while they're on duty that they're going to get reported...*" (Bernert, 2011, p. 138). This emphasis on the potential for sexual abuse, exploitation, and the need for protection, may lead support-workers to see all sexual behaviours as in need of risk-management (McConkey & Ryan, 2001). Support-workers, family members, and others are perhaps placed in a position where they feel they are striving for competing goals, protection, and support to access sexual rights, this tension is perhaps eloquently summarised in the following comments from a support-worker;

*I know it's like scary territory for providers to deal with, but these are humans, these are adults. Even in adolescence, if that's the stage you're at, that sexual drive is very strong. It's almost as strong as eating, and definitely as strong as a drive to work. The drive to want to work and make money, we push that so much, but yet, we say, 'No way' on the sex stuff* (Bernert, 2011, p. 139).

It is argued that service-providers tend to emphasise practical day-to-day tasks, such as going shopping, over supporting individuals to engage socially with others (Jones, 2009; McVilly et al., 2006a). Researchers have suggested that agencies value administrative neatness and prioritise risk-management, over supporting the right of individuals labelled with intellectual disability to live the kinds of lives they want to live. This reluctance to address issues concerning sexuality, and close relationships is noted across various studies. Support-staff may wish to support the sexual rights of their clients, which may conflict with the view of family members or guardians, and vice versa (Brown, 1994). Family members, support-workers, and guardians may engage in unspoken contracts surrounding what is, and is not appropriate support. Individuals labelled with disability, their support-workers, family members, and service-providers are engaged in settings which pose complex and paradoxical moral, legal, and political tensions (Brown, 1994; Mall & Swartz, 2012). Foley (2012) suggests that introducing legal policy, guidelines, to protect the sexual rights of individuals labelled with intellectual disability may not lead to change, or the protection of these rights in real-world settings. He suggests that parents, and others, have a moral responsibility to ensure that the legal rights of so-labelled individuals are maintained.

Saying “no way” to sexuality, relationships, and intimacy in service-settings and within the family home contributes to an atmosphere of prohibition and restriction. This discourse suggests there is a paradox in establishing formalised sexuality and relationship policies within service-providers. Policies which are in place to protect and support individuals labelled with intellectual disability may in fact pose risks for sexual health. Hollomotz and The Speakup Committee (2008) suggest that it is not possible to prevent sexual activity through limiting privacy, or restricting social engagement, rather, the authors suggest that individuals will seek out alternative settings for sexual activity, which may cause intimacy to be rushed or unsafe. The “secret sex lives” of individuals labelled with intellectual disability is a strong theme

within the literature, where so-labelled individuals are seen to conceal sexual activity, or carry out relationships in a secretive manner (Rushbrooke et al., 2014a). Various studies have found that so-labelled individuals, in the absence of being able to choose to engage in sexual expression in a private and safe setting, find alternative settings to engage in intimacy (Johnson et al., 2002). Rushed sexual activity, or “...*sexual activity behind the wall...*” does not afford sexual rights, nor does it allow for a careful negotiation of personal boundaries (Johnson et al., 2002, p. 93). Individuals labelled with intellectual disability have a right to secrecy, concealment, and privacy, but they should also be able to display intimacy, and celebrate their relationships in the public domain, at home, with friends and family, if they wish. Hollomotz and the Speakup Committee (2008, p. 96) argue that “*Only consistent policy guidance that makes our rights explicit can ensure that being allowed the privacy to lead fulfilling sexual lives becomes the norm, not a privilege.*”

There have been some direct attempts to establish sexuality policy, guidelines, and to promote positive sexuality, documented within the research literature. For example, some researchers document their experiences in developing, and implementing sexuality and relationship education or support programs (Box & Shawe, 2014; Johnson et al., 2002; Johnson, Hillier, Harrison, & Frawley, 2001). Many of these contemporary programs reflect a deliberate attempt to transcend traditional biological discourses around sexuality, and account for socio-cultural issues. Findings from the previously outlined LSSL project (Johnson et al., 2001) project highlighted some of the challenges faced by people labelled with intellectual disability in relation to their close relationships and sexual expression. The final phase of this collaborative action research project involved developing, implementing, and evaluating a range of resources (e.g., workshop modules, information resources) to address the themes of the stories. These resources were targeted to individuals labelled with intellectual disability, family members, and others. The strengths of the LSSL project were the recognition of people labelled with intellectual disability as experts in the field of their own lived-experiences and the exploration of issues of sexuality within the broader context of individual's lives. The LSSL project spawned another program, the respectful relationships education program, which was designed to be delivered collaboratively, by peer-educators and professionals in the disability-sector (Frawley & Bigby, 2014). This new peer-

education model was valuable for empowering educators, and positioning individuals who live with the label intellectual disability as credible resources of information and experts in their own experiences (Frawley & Bigby, 2014).

Another approach to promoting positive sexuality and to negotiating the recognised tensions surrounding sexuality and intellectual disability is the establishment of dating agency services for individuals labelled with intellectual disability. Jones (2009) outlines the *disability agency movement* which took hold in UK in the mid-2000s and led to the establishment of several dating agency services specifically for individuals labelled with disability. The Relationship Support Service (Jenner & Gale, 2006a, 2006b) was established as a means to create opportunities for individuals labelled with intellectual disability to meet friends, and potential romantic partners. The service provided introductions for individuals following various checks, and risk-assessments to determine their suitability for the service. Evaluation of a pilot study for the service reflected that several individuals had submitted applications, and that several introductions had been made (Jenner & Gale, 2006b). The authors highlighted several challenges in delivering the service, many of which centred on practical concerns, such as resource limitations. The authors highlight a concern around continued funding for the program, and suggest that within the broader community the service is often met with apathy, negative attitudes, and lack of understanding (Jenner & Gale, 2006b). Around the same time as the inception of the Relationship Support Service, another service "Stars in the Sky" was also established, and has since branched out into several locations across the UK (Jones, 2009). Mates'nDates, another service also established around this time set out to provide education, support, and to facilitate introductions for individuals looking to meet someone for friendship, sex or a romantic connection. This service also catered for individuals who identify as part of the LGBTIQ community, via the program "Mingle".

While these dating agency style services work to create opportunities for social engagement, intimacy, and positive sexuality among individuals labelled with intellectual disability, they also pose some complex ethical and moral challenges. Jones (2009) identifies the paradoxical nature of specialist dating agency services for individuals labelled with intellectual disability. The author acknowledges that specialist dating agencies undermine the notion of equality in community access for

so-labelled individuals. These dating agency services establish the needs of individuals labelled with intellectual disability as mutually exclusive to individuals who do not live with this label, individuals who are part of the Mainstream (Jones, 2009). As such, in attempting to enhance access to an ordinary sexual life, such services may be further perpetuating the othering of individuals on the basis of the label intellectual disability. This paradox, and tension, is replicated in other service models for individuals labelled with intellectual disability, and is embedded in the pursuit of a normal existence for so-labelled individuals (Shakespeare, 2000). In the pursuit of normality, alternative spaces for habitation are constructed; these alternative spaces may become exclusionary for so-labelled individuals.

### **3.8 Negotiating moral, cultural and legal terrains**

The magnitude of research literature surrounding family member, support-worker, and community member understandings of disability and sexuality indicates the importance of this issue, not only for so-labelled individuals, but for those who surround them, such as family, support-workers, and service-providers. Research findings indicate that family members and support-workers hold generally positive attitudes toward the sexuality of individuals labelled with intellectual disability, and acknowledge the need to support close relationships as a matter of human rights (Garbutt, 2008; Gilmore & Chambers, 2010; C. A. Hamilton, 2009; Meaney-Tavares & Gavidia-Payne, 2012; Pownall, Jahoda, & Hastings, 2012; R. Young et al., 2012). Despite this ideology, there is a recognised lack of proactive support for so-labelled individuals to engage in close relationships, and the disturbing discrepancy between desire to engage in relationships, and experience with relationships remains (Evans, McGuire, Healy, & Carley, 2009). This discrepancy may be reflective of a perpetual negotiation of the complex moral, cultural, and legal contexts surrounding sexuality, relationships, and individuals labelled with intellectual disability (Almack et al., 2009).

Inherent to discourses around sexuality, relationships, and intellectual disability, is an assumption that family members, support-workers, and others have a role to play in supporting, protecting, and empowering the so-labelled individual (Almack et al., 2009; Lafferty et al., 2013). There is a sense that parents, and others, may be considered accountable for the sexual development and relationship experiences, of their son or daughter. This level of accountability may be rooted in myths of



suspended adolescence (Hollomotz & The Speakup Committee, 2008), and assumptions that individuals labelled with intellectual disability are incompetent, vulnerable, and require protection (Bernert & Ogletree, 2013; M. McCarthy, 2014). As such, parents, family members, and support-workers may be placed in a difficult position where they are expected to manage and moderate the sexuality and close relationships of their son, daughter or client (Rushbrooke et al., 2014b). These expectations and roles may be seen in context of broader dominant Western cultural assumptions of what it means to be the parent of an individual labelled with intellectual disability. Potential restrictions in decision-making opportunities within the familial contexts are framed by some parents and siblings as a consequence of interactions within broader social contexts, where their sibling, son or daughter may have experienced hostility, or adverse consequences related to perceived disability-related difference (Saaltink, Mackinon, Owen, & Tardif-Williams, 2012). The notion of parents as mediators between the private world, and public worlds, of adult sons and daughters labelled with learning disability is captured in Todd and Shearn's (1997) exploratory study on the nature of parent-adult offspring and co-residence. The authors found that, in their role as mediators between their adult offspring and the wider world, parents furnished their adult sons and daughters "*...with a particular view of their relationship to it*" (Todd & Shearn, 1997, p. 362). The authors found that parents actively managed interactions with the wider world, to protect the individual from the stigma associated with learning disability. Parents engaged strategies of "*...non-disclosure and fictional identity building*" via constructing false biographies and life plans for their adult son or daughter (Todd & Shearn, 1997, p. 362). These false biographies and life plans are "*...always just a little bit ahead in terms of their realisation*" (Todd & Shearn, 1997p. 362-363) In so doing, the authors suggest, parents may be legitimating those myths and the stigma from which they are working to protect their adult son or daughter, potentially restricting opportunities to engage in close relationships and express sexuality.

The familial dynamic, although traditionally conceptualised as a care-giver-care-recipient dyad, may reflect a more interdependent, relational model, characterised by mutual support and reciprocal engagement among all family members (Knox & Bigby, 2007). Knox and Bigby's findings pose a challenge to the assumption that the individual labelled with intellectual disability "*... is forever the recipient, rather than*

*ever the provider, of help and support*" (Fine & Asch, 1988, p. 13). For example, families participating in a study to explore the notion of midlife care for individuals labelled with intellectual disability reflected on an ongoing change process, where the family unit worked together to negotiate what is termed *Family Business*, a form of family care, rather than "...care *per se*" (Knox & Bigby, 2007, p. 293). Families suggested that this interdependency was a means to maintain collective independence from more formal service-providers, a way to ensure the wellbeing of all family members individually, as well as the family as a unit. Pursuing independence from disability service-providers emerges as a theme within the literature, where some parents consider that the empowerment rhetoric espoused by policy-makers is abstract, and not valuable in terms of practical application, for their sons and daughters (Jingree & Finlay, 2012). Parents and family members, have long been framed as overprotective or reflecting ableist values (Neely-Barnes, Graff, Roberts, Hall, & Hankins, 2010). The parent-child relationship may be experienced very differently, however, by parents and family members, who describe that they work alongside their son or daughter labelled with intellectual disability, as a team, to resist community perceptions and assumptions surrounding ableism (Neely-Barnes et al., 2010).

Various research studies exploring understandings of sexuality and relationships indicate that parents, family members, and support workers are placed in a difficult position where they must navigate a complex paradox surrounding the pursuit of seemingly contradictory goals (Breen, 2009; Rushbrooke et al., 2014b). Parents and support-workers refer to a balancing act, where they must protect their son or daughter, while also empowering and supporting them to engage in close relationships and express their sexuality (Dupras & Dionne, 2013). This balancing act is embedded in socio-cultural emphasis on risk-management, and on the human right to sexual expression (Almack et al., 2009; Rushbrooke et al., 2014b). Parents and support-workers express a need to balance competing roles of protector and facilitator, from a qualitative meta-synthesis of various studies exploring disability, sexuality, and caregiver perspectives, Rushbrooke (2014b, p. 883) identified that:

*...sexuality and relationships appeared to be an area that put caregivers in the position of trying to advocate for something which they then had to stop people from doing in order to safeguard or risk manage.*

This discourse surrounding parental, and support-worker, roles in sexuality, relationships, and intellectual disability, is often posed as a series of binaries. For example, parents may be considered over-protective, or irresponsible, of being proactive, or discriminating against their loved ones through a lack of support (Almack et al., 2009).

Various research studies indicate that parents, and support-workers, may have little information to guide their decision-making processes around supporting, and managing perceived risks, associated with close relationships. In an effort to conform to cultural expectations for risk management, parents may be encouraged to keep their son or daughter close to home (Garbutt, 2008), and support-workers may engage in constant supervision of clients, reluctant to permit absolute privacy (Evans et al., 2009). Research findings suggest that support-workers and family members may rely on various strategies to negotiate sexuality and relationships, including making assessments of the individual's capacities, and competencies to engage in relationships (Grieve, McLaren, Lindsay, & Culling, 2008; Wilson, Parmenter, Stancliffe, & Shuttleworth, 2011). Sexuality was also often considered a conditional construct, where an individual may be considered more or less sexual depending on their perceived level of disability (Wilson et al., 2011). Those individuals considered to experience more severe levels of disability were sometimes denied as sexual beings. Often, support-workers and family members would assess competencies against what they considered to be normal. The extent to which a couple was perceived to be "doing normal" mediated their access to support to express sexuality (C. A. Hamilton, 2009). In this sense, access to support for one's sexual rights, or opportunities to engage in relationships, could be earned through performing, and showing conformity to, normative behaviours (C. A. Hamilton, 2009). In the absence of clear guidelines, policy or education, it is possible to reflect on how parents, support-workers, and others could rely on anything other than personal values and ideologies to manage sexual rights and risk for individuals labelled with intellectual disability (C. A. Hamilton, 2009; Wilson et al., 2011).

Almack et al. (2009, p. 296) suggest that parents and support-workers are placed in an "... *an ambiguous moral position*", where they are afforded mandate to make authoritative decisions regarding their son or daughter's sexuality, but are also open to professional, and public, scrutiny over the nature of the decisions they make. In

this way, the authors suggest, parents, family members, and support-workers are also constructed via a series of expectations, and assumptions, and "...*face a risk to their own identities as good (responsible) parents*" (Almack et al., 2009, p. 296).

Discourses surrounding parenting for individuals who have a son or daughter labelled with intellectual disability focus on the experience of mothers, and often appeals to notions of the "good" versus the "bad" mother (Knight, 2013). As such, family members, and parents, are often scrutinised, and subjected to socio-cultural evaluations of their role, they may be constructed in terms of a dichotomy, as over-protective or conversely, self-sacrificing.

### **3.9 Close relationships as remarkable**

In the not-so-distant past, the majority of research literature around disability and sexuality was conducted via proxy-informants, and usually grounded in prevention, protection and problem-based rhetoric (Walmsley & Johnson, 2003). These historical forms of inquiry contrast with the nature of more contemporary studies, which adopt a rights-based empowerment approach to the exploration of disability and sexuality, acknowledging the need to access lived experiences, and attend to the socio-cultural barriers faced by individuals who live with this label (Walmsley & Johnson, 2003). An interesting feature of contemporary literature is a discourse which presents the close relationship experiences, desires, and aspirations of individuals labelled with intellectual disability as remarkable. A range of research studies endeavour to establish that individuals labelled with intellectual disability do, in fact, desire intimacy and close relationships (e.g., Azzopardi-Lane & Callus, 2014; Stoffelen et al., 2013; F. Sullivan et al., 2013). This rhetoric is evident in the following extract from a study exploring the sexual identities of individuals labelled with intellectual disability:

*The findings generated from this research illustrate how people with intellectual disability are not only aware of their sexuality but also how it is perceived by others. It clearly shows that they are sexual beings and that sexuality is a topic which is of direct interest to them. It is also a topic in which they are engaged at length and depth during the discussions that resulted from the various meetings that were held (Azzopardi-Lane & Callus, 2014, p. 3-4)*

In stating that individuals labelled with intellectual disability are sexual beings, and aware of their sexuality, the authors seem to be subscribing to rhetoric surrounding competency, normality, and capacity. Similarly, other research studies endeavour to report on the frequency, and nature of sexual contact and relationship activity (e.g., Stoffelen et al., 2013), or claim that individuals with intellectual disability are somewhat uncomfortable discussing sexual activity in the research context (e.g., F. Sullivan et al., 2013). These lines of enquiry present sexual activity, sexuality, and the desire for intimacy, in the realm of the remarkable, or extraordinary. Findings such as these infer that individuals labelled with intellectual disability experience sexuality differently, on the basis of this label. These findings are embedded in rhetoric of capacity, as if establishing this capacity warrants or legitimises research and action to support the sexual rights of individuals labelled with intellectual disability. Assuming a social constructionist perspective acknowledges the nature of intellectual disability as a socio-cultural construction and presents findings such as these (e.g., that individuals labelled with intellectual disability are sexual beings) as somewhat redundant. This discourse inherent to contemporary studies suggests that we, as researchers, are engaging in the study of relationships of individuals who are intellectually disabled, rather than relationships of individuals who are so-labelled. As such, the assumptions, myths, and stigma surrounding intellectual disability, which form socio-cultural barriers to engaging in close relationships, are allowed to prevail.

There is also discourse in the research literature which evaluates the authenticity, or legitimacy of close relationships had by individuals labelled with intellectual disability. Various authors suggest that participants in their studies had romanticised views on their relationships. For example, Knox and Hickson (2001, p. 287) suggest that two participants in their study described their relationship “... *in what might be considered an idealized romantic manner*”. Similarly, Lafferty et al. (2013, p. 1076) surmised from the body of research literature that so-labelled individuals tend to hold “... *positive, idealistic attitudes towards love and close relationships*”. Lafferty et al. explain that participants in their own study were generally content with their close relationships, and that they tended to subscribe to a “... *idealised view of the future*” (Lafferty et al., 2013, p. 1085). Arguably, all individuals are susceptible to describing their relationship in an idealised manner, and at the very least, researchers are not in

a position to determine what is and is not romanticised. When it comes to the relationships of individuals labelled with intellectual disability, there is an assumption that these relationships are up for evaluation and scrutiny, and that we, as researchers, are well-positioned to make such judgements.

### **3.10 Conclusion**

In this chapter, I considered the social construction of intellectual disability within the context of relationships, intimacy, and sexuality. In so doing, I presented a critical discussion of the complexities and tensions which seem to pervade the experience of individuals labelled with intellectual disability in negotiating relationships and sexuality. It is necessary to ground this consideration within an historical context, doing so reveals patterns, dynamics, and tensions inherent to contemporary contexts. A key feature of this chapter was a deconstruction of the paradox inherent to exploring the relationship experiences of individuals labelled with intellectual disability; that is, in engaging in this exploration, we, as researchers, can be culpable for presenting relationships had by so-labelled individuals as remarkable or extra-ordinary. Another key feature of this chapter was a deconstruction of the unique social settings occupied by individuals labelled with intellectual disability, family members, friends, siblings, support-workers, and others. The complex moral, legal, and cultural tensions which play out within these settings are disempowering for the so-labelled individual, and for those who surround them (e.g., the parent who may be constructed as “irresponsible”). This chapter reflects an attempt to move away from binaries and individualised discourses which traditionally form the narrative around disability, sexuality, and relationships in favour of a discourse which captures the complex social, cultural, historical, and political context in which these issues are embedded. The content of this chapter provides context for the research inquiry, the details of which are outlined in the following chapter.

## **Chapter four: Ontology, Epistemology, Research Aim, Methodology and Methods**

In this chapter I present the ontology, epistemology, methodology, and methods for this research project. To reiterate, the research aim was to explore what it is like to pursue close relationships, in the context of living with the label intellectual disability. Further, the specific objectives associated with this research were:

- To explore close relationships as they are experienced by adults labelled with intellectual disability, and;
- To explore inclusive processes in research with individuals labelled with intellectual disability, their relationship partners, friends, family members, support-workers, and others.

Prior to outlining the specific methods employed in this inquiry, I engage a critical discussion on epistemology, ontology, and provide an outline of my epistemological position. Subsequently, I engage in a critical discussion of historical, contemporary, and relevant research paradigms. Following on from these sections, I will outline the specific methodological approach, and methods, which underpin this study. In addition, procedures and strategies for establishing the quality, trustworthiness, and rigour of the research findings are discussed. The chapter concludes with a consideration of procedural ethical issues related to the research project.

### **4.1 Epistemological assumptions**

Historically, theories of knowledge, science, and reality are taken for granted within the field of psychological research. Rather than engaging in dialogue on the nature of how we know what we know, the mechanistic worldview has predominated within psychological research, and so has the assumption that knowledge is necessarily obtained through adherence to the traditional scientific method (C. Sullivan, 2010). A reliance on this form of knowledge production denies access to, and appreciation of, various other ways of knowing, such as those referred to by Pepper (1942), which may grant access to differing ways of knowledge or making meaning.

#### 4.1.1 Ways of knowing.

There are various *ways of knowing* through which psychological phenomena may be explored and explained (Jaeger & Rosnow, 1988). Pepper (1942) identifies four *world hypotheses*; *formism*, *mechanism*, *contextualism*, and *organicism*, which represent these different ways of knowing. Similarly, Altman and Rogoff (1987) identify trait, interactional, organismic, and transactional worldviews, representing varying conceptualisations of psychology, the nature of relationships, context, time, change, and differing goals of science. Arguably, interactional or mechanistic worldview predominates within the field of psychology research at present, representing the pursuit of that which Habermas terms empirical-analytical knowledge or knowledge which is generated by objective, scientific processes through controlled observation, experimentation, and measurement (T. McCarthy, 1984). These mechanistic worldviews are concerned with informing an understanding of the environment through prediction of future circumstances and understanding causal relationships (Altman & Rogoff, 1987). Within this framework, time, change, and context have limited utility, and are often seen as external to, or irrelevant for, understanding the phenomena under study (Altman & Rogoff, 1987).

In contrast, contextualism, or the transactional worldview, posits that human action is intentional and occurs within a cultural, social, and political context (Jaeger & Rosnow, 1988). In this way, meaning and human experiences are inferred by context, which is, in turn “...*integrated within the phenomena itself*” (Jaeger & Rosnow, 1988, p. 72). Assumptions of contextualism posit psychological phenomena as a holistic entity comprising interactions between people, events, time, change, and context (Pepper, 1942). The aim is not to determine causal relationships, study events in isolation or control what may be traditionally viewed as confounding external factors. Rather, the aim is to explore phenomena in natural environments, using eclectic and context-appropriate methodologies in effort to “...*understand the pattern and flow of particular events, by means of existing and emergent principles that apply to the event*” (Altman & Rogoff, 1987, p. 27; Jaeger & Rosnow, 1988). Contextualism represents the phenomenological enquiry of the lifeworld, or, the process of gauging how psychological phenomena is experienced by people, on a daily-basis, within context (Giorgi & Giorgi, 2008). Contextualist approaches adopt “...*a pragmatic, eclectic, and relativistic approach to the study of psychological*



*phenomena.*" (Altman & Rogoff, 1987, p. 26). In this form of investigation, context is perceived as constructed by all people, including researchers, who are embedded and interact within it (Dewey, 1938; Jaeger & Rosnow, 1988).

#### **4.1.2 Building a knowledge base: the role of epistemology and ontology.**

Epistemology represents the theory of knowledge, an understanding of how we know what we know, and how knowledge and truth are conceptualised (C. Sullivan, 2010). This theory of knowledge allows consideration of a range of epistemological positions. Typically, there is talk of assuming an epistemological position various positions are constructed as sitting along a continuum. At one end of the continuum, positivism is a theory of knowledge which seems to align most closely with a mechanistic understanding of the world (Pepper, 1942). A key feature of positivism is an understanding that truth and knowledge are universal and exist independently of historical, social, and political contexts. Positivism reflects the pursuit of universal and causal laws through objective, value-free, research processes (Pepper, 1942). As such, the researcher-participant relationship is characterised by distance, and power difference, and research methods tend to be reductive. These are the methodological traditions and implications that result from understandings that knowledge is, and can only be produced by, science. It is suggested that few researchers tend to adhere to what might be described as a traditional *logical-positivist* approach (Madill, Jordan, & Shirley, 2000). A more contemporary form of positivism may be referred to as *post-positivism*, where scientific truths are pursued via objectivity, to an extent; however, the contextual and fluid nature of these scientific truths is acknowledged (C. Sullivan, 2010).

Adhering to a strictly positivist paradigm produces a body of research findings which tends to neglect the various other ways of knowing. Arguably, critical appraisal is not commonplace, historically or contemporarily, within the domain of psychological research which tends to ascribe positivist episteme a privileged position (Breen & Darlaston-Jones, 2010). Engaging in critical appraisal leads to consideration of the episteme which exists at the opposite end of the theoretical continuum- social constructionism. A defining feature of social constructionism is the assumption that multiple realities exist, and that the truth nature of reality is determine through exploration of social, historical, political, and cultural contexts (Gergen, 1985). In other words, sense is made of the world via interactions within it,

and personal and collective representations of truth. Assumptions inherent to social constructionism are that research is necessarily value-laden, that the researcher plays an integral role in constructing reality, and that knowledge is constructed through the discovery of meaning (Gergen, 1985).

While it is acknowledged that social constructionism provides a space within which to consider contextualised, and subjective, ways of knowing, there is a tension inherent to the notion that reality does not exist. A criticism of this form of extreme relativism is the notion that there are features of the world which cannot be refuted, which contribute to the construction of multiple, equally meaningful, realities. Some argue that extreme relativism undermines the ability to evaluate the moral nature of social phenomena (C. Sullivan, 2010). The tension inherent to extreme relativism, and social constructionism, emerges in discourses surrounding disability, reflected in the tension around “real” impairment versus social construction (e.g., tantamount to the debate on medical vs. social models of disability). An alternative view to either extreme realism, or extreme relativism, is to consider some form of critical realism-relativism. This position assumes that there are distinct features of the world which exist independently of human interaction; however, the meanings made of these features are grounded in social, cultural, historical, and political contexts (Lund, 2005).

#### **4.1.3 My epistemological position: A pluralist perspective.**

To provide a context for the meanings and sense derived from the research inquiry, it is necessary to provide a statement of my ontological and epistemological position. To subscribe to one perspective, at the exclusion of other complementary perspectives, seems somewhat limiting and perhaps antithetical. Rather, my understanding of the nature of truth and knowledge, and on a broader level, the research inquiry, is pluralistic, and informed by a range of theoretical, epistemological, and ontological perspectives. I would argue that my epistemological position could be characterised in terms of a combination of social constructionism and pragmatism.

##### ***4.1.3.1 Revisiting social constructionism in context of this research.***

Social construction is one orientation that informs the current research enquiry. A social constructionist orientation reflects an appreciation for the ways in which

meaning is made from the world via complex symbolic interactions which occur within specific social, cultural and historical contexts (Gergen, 1985). Social constructionism is a valuable framework for the deconstruction of issues related to intellectual disability, as this orientation invites challenges to the truths and facts of the world (Gergen, 1985). In this sense, social constructionism provides a platform for the development of new understandings, and alternative interpretations of what it means to live with the label intellectual disability. A social constructionist account acknowledges the transitory and fluid nature of scientific fact, and that “...*the rule for “what counts as what” are inherently ambiguous, continuously evolving, and free to vary with the predilections of those who use them*” (Gergen, 1985, p. 268). A social constructionist approach allows for sense to be made of the social rules which govern the world, elucidating those social patterns which may be exclusionary for certain constructed others.

In many ways, this perspective represents a kind of “jumping off point”- there is no certainty, no objectivity, and no “hard science” to be discovered within a social constructionist approach. As such, social constructionism does not offer the comforts of a traditional empirical-rationalist scientific approach. One could argue, however, that this is the point of social constructionism. This approach allows flexibility, reflexivity, and fosters an understanding that how we know what we know is governed by a collective culturally, historically, and socially bound kind of self-interest. Gergen (1985, p. 273) suggests that social constructionism “...*reasserts the relevance of moral criteria for scientific practice.*” In context of historical approaches to disability studies, grounded in objectivity, positivism, and medicalisation, it seems entirely appropriate that a progressive contribution to the field should be informed by a more reflexive form of enquiry.

#### ***4.1.3.2 Pragmatism in context of this research.***

Social constructionism informs the research enquiry, to the extent that this approach creates an alternative space where the label intellectual disability may be considered in a social and cultural realm. However, an inherent difficulty with this approach is that it employs a relativist perspective. Relativism asserts that all knowledge is constructed, and that no one construction is superior to another (Cornish & Gillespie, 2009). Constructionist approaches have been criticised for this

relativist approach, as it does not lend itself to social action, or commitment to cause (Cornish & Gillespie, 2009). A pragmatist approach is presented as an ideology that reconciles the issue of relativism, in the context of addressing real-world problems. Essentially, pragmatism is deeply pluralistic, where knowledge is conceptualised as a “...*tool that brings us into a more or less satisfactory relation with the world*” (Cornish & Gillespie, 2009, p. 807). Pragmatism offers an action-focussed perspective, where knowledge is evaluated according to its relevance, and application, within specific situated contexts (Albrecht, 2002; Rorty, 1982). To this extent, the truth-value of knowledge is not evaluated according to epistemological assumptions; rather, the truth value of knowledge is entirely contextual (Cornish & Gillespie, 2009). A pragmatist approach seems to offer a framework for negotiating real-world issues, and for identifying opportunities to engage an alternative reality for individuals who experience oppression and inequities. The research inquiry is embedded in a pluralistic perspective, one that is informed by principles of social constructionism and pragmatism.

#### **4.2 Considering a research paradigm**

It is suggested that dominant psychology maintains the status quo for quality of life and division of resources and inadvertently supports institutions which hold power over others (Prilleltensky & Fox, 1997). Dominant psychology achieves this through emphasising the individual's role within psychological phenomena (Prilleltensky & Fox, 1997). For example, psychological issues are addressed on an individual basis, even though these issues might be common among many individuals within society. In contrast, *critical psychologists* may examine factors within general society that contribute to cultural factors which facilitate the development and maintenance of psychological issues for the individual. Rather than focus on individualism and maintenance of the status quo, critical psychologists emphasise the values of “...*social justice, self-determination and participation, caring and compassion, health and human diversity*” (Prilleltensky & Fox, 1997, p. 8). The overarching aim is the re-establishment of the balance of power and self-determinism amongst marginalised and dominant groups within society. Subjectivity is acknowledged as an influence on research production and is considered an authentic element of the research process.

In this section, I will engage in a critical discussion of historical and contemporary research paradigms relevant to this inquiry. I will consider the historical context surrounding participation of individuals labelled with intellectual disability in research, and will outline opportunities to reconceptualise traditional research processes to reflect those exploratory, applied, and collaborative approaches to research that underpin this research inquiry. Given the pre-eminence of positivist research production and an interactional worldview in the field of psychology, much of the research in the area of disability studies has represented a scientific, objective, and quantitative approach. Prior to the twentieth century, individuals living with the label intellectual disability, along with *typically-developing* individuals, were considered research subjects, as opposed to active research participants (Walmsley, 2001). Given social discourses surrounding intellectual disability at that time, along with the presumed inherent vulnerability of individuals living with this label, great violations to the humanity of individuals living with the label intellectual disability took place. In some instances, research in the field of disability studies has served to objectify, manipulate, exploit and coerce individuals living with the label intellectual disability (Walmsley, 2001). For example, Beecher (1966) reported that during World War II institutionalised children with “mental deficiency” were injected with a strain of hepatitis to determine the period of infectivity for the virus. Parents were asked to consent to this research; however, Beecher suggests that they were not fully informed of the negative effects that this study would have on their children. Several children were hospitalised for hepatitis infection, and several others required additional vaccinations to contain this virus. The author argues that research of this nature would not have been carried out with children who did not live with this label. Such research highlights the lack of social value and humanity prescribed to individuals living with the label intellectual disability prior to the twentieth century (McDonald, Keys, & Henry, 2008).

#### **4.2.1 Emerging spaces for the use of “new” research paradigms.**

As outlined in previous chapters, several factors have contributed to the reconceptualisation of the roles ascribed to individuals living with the label intellectual disability, including; normalisation and social role valorisation theory, the social model of disability, the disabled people’s movement, and principles of self-advocacy (Walmsley & Johnson, 2003). Social role valorisation theory impacted

on social policy in both Australia and in the United Kingdom (UK), influencing the development of disability-policy which furthered the rights of individuals living with the label intellectual disability. Social role valorisation theory also provided a rationale for developments in the field of disability-research, for example, leading to numerous studies which evaluated the quality of disability service-providers and, in the USA, led to the deinstitutionalisation and study of community integration of many individuals living with the label intellectual disability (Walmsley & Johnson, 2003).

While social role valorisation theory spawned a wealth of literature which focussed on needs of individuals living with the label intellectual disability, research inspired by social role valorisation theory was not necessarily any more inclusive than previous research in the field of disability studies (Walmsley & Johnson, 2003). That is, individuals living with the label intellectual disability still occupied the role of research subject, rather than active participant. In addition, social role valorisation theory is also criticised on the basis that it did not originate with individuals living with the label intellectual disability; rather, typically-developing individuals conceived the theory to conceptualise the marginalisation of individuals living with the label intellectual disability. However, social role valorisation theory did indirectly influence the development of a more inclusive research paradigm for individuals living with the label intellectual disability. For example, social role valorisation theory motivated the closure for many institutions, thus, individuals living with the label intellectual disability became more accessible to researchers, and vice versa.

In addition, social role valorisation theory encouraged the perception of individuals living with the label intellectual disability as human beings (Osburn, 2006), thus, indicating to researchers that they may provide a meaningful contribution to research (Walmsley & Johnson, 2003). Furthermore, social role valorisation theory provides impetus for individuals living with the label intellectual disability to self-advocate as, in accordance with this theory, adopting the valued-laden role of self-advocate may release an individual from the socially devalued roles which once contained them (Walmsley & Johnson, 2003). Similarly, social role valorisation theory also provides rationale for the inclusion of individuals living with the label intellectual disability as active research participants in inclusive research

projects. For example, the inclusion of people as active participants, contributors, advisors, researchers, and co-researchers in disability studies constitutes individuals living with the label intellectual disability adopting socially-valued roles.

There are however, various tensions associated with social role valorisation theory. For example, some suggest that social role valorisation theory is a model which advocates that devalued individuals mould themselves to fit with an inherently oppressive society (Race et al., 2005). That is, social role valorisation theory is rooted in normalising ideologies, which reject and undermine diversity. Another tension inherent to social role valorisation relates to concepts of power and empowerment. Wolfensberger (2002) notes that empowerment, or the acquisition of power, is often posited as the end-goal of social role valorisation. Wolfensberger rejects the assertion that empowerment is the means through which individuals achieve the "good things in life". He suggests that one only achieves an elevated status through enhancing one's image, or adopting socially-valued roles. Wolfensberger also suggests that some individuals, those who are "competency impaired", will not benefit from empowerment alone, as they require support from competent individuals to navigate day to day and life decisions. Reflecting on this tension, Race et al. suggest that competency-impairment or not, all individuals have the capacity to make decisions which may be deemed unwise. The authors reflect that Wolfensberger's assertions undermine disability as social category, and imply that some individuals have the natural right, on the basis of competency, to make decisions on behalf of others. Race et al., however, do suggest that social role valorisation holds value, creating alternative settings, and roles, on an individual level. From the early 1990s onwards, researchers have been inspired by the notion that, through societal change and accessing the lived experiences of individuals living with the label intellectual disability, individuals who are ascribed with this label may be emancipated from social injustices and marginalisation (Walmsley & Johnson, 2003). In this way, normalisation and social role valorisation theory, the social model of disability, the disabled people's movement and principles of self-advocacy have provided the space and rationale for involving people with disability in the research process (Walmsley & Johnson, 2003)..

#### 4.2.2 Contextualism and applied research.

Contextualist worldviews are evident in applied research methods such as *participatory action research*, other forms of *action research*, *participatory research*, and *emancipatory research* which access the lived experiences of typically marginalised individuals, often, with an emphasis on generating some form of social change (Chappell, 2000; Greenwood & Levin, 1998; Reason & Riley, 2008; Stringer, 2007). Cocks and Cockram (1995) suggest that a taxonomy of research traditions exists where traditional positivist research methods reside at one end of the continuum and applied, action research methods at the other. Walmsley and Johnson (2003) also adopt a view of applied research methods as situated on a continuum, arguing that there are often no clear distinctions between the various forms of applied research. The authors suggest that boundaries for various research traditions are fluid and shift throughout the research process. Hence, while these applied forms of research differ from one another in terms of their specified processes, the level of involvement of community members in the research process, the role of the researcher, and the outcomes of the research, they also share several common themes (detailed in Table 1; Walmsley & Johnson, 2003).

Table 1

*Common Principles of Applied Research*

Principle	Description
Commitment to social change	The aim of research is to facilitate a more equitable society, where individuals in marginalised groups experience social justice. Research production in itself engenders liberation of those who are participating in it.
Empowering participants	Participants may be empowered to take on issues prevalent in their own lives or they may adopt new skills.
Focusing on the individual	The focus is on the lived experiences of participants where they are viewed within context and appreciated for the knowledge that they contribute to the



Emancipatory in nature	research process. A primary aim is to identify and attempt to eradicate barriers to social justice. Research production, to the greatest extent possible, is under the control and manipulation of individuals living with the label intellectual disability.
Reflexivity	Applied research demands reflexivity from researchers. Identification of researcher attitudes and values is essential.

---

*Note.* Contents are adapted from Walmsley and Johnson (2003, pp. 29-41)

#### 4.2.3 Inclusive research.

Likewise to participatory action research, participatory research, emancipatory research, and action research, *inclusive research* operates from a transactional or contextualist worldview where human actions are examined within context and lived experiences are explored collaboratively (Walmsley & Johnson, 2003). Inclusive research is understood as an approach where "...both researchers without disability and people with intellectual disabilities conduct the research together on issues that are important and relevant to people with intellectual disabilities" (Strnadová & Cumming, 2014, p. 1). Walmsley and Johnson define the principles of inclusive research, slightly differentiating it from other applied research methods (see Table 2). In inclusive research, emphasis is placed more so on these principles, than on the adoption of specific research methodologies (Walmsley, 2004). Consistent with a contextualist worldview and principles of applied research, inclusive research methods are pluralistic, flexible, and responsive to research questions and desired outcomes (Burke et al., 2003; Walmsley & Johnson, 2003).

Table 2

*Principles of Inclusive Research*

Principle	Description
Individuals with intellectual disability must own the research problem	The research problem must be relevant to or owned, although, not necessarily

---

	initiated, by individuals living with the label intellectual disability
Research should further the interests of individuals living with the label intellectual disability	Researchers should defer to the opinions, and respect the lived experiences and knowledge of individuals living with the label intellectual disability
Research should be collaborative	Individuals with intellectual disability should be involved in conducting the research or be a part of the research process
Individuals living with the label intellectual disability should exert some control over the research process	Individuals with intellectual disability should not have to consistently defer to the researcher, rather, they should exercise control over the research design, process, outcomes and dissemination
The research question, process, and outcomes must be accessible to individuals living with the label intellectual disability	All stages of research production are accessible and understood by individuals living with the label intellectual disability

---

*Note.* Contents are adapted from Walmsley and Johnson (2003, p. 64).

#### **4.2.4 Inclusive research, applied research, and contextualist principles in practice.**

The pluralistic and flexible nature of inclusive, contextualist, and applied research approaches presents a practical consideration; *how does one actually conduct such research?* Past inclusive research projects have adopted a range of strategies, including, although not limited to, life histories (e.g., Björnsdóttir & Svendsdottir, 2008; Johnson et al., 2001), interviews (e.g., Bernert, 2011), focus groups (e.g., Kelly, Crowley, & Hamilton, 2009), community conferences (e.g., Burke et al., 2003), photo-voice (e.g., Booth, 2003; Povee, Bishop, & Roberts, 2014), self-authored stories (e.g., Milner & Kelly, 2009), reference groups, and working groups (e.g., Johnson et al., 2002), to successfully and collaboratively engage individuals living with the label intellectual disability in research processes. At present, there is limited research on the processes through which individuals living

with the label intellectual disability, researchers, and members of the community engage in collaborative research and group processes (Frawley & Bigby, 2011; Povee et al., 2014; Strnadová, Cumming, Knox, & Parmenter, 2014).

Often, perhaps due a tendency to engage in binary thought, research may come under scrutiny for the extent to which it truly is participatory (Breen & O'Connor, 2014). These discussions tend to decontextualise the research processes and dynamics, in attempt to objectively evaluate the participatory qualities of a project or inquiry (Montero, 2000). These discussions represent a tension within the field of applied research; that is, negotiating loyalty to prescribed qualities of a particular paradigm of research enquiry, and allowing research processes to be responsive to issues emerging within the community (Montero, 2000). Perhaps it is more sophisticated to consider the nature of participation in-context and to reflect inclusive processes as informing on this socio-cultural context. That is, striving to achieve and implement principles of applied research paradigms while also engaging in critical consideration of how research processes actually inform understanding of the phenomena under study.

Bigby, Frawley, and Ramcharan (2014) have called for greater conceptual clarity around the nature of inclusive research. Bigby, Frawley, and Ramcharan voice concern that inclusive research might be considered as a “panacea”, or a “...universal remedy for including perspectives of people with intellectual disability, or for the generation of knowledge about their lives, policy or services they use.” (p. 10). The authors suggest that this approach should be subject to the same critical examination as are other research approaches. For example, the authors suggest that there are some topics which will not lend themselves to an inclusive research approach, and, that inclusive research tends to be exclusionary of individuals who are labelled with severe or profound intellectual disability. The fervent uptake of inclusive research methods as the ‘way forward’ by funding bodies, policy-makers and institutions may lead to the tokenistic application of the approach, in order to avoid penalty, and to attract financial support (Bigby et al., 2014).

The model of the participant-conceptualiser (K. K. Smith, 1983) perhaps provides a framework to deconstruct how content, process, context, and culture integrate to construct the phenomena under study. The notion of participant-conceptualiser is embedded in a theory that human systems are unpredictable and

transactional, and that “...*what any social entity is like is as much a product of its interaction with other entities as an expression of its original design*” (K. K. Smith, 1983, p. 145). Taking on a role as participant-conceptualiser reflects the pursuit of understanding at multiple levels, within multiple settings. Smith (1983, p. 157) asserts that the central task of the role of the participant-conceptualiser is to “...*create a system of parallel conversation where talk occurs not only within prevailing frames but about the framing dynamics themselves...*” this “frame talk” is achieved as a function of attending to both process and content in order to develop a multi-levelled and contextualist understanding of the issues at play, and the meta-processes and dynamics which appear to govern these issues.

#### **4.2.5 Reconceptualising the researcher-participant relationship.**

Inherent within collaborative research is a constant re-negotiation of the roles of the formally-trained researcher and other involved parties. As collaborative research seeks to access the lived-experiences of individuals living with the label intellectual disability, formally-trained researchers must reconceptualise their role of expert to that of a *naïve enquirer* (Morrow, 2005). Equally, the role of individuals living with the label intellectual disability and other parties must be re-conceptualised from research subject to expert. However, this role reversal does not imply that individuals living with the label intellectual disability must take on the role of a formally-trained researcher, as was almost the case in Bigby and Frawley’s (2010) inclusive research project “Making Life Good in the Community”. In this 3.5 year study focusing the experience of community living of individuals living with the label intellectual disability following deinstitutionalisation, Alan (a man with living with the label intellectual disability) was employed as a co-researcher. Alan received-support from a “research-mentor” to engage in the research process. Alan’s role was to spend time with individuals living with the label intellectual disability who had experienced the move from institutions to community living and find out about their experiences of living in the community. Bigby and Frawley (2010, p. 56) reflect that their initial emphasis had been on developing in Alan research skills and knowledge, rather than “...*accepting and valuing Alan for who he was and acknowledging the way he preferred to do things...*” The authors suggest that they were fixated on the definition of a formally-trained researcher and, through trying to teach Alan to fit this description they were disempowering him. Equally, Alan expressed to the authors

that he was not interested in the formalities of research. Rather, Alan expressed the desire to "...*get on with it*" (Bigby & Frawley, 2010, p. 57). Bigby and Frawley suggest that their emphasis on trying to teach Alan, rather than valuing his strengths, ultimately had a negative impact on his confidence and efficacy to form a part of the research team.

Bigby and Frawley's (2010) reflections highlight the benefit of collaboratively exploring roles of individuals throughout the research process (Burke et al., 2003). It is also important to recognise that the level of collaboration may fluctuate throughout the research project, and is largely dependent on the skills and interests of everyone involved (Björnsdóttir & Svendsdóttir, 2008; Walmsley, 2004). For example, Walmsley (2004, p. 59) argues that individuals may not want to "...*choose the topic, devise the methodology, manage the budget, analyse the data and write up the findings...*". Equally, individuals must be respected for those insights which they alone bring to an inclusive research project. For example, "...*how to word questions, how to make ideas accessible, what to look out for, what practices in services need to be taken into account, and how to disseminate good ideas...*" (Walmsley, 2004, p. 58). In other words, there exists an indispensable role for both individuals living with the label intellectual disability (as experts of the lived experience) and formally-trained researchers (through resources and research knowledge) in collaborative research.

### **4.3 Method**

The specific research design, methods, and processes of the research project are outlined in the following sections. Initially, the research design is outlined, with regard to underlying epistemological assumptions, and detailing the specific research paradigm of the project. Subsequently, the research processes are detailing, including the rationale underpinning the various methods employed. Following on from this, quality, rigour, and procedural ethical considerations for the project are considered.

#### **4.3.1 Research design.**

In identifying my epistemological position as researcher within this study, I find myself positioned within a contextualist paradigm, informed by social constructionism and pragmatism. My sense is that this position is necessitated by the nature of the research, in its aims and objectives. That is, the exploratory, context,

and systems-dependent nature of the research aim best suits a context-laden form of inquiry. Additionally, this episteme affords me the role of researcher as active mediator (Bishop, Sonn, Drew, & Contos, 2002) and allows the reconceptualisation of the traditional power distance between the researcher, and those who are researched. Embracing these assumptions, it is perhaps possible to construct an understanding of what it means to live with the label intellectual disability and to pursue close relationships. Inherent to this position is an acknowledgement that I have co-constructed the realities which emerge from this study, and that this reality does not represent some form of ultimate truth about the diverse, context-dependent, and complex experiences of individuals who are identified by labels to which there is an attached social-cultural value.

This research project is theory-generative (Moghaddam, 1990), adopting principles of contextualism, applied, and inclusive research to explore the close relationship experiences of individuals living with the label intellectual disability (Pepper, 1942; Walmsley & Johnson, 2003). Individuals living with the label intellectual disability, their family members, and support-workers were engaged as experts, informing the project through their lived-experiences (Morrow, 2005). My role as researcher in this project was that of a naive enquirer (Morrow, 2005). This research project represents a collaborative process, and was responsive to emergent themes and expertise of all involved individuals (Harrison, Johnson, Hillier, & Strong, 2001). Additionally, principles of reflective-generative practice (Bishop et al., 2002; Docecki, 1996; Polkinghorne, 2005) and the participant-conceptualiser (K. K. Smith, 1983) were adopted to identify the development of shared understanding amongst individuals living with the label intellectual disability, their families, support-workers, the researcher, and others, in order to deconstruct those social-cultural influences on opportunities by individuals living with the label intellectual disability to engage in close relationships.

#### **4.3.2 The research process.**

This research project was conducted in three phases (see Figure 1). The initial phase of the research involved an informal process of gauging community<sup>7</sup> interest and ownership over the research problem. In the second phase of the research,

---

<sup>7</sup> The term 'community' is used to refer to a collective of individuals who share relational, social and cultural bonds.

individuals from the community were engaged in conversational interviews on their close relationship experiences, interview transcripts were analysed and findings generated. The final phase of the research project attended to processes of feeding findings back to the community, where feedback and commentary was sought from community members<sup>8</sup> in a range of formats and settings. These three phases are outlined in the following sections, along with a commentary of key decisions made to guide the research process in an iterative fashion.

---

<sup>8</sup> The term 'community members' is used to refer to individuals who are located within a community characterised by relational and social bonds.

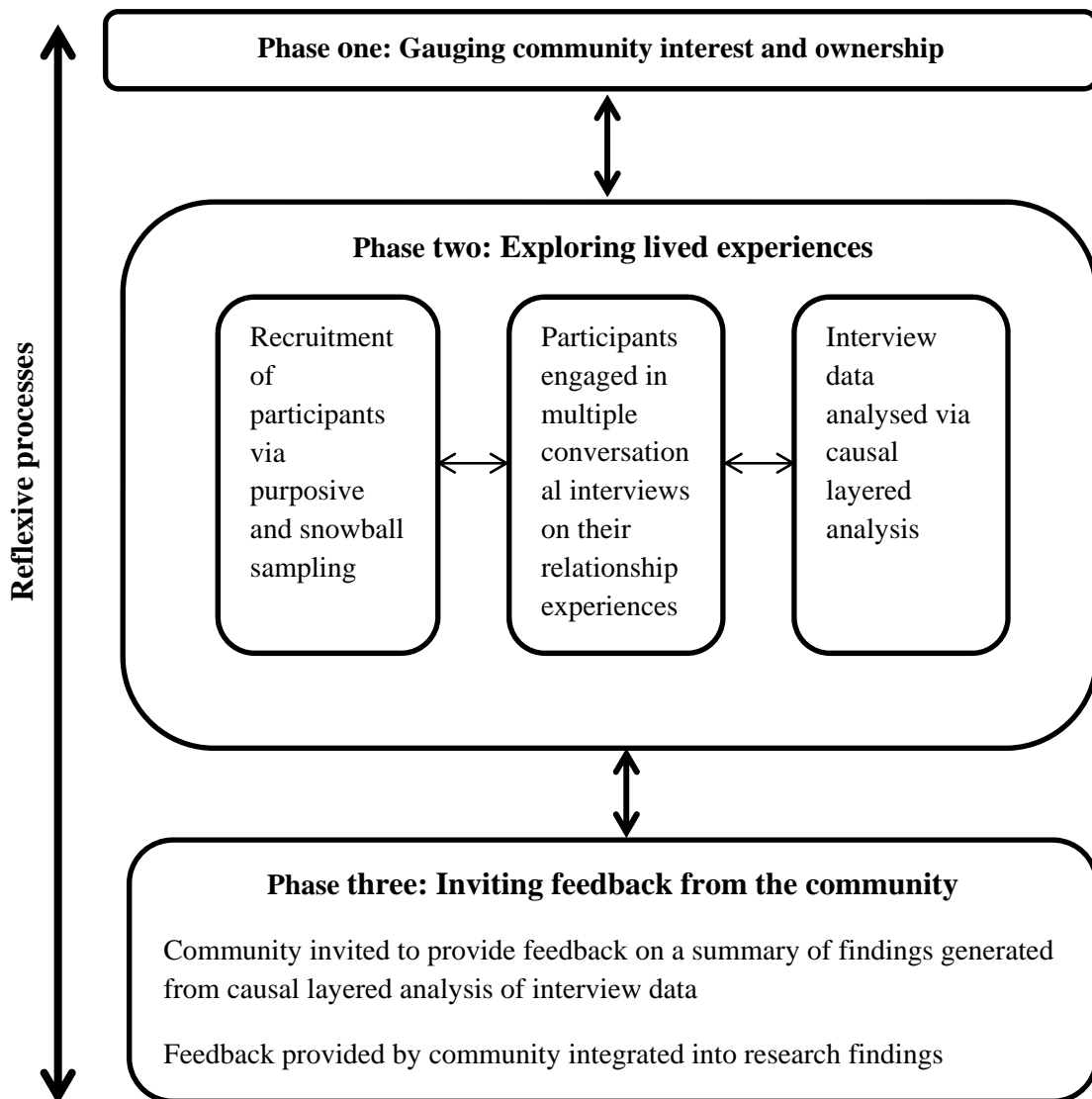


Figure 1. Visual representation of research process.

**4.3.2.1 Phase one: Gauging community interest and ownership.**

Community members (including individuals labelled with intellectual disability, family members, support-workers, disability service-providers, and others) were engaged informally at this stage, not for purposes of data collection, rather in informal advisory roles. Conversations with community members, in a range of settings (e.g., local sporting clubs, within educative settings, in self-advocacy settings) highlighted that the focus of the research project (e.g., to explore sexuality and close relationships) is an area of great interest, and concern, within the community. This phase in the research project may be related to the notion that the



research problem should, ideally, be “owned” by the community (Walmsley & Johnson, 2003). This principle suggests that it is necessary for the problem to be relevant to the community, and deemed acceptable, by the community, for research inquiry. My sense in engaging with the community on an incidental and informal basis was that there was a need, and space, for such a research project to be conducted. I was in a position to engage with the community in this way as I am a member of and immersed within this community. It is important to note that my engagement would have manifested entirely differently, or perhaps would not have been at all possible, if I was not embedded within the community. During discussions with individuals living with the label intellectual disability, and with family members and others, there was a sense that relationships and sexuality of individuals labelled with intellectual disability represented a final frontier for individuals who are so-labelled. These discussions highlighted the complexity of relationships and sexuality, in the context of the construction of intellectual disability. Through talking with community members, this problem emerged as complex and overwhelming. At this stage, in consultation with my supervisory team, I made a decision not to establish a formalised reference group. A primary reason for making this decision was a sense that my intentional organising of individuals from the community in this way would become tokenistic. I was aware that the procedural and formal constraints inherent to conducting a PhD project would impede genuine collaboration with a reference group; these tensions will be explored in greater depth in chapter seven, which is devoted to a discussion of the research process.

As Montero (2000) suggests, participatory paradigms should not replicate those dynamics or relationships which lead to the othering and marginalisation of particular individuals. I expressed this sense of uneasiness, and concern, to my supervisory team, who suggested that advisory relationships may be better engaged on an informal basis. This is a particularly complex issue, and at the risk of oversimplifying the paradox, I was also acutely aware that sexuality and relationships represents a private issue, and to organise individuals to discuss this topic in a group may work against the social justice imperative, and recreate a dynamic where sexuality and relationships are presented as remarkable in the context of intellectual disability. It was also important to reflect upon the particular cultural context within which individuals, and myself, were immersed. The nature of the label intellectual

disability tends to evoke perceptions of vulnerability, incompetence, and dynamics where individuals do not have choice, control or access. I was concerned, as were individuals acting in informal advisory roles, that engaging individuals in a formal reference group would be token, and necessarily perpetuate power imbalances within the community (e.g., reinforce gatekeeper roles).

These same concerns were prevalent in discussions among my supervisory team and I when considering how to engage in ethical processes of obtaining feedback on findings from the community (to be discussed further in phase three of the research process). Consultation was not limited to individuals who are identified as having an intellectual disability, but extended to family members, siblings, support-workers, peer researchers, professionals, and self-advocates. Engaging with various community members was considered necessary for exploring how sexuality and disability was constructed among all community members. Through various conversations, and incidental interactions, I was able to navigate the process for recruiting participants, and engaging with participants in a way which seemed culturally sensitive, and acceptable, within the community. A number of individuals who were known to me, and embedded within the community, provided guidance and advice on the process of engaging with the community, and how experiences may be best explored.

#### ***4.3.2.2 Phase two: Exploring lived experiences.***

Those individuals who were engaged as participants<sup>9</sup> to share their lived experiences were community members aged 18 years or older who identified as having an intellectual disability, or were embedded within the community (e.g., family members of individuals labelled with intellectual disability). Participants were recruited via purposive sampling to participate in a series of face-to-face conversational interviews (Burgess-Limerick & Burgess-Limerick, 1998). Criteria for engagement were that individuals were able to communicate verbally with me, and on the basis of their experiences with close relationships, for example,

---

<sup>9</sup> While I would like to be able to refer to individuals who shared their stories for this research in other terms (e.g., as co-researchers), the terminology *participant* most accurately reflects the level and nature of participation of community members in the research project. To refer to individuals who shared their stories in any other terms would misrepresent the level of participation inherent to this inquiry.

participants shared a range of relationship experiences, including, being single, having a long-term boyfriend or girlfriend, looking to get married, and so on.

Having obtained ethics approval from Curtin University's Human Research Ethics Committee (see Appendix A), participants were recruited via range of strategies. For example, I contacted disability service-providers and sought permission to approach service-users for recruitment. Once permission was granted, I contacted potential participants via telephone or through informal face-to-face meetings explaining the research project and providing each with information and consent forms<sup>10</sup>. I also engaged a snowball sampling strategy to contact and recruit participants. Often, individuals who participated in the research would refer me to others who they felt may also be interested in taking part. My experience within the community, and my incidental access to potential participants (e.g., through regular attendance to events run within the community) allowed for an informal process of recruitment. For example, as word-of-mouth grew within the community surrounding the research, some individuals approached me to express their interest in taking part, or to suggest individuals who they felt may be interested in taking part.

Following an initial conversation (either face-to-face or over the telephone) with each potential participant on the nature of the project, I negotiated a time and venue for the initial interview to take place. Prior to commencing the interview process, verbal informed consent, via the verbal consent protocol or, if appropriate, written informed consent was obtained from each individual. Consent is understood as an ongoing process in collaborative research, and was re-negotiated with each participant throughout the duration of the project. As such, I obtained verbal consent to participate from each individual at every interview. Verbal consent was audio-recorded, and informed each participant on their anticipated role, responsibilities, and the consequences of being involved in the project. Initial consent procedures were revised as, in practice, they were cumbersome, and inefficient for obtaining informed consent. The revised consent procedures allowed for a more open and accurate consideration of issues related to consent and gave a sense of confidence that this procedure was accessible to each individual participating in the study

---

<sup>10</sup> Due to the iterative nature of this research project a range of strategies were employed to invite participation. A series of information sheets, consent procedures and forms were used in this research (see Appendix B for all iterations of information sheets and consent procedures).

Within this project, as has been the case in numerous other research studies (e.g., Campain & Wilson, 2010; Johnson et al., 2001; Kelly et al., 2009), the capacity for individuals labelled with intellectual disability to provide informed consent was unquestioned. Literacy skills did not form part of the inclusion or exclusion criteria. As such, the primary procedure for obtaining informed consent was via a verbal consent protocol. In order to ensure accessibility and comprehension of materials related to the research project (e.g., information sheets, consent forms etc.), all materials were provided in plain-English format and accompanied by visual imagery (Boxall & Ralph, 2009). Additionally, participants were read information and consent forms aloud, and encouraged to discuss their potential participation in the project with an individual who familiar to them. Informed consent was obtained on an individualised-needs basis (Cambridge & Forrester-Jones, 2003), and every effort was exhausted to accommodate the individual communication needs of each participant and increase the accessibility of the research project for all potential participants.

#### ***4.3.2.2.1 Participants.***

In total, 17 participants (16 individuals labelled with intellectual disability, and one parent; 11 females and six males) were engaged in a total of 26 conversational interviews on their close relationship experiences. The parent participant was included by request of a participant labelled with intellectual disability, who asked that his mum sit in and participate in the interview. The number of participants engaged allowed for in-depth analysis of individual cases as well as comparison between cases (Burgess-Limerick & Burgess-Limerick, 1998; Eatough & Smith, 2008; J. A. Smith & Osborn, 2008). In the interests of maintaining privacy of participants, particularly within such a small relational and geographic community, the level of demographic detail I can provide is limited. For the same reasons, I have not ascribed a pseudonym to participants, and have de-identified demographic information (e.g., names of clubs) in excerpts of interviews. All participants (excluding the parent participant) were aged in their mid-to-late twenties, and resided in their family homes (some individuals lived with one or both parents, step-parents and or siblings). Six participants labelled with intellectual disability identified as being single, while the remaining 10 participants labelled with intellectual disability

identified as being in a relationship. Details of participant's gender, living arrangements and relationship status are summarised in Table 3. Information linking participants' identities and the research data is stored in separate locations.

Table 3

*Gender, relationship status, and living arrangements of participants' labelled with intellectual disability*

Gender		Relationship Status		Living Arrangements	
Male	Female	Single	In a Relationship	Living in Family Home	Other
6	11	6	10	16	0

*Note.* Information included in this table represents details of participants labelled with intellectual disability only (e.g., parent participant is excluded).

#### **4.3.2.2 Conversational interviewing.**

Consenting participants were interviewed via conversational interviewing. Conversational interviewing is a collaborative exercise between interviewer and interviewee where the objective is to develop a shared understanding of the interviewee's experiences (Burgess-Limerick & Burgess-Limerick, 1998). Interviews ranged from 45mins to 90 mins in duration. Some community members were interviewed on their own, while others were interviewed in couples (e.g., some were interviewed with a boyfriend, girlfriend or parent) or groups (e.g., a group of friends with a mutual interest in the topic). Early on in the research process, community members were interviewed multiple times. Engaging in multiple interviews allowed for elaboration, clarification, and exploration of multiple and contradictory elements of interview content (Burgess-Limerick & Burgess-Limerick, 1998). This approach advocated by Polkinghorne (2005), who suggests that the depth and complexity of experience cannot be captured in a one-off encounter with a participant, rather, it is necessary to take time to build rapport, and to reflect on concerns or experiences shared by participants during the interview. These "long conversations" set a foundation for developing a trusting relationship, where self-disclosure becomes mutual (Harrison et al., 2001, p. 65) and the researcher-participant relationship can be reimagined.

As the project progressed and a sense of saturation became apparent, some community members were interviewed only once. Most participants were engaged in at least two interviews, while some community members were interviewed three, four or five times. The completion of an interview series was determined via negotiation with each participant on the basis that we had discussed their experiences sufficiently to construct a shared understanding. Termination of interviewing processes was guided by the concept of saturation (Eatough & Smith, 2008; Mason, 2010). Within this project, saturation was considered in a multi-levelled fashion. For example, saturation could occur for a particular community member, and also in a broader sense, across the sample as a collective. Saturation in the context of this research project is somewhat problematic. My role as a naïve enquirer (Morrow, 2005) does not permit me to state with any certainty that I understand participants' lived experiences to the extent that I anticipate no novel information will emerge. This assertion would undermine my understanding that I co-construct the realities, and the findings, generated from this research. I do, however, recognise that at a certain point within the interviewing process patterns began to emerge, and information of a similar ilk was being shared by multiple individuals. Causal layered analysis (Inayatullah, 1998) perhaps provides a useful framework within which to conceptualise saturation according to principles of contextualism. For example, while it is reasonable to expect diversity and variability in individuals' stories at the Litany layer and the deeper layers of understanding (e.g., Social Causal, Worldview Discourse and Myth Metaphor layers) the same symbols, rhetoric, dynamics, tensions, paradoxes, and complexities appear to emerge. It is at these deeper-layers of understandings at which I understood saturation, in the context of this research, to be achieved.

The role of experts as story-tellers, as opposed to respondents, is emphasised in this approach (Eatough & Smith, 2008). My role as the researcher was to be reflexive and responsive, posing questions which might encourage participants to elaborate on their lived-experiences (Burgess-Limerick & Burgess-Limerick, 1998). I did not approach interviews with pre-determined interview questions, but with various topics which may be relevant for discussion – present and past experiences with close relationships, meanings associated with close relationships, barriers and facilitative factors of close relationships, and aspirations for close relationships. These

conversational interviews were audio-recorded and took place in a range of locations, including; in the family home, a local park, or a local café. At all times, the privacy of the interviewee was considered paramount. Community members were invited to take breaks throughout the interviews. At the conclusion of each interview, where appropriate, a date and time for a follow-up interview was arranged.

Following each interview, I engaged in reflexive journaling, as a preliminary data analysis process, and in order to develop issues or concerns for further exploration during subsequent interviews. Reflexive journaling will be discussed in greater detail in a subsequent section of this chapter. Each follow-up interview commenced with a reflection on what had previously been discussed, we then entered into further conversation on the nature of relationships and the participant's reflections and experiences. This approach allowed for the development of a shared understanding between each participant and me, and exploration of the deeper-level meaning experiences of participants (Polkinghorne, 2005).

#### ***4.3.2.2.3 Data analysis: Causal layered analysis.***

Causal layered analysis is a method emerging from the field of Critical Futures studies (Bishop & Dzidic, 2014; Inayatullah, 2004; Riedy, 2008). Critical Futures studies is concerned with creating spaces for change to occur, and for alternative realities to develop, through a deconstruction of a phenomenon in the context of social, historical, political, and cultural contexts (Bishop & Dzidic, 2014). Inayatullah sought to extend upon practices within Futures studies, positing causal layered analysis as a method which would allow for exploration of "...*How a particular future has become hegemonic*" (Inayatullah, 2004, p. 12). Inayatullah refers to the works of Michel Foucault, and of the field of complexity theory to inform causal layered analysis as a method which allows deconstruction of language, social practices, and *civilisational codes* which construct any particular future or reality as truth (Inayatullah, 2004). He proposed that through developing an understanding of these various representations, scripts, and symbols a space is created within which to question the future and consider the possibility of alternate futures. In other words, causal layered analysis:

*...contextualizes data (the predictive) with the meanings (interpretive) we give them, and then locates these in various historical structures of power/knowledge – class, gender, varna and episteme (the critical), along with the unconscious stories that express and to a certain extent, define the episteme. (Inayatullah, 2004, p. 11-12)*

As such, causal layered analysis provides an analytical framework, or “jumping off point” to engage in action research imperatives. This framework is informed by various ways of knowing that influence and mould meaning making, and so, possible futures. Employing causal layered analysis as methodology promotes consideration as to why a particular phenomenon is constructed as a problem, rather than merely accepting that a particular phenomenon is problematic.

The contextual nature of causal layered analysis allows for exploration of the construction of phenomena, via exploration of cultural scripts constructed by historical, social, and political events. In establishing causal layered analysis as an analytical framework, Inayatullah (2004) advocates for a vertical typology of understanding, achieving insight and enlightenment through exploring issues at increasingly deeper levels of understanding. Subsequent to deconstructing issues in a typological fashion (progressing from literal to increasingly metaphorical ways of knowing), issues are reconstructed according to a new commentary, one which is self-conscious of the cultural contexts within which phenomena are embedded. In this way, causal layered analysis offers a transformative methodology (Inayatullah, 2004), allowing for insight beyond typically unquestioned aspects of the world, to promote collective self-awareness, and create a space for alternative futures to take hold (Bishop & Dzidic, 2014).

Bishop and Dzidic (2014) relate the opportunity for social action created by causal layered analysis to the distinction between first-order and second-order change<sup>11</sup> (Watzlawick, Weakland, & Fisch, 1974). The aim of causal layered analysis is to “drill down” to the core of an issue, to uncover those factors that perpetuate a particular phenomenon. Causal layered analysis creates this deeper level analysis, as the user is encouraged to consider issues from various perspectives, and to determine

---

<sup>11</sup> First-order change refers to change directed at an individual within a setting, whereas second-order refers to change targeted at the social-cultural context in which the individual is embedded.



the root causes of an issue, within a cultural context. In understanding issues at this deeper-level, and being able to uncover the key aspects of the issue, there is scope to formulate alternative futures which challenge structures and systems, and may lead to second-order or meaningful change. Bussey (2009, p. 21) eloquently describes the potential for causal layered analysis to offer an alternative existence, create social change, and reaffirm the agency of individuals bound up within systems:

*If they feel battered by the day-to-day chaos of the Litany, CLA [causal layered analysis] offers them a way to ground their experiences in deeper contexts that are broader and more meaningful; if they feel the system drives everything, CLA allows them to see the values that inform this process and helps them to identify contradictions and ways in which their values, once submerged, can become clearer and more relevant.*

Bussey (2009) refers to causal layered analysis as a method to assist in resolving the inherent tension between objective, and subjective existences. Causal layered analysis is inherently empowering, it is a method which encourages the individual to understand their experiences in terms of a broader social-cultural context. In this way, "...meaning is no longer imposed on the individuals in the structure they inhabit but becomes fluid and negotiated" (Bussey, 2009, p. 20).

#### **4.3.2.2.3.1 Layers of causal layered analysis.**

Causal layered analysis is a methodology in the sense that it carries with it a range of epistemological, ontological, and rhetorical assumptions. Causal layered analysis may also be applied as a method, and can be successfully used in the context of qualitative data analysis (Bishop & Dzidic, 2014). The causal layered analysis framework assumes that there are four layers of understanding. These layers are typological, moving from metaphorical or symbolic to increasingly literal and surface ways of conceptualising an issue (Inayatullah, 2004). The four layers of causal layered analysis are; the *Myth Metaphor* layer, the *Worldview Discourse* layer, the *Social Causal* layer and the *Litany* layer.

At the deepest layer of understanding, the Myth Metaphor layer, an issue can be understood via symbolic representations of the phenomena. At this layer, symbols, metaphors, and myths may act as relics of civilisational codes (Inayatullah, 2004).

Goodman (1978) noted the value of such symbols, myths, and metaphors (e.g., those captured through artistic works) in revealing the nature of world(s). He suggested, as is advocated by Inayatullah, that these symbols capture the emotions and deeply-rooted, culturally constructed meanings inherent to experiences and the issue more specifically. Shifting to the next layer of understanding, the Worldview Discourse layer captures commonly held views or rhetoric concerning an issue. At this layer, the meanings and understanding which reflect implicit understandings surrounding the phenomena are explored. Often, worldviews and discourse are not explicitly stated, rather, can be inferred by the language used to describe an issue. Moving along the typological structure, the next layer is the Social Causal layer, where phenomena are deconstructed in terms of those structural or systemic factors which interact with, or relate to the construction of the phenomena. At this layer, the influence of ecological factors is considered, and the information is contextualised in regard to social practices and paradigms. The Litany layer reflects the way that problems or issues are commonly described or explained. This layer represents a literal interpretation of this issue, and is often evident in the stories and rhetoric surrounding phenomena. At this layer, the issue or problem is decontextualised.

The four layers of causal layered analysis are to be understood as equally valuable and meaningful (Bishop & Dzidic, 2014). No one layer is considered superior to another, they each inform on a different aspect of the collective and individual experience. Understanding at each layer interacts, and facilitates understanding at all other layers. These layers are mutually sustaining, they are not causative as such (Bishop & Dzidic, 2014), rather, they influence one another in an iterative and reflexive manner (Bussey, 2009).

#### ***4.3.2.2.3.2 Application of causal layered analysis.***

Causal layered analysis is a methodology considered appropriate for “wicked problems” (Bishop & Dzidic, 2014), that is, those social-cultural problems which are viewed as particularly complex, persistent, to which there are no identified “easy” solutions, and may elicit a sense of overwhelming hopelessness or despair (Rittel & Webber, 1973, as cited in Bishop & Dzidic, 2014). I propose that issues related to disability, sexuality, and relationships fall into this category of wicked problems. Sexuality and relationships, in the context of the construction of disability, often

presents as a taboo issue, and seems to provoke controversy, polarising the community. Applying a causal layered analysis to unpacking issues surrounding disability, sexuality, and relationships allows for deconstruction of the problem and to understand it on multiple levels. In doing so, the intent is to diminish the sense of hopelessness, and to capture, and contain some of the complexity inherent to this issue. Causal layered analysis provides a structured framework for understanding wicked problems, so that the root causes, dynamics, and influences on an issue may be identified and subsequently addressed.

Over the past few decades, disability studies have experienced rapid change and development, in terms of how disability is constructed and with regard to paradigmatic shifts in the ways issues are constructed in the context of disability (as is outlined in chapter two). Causal layered analysis offers an opportunity to consider issues related to disability beyond a surface-level understanding, providing a framework for exploring this issue, in a contextual and holistic manner, with regard to the various systems and structures which interact to influence what it means to be labelled with intellectual disability in dominant Western culture. There is a rich socio-cultural, political, and historical context to the field of disability studies which may be unpacked, in order to understand the core of the issue. Historically, attempts to explore and address issues in the context of disability tend to adopt an individualised focus, and tend to problematise the individual, rather than view that person within their socio-cultural context or the person as part of the context. Causal layered analysis offers an opportunity to engage in a more holistic, contextualised analysis of the issues at hand, filling a recognisable gap within the research literature on disability, sexuality, and intimate relationships.

#### ***4.3.2.2.3.3 Steps in conducting a causal layered analysis.***

There are several stages in conducting a causal layered analysis, as outlined by Bishop and Dzidic (2014), including; ensuring that the research question is best attended to via a causal layered analysis methodology, familiarising oneself with the data, coding within the layers, coding between the layers, and reconstructing the issue. The analytical processes take place in the phases of coding within and between the layers, and reconstructing the issue. The process of coding between the layers refers to coding the data (e.g., transcripts, line by line) and attempting to locate each

section of text within a particular layer. Subsequent to this process, the researcher turns their attention to each layer, effectively conducting a thematic analysis within each layer of understanding. Bishop and Dzidic note that the process of coding is iterative, suggesting that text coded into a particular layer, on reflection, may later be re-coded into another layer. This iterative-generative reflexive practice resembles that outlined by Charles Pierce as a process of *abductive reasoning*, where one may begin with an inference, consult with data and reflect on said inference, in an iterative fashion to further develop understanding (Frankfurt, 1958). Similarly, the analytical process could be identified as *substantive theorising*, outlined by Wicker (1989, p. 540) as an open rather than static process where one oscillates between generating ideas grounded in insight, culture, and assumptions, working to further explore the quality of these assertions through "...*expanding, elaborating, refining, and reorienting working concepts and propositions*". It is during the process of coding within the layers that themes emerge and are consolidated. The final stage of causal layered analysis, reconstructing the issue, refers to a process of communicating the overall meanings associated with the issue to the reader and community. Inherent to the process of reconstructing the issue, is the notion of posing alternative futures, that is, critically considering how findings from the causal layered analysis relate to the initial research question, and what opportunities may exist to facilitate social change.

#### **4.3.2.2.3.4 Undertaking the data analysis.**

The data were analysed in an iterative-generative reflexive manner (Bishop et al., 2002), using the analytical framework provided by causal layered analysis. The specific steps engaged to conduct a causal layered analysis were adapted from those outlined by Bishop and Dzidic (2014). All audio-recordings from each interview were transcribed verbatim into a word document, and then imported into QSR International NVivo 10 for data management purposes. The transcription phase is considered a preliminary analysis phase, as it offers an opportunity for the researcher to become familiar with the data, and to record critical reflections on emerging ideas and assumptions regarding the findings. Following transcription, and prior to coding phases, I re-read each transcript to further enhance my familiarity with the data. Subsequently, I began a process of coding between the layers, analysing each transcript, line-by-line, to determine sections of text which could be understood at

the Litany, Social Causal, Worldview Discourse, and or Myth Metaphor layers. When coding between the layers, I found that some sections of text could be understood at multiple layers, and would code them accordingly. At this stage in the analysis, I found it particularly useful to maintain a series of analytic memos (Morrow, 2005) or reflections on initial interpretations and assumptions, reactions, and “hunches” regarding the research findings. Recording these analytic memos formed a kind of paper trail (Yardley, 2008) for the development of themes and findings. I found it a useful strategy to code all transcripts between the layers, prior to moving onto the second round of coding, within the layers. During this phase of coding, I conducted a thematic analysis (according to the framework outlined by Braun & Clarke, 2006) on text coded within each layer of understanding. This stage of coding generated some initial themes, which were summarised in a series of thematic maps.

This phase of the research and analysis was iterative, punctuated by weekly meetings with my supervisory team, who offered reflexive conversation and an opportunity to share the process of mapping out, and understanding, themes. These reflexive processes, in combination with recording analytic memos, contribute to truth-value of the claim that findings are representative of the experiences and meanings-made by participants who shared their stories for this project (Morrow, 2005). The iterative nature of the analysis was also reflected in the interaction between writing-up themes and findings, and continuing with analysis. In this sense, I found myself shifting from recording analytic memos, to formally writing up themes. I found that as I wrote and reflected on themes, my understanding of the dynamics, paradoxes, and patterns within the data continued to develop. Subsequent to conducting the formal analysis, and writing up themes and reconstructing the issues (Bishop & Dzidic, 2014), the final stage in the causal layered analysis process involves posing alternative futures. This final phase of the analysis is represented in the concluding sections of chapter eight of this thesis, the discussion.

#### ***4.3.2.3 Phase three: Inviting feedback from the community.***

This phase of the research involved disseminating the research findings to the community and inviting the community to provide feedback on the research findings. There are ethical and moral tensions associated with these processes. A key concern

with employing a traditional method of respondent validation (e.g., sending a summary of findings to individuals who engaged directly in the research) was the extent to which this method of feedback would be appropriate and meaningfully received by individuals who took part. My contact with participants, and their parents and family members, was generally via telephone rather than electronically via email. By extension, any feedback would have to be provided in person, over the telephone, or via a letter sent to participants' residences. My concerns surrounded the ecological acceptability of these processes. For example, as written literacy was not an inclusion criterion for participation, it was determined that providing findings in written form may not be an appropriate or accessible means of communication. Additionally, my contact with participants was mediated by parents, carers or family members, and all participants lived in the family home. As such, it is reasonable to speculate that a letter may not have been received directly by participants, and perhaps not at all. This process posed a dilemma of ethics-in-practice, and had the potential to replicate some of the processes emerging from the research findings (outlined in chapter seven). My concern was that participants would not be privy to this feedback process, which would undermine the value of engaging in a respondent validation procedure.

Based on these concerns, an alternative procedure was engaged. Rather than invite participants to give commentary on the findings, findings were distributed to a range of stakeholders within the community for feedback and commentary in two formats – via workshops, seminars, and conferences, and via a circulating a summary of findings to key representative groups within the community. Phase three took place iteratively, overlapping with phase two of the research. Over the course of the research project, during the planning, data collection, analysis and, write-up phases, I had the opportunity to attend and participate and also present the research process, preliminary findings, and my reflections to a range of community and representative groups, in a range of settings (summarised in Table 4). I assumed various roles within each of these settings, as attendee, con-contributor, co-facilitator, presenter, and so on. In each of these settings, I observed, posed questions, shared ideas and invited questions, feedback and facilitated discussion on my findings and reflections on the research. I reflected on the conversations and feedback given in these settings, which informed the iterative processes of planning the project, collecting data, data

analysis, and meaningful interpretation of findings. A summary of messages emerging from engaging in these settings, and my reflections on these messages, is provided in chapter six.

Table 4

*Summary of Seminars, Workshops, and Conferences attended*

Setting	Role	Location	Month, year	Attendees
Seminar: <i>Inclusive research seminar</i> Hosted by Centre for Disability Studies, The University of Sydney, Griffith University and Social Policy Research Centre	Attendee	Sydney, New South Wales	March 2011	Disability service-provider representatives, students, health professionals, support-workers, self-advocates, advocates, and researchers
Workshop: <i>What about me? Working with disability and sexual trauma</i> Hosted by Sexual Assault Resource Centre	Attendee	Perth, Western Australia	April 2011	Disability service-provider representatives, students, teachers, health professionals, support-workers, researchers, parents of individuals labelled with disability, self-advocates, advocates
Workshop: <i>Boundary setting and protective behaviours</i> Hosted by Sexuality Education Counselling and Consulting Agency (SECCA)	Attendee	Perth, Western Australia	May 2012	Disability service-provider representatives, teachers, students, health professionals, support-workers, researchers, parents of individuals labelled with disability
Workshop: <i>Menstrual management, personal</i>	Attendee	Perth, Western Australia	June 2012	Disability service-provider representatives, teachers,



<i>hygiene and sexual health</i>					students, health professionals, support-workers, researchers, parents of individuals labelled with disability
Hosted by Sexuality Education Counselling and Consulting Agency (SECCA)					
Forum:	Attendee	Perth, Western Australia	July 2012		Disability service-provider representatives, students, teachers, health professionals, community members, support-workers, researchers, parents of individuals labelled with disability, self-advocates, advocates
<i>Evening screening of 'Scarlett Road' with Q&amp;A discussion with Rachel Wotton</i>					
Hosted by Western Australian Sexology Society					
Forum:	Attendee	Perth, Western Australia	July 2012		Disability service-provider representatives, students, teachers, health professionals, community members, support-workers, researchers, parents of individuals labelled with disability, self-advocates, advocates
<i>'Scarlett Road' and associated issues</i>					
Hosted by Western Australian Sexology Society					
Seminar:	Attendee	Perth, Western Australia	July 2012		Disability service-provider representatives, health professionals, support-workers, and researchers
<i>Childhood to adulthood: providing people with disability the foundations so they need so that can</i>					

---

*have sensual and sexual experiences*

Hosted by Western Australian  
Sexology Society

---

Seminar:  <i>Supporting people with intellectual disability to live good lives in the community – the role of group homes past and future</i>	Attendee	Perth, Western Australia	November 2012	Disability service-provider representatives, students, health professionals, support-workers, and researchers
Hosted by Disability Services Commission and the Australian Society for Intellectual Disability				

---

Workshop:  <i>Sexuality and disability</i>	Attendee	Perth, Western Australia	February 2013	Disability service-provider representatives, teachers, students, health professionals, support-workers, researchers, parents of individuals labelled with disability
Hosted by Sexuality Education Counselling and Consulting Agency (SECCA)				

---

Conference:  <i>Pacific Rim 29<sup>th</sup> Annual Conference on Disability and Diversity</i>	Attendee and topical presentation:  <i>“I need a normal boyfriend that I can kiss”: Exploring the close relationship experiences of individuals with an</i>	Hawai’i, Honolulu, USA	April 2013	Disability service-provider representatives, teachers, health professionals, support-workers, researchers, parents of individuals labelled with disability, self-advocates, advocates
---	---	---------------------------	------------	---

---

---

<i>intellectual disability</i>				
Conference: <i>Society for Community Research and Action, 14th Biennial conference</i>	Attendee and Poster presentation: <i>Growing relationships: Reflections on a community-based participatory project</i>	Miami, Florida, USA	June 2013	Disability service-provider representatives, teachers, health professionals, support-workers, researchers, parents of individuals labelled with disability, self-advocates, advocates
Small group discussion: <i>Sexuality, relationships and disability</i>  Hosted by health professionals	Attendee and Co-facilitator	Perth, Western Australia	December 2013	Health professionals, parents of adults labelled with intellectual disability
Seminar: <i>Collaboration and Participation in Research</i>  Hosted by Curtin University	Attendee and topical presentation: <i>Reflections on participation and action within "Growing relationships" project</i>	Perth, Western Australia	March 2014	Disability service-provider representatives, teachers, health professionals, support-workers, researchers, parents of individuals labelled with disability, self-advocates, advocates
Forum: <i>A discussion about access to sex workers, sexual surrogacy,</i>	Attendee	Perth, Western Australia	May 2014	

---

---

*facilitated sexual activity and  
Sexological bodywork for people  
with a disability*

Hosted by Western Australian  
Sexology Society

---

Workshop:

*Disability, sexuality and  
relationships*

Hosted by disability service-provider

Attendee and Co-  
facilitator

Perth, Western  
Australia

July 2014

Disability service-provider  
representatives, teachers,  
health professionals,  
support-workers,  
researchers, parents of  
individuals labelled with  
disability, self-advocates

---

Seminar:

*Disability and sexuality*

Hosted by Western Australian  
Sexology Society

Co-facilitator, attendee  
and topical  
presentation:

*Wanting to be  
important, with  
someone: Exploring the  
close relationship  
experiences of  
individuals with an  
intellectual disability*

---

Perth, Western  
Australia

October 2014

Disability service-provider  
representatives, health  
professionals, support-  
workers, researchers,  
parents of individuals  
labelled with disability,  
self-advocates, advocates

Additionally, a summary of the research findings was circulated to stakeholders, organisations, and community groups for commentary and feedback (see Appendix C for summary of findings circulated to community). Initially, I circulated the summary of findings to several local and national organisations and stakeholders, in the domains of advocacy, service-provision, and disability research. Community members were invited to make contact via email or telephone to provide feedback on findings. The scope of the circulation of this document is not known, however, I did receive feedback from some individuals and organisations with whom I did not make direct contact. I speculate that the number of individuals who read the document is greater than the number of individuals who subsequently made contact with me to provide feedback. A summary of key messages, feedback, and patterns emerging from these processes are provided in chapter six.

#### ***4.3.2.4 Trustworthiness and rigour.***

Trustworthiness and rigour refers to extent to which the findings and interpretations of the research might be considered transferable, credible, dependable, and confirmable (Lincoln & Guba, 1985). This project rests on the assumption that different individuals construct equally valid representations of reality and, as such, subjectivity is embraced (Yardley, 2008). Throughout the project, there was an attempted to manage subjectivity to ensure that the views represented reflect those of the participants who shared their stories (Morrow, 2005). As is recommended by Burgess-Limerick and Burgess-Limerick (1998), prior to commencing the project I engaged in a reflection on my values and attitudes on close relationships and individuals living with the label intellectual disability. Acknowledging these assumptions via bracketing does not eliminate them; rather, engenders transparency as to whose views are represented within research findings (Burgess-Limerick & Burgess-Limerick, 1998). In accordance with principles suggested by Montero (2000), in reporting findings I have been mindful to avoid being selective on the details included. In other words, I have made an attempt to be as transparent as possible, and to report findings in their entirety. Including reflections throughout this thesis contribute to the transparency of the project.

#### 4.3.2.4.1 *Reflexivity.*

Reflective-generative practice is central to the execution of collaborative and applied research, and to the active re-negotiation of the researcher-participant relationship. In reflective-generative practice the researcher adopts a reflexive stance or an "...*awareness of one's own processes...*" (Elias, 1994, p. 301) to be present in an empathic relationship with the informant, whilst maintaining their role as the naïve enquirer (Dokecki, 1996). The nuances and complexities of engaging my role as a naïve enquirer, while being immersed within the community will be discussed in greater depth in chapter seven. Reflexivity is particularly important when conducting research which is collaborative and steeped in contextualism, offering a means by which to address power differences and distances between researcher and participant in the research process (Etherington, 1997). For example, inclusive researchers may find themselves immersed within the culture of those with whom they are investigating, a phenomena referred to as going native (Gold, 1958). A researcher may become so immersed that they begin to accept community member's views as their own. This process represents the development of a shared understanding amongst the researcher and community members (Bishop et al., 2002). Shared understanding is characterised by reflection-in-action where the researcher and informant share responsibility for exploring and examining their lived experiences (examples of this process can be found in chapter seven; Dokecki, 1996). In order for the researcher to represent this shared understanding to the wider community, one must avoid assuming that this understanding is based on obvious truths, and reflect upon how it developed (Bishop et al., 2002; Elias, 1994; Guilleman & Gillam, 2004). Hence, reflexivity must be engaged in throughout collaborative research processes to facilitate an understanding of the research process and outcomes developed.

Processes of reflexivity have been employed extensively throughout the course of this research project. Prior to, and throughout the course of the project, I have maintained a personal reflexive journal, detailing reflections on my assumptions, developing understandings, and hunches regarding the nature of the socio-cultural context (examples from my reflexive journal are provided in chapter seven). I also engaged with my supervisory team in ongoing reflective and critical discussion throughout the research project. In these discussions, my supervisors served as a kind of "mirror", highlighting my responses to the research process and emergent themes

(Morrow, 2005). Reflexivity allowed for an examination of the extent to which the research was collaborative and, when necessary, allowed for the adaptation of research processes to enhance collaboration (Björnsdóttir & Svendsdóttir, 2008). As previously outlined, I have also engaged in critical conversation with various community members, including education support assistants, community members, family members of individuals living with the label intellectual disability, higher degree by research peers, professionals, and community members at conferences, workshops, and seminars. These experiences of exchanging ideas, reflections, and engaging in critical discussion with community members have informed a developing understanding of the phenomena under exploration.

These formal (e.g., journaling) and informal (e.g., conversations with and immersion within the community) reflexive processes are recognised as key elements of a rigorous qualitative research process as they contribute to the quality, trustworthiness, and social relevance of the research findings (Koch & Harrington, 1998; Morrow, 2005). Offering reflexive experiences as data provides the community with an understanding not only of the meaning made from stories shared by participants in the study, but also provides insight on the process of constructing that meaning (Etherington, 1997; Morrow, 2005). For example, reflexive processes provided me with insight into my own assumptions regarding disability, sexuality, and relationships, and how these may be represented in the research findings.

Reflexive processes may be considered in context of *bracketing*, promoted within phenomenological enquiry, as a process of identifying one's views and assumptions, in order to then set them aside and maintain impartiality in the research process (Creswell, 2013). In the context of this project and in consideration of the epistemological, theoretical, and analytical frameworks underpinning the inquiry, I do not feel it is possible, or necessary, to attempt to remove myself from the interpretive process. Rather, reflexive processes have been engaged in attempt to elucidate the nature of inclusive research processes, and to provide context for the development of research findings. In this way, adopting reflexive practices enhances the transparency of the research process and contributes to the quality, rigour and trustworthiness of the research findings (Etherington, 1997).

#### **4.3.2.4.2 Adequacy of data and interpretation.**

Adequacy of the data can be inferred by the extent to which there is sufficient evidence within the data, a variety of types of evidence, adequate interpretation of evidence, and disconfirming evidence and discrepant case analysis (Morrow, 2005). In the context of this project triangulation (Yardley, 2008) referred to enriching the depth of understanding of close relationships in the context of intellectual disability, through exploring various perspectives (e.g., individuals labelled with intellectual disability, their family members, support-workers, and other community members) at various layers (e.g., with regard to causal layered analysis). Given the typically emergent nature of research design within inclusive and qualitative research, it is common practice for researchers to maintain a *paper trail* which demonstrates how the research process developed (Yardley, 2008). Throughout the project, I maintained a paper-trail in the form of field notes, formal notes, and reflections, minutes of meetings, and emails which highlight the research process and rationale for adopting particular methods at the expense of others.

#### **4.3.2.5 Ethical considerations.**

Given the emergent nature of collaborative research design and processes, principles of *ethics in practice* were adopted throughout the research project (Guilleman & Gillam, 2004). As is recommended by Guilleman and Gillam, I engaged in critical self-reflective strategies and discussions with supervisors to identify and address potential ethical issues as they may arise. As is typical of qualitative research, relationships between participants and myself transformed throughout the project to reflect relationships based on mutual respect and collaboration, rather than the traditional participant-researcher dynamic (Haverkamp, 2005). Reflexivity provides transparency and accountability as to the ethical nature of these relationships (Guilleman & Gillam, 2004). Issues related to ethics in practice are discussed in greater detail in chapter seven of this thesis, the process chapter.

In this section, I will outline ethical considerations of the research with regard to procedural concerns. The processes and parameters of this research project are in compliance with the Australian Psychological Society Code of Ethics (2007), the National Statement on Ethical Conduct in Human Research (2007), and, prior to commencement of the research, approval to conduct the research project was



obtained from the Human Research Ethics Committee at Curtin University. In this research project the risk of social or psychological harm was minimised through use of ethics-in-practice principles, and via the adoption of specific strategies and protocol. For example, prior to engaging with participants, a range of topics (e.g., illegal activity, experiences of trauma) which may cause psychological discomfort were identified, and were intentionally avoided in in conversational interviews. The risk of social discomfort was minimised through the de-identification of participants' data to preserve confidentiality. Additionally, contact details for my primary supervisor and I were provided to all participants in the event that they wished to discuss any issues related to the project. All information collected as part of the project will be kept in a locked cabinet for seven years following completion of the project, before it is destroyed.

#### **4.4 Conclusion**

The ontology, epistemology, research aims, methodology, and methods for this research project were outlined in this chapter. A critical discussion on ontology and epistemology, and a statement of my own epistemological position was provided. Following on from this, I engaged in a critical discussion of historical, contemporary and relevant research paradigms and highlighted principles of applied and inclusive research as underpinning the research project. The specific methodological approach and methods were detailed. In addition, procedures and strategies for establishing the quality, trustworthiness and rigour, and ethical considerations of the research project were discussed. Findings generated from a causal layered analysis of interviews with participants are outlined in the following chapter.

## **Chapter five: Findings**

### **5.1 Introduction**

In this chapter I present the findings from the research. These findings have been generated via a causal layered analysis of conversational interviews with participants who consented to share their stories for this project. In my role as participant conceptualiser (previously outlined in chapter four), it is important to note that these findings are grounded in the interview data, but are also understood in context of the research process, my reflections, and my experiences of engaging with the community. This chapter is presented in several sections. Prior to presenting the themes generated from the causal layered analysis, a vignette is presented to provide some socio-cultural context for the stories and experiences shared by participants. A thematic map (see Figure 2) detailing the themes within each layer of understanding is presented as a visual representation of the findings, and is accompanied by a summary of themes generated at each layer of analysis (see Table 5).

The findings are then presented typologically, according to the layers of understanding within causal layered analysis, commencing with the Myth Metaphor layer of understanding, and concluding with the Litany layer of understanding. Each layer begins with an introduction outlining the features of the layer, is followed by presentation of themes and concluded with a summary of themes and key messages. Following presentation of all layers, a vignette is presented to the reader, in an attempt to contextualise the messages emerging from the analysis. This vignette represents the final phase of the causal layered analysis, providing the reader with a reconstruction of the issues.

### **5.2 Vignette: Presenting a complex cultural context**

This vignette is presented with the aim of providing the reader with an understanding of the socio-cultural context surrounding individuals who live with the label intellectual disability. This vignette does not tell one community member's story in particular, rather, it is a compilation of various key themes and experiences shared by community members, and emerging from the analysis. This vignette is presented with the hope that it will foster sense-making, and provide a context, to the findings emerging from the interview data and themes generated from the causal layered analysis.

### 5.2.1 Rhiannon's story.

*Hi, my name is Rhiannon. I'm 24 years old, and I live at home with my Mum, dad, sister and younger brother. My days are pretty busy, I work three days a week packing shelves at a grocery store. On Wednesday nights I have basketball, on Thursday nights I go to Drama club and on Saturdays I go to bowling. Oh, and once a month on a Friday I have social night. On social night, there are about ten of us that get together at my disability service-provider to have a disco, cook some food, or watch movies. Last month our carers helped us to make spaghetti for dinner, and we watched a movie. I'm not sure what we are doing this month; I will have to ask my mum.*

*During the week, on a Tuesday afternoon, I spend time with my carer, Wendy. Wendy and I usually go to the shops together; we get some groceries, look at clothes, and maybe get some lunch. Wendy has worked with me for a long time; I count her as one of my good friends. If Wendy is sick, or can't make it, then another adult will come out with me. It's a bit different when that happens, because I usually don't know until that afternoon that a new person is coming to work with me. Apart from my bowling, drama and basketball, I have other hobbies too. I really love to sing and dance and I love music and watching the football. Sometimes dad and I go to the football together, and sometimes my friend Chelsea comes too. A few weeks ago, my boyfriend and, his name is Richard, went to a concert. My sister and her boyfriend came as our carers. We all sat together, we sang, and we had a great time.*

*Usually, I only see Richard at bowling, or at social night. He lives far away from me, and I don't drive, so it's a bit hard for us to see each other. I would like to see him more, maybe go out for dinner, or to a movie. I'm always telling mum that. She said she will call his mum to organise for us to see each other. I guess I'd like to spend time with him on our own. At social night, and bowling, we are surrounded by our friends, we don't get much private time. I mean, it's good that we are all friends; but sometimes it gets a bit hard. Sometimes he comes to my house for dinner, we are allowed to watch TV in the lounge room, or in my bedroom, but mum and dad say that "the door has to stay open!" They have a rule against boys in my bedroom, and I'm definitely not allowed to have a boy sleep over in my room – not until we're married.*

*I have spoken to Richard about getting married. We have been together for five years. I think we would both like to – one day. My sister is engaged actually, it is very exciting. She is going on a honeymoon to Los Angeles. Mum and dad say marriage is complicated. Maybe we can do it when we're older. I do like living at home, and I know my family cares about me, but sometimes I dream about living with my friends or my boyfriend. I like to imagine our house, and all of the things we would put in it. I'd have to have space for all of my basketball trophies. I think I will move out one day, when I'm ready, when I know how to look after myself. I mean, I can cook some things, and I do my own washing, but I have to keep practicing – practice makes perfect!*

### **5.3 Thematic map**

Themes generated from the causal layered analysis are represented visually in a thematic map (see Figure 2). The findings have been represented visually in the format of a series of concentric circles, where each circle represents a layer of understanding (e.g., Litany, Social Causal, Worldview Discourse, and Myth Metaphor). I have chosen to represent the layers of understandings, and themes, in this nested structure as this reflects the fluid, iterative and multi-directional influence of each layers upon the other. Boundaries between the layers are represented by a dotted line, to reflect this level of fluidity. This visual representation reflects that no one layer is considered more important than another, instead, the layers inform one another, and are nested within one another. This visual representation of the findings is an acknowledgement that layers of understanding serve as a context for understandings at each subsequent layer. A summary of the themes across each layer of understanding is presented in Table 5.

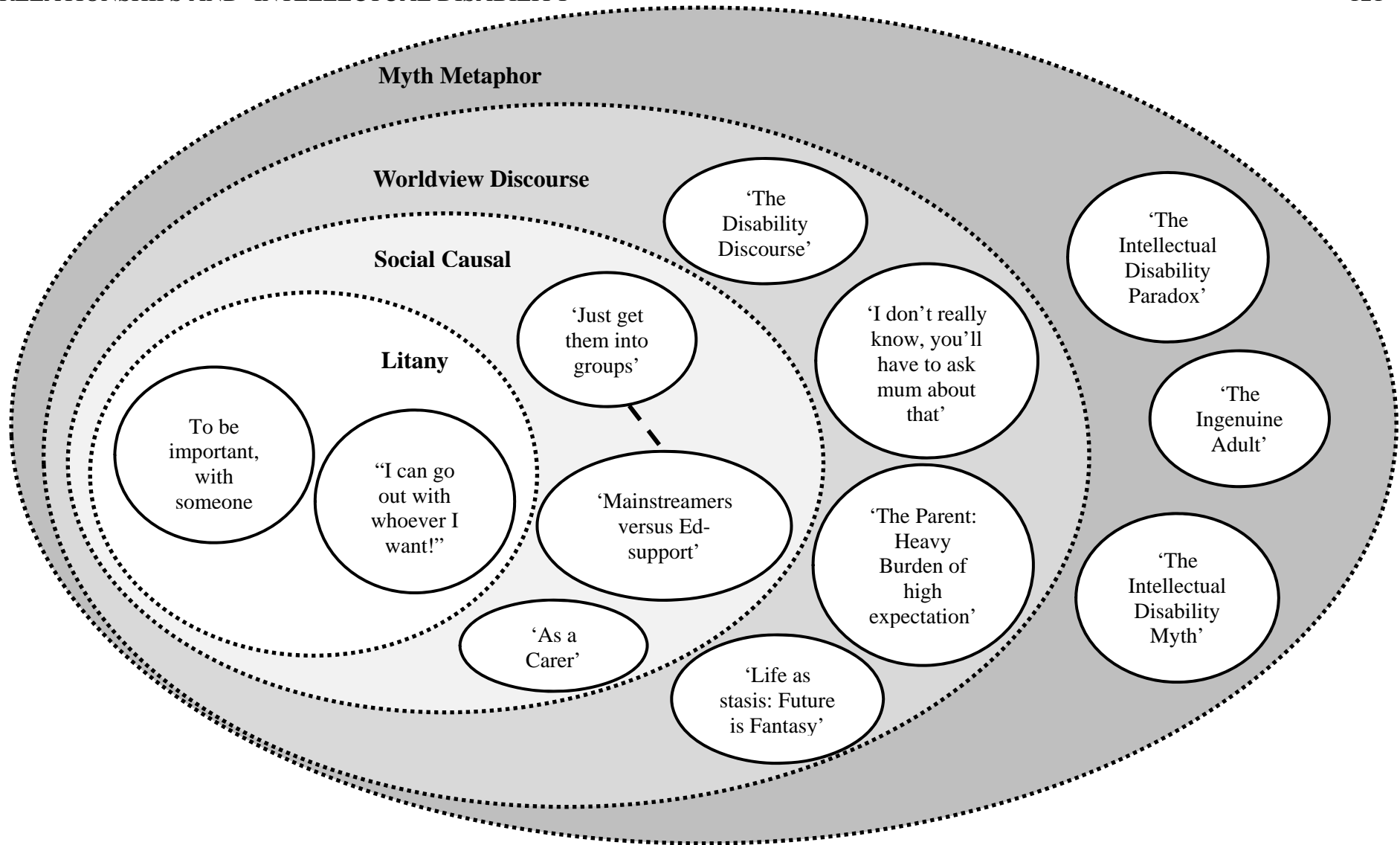


Figure 2. Thematic map of findings generated from causal layered analysis.

Table 5

*Summary of Themes Generated from Causal Layered Analysis*

Layer of understanding	Theme	Description
Myth Metaphor	'The Intellectual Disability Myth'	<ul style="list-style-type: none"> <li>• Intellectual disability as a social construct versus an undeniable truth</li> <li>• Represents more than diagnostic criteria, takes on socio-cultural value</li> <li>• Abnormality, and being inherently different</li> <li>• A master status, a fixed identity</li> <li>• Assumptions on intellectual disability</li> <li>• Incompetency, vulnerability, passivity</li> </ul>
	'The Intellectual Disability Paradox'	<ul style="list-style-type: none"> <li>• A socio-cultural process or dynamic</li> <li>• Intellectual disability as a rhetorical construct</li> <li>• Pathologising/attributing behaviours to intellectual disability</li> <li>• Paradox is that in pursuit of a normal life, life becomes distinctly less normal</li> </ul>
	'The Ingenuine Adult'	<ul style="list-style-type: none"> <li>• Symbolic representation of individuals labelled with intellectual disability as child-like</li> <li>• Rhetoric of permission, or being allowed to do things</li> <li>• Missing markers of adulthood</li> <li>• Identities ascribed are consistent with assumptions of child identity</li> </ul>
Worldview Discourse	'The Disability' Discourse	<ul style="list-style-type: none"> <li>• Language as means of conveying worldviews, assumptions and myths on intellectual disability</li> <li>• Alternative spaces for habitation</li> </ul>

- Rhetoric of permission, of being allowed to do things
  - Disruptive discourses
- 'I don't really know, you'll have to ask mum about that'
- Dynamic of deferring to another individual on the details of one's own life
  - Control, choice, and independence
  - Gatekeepers
  - Surveillance and support
- 'The Parent: Heavy burden of high expectation'
- Social construction of a parent of an individual labelled with intellectual disability
  - Expectations to balance roles of protector and facilitator
- 'Life as stasis: Future is fantasy'
- Notion that future was fantastical, may never come
  - A 'pretend life'
  - Being ready for the future
  - Protection

Social Causal

- 'Just get them into groups'
- Intellectual disability a problem to be solved
  - The solution is to 'get them into groups'
  - Disability-specific settings
  - Spontaneity, privacy, control, and choice
- Subtheme: 'Mainstreamers versus Ed-support'
- A subtheme of theme 'Just get them into groups'
  - Australian education system
  - Terms Mainstream and Ed-support indicate differences between

		<p>students</p> <ul style="list-style-type: none"> <li>• System legitimises differential treatment</li> </ul>
	'As a Carer'	<ul style="list-style-type: none"> <li>• Relinquishing familial or relational roles for a carer role</li> <li>• Care-giver-care-recipient dyad</li> </ul>
Litany	'To be important, with someone'	<ul style="list-style-type: none"> <li>• Desire for belonging, connectedness, intimacy, and close relationships</li> <li>• Developing personally and as a couple</li> <li>• Unmet desires</li> </ul>
	"I can go out with whoever I want"	<ul style="list-style-type: none"> <li>• Relationships and sexuality in the context of intellectual disability</li> <li>• Assumptions of intellectual disability influence opportunities to engage in relationships, to experience privacy, choice, and control</li> <li>• Notions of normal</li> <li>• Access to relationships contingent upon label of intellectual disability</li> </ul>



#### **5.4 Myth Metaphor Layer**

At the Myth Metaphor layer of understanding, an issue can be understood via symbolic representations of the phenomena. At this layer, symbols, metaphors, and myths may act as relics of civilisational codes (Inayatullah, 2004). Goodman (1978) noted the value of such symbols, myths, and metaphors (e.g., those captured through artistic works) in revealing the nature of world(s). He suggested, as is advocated by Inayatullah, that these symbols capture the emotions and deeply-rooted, culturally constructed meanings inherent to experiences and the issue more specifically.

Themes identified at this layer of understanding include 'The Intellectual Disability Myth', 'The Intellectual Disability Paradox', and 'The Ingenuine Adult'. Each of these themes is explored in depth in the following section (see Figure 3).

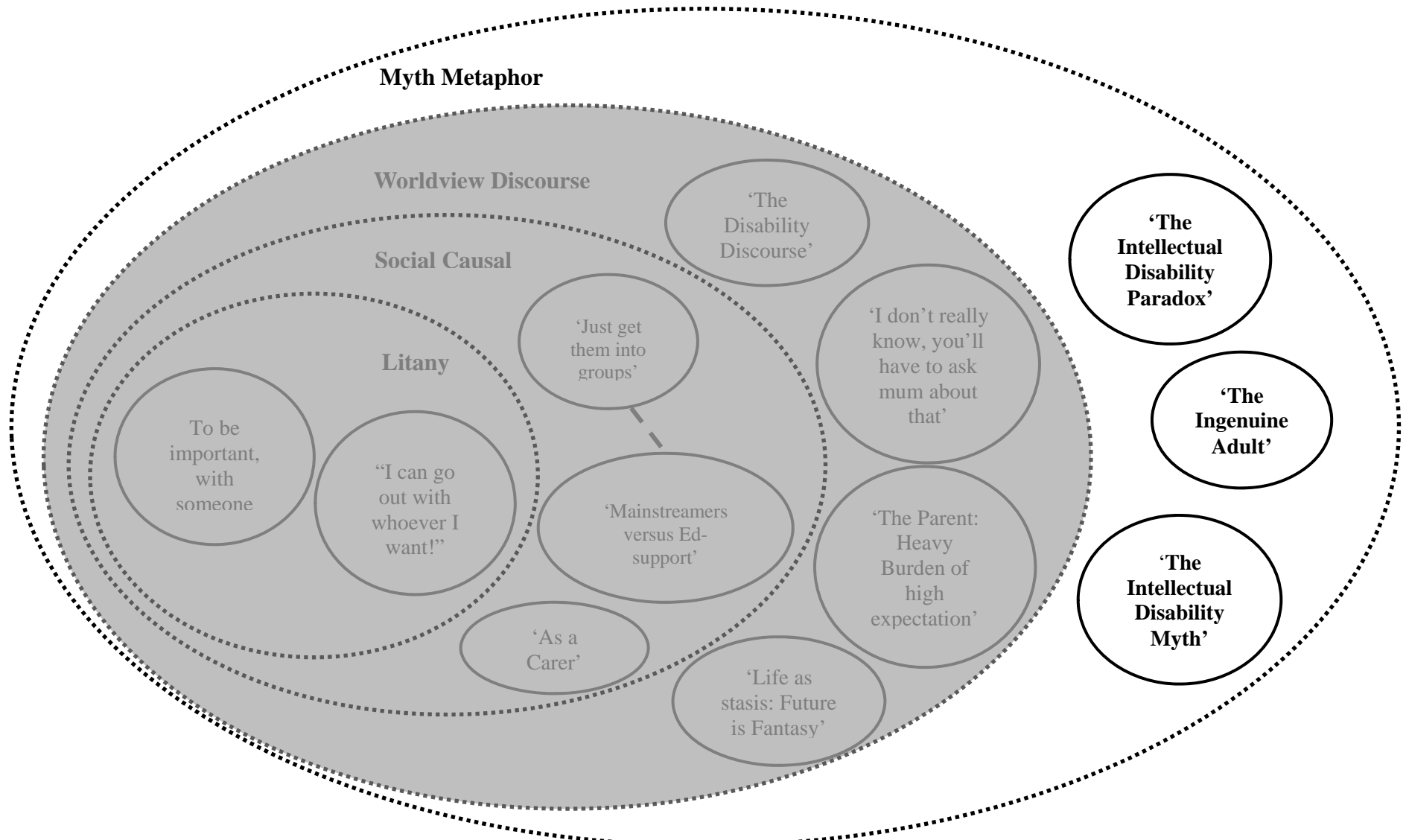


Figure 3. Thematic map of findings with emphasis on Myth Metaphor layer of causal layered analysis.

#### 5.4.1 'The Intellectual Disability Myth'.

The theme 'The Intellectual Disability Myth' reflects the construction of intellectual disability as a social and culturally value-laden identity. Intellectual disability is presented as a myth in the sense that it is a label which transcends its meaning as a series of diagnostic criteria or cognitive strengths and difficulties, rather, intellectual disability is a socially-constructed label, which infers a range of assumptions and expectations about the individuals to whom it is affixed. Intellectual disability seems to represent an identity that can be affixed to an individual, an identity which represents a series of implicit assumptions and understandings about that individual. Intellectual disability is spoken of by participants as though it forms part of an individual's character, for example, in this extract, a participant explains that a family friend recently gave a speech about Down syndrome:

*He got up to give a talk about what it's like be Down syndrome, so he's actually well-spoken...*

The participant suggests that an individual can *be* Down syndrome. The language in this extract is symbolic of the construction of intellectual disability as a central part of an individual's identity. This extract also poses the idea that individuals who live with the label intellectual disability (or Down syndrome) are perceived as having a unique experience of life, on the basis of living with this label. The family friend seems to be acting as a representative for individuals with Down syndrome, suggesting that there is an assumption that individuals with Down syndrome, on the basis of sharing this label, have a remarkable, yet homogenous, experience of life. Throughout participants' stories, individuals who live with the label intellectual disability were presented as inherently different from those who live without this label. For example, one participant describes how she would like to be normal:

Participant: *I'd like to be normal (laughs)*

Emily: *normal? What do you mean by normal?*

Participant: *like... to have a normal boyfriend (laughs)*

Emily: *oh ok, and what would that be like, to have a normal boyfriend?*

Participant: *I don't want to have, I don't want to be Down syndrome, I want to be normal*

The participant makes a distinction between individuals who have Down syndrome, and individuals who are normal, or who do not have Down syndrome. The participant is suggesting that she is not normal, as a function of living with the label Down syndrome, and that this means she cannot expect to have a relationship with a normal boyfriend. This rhetoric of difference, on the basis of intellectual disability, suggests that the term intellectual disability represents more than a quantifiable set of skills, or difficulties, rather, that intellectual disability is a label which differentiates individuals into "us" (i.e., normal people) and "them" (i.e., individuals with intellectual disability), for example:

Participant: *"...they are, like, don't think that we're good enough or, umm, we have some kind of disease or ..."*

The participant presents a metaphor, suggesting that intellectual disability is conceptualised much like a "disease". In this regard, disability has achieved a mythological status. This label reflects more than diagnostic criteria, or a particular cognitive profile, this label is a means of distinguishing between "us" and "them". The conversation continued:

Participant one: *But we're, like, we've got hair, like, we've got a heart. We're still human ...*

Emily: *Yeah.*

Participant one: *... in every single way, but we do things differently.*

Participant two: *We're all individuals.*

Participant one: *Yeah, but, we have the same heart, hair, probably not the same quite hair colour, but, and it's just, and it's hard ...*

Emily: *Do you- ...?*

Participant one: *... because we, umm, have some, but we need help.*

Emily: *Yeah.*

Participant one: *We need to get a little bit more push.*

Emily: *Hmm.*

Participant one: *And they don't.*

Emily: *Hmm.*

Here, two participants contest the myth that intellectual disability represents an inherent difference, they highlight that individuals with intellectual disability are human. This extract is symbolic of the amorphous nature of the label intellectual disability, as individuals who live with this label are forced to defend their very humanity. There is a paradox evident in this extract, on the one hand, the participants reject the identity affixed to them by the label intellectual disability, at the same time, they seem to be subscribing to the assumption that individuals who live with the label intellectual disability are inherently different (e.g., "*we need to get a little bit more push... and they don't*"). Perhaps the tensions operating here are a reflection of an interaction between various worldviews, and myths surrounding intellectual disability. On the one hand, participants may reject the notion that they are inherently different on the basis of intellectual disability, but it seems as though the myths surrounding disability are so entrenched, that they become internalised, and implicit to, the identities of individuals who are ascribed this label. On one level, there is a rejection of the assumptions inherent to the label intellectual disability, yet on another level, individuals subscribe to these assumptions, and infer that intellectual disability forms a part of their identity, setting them apart from individuals who live without this label. Individuals who are affixed with the label intellectual disability are not free to forge an identity. Rather, they are ascribed a particular identity, an identity characterised by assumptions of intellectual disability. One participant reflected on their experience of negotiating their identity, in the context of living with the label intellectual disability:

Participant: *I love talking to my [sibling]. I know it sounds really dumb but umm....I can't even tell [sibling] what I'm feeling...I have mixed feelings...hmm... it's really hard to explain but that's what I was feeling a long time ago like, when I was doing school... but I know that has passed like now and I'm a lot older now... but when I'm with the social group and I first*

*started I wasn't sure who I was but umm...I kind of realised it when I was watching a movie before, a midday movie...*

Emily: *Do you remember what movie it was?*

Participant: (Crying) *umm...It was about this kid's life more...umm... he had umm... a disability umm...or was it...autism? He had autism umm...but when he doesn't get his own way he will flip out and that's really embarrassing like for a lot of people to see and umm...like when he got stuck he would flip out and that kind of thing....but it was really emotional...*

Emily: *Those midday movies can really get you, can't they?*

Participant: (Crying) *Yeah! They really do! Yeah, but it was on the weekend, that kind of movie kind of thing...and that's what I was thinking at the time, about myself and what that kid had went through...*

The participant describes a complex process of introspection surrounding who she is. The participant explains that she has mixed feelings, and reflects on how difficult it is to share these feelings and thoughts with others. It seems as though watching a midday movie about an individual with a disability afforded the participant an opportunity to reflect on her identity. The participant seems to identify with the experiences of the character in the film, noting that they share similar experiences. The participant explains that she identifies with this character, on the basis that they both live with the label intellectual disability, it may be assumed that the participant has internalised what it means to live with this label, and to be different, as part of who she is. In this way, intellectual disability does not merely reflect skills, difficulties, and cognitive profiling. Intellectual disability, rather, is a value-laden amorphous identity which can be affixed to an individual, inferring a range of assumptions about that individual. For example, in Fitzgerald and Withers (2013) exploration of what women with intellectual disabilities think about sex, sexuality, and themselves, the authors found that being "handicapped" represented a master identity, and that other aspects of identity, such as considering oneself a "woman", were secondary. The label intellectual disability has a collective quality, promoting the idea that all individuals with this label are not, in fact, individuals, rather, they are a homogenous group. Where intellectual disability is considered the

total sum of one's identity perhaps opportunities to engage in close relationships, and to express one's sexuality, are simply not promoted.

The mythological status of intellectual disability is evident in rhetoric surrounding what it means to live with this label. While some participants tended to construct intellectual disability in terms of particular personal strengths and difficulties, this construction was still embedded in rhetoric of inherent difference, and othering, for example, one participant explains what "learning disability" means to them:

*... because we're different and it's hard for us to do things, like, like, with mine I've got a learning disability and it's hard for like, to communicate with people sometimes and, hard to... I like to talk an, you know. Umm... yeah so...like Maths, reading and other things...*

On one level, the participant explains learning disability in terms of pragmatic skills, and difficulties, there appears to be no value attached to these difficulties. However, the participant's reflection is prefaced by the comment "*because we're different, and it's hard for us to do things*". It seems as though what it means to have a learning disability is represented at multiple levels. On the surface, the participant explains that she experiences some particular difficulties, however, at a deeper level; there is a value-laden rhetoric around these difficulties, and a discourse of inherent difference. Some participants explicitly reflected on the social-cultural value associated with the label intellectual disability, and their experiences of living with widely held assumptions about intellectual disability, for example, one participant reflects on her and her partner's experiences of living with the label learning disability:

Emily: *Yeah. So what's [partner] like. What about him makes you like him?*

Participant: *...he's got a learning one as well. And I've found out that I've got a learning disability, and each are exactly the same.*

Emily: *Ok.*

Participant: *He gets picked on sometimes, and I get picked on as well... so it's like, oh, we both get picked on sometimes, from each other. Normally if we have a friend that we don't like, we always get picked on by them, so...*

The participant explains that she and her partner are both ascribed with the label 'learning disability', and extends upon this comment, reflecting that "...*each are exactly the same...*" the participant's phrasing suggests that homogeneity is central to the construction of 'The Intellectual Disability Myth' and that living with the label is a shared experience over which she and her partner can connect. The participant's discourse (e.g., "them" and "we") suggests that she and her partner occupy a distinct space on the basis of living with this label. The conversation continued:

Emily: *So what's that about? Why do you think it matters if you have a disability?*

Participant: *Um, it doesn't really matter, but it depends on how, like, Mainstream treated us as well...*

When asked why it matters if they have a disability, the participant says that it doesn't, and suggests that this label only matters to the extent that other individuals (specifically Mainstream individuals, or those without an intellectual disability) attach value or meaning to it. The participant's reflection on living with the label intellectual disability undermines the value of this label as an objective means for identifying diagnostic criteria. Rather, the participant's reflections reinforce the mythological nature of the label intellectual disability, suggesting that this label attaches expectations, and negative values to the experiences of individuals who live with this label. In this way, the label intellectual disability, and the mythology associated with it, provides a platform for othering of individuals who live with this label.

The theme 'The Intellectual Disability Myth' reflects a tension which is inherent to the stories and experiences shared by participants in this project. In order to outline this theme, and explore the complexities associated with the 'The Intellectual Disability Myth', it is necessary to provide some cultural context to the understanding of the term intellectual disability. As outlined in chapter two, the



construct of intellectual disability is founded on a notion of science, objectivity, and truth. Intellectual disability is considered cognitive impairment of the individual, which can be measured and diagnosed. It is possible to locate this understanding of intellectual disability within the individual model of disability (Oliver, 1996a). Perhaps the predominance of logical-positivism within dominant Western culture (Breen & Darlaston-Jones, 2010) has laid the foundation for the notion that intellectual disability holds some ultimate ontological value (Rapley, 2004). It might be argued that intellectual disability as a construct represents the mythological manifestation of logical-positivism and Western bio-medicine within dominant Western culture. As noted in chapter two, perhaps the “stickiness” of the label is an example of science as “...another party line, a way of thinking no less confining than religion...” (Kauffman, 1999, p. 268). This party line might be considered an ideology enacted by structures of governance, and governmentality (Foucault, 1991).

Science is the ideological structure which affords the construct of intellectual disability power to qualify, or deny, one's humanity or personhood (Kliewer et al., 2006). As such, it is speculated that an individual labelled with intellectual disability perhaps must not only contend with the assumptions inherent to the label intellectual disability, but with the power that the label is afforded by the ontological value of science within dominant Western culture (Jenkins, 1998). The theme 'The Intellectual Disability Myth' reflects the authoritative power of science to lead rather than follow one into citizenship (Kliewer et al., 2006). 'The Intellectual Disability Myth' is problematic; however, as by definition it is mythological and constructed by socio-cultural value. Burton Blatt, an advocate for the deinstitutionalisation of individuals labelled with intellectual disability, reflected on the mythological nature of intellectual disability in his essay “Man through a turned lens” (1999, p. 90), suggesting that “...the mentally retarded are no more people than is the photograph of a person”. Blatt's analysis of the construct of intellectual disability is one which dismantles its truth-value and suggests that it is a figment of collective imagination. The tension inherent to 'The Intellectual Disability Myth' is that, in fact, it is not the stuff of myths; it is the lived reality for individuals who are so-labelled.

#### **5.4.2 'The Intellectual Disability Paradox'**

The theme 'The Intellectual Disability Paradox' captures a complex dynamic which emerged from participants' stories. Essentially, 'The Intellectual Disability

Paradox' refers to an interaction between myths, and understandings, surrounding the label intellectual disability which creates tensions, discrepancies, and contradictions in rhetoric surrounding intellectual disability. The theme 'The Intellectual Disability Paradox' reflects a process by which individuals living with the label intellectual disability are not conceptualised as individuals. Rather, they are evaluated in terms of a series of assumptions related to this label. At a Myth Metaphor layer, the label intellectual disability seems to form a demarcation of "them" (individuals with intellectual disability) and "us" (individuals without intellectual disability). Bound up in the previously outlined theme, 'The Intellectual Disability Myth' are assumptions, and expectations of someone who lives with this label. In this way, intellectual disability captures what it means to be different. Myths associated with the construct of intellectual disability include; incompetence, vulnerability, abnormality, and passivity. Individuals living with the label intellectual disability are constructed as "falling short" of what it means to be an adult, a woman, a man or part of humanity. Perhaps individuals labelled with intellectual disability, on a mythological level, are constructed as approximating a human or person, as opposed to being human, or having a personhood. In this way, there is no mobility in the label intellectual disability, nor are there opportunities to legitimately "cast-off" this ascribed identity, and forge an individual identity. Individuals with intellectual may be trapped in a dynamic of redundant reasoning, where, individual's actions and behaviours can simultaneously be explained by, and attributed to, intellectual disability. The infallible nature of the construct of intellectual disability is evident in the stories shared by participants, where someone's disability is often used as a vague explanation for behaviours, feelings or experiences. For example, one participant notes that her lecturers tend to attribute a fellow student's behaviour to disability:

*I don't know what kind of disability she has but she saying like, they'll [lecturers] say, "oh, it's because of her disability" I'm like, it may not be of her disability, it's probably because she's jealous of I've got friends*

The student's disability is provided as an arbitrary and vague explanation for behaviour. The student's behaviour is pathologised as part of her disability. This extract is an example of the attributions which are made on the basis of the label intellectual disability. The participant highlights that the student's behaviour could be attribute to other factors, outside of her disability. In this way, the construction of

intellectual disability reflects circular logic as one's behaviour is seen to be precipitated, and perpetuated by disability. Disability is not restricted to a biological construct, it becomes a label which is value-laden and engenders a range of expectations and assumptions about an individual. Reflecting on her lecturer's comments, the participant highlights the vague nature of these attributions:

*I don't know really why but they think it's her disability, but I think it's more than her disability...*

The label intellectual disability seems to function as a way of making sense of individuals who live with this label. In these contexts, the term disability is not used in reference to any specific difficulty, or impairment, rather, the term conveys something inherent to an individual's nature. The student is defined by her disability, where evaluation of her behaviours and character is embedded in 'The Intellectual Disability Myth'. The theme 'The Intellectual Disability Paradox' reflects a dynamic highlighted by authors such as Fine and Asch (1988), and Rapley (2004) who suggest that individuals labelled with intellectual disability are cloaked with a presumption of incompetence (Bogdan & Taylor, 1982), and must work to prove their competence. Whereas competence is generally considered context-dependent, for individuals labelled with intellectual disability, competence is constructed as context-independent (Rapley, 2004) and so disability becomes a master status.

This reductionist dynamic is problematic, as the intellectual disability becomes a master status, and behaviours and expectations are set according to assumptions of intellectual disability. These processes resemble those outlined by Goffman (1963), in his conceptualisation of stigma, where an individual can be reduced to a tainted, or spoiled, identity. This dynamic is problematic in the context of relationships and sexuality, where these aspects of the human experience are not considered important or necessary for individuals who are so-labelled. For example, Fitzgerald and Withers (2013) found that the women in their study indicated that their identities were more closely tied with disability than with other identities, such as being a woman. Denying one's woman or personhood undermines the value in promoting exploration of sexuality and identities of individuals labelled with intellectual disability. Rather than focusing on these aspects of the human experience, emphasis is placed on fostering a normal life for individuals labelled with intellectual disability. The relative value placed on a normal life, and sexuality and relationships, as noted in

chapter three, is evident in the conceptualisation of relationships and sexuality as the final frontier within the disability movement (Aunos & Feldman, 2002). To date, this aspect of the human experiences has been conceptualised as largely irrelevant for so-labelled individuals.

### 5.4.3 'The Ingenuine Adult'.

The theme 'The Ingenuine Adult' reflects a symbolic representation of individuals who live with the label intellectual disability as lacking in those qualities which form the marker of adulthood. The term "ingenuine adult" is used in a metaphorical sense, to denote the assumption that individuals who live with the label intellectual disability are suspended in development, somewhere between childhood and adulthood. That is, individuals living with this label are not conceptualised as children due to their chronological age (i.e., over 18 years of age), nor can they be conceptualised as adults due to the assumption of incompetence which is inherent to the construction of intellectual disability. As such, individuals with intellectual disability may be conceptualised as existing in a perpetual phase of suspended development. This suspended phase of development, and the conceptualisation of individuals with intellectual disability as ingenuine adults, is evident in the language that participants used to differentiate individuals with intellectual disability from those living without this label. In the following extract, a participant is asked whether his work colleagues are also employed via an employment assistance agency for individuals with disability, he responds:

Participant: *Umm... no. they, umm... they're adults...*

Emily: *Oh, ok... right. So would you say you and your friend are adults as well? or...?*

Participant: *Umm... teenage adults.*

Emily: *Teenage adults...*

Participant: *Yeah.*

The participant differentiates he and his friend, from work colleagues, self-identifying as a "teenage adult". The participant does not self-identify as a child, or as adult as their work colleagues, the participant suggests that he and his friend exist somewhere in between these socio-cultural identities. There is a clear distinction here between the symbolic representation of individuals who have an intellectual

disability, and individuals who do not live with this label. While this extract reflects a more overt representation of the myth, more covert constructions of individuals living with the label intellectual disability as ingenuine adults also emerged. Another participant makes a clear distinction between themselves, as an individual living with this label, and the care-providers or parents with whom they spend time:

Emily: *So when you go out with [boyfriend] normally, who goes out with you?*

Participant: *umm... a adult*

Emily: *an adult*

Participant: *another adult, yeah, like a young adult, or a older adult, unless its parents*

Emily: *or parents?*

Participant: *Yeah*

The participant explains that when out with their boyfriend, they are chaperoned by an adult, an individual who may be a parent, carer or family member. It is important to note that in this example, and the previous, the individuals who distinguish themselves as not quite as adult as their parents, carers, work colleagues, and others who live without the label intellectual disability, are all over the age of 18 years. According to cultural norms, individuals who are over 18 years of age may be considered as progressing toward a state of adulthood. It seems, however, that this cultural norm may not apply for individuals who live with the label intellectual disability. It appears that reaching adulthood and being able to call oneself an adult may be disrupted by the label intellectual disability. The construction of individuals labelled with intellectual disability as eternal children is well-recognised within the research literature (Bane et al., 2012; Bernert, 2011; Fitzgerald & Withers, 2013; Rogers, 2010; Tepper, 2000). Individuals labelled with intellectual disability identify as being treated like children, looked down upon and sometimes located themselves in terms of pre-adult stages of development, for example, as teenagers, rather than adults (Fitzgerald & Withers, 2013; Hollomotz & The Speakup Committee, 2008).

The metaphor of the ingenuine adult reflects an understanding that chronological age is inconsequential as a cultural-marker which symbolises when an individual living with the label intellectual disability has reached adulthood. In this

way, individuals living with the label intellectual disability may be perpetually suspended between childhood and adulthood, in the symbolic sense, are unlikely reach adulthood. This dynamic seems to be captured by Arnett's (2000) theory of emerging adulthood. Arnett asserts that emerging adulthood is an intermittent period between adolescence and adulthood, where individuals may consider that they have taken on particular social roles and expectations, however, have not yet attained the level of self-sufficiency and those roles (e.g., parent, wife, husband) which characterise adulthood. Arnett suggests that notions of adulthood are entirely subjective, culturally constructed, and are distinct from objective demographic markers (e.g., such as age). Emerging adulthood may articulate the experience of individuals labelled with intellectual disability who refer to themselves as teenage adults, or not quite as adult as others. In his research, Arnett has found that a subjective sense of adulthood is not fostered so much by demographic qualities (e.g., age, being married, having a career), as it is by attaining individual qualities which are seen to correspond with adulthood (e.g., achieving financial independence, becoming self-sufficient, exercising independence, control, and choice over one's life). In the context of the experience of individuals labelled with intellectual disability, it might be speculated that a lack of opportunity to exercise independence, to become financially self-sufficient precludes transition into a subjective state of adulthood. Assumptions of intellectual disability inform what the life of an individual living with the label intellectual disability will look like, directing opportunities to engage choice, control, and independence. For example, it may be assumed that an individual living with this label will depend on others, that they may not be capable of engaging in intimate relationships, or having children. These implicit assumptions surrounding what it means to live with the label intellectual disability are evident in rhetoric around particular identities and social roles that are synonymous with adulthood. For example, a participant explains that individuals with Down syndrome are allowed to have children:

Participant: *yes, yes, and Down Syndromes do allow to have babies*

Emily: *They're, you're allowed to have babies?*

Participant: *yeah, they do, yeah*

Emily: *yep, is that something that you want also?*

Participant: *yeah, I want to be a father*

Inherent to this extract is an assumption that individuals with Down syndrome are not allowed to have children. The participant's comments suggest that the role of parent is inconsistent with the social construction of Down syndrome. The language used by the participant suggests that a father, or mother, with Down syndrome might represent an enigma, a remarkable occurrence. This extract, the theme itself, perhaps represents the explicit, or overt, manifestation of some deeply held myths and implicit assumptions of intellectual disability. One might also argue that rhetoric of permission reflects a lack of opportunity for independence, self-sufficiency, and control over one's life. This assumption is evident in the findings of other research studies, where individuals labelled with intellectual disability have been denied their reproductive rights, or advised against having children (Fitzgerald & Withers, 2013). The rhetoric of permission, and the expectation that one's sexuality will be managed by an external party, is contested by individuals labelled with intellectual disability, and considered a violation of rights (Bane et al., 2012; Rushbrooke et al., 2014a). The theme 'The Ingenuine Adult' captures an assumption that the primary identity of an individual living with the label intellectual disability is their intellectual disability, and that roles which are symbolic of adulthood, such as parent, volunteer, spouse, partner, are seen as contrary to this identity. This dynamic is evident where relationship roles and sexual identities are constructed as remarkable in the context of intellectual disability. For example, as highlighted in chapter three, there is an emphasis in the research literature on determining that individuals labelled with intellectual disability do, in fact, want to have relationships. These lines of enquiry are perhaps embedded in an understanding that individuals labelled with intellectual disability are childlike. These dynamics, in context of the theory of emerging adulthood (Arnett, 2000) suggest that individuals labelled with intellectual are precluded from entering into adulthood in the culturally constructed sense.

#### **5.4.4 Summary.**

Several themes have been identified at the Myth Metaphor layer of understanding, including; 'The Intellectual Disability Myth', 'The Intellectual Disability Paradox', and 'The Ingenuine Adult'. There are several key features to the themes identified at this layer of understanding. The theme 'The Intellectual Disability Myth' reflects the mythological and amorphous nature of the label

intellectual disability as a series of assumptions and myths about an individual, which transcend diagnostic criteria, and take on socio-cultural value. Within this theme, the tensions inherent to the construction of intellectual disability as an undeniable truth, and a social construction, are explored. The theme 'The Intellectual Disability Paradox' provides a commentary on the process of othering which occurs as a function of the label intellectual disability. This theme outlines the paradoxical nature of a label which is affixed to "help" individuals live a "normal life", which also functions to position individuals with intellectual disability as "abnormal". The theme 'The Ingenuine Adult' captures the symbolic representation of individuals with intellectual disability as suspended in between the developmental phases of childhood, and adulthood. 'The Ingenuine Adult' is a metaphor for the socially-constructed identities, expectations, and assumptions of individuals who live with the label intellectual disability.

The key messages emerging from the Myth Metaphor layer of understanding suggest that there are some meta-processes and paradoxes associated with the label intellectual disability. For example, there is an acknowledgement that the label is socially-constructed, but this understanding seems to be embedded in an assumption that individuals with intellectual disability are inherently different. Assumptions surrounding intellectually disability seem to be embedded in logical-positivism, where this label has come to represent the undeniable truth of the individual. These deeply-rooted myths and metaphors of intellectual disability provide a foundation for the expression of worldviews and ideologies, social and systemic structures, and inform the ways in which issues are defined and addressed at a surface level. These myths perhaps undermine the value of exploring sexuality and relationships in the context of intellectual disability, and contribute to a socio-cultural context where relationships, sexuality, parenthood, and independence are seen as remarkable in the context of intellectual disability.

### **5.5 Worldview Discourse Layer**

The Worldview Discourse layer of analysis captures commonly held views or rhetoric concerning an issue. At this layer, the rhetoric which reflects implicit understandings surrounding the phenomena is explored. Often, worldviews and discourse are not explicitly stated; rather, can be inferred by attending to symbolism and language. Themes identified at this layer of understanding include 'The



Disability Discourse', 'I don't really know, you'll have to ask mum about that', 'The Parent: Heavy burden of high expectation', and 'Life as Stasis: Future is fantasy' (see Figure 4). Each of these themes is explored in depth in the following section.

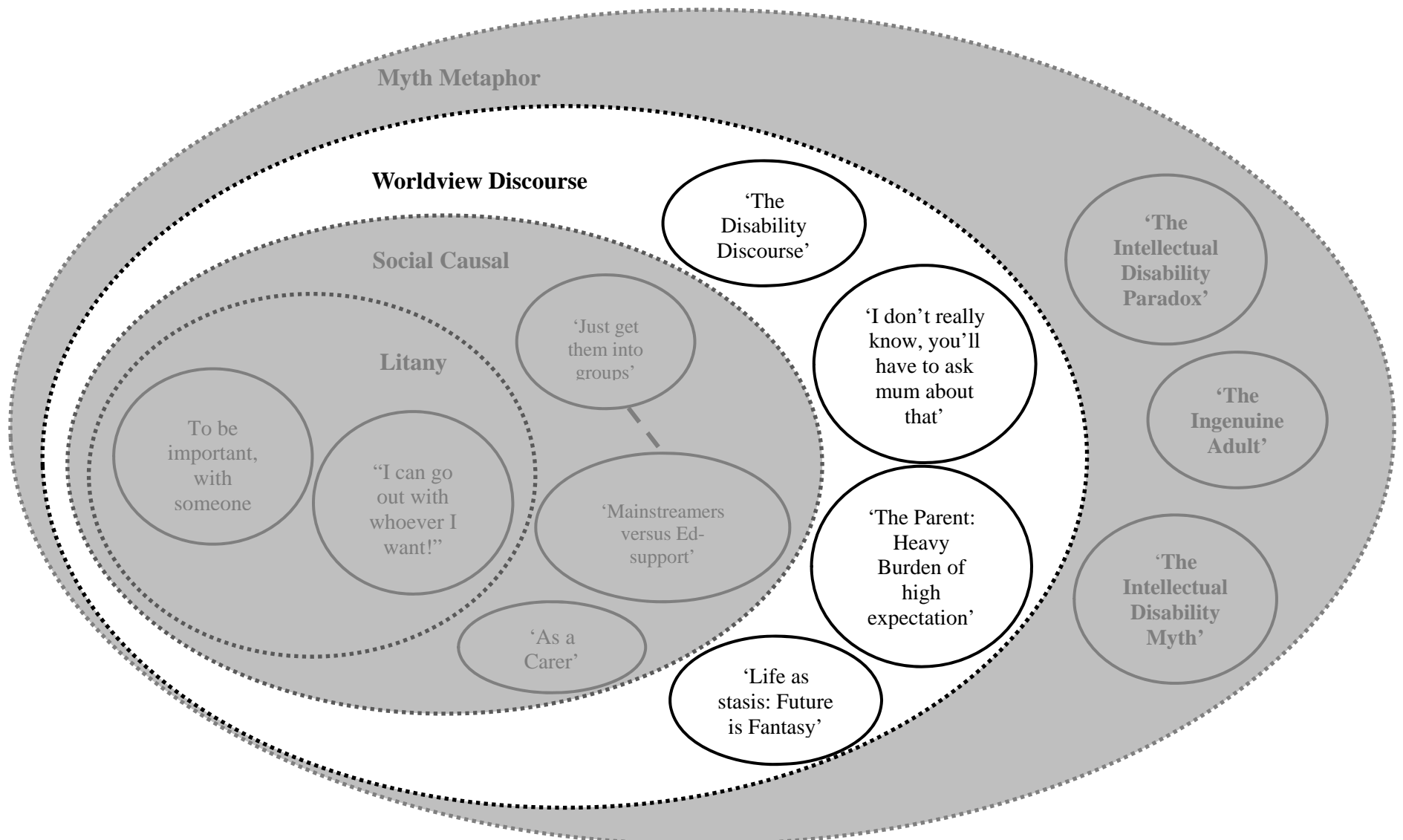


Figure 4. Thematic map of findings with emphasis on Worldview Discourse layer of causal layered analysis.

### 5.5.1 'The Disability Discourse'.

The theme 'The Disability Discourse' captures the language used around the label intellectual disability. Language is an explicit representation of deeper and widely-held understandings and beliefs, and forms a vessel for conveying worldviews and assumptions of intellectual disability. A strong intellectual disability discourse emerged throughout interviews with participants. Terms such as "them", "we" and "us" were commonly used to differentiate between individuals living with the label intellectual disability, and individuals living without this label. Extending on this notion of "them" and "us", participants also employed disability-specific terminology, such as "Ed-support"<sup>12</sup> and "Mainstream", to denote individuals with and without an intellectual disability. This language establishes a discourse of inherent difference, suggesting that individuals living with the label intellectual disability are inherently different to individuals who live without this label.

Value-laden terms such as "normal" and "perfect" were often used to describe individuals from the Mainstream, that is, individuals who do not have an intellectual disability. By implication, individuals living with the label intellectual disability are identified as "abnormal" or "imperfect", reinforcing the rhetoric of inherent difference, and establishing intellectual disability as a derogatory label or identity. This language is an explicit manifestation of the theme 'The Intellectual Disability Myth' identified at the Myth Metaphor layer, reinforcing the discourse that individuals living with the label intellectual disability are abnormal, less-than, and inherently different to those without intellectual disability. The value-laden nature of the label intellectual disability is reflected within the research literature, where it is recognised that terms such as Mongol (W. M. Finlay & Lyons, 2005) and retard (Gelb, 2002) are used in a derogatory or abusive sense. One's very identity as an individual with intellectual disability may be the embodiment of abnormality, otherness, and disgrace.

---

<sup>12</sup> Ed-support is a colloquial term used to refer to schools of special educational needs within Australia. Special educational schools may be attached to Mainstream schools, or alternatively, exist independently of other educational settings. These schools provide education to students with special and diverse educational needs.

Discourses of inherent difference were also represented in systemic structures, where participants explained that they attended disability service-providers, *Special Olympics*<sup>13</sup> and an annual event for a particular disability service-provider. The language attached to these settings and activities imply that they are alternative spaces appropriate for the habitation of individuals living with the label intellectual disability. The discourse here suggests that individuals with intellectual disability exist outside the realm of normality, and are othered via implicit and deeply-rooted worldviews surrounding difference and inferiority.

A strong discourse surrounding the notion of competence also emerged from interviews with participants. Phrases such as; “...we need help, and they don't...”, “...it's hard for us to do things...” and “...we need a bit more push...” and the notion of having a carer or attending a service-provider suggest that individuals living with the label intellectual disability are inherently vulnerable, or incompetent. This discourse of incompetence and vulnerability was also evident in the dynamics or social processes outlined in participants' stories. For example:

*...my sister goes to, like, rock band concerts more often, but I can't go because I'm not authorised because of, because I'm sensitive, though, to very loud bass noise.*

Participants also referred to getting into “trouble” for not following particular rules or conforming to expectations. The notion of getting into trouble, or being “...authorised...”, constructs a discourse of vulnerability and incompetence, and also symbolically constructs individuals living with the label intellectual disability as ingenuine adults, identified in themes at the Myth Metaphor layer. These discourses suggest that individuals living with the label intellectual disability are not competent or capable of making decisions related to their own lives. There is a strong discourse of permission evident within participants' stories, where participants referred to gaining permission from a parent, carer or another in various domains of their lives, for example:

Participant: *yeah I do. I like beer.*

---

<sup>13</sup> The Special Olympics is a not-for-profit organisation which provides settings and opportunities for individuals labelled with intellectual disability to engage in and compete in a range of sports at local, national and international levels (Special Olympics Australia, n.d.).

Emily: *so just every now and then? Or...?*

Participant: *well actually my mum lets me have one cider on a, a week on a Saturday...yeah, only on a, only on a Saturdays I'm allowed a cider, just one.*

The participant refers to being allowed to have one cider on a Saturday evening, a rule set by the participant's mother. This rhetoric of permission, and deferring to others, was a strong dynamic across participants' experiences. It seems as though decisions, and activities, undertaken by an individual, are framed in terms of what they are allowed to do. This rhetoric is symbolic of a parent-child interaction, perhaps reflecting a paternalistic attitude toward individuals living with the label intellectual disability. What is particularly significant about this parent-child paternalistic dynamic is that it transcends the familial parent-child relationship, and extends to a broader social context, where individuals living with the label intellectual disability may experience life as ingenuine adults, and are subjected to a paternalistic and protectionist dynamic within various other relationships (e.g., siblings, friend, support-workers), and within broader social systems (e.g., disability service-providers). This paternalistic dynamic is reflected in the research literature where it is recognised that parents, support-workers and others are ascribed accountability, or assume accountability, for taking care of, and managing risk, on behalf of individuals labelled with intellectual disability (Almack et al., 2009; Perske, 1972).

A tension emerged surrounding this discourse of incompetence and vulnerability as participants challenged the legitimacy of these worldviews, for example, comments such as "*...it's not up to you...*" and "*...even the people in the Mainstream, they all, they aren't always perfect...*" pose challenges to the notion that individuals living with the label intellectual disability should conform to special rules and expectations on the basis of the label intellectual disability. This resistant discourse is evident in the findings of other research studies, where individuals labelled with intellectual disability advocate their right to choice, control, autonomy, and independence, and challenge the idea that those from the Mainstream are the embodiment of perfection (W. M. Finlay & Lyons, 2005; Hollomotz & The Speakup Committee, 2008).

Discourses surrounding the label intellectual disability seem to reinforce and be reinforced by expectations on roles and social processes. The language surrounding the construction of intellectual disability is perhaps performative, and implies that individuals living with the label intellectual disability, and their parents or carers, should occupy particular roles, for example, the care-giver and care-recipient, or the parent and the ingenuine adult.

### 5.5.2 'I don't really know, you'll have to ask mum about that'.

The theme 'I don't really know, you'll have to ask mum about that' reflects a dynamic evident in the experiences of participants, which seems to challenge the assumption that individuals are the experts of their own lived experiences. The theme title is an extract from an interview with a participant, who responds "*I don't really know, you'll have to ask mum...*" when I asked about their new boyfriend. My sense is that the participant felt that their mother was best positioned to answer the question. In this sense the participant, positions their mother as the authority, and positions themselves as a passive participant in their own love life. This dynamic of deferring to another individual emerged as central to the stories shared by participants. For example, one participant notes that she is "allowed" to hug her cousin, and by implication, not others:

Participant: *like, he's my favourite* [Cousin]

Emily: *yeah*

Participant: *I'm allowed to hug him*

The notion of being allowed to do something is perhaps commonly associated with a child, or an individual who is facing some form of sanction. It seems as though this rhetoric of being allowed violates an expectation of the choice, control and autonomy usually afforded to adult individuals. In this sense, those individuals who are in a position to state what is and isn't allowed may be taking on the role of gatekeepers. For example, a participant explains that, at local sporting club, she and her friends can get into trouble for kissing:

Emily: *oh yeah, so do some people in the group, do they kiss each other?*

Participant: *no*

Emily: *no*

Participant: *they get in trouble*

Emily: *from who?*

Participant: *umm... the adults... the mums*

Emily: *ok, but aren't you guys all adults?*

Participant: *oh no, I mean mums*

In this sense, the participant is indicating that the parents or adults within their group take on the role of gatekeepers, passing judgement on the acceptability of engaging in intimate behaviour. Arguably, this dynamic violates the expectation that individuals should be able to engage in positive expressions of sexuality, and in intimate relationships. This is an explicit example of a dynamic widely reported in the literature, that those who act as gatekeepers exercise an inordinate level of control over the experiences of individuals who live with the label intellectual disability (S. Abbott & Mcconkey, 2006). Participants shared experiences and examples of the rules set for them by others, rules which impact on their opportunities to engage with others. For example, one participant describes wanting to get a driver's licence:

*I really want to....then I can go see friends, take them out, and go shopping with them. Mum says "if get your licence, then you can have your own card back"... my own [bank] card...*

The participant describes how her mother currently carries her bank card, and imagines that getting a driver's licence would afford more personal freedoms and opportunities to see friends. The participant is an adult, yet, does not seem to experience the freedoms, choice, and control that she desires. It is suggested that this gatekeeping dynamic contradicts the rights that are afforded to adults within dominant Western culture. It is argued that in other contexts, this dynamic would not prevail, and would be met with resistance. This dynamic perhaps is the explicit manifestation, of more implicit myths and assumptions constructing intellectual disability.

Deconstructing and exploring this theme represents a tension inherent to exploring relationships in the context of intellectual disability. The dynamics emerging from participants' stories may become more, or less, remarkable depending on the context in which they are considered. For example, if these dynamics are considered in the broader social-cultural context, and any rhetoric of intellectual disability removed, these dynamics appear remarkable (e.g., it might be considered that individuals have a right to kiss who they wish, or a right of access to their bank card). If these dynamics are considered within the social-cultural context of the disability community they may appear less remarkable, and may become more or less appropriate depending on various other factors. In this sense, it is the construction of intellectual disability which forms a lens through which judgment is passed on the acceptability of various dynamics. A perspective which is not appreciative of the social-cultural context of the disability community may misrepresent the phenomena under exploration. This, however, is an interesting conundrum, as one may wonder why a different cultural context is necessary for individuals who live with the label intellectual disability. This paradox is reminiscent of the theme 'The Intellectual Disability Paradox' identified at the Myth Metaphor layer of this analysis. The theme 'I don't know, you'll have to ask mum...' provides a tangible example of the tension inherent to socially constructed identities. It seems that the tension which may be operating here is the pitting of social constructionism against biology and hard science. When there is no comfortable way of explaining "why things are the way they are" biological explanations (e.g., 'these people are different because they have a cognitive impairment') are used to justify cultural convention.

This rhetoric of "why things are the way they are" is represented in a conversation had by two individuals taking part in an interview for this study. In the following extract, two participants discuss their friend's relationship with her mother, and the extent to which they each feel their friend has independence. For example:

Emily: *So, umm, so, why do you think [friend's mother], like, hangs around?*

Participant one: *I don't know.*

Participant two: *Because, umm, [friend's mother] lives all the way on the other side, so ...*



Emily: *Oh okay.*

Participant two: ... *it's like easy for her to stay.*

Emily: *Okay.*

Participant two: *Like for, with rock climbing, she, umm, so [friend's mother] dropped [friend] off here then [friend's mother] went off and then came back and pick [friend] up at my place.*

Emily: *Okay. So it's more like just because it saves her going all the way home and then all the way back?*

Participant one: *Yeah. Whereas I find with one thing that, not that this is really my place to say this, but I find with [friend's mother], she doesn't give [friend] a lot of independence.*

Emily: *Hmm.*

Participant two: *She does.*

Participant one: *Well...*

Participant two: *It's just hard for her because [friend] lives all the way over the other side of the river.*

Participant one: *What I'm going to say is that, umm, I've caught up with [friend] for coffee on holidays, and, umm, you know what [friend's mother] does? She walks, she comes, [friend's mother] comes with [friend] to meet me at the very place.*

Emily: *Hmm.*

Participant two: *And then she leaves.*

Participant one: *Yeah. But shouldn't ...*

Participant two: *My mum does that as well.*

Participant one: *My mum doesn't. Shouldn't, shouldn't, shouldn't her, shouldn't [friend's mother] give [friend] a little bit of, a little bit more independence?*

Participant two: *It depends on how far she has to go back and all the way. Mum would stay, but she would leave us alone, and we'll go off, like, shopping.*

Participant one: *Yeah. If my mum was, if my mum was going to, umm, if I was coming with my mum to the shops, what she would do is, she would let me go on my own and do what she would have to do.*

Participant two: *Yeah. That's what, that's what ...*

Participant one: *Yeah, my mum ...*

Participant two: *... [friend's mother] does.*

Participant one: *No. What I mean is, [friend's mother] actually walks, actually takes [friend] to the very place to meet me instead of just ...*

Emily: *So do you feel like ...*

Participant two: *It's to make sure safe she's because [friend's] a little, [friend] doesn't like, umm, [friends] umm, still, trying to, you know, do it. Like trying to get [friend's] independence. But [friend's mother] makes sure [friend's] safe and you know, and then, then she drives off.*

Participant one: *Yeah, I know. But shouldn't [friend's mother] let [friend], shouldn't [friend's mother] give [friend] a bit of independence to just walk there to meet me on my own? That's what I mean.*

Participant one suggests that their friend's mother, by "hanging around" social activities, does not afford her adult child independence. In contrast, participant two argues that perhaps their friend's mother hangs around for practical reasons (e.g., it is too far for her to drive to go home, and come back to pick up their friend), and also suggests that their friend needs a parent to stay close, and their friend is not safe without a parent. Participant one acknowledges participant two's point, but still ponders why the mother hangs around. Here, participant one seems to be posing a

challenge to the notion that individuals with an intellectual disability require constant support from a parent or guardian. Participant one questions the idea that their friend needs this level of support from their mother, arguing that the mother should give more opportunities for independence. What is of particular interest within this discourse is the implication that independence, control, and autonomy are the gifts of the gatekeeper, parent, support-worker, or at broader level, culture, to give the individual labelled with intellectual disability. Inherent to this discourse is a power imbalance, and an assumption that power can be gifted by the powerful.

This exchange is particularly poignant, and significant in the context of this research project. The active, and critical nature of participant one's voice in this exchange, and the way that the participant questions the status quo, represents a rarity in the context of this project. In this exchange, participant one's voice contrasts with the passivity evident in the dominant rhetoric summarised in the excerpt "*I don't really know, you'll have to ask mum...*" The infrequent nature of this active, and critical discussion, is perhaps a reflection of the theme itself. It may or may not be remarkable, or appropriate, for individuals to have access to a bank card, or be able to kiss whom they wish- these details of individuals lives are not for anyone to evaluate. What is remarkable, however, is the apparent lack of opportunity to challenge the status quo, to disrupt the dynamics, and to ask why things are the way they are.

This discourse of permission, and conforming to rules, is reflected in the research literature and is raised as a key issue in chapter three in the section on 'Boundaries, power and regulations'. Research findings suggest that some individuals are expected to conform to rules (formal and informal), in order to earn opportunities to explore sexuality, or to engage in relationships (Bernert, 2011; Hollomotz & The Speakup Committee, 2008; Rushbrooke et al., 2014a). The implication is that if individuals could conform, they could appeal to the good will of others to gain access to these aspects of the human experience. Within the findings of the current study, and previous studies (Bernert, 2011; Fitzgerald & Withers, 2013), there seems to be an expectation that individuals labelled with intellectual disability will surrender control of even the most routine, or conversely, significant (e.g., relationships, sexuality, birth control) to others. Conversely, there is an expectation

that external parties (such as parents, support-workers, and others) will take on this role.

### 5.5.3 The Parent: Heavy burden of high expectation.

The theme 'The Parent: Heavy burden of high expectation' captures the worldviews and assumptions that seem to construct the role of a parent of an individual living with the label intellectual disability. In constructing individuals living with the label intellectual disability as passive, incompetent, and as ingenuine adults, it seems as though parents of individuals with intellectual disability are also ascribed a particular role. The theme is titled with reference to Graeme Innes' (former Disability Discrimination Minister) oft-cited sentiment that individuals labelled with disability "Carry the soft burden of low expectation" (S. Young, 2011, May 6). The identity of a parent presents as a compensatory and complementary role to the identity ascribed to their sons and daughters living with the label intellectual disability. If individuals living with the label intellectual disability are seen to carry the "soft burden of low expectation", then parents are perhaps constructed as shouldering the "heavy burden of high expectation". This theme reflects a performative dynamic (identified in the theme 'The Disability Discourse') surrounding the construction of intellectual disability, where individuals living with this label are ascribed the role of care recipient, and others, such as parents, are ascribed the role of care-provider and protector.

This discourse of protection is perhaps underpinned by the theme 'The Ingenuine Adult', identified at the Myth Metaphor layer of the analysis. The construction of individuals living with the label intellectual disability as inherently vulnerable, gives rise to a notion that individuals living with this label must be protected. Equally, the assumption of incompetence which is inherent to the construction of intellectual disability also gives rise to a dynamic where care-providers, such as parents, are constructed as responsible for making decisions on behalf of their son or daughter. A good example of this dynamic emerged during a conversation with two participants, a parent, and a participant labelled with intellectual disability, who expressed the desire to drive a motorbike:

Participant one: ...*and yeah, [Participant two's] very impressed by the motorbike so... to impress the girls, you get a motorbike.*

Participant two: *Yep*

Participant one: *But they're very dangerous.*

Participant two: *But I know it's dangerous. First I have to learn about the safety course first.*

Participant one: *Maybe you and [participant two's girlfriend] could go on a motorbike ride like you and [friend] did...?*

Emily: *Mm...*

Participant two: *First I go to safety course.*

Participant one: *No, not you riding it, you go for a ride, someone takes you and [girlfriend] on the motorbike. That would impress [girlfriend]. That would be a fun date.*

Participant two: *I mean, mum, please don't do that please.*

Participant one: *You want to drive the motorbike?*

Participant two: *Yes.*

Participant one: *A bit tricky.*

The participant's mother turned to me and said "*it's tricky*", communicating that this is perhaps a topic which is not often discussed, or which tends to cause tension between her and her adult child. In this interaction, participant two is stating that he would like to ride a motorbike, and his Mum is placed in a difficult position, she is ascribed a protective role, where she must assume responsibility for telling her adult child that he cannot ride a motorbike. The conversation continued:

Participant two: *But, I like it. Stop it mum.*

Emily: *So have you been on the Harley Davidson before?*

Participant two: *Umm... I did, I mean no.*

Participant one: *You went with [family friend] didn't you?*

Participant two: *I went before but I got very lost...*

Participant one: *Just a little ride*

Participant two: *Yeah*

Emily: *Is it scary?*

Participant two: *Mm... not really, umm... I always think, safety first... safety, safety... always need safety first. Like, putting your helmet on, or maybe a Jacket or T-shirt, or Jeans, shoes and T-shirts...*

Participant one: *Shoes, not thongs.*

Participant two: *Shoes*

The participant and his mother discuss the dangers involved with riding a motorbike. There is a tension in this interaction, as the participant expresses a desire to ride a motorbike, and his mother is placed in a protective role, which precludes the opportunity to ride a bike. There is a strong discourse of safety in this interaction, and the participant provides a kind of script indicating what is expected of them, for example, "...*safety first... safety, safety...always need safety first.*" The focus of the discussion turns to safety, as opposed to a discussion of any specific reason why the participant may not be able to ride a motorbike. What is particularly significant about this interaction is that the participant's mother is ascribed the role of gatekeeper, and protector, she assumes responsibility for making this decision on the participant's behalf, perhaps for protecting them from the reality of the negative social stigma and perceived impairment associated with the label intellectual disability (Todd & Shearn, 1997). This extract is symbolic of the discourse of protection and the dynamic of the gatekeeper which emerged from participants' stories. Discourses around what participants were allowed to do related to safety, and protection, as opposed to any specific concerns related to their competencies, or the particular activity. This dynamic perhaps reflects the secrecy, and collusion, surrounding the negative social identity of intellectual disability (Todd & Shearn, 1997). The difficulty associated with this dynamic is that it undermines the participants' opportunity to challenge perceived impairment or limitation, and subvert the stigma ascribed to them as a function of the label intellectual disability. This discourse places parents in a role of care provider, and individuals living with the label intellectual disability as care-recipients. Parents are constructed as responsible for making decisions on behalf of their adult children, and individuals living with the label intellectual disability are ascribed a passive, rather than active, role in their own lives.

Participants alluded to, and explicitly described, the active role that their parents, support-workers, siblings, and others assumed in various aspects of their

lives. For example, parents provided transport for their adult children, and perhaps friends, to attend activities and events. Participants also described that their parents played an active role in coordinating opportunities for them to meet up with a friend, girlfriend or boyfriend. For example, communicating with the parents of a boyfriend or girlfriend to organise a time to meet up and spend time together. One participant explained the role that her mother plays in arranging for her to spend time with her partner:

Participant: *well, if me and my boyfriend even want to see each other we do a text message to say, see what the other want to see, think about what we want to do...*

Emily: *yeah*

Participant: *...we need to do a text message, like that, and so mum and his mum, and they go into conversation, go into conversation on what mums ... of my mother*

Emily: *yeah, so they'll talk about it...*

Participant: *...that's with the phone, that's with the phone and go into, go deep into conversation and they, they think like, "[participant] wants to get out more, [participant] wants to get out of the house more" and like, "... [participant] wants be out all the time on weekends" ... yeah, stuff like that, yes, she does things so that I can go out with [boyfriend].*

Emily: *yep, is that...?*

Participant: *like, "[participant] wants to see all the time on weekends" ...yeah, stuff like that ... she says things, so that I can just go out with [boyfriend].*

The participant explains that her mother plays a key role in facilitating opportunities for her to spend time with her partner. In this extract, the participant outlines that she communicates with her boyfriend, and that their parents work out the details on their behalf. The participant later goes on to say that they wish they could spend more time with their boyfriend, and that they would like to spend more time with their partner on the weekends. The participant's reflections imply that if

their mothers did not take on this role, time spent with their partner may be limited or less frequent. This dynamic seems to reflect my experiences encountered as a researcher in this project, where my contact with participants was mediated through parents; this dynamic is considered in detail in chapter seven.

In the same way that individuals living with the label intellectual disability are ascribed a particular role, so are their parents. Parents are placed into a difficult position, where they are expected to negotiate the complexities associated with the label intellectual disability in a culture where intellectual disability is constructed as incompetence and ingenuine adulthood. As such, parents face various constraints, and expectations, associated with their role as parent to someone who lives with the label intellectual disability. The assumption of vulnerability, identified at the Myth Metaphor layer of analysis, ascribes a protective and active role to parents, implying that they are accountable for the decisions, and actions, undertaken by their adult children. The expectation placed on parents to negotiate complex legal, moral, and ethical issues associated with relationships and sexuality is acknowledged within the research literature. Research findings suggest that parents are expected to pursue seemingly competing goals of managing risk, and promoting sexual expression, on behalf of their son or daughter (Dupras & Dionne, 2013; Rushbrooke et al., 2014b). Parents may also come under scrutiny and judgement in this position, for example, as being overprotective or conversely, irresponsible (Almack et al., 2009).

There is a tension which is inherent to presenting and deconstructing this dynamic, a tension which replicates those which are evident in the theme 'The Intellectual Disability Paradox', outlined at the Myth Metaphor layer of the analysis. It seems as though the gatekeeping role performed by those surrounding individuals who live with the label intellectual disability is paradoxical. The role of the gatekeeper is simultaneously necessary, and self-perpetuating, reinforcing those myths and assumptions which foster a need for such a role to be performed. Perhaps this dynamic is captured by Perske's (1972) notion of dignity of risk (as outlined in chapter two), where management of risk, rather than protecting one's humanity, can in fact be dehumanising. The parent-child dynamic may be considered a microcosm which is symbolic of a gatekeeping dynamic which occurs on a broader cultural and systemic level. This gatekeeper dynamic aims to promote access, equality, and a "good life" for individuals living with the label intellectual disability, but perhaps



also constructs the conditions under which individuals with this label are denied access to the full human experience.

#### 5.5.4 Life as stasis: Future is Fantasy.

The theme 'Life as Stasis: Future is fantasy' reflects a discourse about the future emerging from participants' stories. During interviews, I discussed with participants their desires, hopes, and aspirations for the future. Some participants noted that they would like to get married, have children and live with their partner. Others imagined that they would travel, live with friends, and meet new people. Some participants reflected on a desire to have a boyfriend, girlfriend or close friend with whom they would share a close bond. When contemplating the future, there was a sense that ideas about the future were somewhat fantastical, or that the future was an entity that may never come to fruition. For example, one participant commented that her adult child is "...*getting ready for living in the future.*" This language is symbolic of a discourse surrounding future, development and opportunity for individuals living with the label intellectual disability. This kind of symbolism was evident in the way that participants' spoke about their plans for the future, for example:

Participant: *yes, so I'm engaged so now we're planning, a wedding planner*

Emily: *hmm... to get a wedding planner*

Participant: *I've done my umm... vows and my dancing lessons already*

Emily: *oh cool*

Participant: *yeah, I'm almost out there, for the future*

The participant is talking about his plans to get married. The participant concludes his comments, with a reflection that he is "*almost out there*". This language is passive, the participant suggests that the future is entity that can be planned for, but there is an absence of an active voice. There is a sense that the participant is waiting for the future to arrive, rather than actively pursuing the future. This discourse of the future as an entity that will arrive, rather than as something which one actively pursues, is symbolised in discourse around having a "pretend life". For example, one participant discussed that she has a pretend life, or a fantasy of the future, which she shares with a good friend:

Participant: ... *Me and [friend] got our pretend life, we like to talk about it...*

Emily: *a pretend...?*

Participant: ...*life.*

The participant makes the distinction between “real life” and pretend life, for example, when asked about whether she would like to have children, the participant states “...*not children, no way!* [Laughs] *Not in real life, no.*” Here, the participant suggests that there are aspects of their pretend life, which she would not want to pursue in real life. When asked whether she has a partner, the participant explains:

Emily: *and you don't have a boyfriend do you?*

Participant: *no, I just pretend*

Emily: *yeah, is that something that you want?*

Participant: *yes*

The participant later refers to a fantasy where a popular music artist is their “pretend husband”. The participant’s pretend life is perhaps symbolic of discourses surrounding the future. The participant’s pretend life, and the desire to have a boyfriend, is presented as somewhat fantastical. The participant’s pretend life is symbolic of the discourse that getting married, having a boyfriend, moving out of home, travelling the world may also represent a fantasy, considered unachievable in real life for individuals who live with the label intellectual disability. While having a celebrity crush, or imagining a fantasy life is not exceptional, where this fantasy life is conceptualised as just as realistic as having a boyfriend in real life, it is indeed remarkable. The following exchange is perhaps symbolic of the fantastical nature of the ‘future’:

Emily: *so before when we were speaking, you were, you were saying that you might want to get married when you're like 28, and you're also talking about moving out, is that the same or...?*

Participant: *umm... too much imagination (laughs) it's too hard. Sorry yeah. Sorry...too much imagination.*

Emily: *too much...?*

Participant: *imagination.*

Participant's parent: *Imagination*

The participant suggests that his previously expressed plans to move out, and get married, reflect "*too much imagination*". The participant's comments suggest that to move out, and to get married, reflect lofty or unachievable goals. This worldview is reflected in rhetoric that individuals living with the label intellectual disability must be ready for *independent living*. Independent living is a term used by participants to describe living out of the family home, or "independently" from one's family. For example, one participant explains what he feels he must do in order to be ready to move out of the family home:

Emily: *so how will you know when you're ready to move into an apartment?*

Participant: *first I have to look after myself first*

Emily: *ok, do you think you can do that now or?*

Participant: *Not yet, I need a bit more practice, practice, practice (laughs)*

Emily: *ok*

Participant: *something like, washing my own clothes, handing the, wait, something that the apartment does... like umm... cooking your own foods...*

Emily: *yeah, can you do those things now?*

Participant: *umm... getting there, but not yet, bit more teaching (laughs)*

The participant suggests that he must achieve a level of competence with *independent living skills* in order to be ready to move out of the family home, and live independently. This rhetoric is reflective of the sense that the future is an entity that one can plan and prepare for, but perhaps not actively pursue. This rhetoric suggests that one cannot actively pursue goals and ambitions on one's own volition. Rather, that one must be deemed ready for the future, in order to pursue these goals. The notion of "*practice, practice, practice...*" reflects rhetoric associated with the concept of 'being ready' to engage in the future.

The notion of being ready for the future is interesting in context of cultural norms around development and transitioning from dependence, to independence. For example, often individuals move out of their family home whether or not they are

ready or competent. In contrast, individuals living with the label intellectual disability appear to have to illustrate and prove their competencies, before they are afforded an opportunity to be independent. Similarly, Goodley (2001) suggested that, when engaged in the community, individuals labelled with intellectual disability are expected to behave perfectly and that instances of less-than-perfect behaviour could be used as evident to deny future access to community settings. This worldview is inherent to service-settings, where engagement in independent living programs implies that there is scope to one-day relinquish one's intellectual disability, to execute a kind of exit from the social category (W. M. Finlay & Lyons, 2005).

Perhaps the idea of being ready to move out of home is underpinned by myths which suggest that individuals living with the label intellectual disability are inherently vulnerable, or incompetent. The theme 'Life as Stasis: Future is fantasy' is also related to the theme 'The Parent: A high burden of expectation', in the sense that parents, or other care-givers, take on a protective role, to mitigate circumstances where individuals may come to some harm, or experience failure. As is noted in Todd and Shearn's (1997) research findings, in an effort to protect their adult son or daughter from perceived impairment associated with disability, parents may construct false biographies or life plans which are presented as always just a little out of reach, or as a goal to work toward, in reality, often unrealised.

One participant, while discussing the idea of independence, choice, and control, reflects; "*I've done plenty of things in my life that I wished that I hadn't done and regretted it. But we live and learn. I know not to do it again*". The participant's reflections capture a rhetoric which challenges the notion of being ready to live in the future. The participant suggests that growth and development is embedded in challenging experiences. This dynamic seems to reflect a recurring paradox, where efforts to promote access, and to protect, on the basis of assumptions of intellectual disability, in fact may maintain those circumstances which prevent or preclude individuals from exercising choice, control, and independence

A key feature of the theme 'Life as Stasis: Future is fantasy' is the notion that the future is conditional upon meeting a particular standard, or conforming to particular rules. This dynamic has been noted within the research literature, for example, Brown (1994) notes that for some individuals labelled with intellectual

disability, living with a partner is contingent upon perceived capacity to manage one's finances, and to have achieved independent living skills. To this end, Brown (1994, p. 127) notes that "...sex as a reward for good behaviour lives on as a powerful myth." Individuals labelled with intellectual disability, unlike those who do not live with the label, are expected to prove their competencies and capacities, to gain access to the full human experience. This dynamic resembles Bernert's (2011) notion of socio-cultural scripts which direct and govern rules of engagement and expectations around sexual expression and relationships. The operative script here is perhaps that individuals labelled with intellectual disability must be ready to engage in the future.

Findings from the current study reflect those outlined by May (2000), who found that the futures of individuals labelled with intellectual disability were largely unrealised, and often metaphorical in nature. A concern inherent to the findings of the current study, and the findings represented within the research literature, is the notion that individuals may be engaged in a never-ending program of skill development. Perhaps this dynamic is underpinned by 'The Intellectual Disability Myth', and 'The Intellectual Disability Paradox' identified at the Myth Metaphor layer of analysis, where behaviours are pathologised, and identities evaluated, in light of assumptions of what it means to have an intellectual disability. Similarly, one's opportunities for the future are parametrised by perceived impairment, incompetency and by a desire to protect the individual from the reality of a wider world which ascribes a negative social identity. This dynamic perhaps reflects what Corbett (1994) terms the pursuit of false normality, where individuals are subjected to an enduring pressure to be evermore normal. It would seem, based on findings from the present study, and those reflected in the research literature, that individuals labelled with intellectual disability are expected to be more normal than are so-called normal people.

#### **5.5.5 Summary.**

Several themes have been identified at the Worldview Discourse layer of understanding, including; 'The Disability Discourse', 'The Parent: Heavy burden of high expectation', and 'Life as Stasis: Future is fantasy'. There are several key features to the themes identified at this layer of understanding. The theme 'The Disability Discourse' is an exploration of the language surrounding the social

construction of intellectual disability. Strong discourses emerged around notions of vulnerability, inherent difference, and incompetence. The theme 'I don't really know, you'll have to ask mum about that' represents a dynamic where individuals seem to assume a passive, rather than active voice, and tend to defer to the experiences and authority of others (e.g., parents). This theme perhaps symbolises the negotiation for choice, control, and autonomy in the context of living with the label intellectual disability. The theme 'The Parent: Heavy burden of high expectation' represents the protective role ascribed to those individuals who are constructed as responsible or as care-providers to individuals living with the label intellectual disability. This theme contends that parents of individuals labelled with intellectual disability are placed in a difficult position, as they must pursue seemingly competing goals of protecting and managing risk, while also promoting access to relationships and sexuality. The theme 'Life as Stasis: Future is fantasy', reflects rhetoric that engaging in one's future is contingent upon proving a level competence, that one is ready for the future. This theme touches on the notion that individuals labelled with intellectual disability are subjected to high standards for proving normality and competency, and that one's access to the human experience may be contingent upon meeting this high standard.

The themes identified at this layer are underpinned by myths and assumptions surrounding intellectual disability, identified at the Myth Metaphor layer of understanding. The themes identified at the Worldview Discourse layer are linked in the sense that they embedded within 'The Intellectual Disability Paradox'. For example, discourses are worldviews are concerned with normalising and protecting individuals labelled with intellectual disability. Paradoxically, these efforts perhaps perpetuate a lack of opportunity to experience the depth and breadth of human experience, to explore one's sexuality, and to have a relationship. Intellectual disability is established as a tainted identity, and one's fate as an enduring member of the social category is sealed by unattainable expectations for normal behaviour. Of interest at this layer of understanding are the power imbalances, and the expectations placed on individuals labelled with intellectual disability, and their parents, support-workers, and others who appear to perform these gatekeeping roles.

## **5.6 Social Causal Layer**

The Social Causal layer within a causal layered analysis allows for phenomena to be deconstructed in terms of structural or systemic factors which interact with, or

relate to the issue under exploration. At this layer, the influence of ecological factors is considered, and the information is contextualised in regard to social practices and paradigms. Myths and worldviews (identified in the preceding layers of understanding) that underpin an issue, manifest into systems and structures, serving as explicit expressions of assumptions and values surrounding intellectual disability. Themes presented and deconstructed at the Social Causal layer, include; 'Just get them into groups', 'Mainstreamers versus Ed-support', and 'As a Carer' (see Figure 5). Each of these themes with subthemes is explored in depth in the following section.

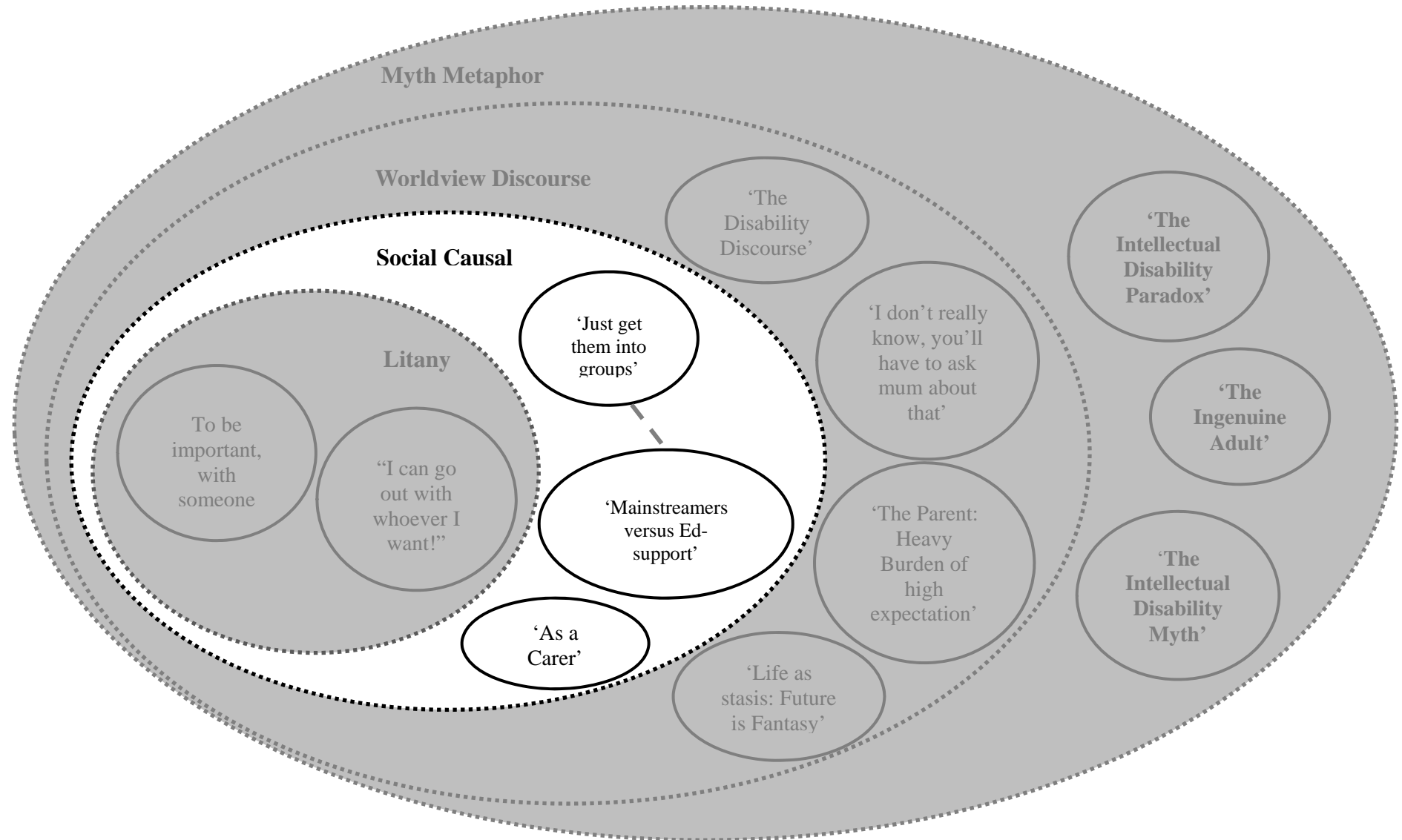


Figure 5. Thematic map of findings with emphasis on Social Causal layer of causal layered analysis.



### 5.6.1 'Just get them into groups'.

The theme 'Just get them into groups' is manifestation of worldviews and myths, at the Social Causal layer of understanding. At the Myth Metaphor layer of the analysis, the construction of intellectual disability as inherent difference suggests that intellectual disability is problematic, reflecting vulnerability and incompetence. At the Worldview-Discourse layer of the analysis, these myths manifest into roles which are ascribed to both the individuals living with the label intellectual disability, as care-recipient, and the parent, as care-provider. This care-recipient-caregiver dyad manifests at the Social Causal layer as a model of service-provision to "solve" the metaphorical problem of intellectual disability. The assumption of inherent difference, identified at the Myth Metaphor layer, gives rise to the notion that individuals living with the label intellectual disability should exist in particular settings, to suit the perceived particular needs of the so-labelled individual. For example, when asked what could be done to help individuals living with the label intellectual disability who might want to make friends, one participant labelled with intellectual disability, suggested, 'Just get them into groups'. It is true that the dominant paradigm for service-provision within the Western Australian disability service sector reflects a congregative care model and participants in this study spoke of their involvement with formalised disability service-providers, such as sporting clubs, alternatives to employment service-providers, art groups, and independent living skills programs. Each of these programs is designed for service-users with an intellectual, and/or other, form of disability. Often, disability service-providers are funded by the Disability Services Commission, a Department of the Government of Western Australia.

A tension associated with these formalised services is that they tend to be orchestrated by service-providers, rather than service-users and, perhaps due to resource limitations, tend to offer little spontaneity, choice or control for the individual who is a service-user. While some participants explained that they engaged in these programs, sometimes over the course of several years, other participants explained that they had made a choice to avoid certain programs, as they did not feel they were appropriate:

Participant one: *I used to go there too, I didn't like it.*

Emily: *Oh, why's that?*

Participant one: *Um, I thought it was a bit childish.*

Participant two: *The games that we were playing.*

Participant one: *Yeah, they were a bit childish.*

Emily: *Oh.*

Participant two: *Duck duck goose<sup>14</sup>, that sort of thing.*

Emily: *Oh really?*

Participant one: *Yeah, didn't like it. So I don't go there anymore.*

The participants refer to the activities as “childish”, and have made a choice not to attend. Inherent to the design of congregative care settings, is that service-users will share needs, and will benefit from a particular style of support and program. The notion that individuals living with the label intellectual disability are best served in congregative settings presents as an implicit understanding or assumption within the community. This extract, however, poses a challenge to this assumption of homogeneity. These participants refuse to attend the program, as they believe it is too childish for them. The sentiment was reflected in the experiences of another participant, who had recently stopped attending a program as they felt they were “*getting too old*” for the activities, while their peers continue to attend the program.

These services are often embedded within disability-specific settings, where program participants or service-users are eligible for services on the basis of a diagnosis of disability. These services are then designed on the basis of collectively sharing the label intellectual disability. Perhaps the form and structure of services is underpinned by myths and worldviews identified at pre-ordinate layers of this analysis (e.g., an assumption of vulnerability, and a discourse of safety and

---

<sup>14</sup> A game usually played by children. All children sit in a circle. One child at a time walks around the outside of the circle and identifies each child as either a duck or goose. A child identified as goose must chase the first child around the circle. The first child must try to get back to the goose's position in the circle before being caught by the goose. Both children then return to sitting in the circle and another child has a turn identifying each child as either a duck or goose.

protection). By nature, these formalised services represent congregative care settings. Participants in this study described that they engaged in a range of activities and events occurring in disability-specific settings, for example, bowling, basketball, swimming, independent life skills programs, employment programs, social dances, and drama groups. Participants indicated that these formal events offered the chance to see friends, and be social. Several participants in this study formed a core friendship group, who met on a regular basis at formalised service-provider activities and events. For some participants, these formalised services seemed to form the primary setting for social engagement. The landscape of the social and day-to-day lives of individuals who shared their stories for this research is consistent with findings from other research studies, where sometimes the sole source of contact with others occurs within disability-specific settings (Brown, 1994; Healy et al., 2009).

The formalised nature of the programs often means that events are scheduled weeks in advance, and that participants must register well beforehand. Sometimes, participants register for an event without knowing who else will attend. Inherent to this model of service-provision is a lack of spontaneity for the service-user, for example, a participant describes her weekly schedule:

Emily: *Oh, ok, so you do swimming at [sporting club] on Wednesday nights, and fitness on Monday nights, and do you do anything on Tuesday nights?*

Participant: *No, I stay at home.*

Emily: *Thursday nights.*

Participant: *No, I stay at home.*

Emily: *Friday night's [social] night.*

Participant: *Yeah. [social] night. Oh, yeah, we're going to the town centre.*

The participant's language is significant; she refers to Friday night as "[social] night". This language is perhaps symbolic of the lack of spontaneity inherent to the social and daily lives of individuals who are embedded in congregative care settings. The participant refers to social night as something that she "does" as part of her week, rather than as an organic, natural, and informal process. A desire for a greater

level of spontaneity, and informal socialisation, was reflected by some participants. For example, I had a conversation with one participant about their long-term boyfriend, during which, they suggested that they don't get to spend much "private time" together. When asked why this was the case, the participant explained:

Participant: *umm... 'cause we never get to see each other on weekends*

Emily: *hmm*

Participant: *like I expect, on weekends more likely to see each other more often on weekends*

Emily: *yeah, so why is that do you think? How come you don't see each other on the weekends?*

Participant: *umm... cause we never go out on Friday night, we never see each other Friday night, and we see each other at [sport club], and that's good, that's amazing, but we feel like going out more, like going out for dinner and... going out for dinner in private, like, alone.*

Emily: *yep*

Participant: *for when, our parents would just back off and leave us alone, we never get time to ourselves*

Emily: *yeah, do you ever get to do that? Just go out for dinner on your own?*

Participant: *umm... we did one time, and it was really, really good (laughs)*

The participant reflects that she would like to see her boyfriend more often, and in private, without the accompaniment of a parent, and at a setting other than at the sport club. The participant's experience is reflective of others, who share a desire to interact, socialise, and spend time with friends, unsupervised. It seems as though disability service-provider settings offer service-users little in the way of privacy, and independence from parents, guardians, and support-workers. Anecdotal evidence suggests that formal service providers often require, and encourage, the presence of a support-worker or parent to accompany a participant at an activity or event. In this sense, it seems as though there is a tension inherent to these formalised disability-specific services. On the one hand, these services are established with an aim to

promote socialisation, inclusion, and community participation for individuals living with the label intellectual disability, while at the same time, these services seem to create settings which identify individuals on the basis of a shared label, and offer little choice, control, and opportunity for privacy and independence. Perhaps in the same way that the gatekeeping role performed by parents is legitimated by, and legitimates assumptions of intellectual disability, so too do disability service-settings exist within this dynamic. The lack of spontaneity, privacy, choice, and control experienced by service-users within disability service-settings is well-recognised within the research literature (Hollomotz & The Speakup Committee, 2008; F. Sullivan et al., 2013). In this way, these formalised disability services seem to present a paradox, one which simultaneously aims to promote wellbeing, and also seems to perpetuate isolation, dependence, and passivity. Perhaps the dynamic here resembles that referred by Wolpert (1980) as the ghettoization of individuals labelled with intellectual disability into protective zones, seemingly, for their own good, and for the good of the wider community. The notion that congregative care is for the good of those who are congregated is perhaps a legitimating myth (Taylor & Bogdan, 1980), which serves the purpose of defending, and qualifying the role of the institution, or social-systemic structures. The experience of participants in this study seems to suggest that there is an overarching issue with gaining access presented by systems which are geared toward promoting access. At the Social Causal layer, it appears that opportunities to socialise and engage in relationships are mediated by gatekeepers, such as support-workers, service-providers, parents, and family members (Bernert, 2011; Fitzgerald & Withers, 2013; Todd & Shearn, 1997).

#### ***5.6.1.1 'Mainstreamers versus Ed-support'.***

The theme 'Mainstreamers versus Ed-support' emerged as a subtheme within the larger theme 'Just get them into groups'. The Australian Education system is presented as a context within which the dynamic presented within the theme 'Just get them into groups' is enacted. In the Australian education system, students are placed into an education-support unit or enter into the Mainstream system. Students may attend Mainstream schooling or attend some form of Ed-support schooling (in the form of Ed-support centres, schools or units). All of the participants who shared their stories for this study were either placed into the education-support system exclusively, or were enrolled in a combination of both education-support and

Mainstream classes. The decision to place a student into either schooling system is contingent upon the level of assistance the individual may require. It seems however, that these terms have been appropriated, and have taken on meaning beyond merely referring to a particular social structure. For example, a participant explains the meaning of the terms Mainstream and Ed-support:

Emily: *Yeah, so to be Mainstream, that means, uh...?*

Participant: *That they don't need any help.*

Emily: *OK.*

Participant: *but with Ed-support, they need help, help.*

The participant explains that the terms Ed-support and Mainstream indicate group membership, on the basis of competency and dependency. In this sense, one is not merely *part of* the Mainstream or Ed-support, the individual *is* Mainstream or Ed-support. These terms become labels for individuals, and are inherently othering. That is, if you are Ed-support you belong to a homogenous group, who are defined by a presumption of incompetency. While people who are Ed-support are presumed incompetent, those who are part of the Mainstream are constructed as perfect and normal, for example:

Participant: *they think they're above people with disabilities, that they should put us down...*

Emily: *hmm... and you think that's like a big obstacle to...?*

Participant: *yeah, making friends... but when they get to know the people and get to know us... it's ok and that it's...*

Emily: *people with disabilities are people...*

Participant: *yeah we're just like, we're just like normal but with a little bit of problems*

Emily: *yeah, and don't you think everyone has some problems?*

Participant: *yeah, even the people in the Mainstream, they all, they aren't always perfect*

The participant explains that it may be difficult for individuals living with the label intellectual disability to make friends because other people (e.g., those in the Mainstream) think that they are better than, or different from, individuals with an intellectual disability. The participant highlights the othering nature of these labels, suggesting that once people 'get to know' people with disabilities, then they realise that they are just normal people. What is of interest is that the schooling system seems to give legitimacy to the perceived inherent difference between individuals labelled with intellectual disability and those without.

Participants in this study, and their parents, referred to students enrolled in Ed-support classes as Ed-support, and students enrolled in Mainstream classes as Mainstream or "Mainstreamers". The formation of formalised disability service-providers, or disability-specific, congregative care settings seem an intuitive solution to the problem of intellectual disability:

*... all that is pretty hard with school and kids as well that, that's why we get people like, people with disabilities like to go out and do things like, make some friends, at [sporting club for individuals labelled with disability] and all that, that's ambassadors are trying to get people with disabilities to join in our groups, all that, to make friends, you know.*

A strong discourse emerging from the interviews involves the assumption that individuals living with the label intellectual disability "belong together" in disability-specific settings. This structure seems to represent a paradox; on the one hand, this system is created to provide additional support to those students who may require it, however, on the other hand, this system also seems to set students apart from their peers, reinforcing an assumption that individuals living with the label intellectual disability are inherently different from those who do not live with this label. One participant shares her experience of being an Ed-support student:

*Some people are a bit iffy with people with disabilities and it's pretty sad, when you like, when, especially when you're at school and, like, people pick on you, you know?*

The participant's experience suggests that there is a distinct class-system operating within the school system. People with disabilities are congregated within

the education setting, and are known as Ed-support, whereas as other students are considered Mainstream or normal. This system may foster a sense that one is less-than individuals considered Mainstream, as is explained by another participant:

*...when I was in the Ed- support unit, I kind of knew what other people thought...like, you know how other people can say things to you, but, it really hurts, but, you kind of believe it....like when I was in the Ed-support unit, like, I wasn't worth anything*

The participant's experiences reflect an interesting phenomenon, her experiences highlight a process by which the label Ed-support does not merely infer participation in a category of schooling, rather, this term has taken on a deeper-level meaning, forming a symbolic representation of difference. In other words, to be in Ed-support means much more than attending a particular class, to be in Ed-support means an individual is inherently different to others. In the same way that the once clinically-sanctioned term mental retardation is used as a derogatory term (Gelb, 2002), perhaps contemporarily so too is the label Ed-support.

The labels Ed-support and Mainstream are not exclusive to the education setting; they have transcended this setting, and are used as what seems to represent a politically correct way of identifying an individual as having an intellectual disability, or as normal. Perhaps this dynamic is captured by Goodley's (2013, p. 640) reflection, "...When disabled people (and non-disabled people for that matter) ask 'who am I?' they risk being hit with the mirror of the abled self." All of the participants in this study were in their early to mid-twenties, and yet, no longer in school, would continue refer to themselves, and their friends as Ed-support, Mainstreamers, and normal. For example, when I asked one participant whether her friend plays sports at their club, she responded:

*Emily: ...Right, so does she umm...play basketball?*

*Participant: no, she's like, Mainstream*

The participant's use of the term Mainstream is symbolic. The friend to whom the participant is referring is not school-aged, she, like the participant and fellow sports club members, is an adult. The participant is using this term to convey something else about her friend, perhaps that the friend is normal, or unlike the participant and her team mates. Here, the current school system, and the congregative



care model, perpetuates difference, and othering of individuals who live with the label intellectual disability. The use of these terms is particularly interesting in the context of this research, as all of the participants were no longer of school age, and many were aged well-into their mid-late twenties. In other words, these labels (perhaps appropriate within the schooling context) have been appropriated, and have continued to be used as labels into early adulthood. For example, one participant describes a recent experience of being bullied by Mainstreamers on the basis of having a partner who also lives with the label intellectual disability:

*... We get pushed around by Mainstreams... saying, oh, you aren't worth going out with anyone else.*

It seems as though these labels form a pervasive and eternal influence on the lives of individuals living with the label intellectual disability, setting up a dynamic where individuals who live with this label are less-than individuals who do not. I speculate that the terms Ed-support and Mainstream have contributed to an overt and explicit form of othering, reflecting the myth that disability is an inherent quality, which sets the individual apart from those who are normal, establishing these individuals as less-than, and influencing opportunities to engage in the full range of human experiences. It seems as though this system represents a paradox, as the system is in place to provide assistance and support, yet reinforces assumptions of difference, and the other. Bullying, social isolation, and rejection within Mainstream schooling settings of individuals labelled with disability is reflected within other research findings (Pitt & Curtin, 2004).

It might be speculated that the Australian education system serves a legitimising function for the label intellectual disability. The dynamic emerging from participants' stories in this research is similar to that outlined by Finlay and Lyons (2005) in their socio-constructionist analysis of intellectual disability, discussed in detail in chapter two, where the authors determined the label largely represented an administrative construct. Ascribing an individual with the label Ed-support qualifies their status as an individual with intellectual disability, and individual is inherently different, abnormal, and essentially incompetent. Perhaps these social structures act as a short-hand, to identify difference in ways which are condoned and qualified by social systems. Within these settings, individuals labelled with intellectual may be

subject to particular forms of instruction, or education (or a lack thereof). For example, individuals within Ed-support may be delivered sex education programs for people with disability, and may learn or not based on the discretion and values of the school, and teaching staff. As is highlighted in chapter three, the lack of formal and informal (via socialisation with peers) sex education is widely acknowledged within the research literature (Johnson et al., 2002; Lafferty et al., 2013; Williams et al., 2014). The impacts of which can be detrimental to developing sexual self-esteem (Shakespeare, 2000), and exploring one's sexual identity (Bernert & Ogletree, 2013; Eastgate, 2008; Fitzgerald & Withers, 2013).

### 5.6.2 As a carer.

The theme 'As a Carer' reflects a particularly complex relationship dynamic which emerged from the analysis of participants' stories. This theme links to the theme 'The Parent: Heavy burden of high expectation', as the worldviews which underpin the construction of parent, perhaps foster the rhetoric of care at the Social Causal layer. A paid support-worker, family member, friend, or another may take on the role of a carer for an individual living with the label intellectual disability. Parents, brothers, sisters, and friends appear to transform a social or familial role for a carer role. This dynamic extended to familial, or social relationships, where a family friend, a group of school friends or a sister might go out with, or "take out" their friend or sibling with an intellectual disability as a carer. For example, one participant explains that her adult child labelled with intellectual disability recently attended an event with his partner, accompanied by his sister and another family-friend:

Participant one: [Participant two's sister] *took you as the carer...*

Participant two: *And [family friend] is with us too.*

Participant one: [family friend] *and [participant two's sister] were your and [participant two's girlfriend] carers.*

Participant one explains that participant two's sister and a family friend attended the event *as* participant two's and his girlfriend's carers. This extract provides an example of the apparent dual-role which can be adopted by parents, friends, and family members of individuals living with the label intellectual disability. Sometimes, brothers, sisters, mothers, and friends may cast-off their familial or

social role in particular contexts and settings. In this particular example, participant two's sister and family-friend are identified as carers, rather than as per their familial or social roles. It is interesting to consider what significance this relationship dynamic may hold for the participant, the participant's girlfriend, and the participant's sister. This dynamic is perhaps reflective of assumptions and conventions around what it means to have an intellectual disability, and also perhaps what it means to be the sibling or friend of someone living with this label.

This relationship dynamic suggests that relationship roles are transient, and fluid, and that an individual may become someone's carer when the need arises, as is illustrated in the following extract:

Emily: *And do you go out just you and [friend] or do you have someone...?*

Participant: *and a carer as well*

Emily: *... and carer...*

Participant: *...but, my carer is in hospital having [an operation]*

Emily: *okay, yeah*

Participant: *...that's why we've got Mum and [friend's] mum helping us*

Emily: *yep, so instead of your carer your mum and [friend's mum] are going to help you with things that you normally do with your carer?*

Participant: *yes.*

The participant explains that her carer (a paid support-worker) has been unwell and that in the carer's absence, her own mother, and a friend's mother, have taken on this role for them. This dynamic is interesting as, indeed, there are cultural assumptions surrounding what it means to be a mother, there is an assumption that mothers provide informal, and formal care. This relationship dynamic suggests that there is complexity, and tensions, inherent to negotiating a relationship, in the context of the construction of intellectual disability. Identifying a sister as carer and, by implication, brother as care-recipient, seems to be just another aspect of family relationships.

Wolfensberger's (2000) Social Role Valorisation theory provides a framework to understand how roles, such as carer and the care-recipient may construct an

individual, or a group of individuals living with a particular label, as valued or devalued members of society. Wolfensberger suggests that individuals can be ascribed valued or devalued roles depending on the extent to which they are constructed as valued members of society, further, these valued or devalued roles can serve to confirm one's worth within society. In this context, individuals living with the label intellectual disability are ascribed a care recipient role, and family members, friends, and others are ascribed a caregiver role. Wolfensberger suggests that individuals living with the label intellectual disability are likely to be cast into devalued roles, as this identity or social construction is met with negative assumptions, such as unintelligent, incompetent, dangerous or impaired. Objectively positive assumptions of mental impairment, such as, innocence, moral reasoning, "childlike wonder", also cast individuals with this label into devalued roles, which are characterised by incompetence, and passivity, and imply the need for a carer. These assumptions of intellectual disability necessitate those surrounding individuals living with the label intellectual disability take on a complementary role, that of caregiver. For example, to go *as* someone's carer implies that a carer role may be adopted as necessary, and that this role takes precedence over other roles, such as, sibling, mother or friend. In this way, going *as* someone's carer rejects the identity of both the individual living with the label intellectual disability as a brother, sister, son or daughter, and also rejects the identity of a sibling, or parent, as that individual's sister, brother, mother or father. The relationship transforms into one based on a directional care relationship, perhaps void of reciprocity, and characterised by a power imbalance. Perhaps this relationship dynamic reflects the assumption that individuals living with the label intellectual disability are care-recipients, rather than individuals who can actively participate, and provide care as a brother, sister, friend, son or daughter.

The construction of family member as carer and an individual's living with the label intellectual disability as care recipient undermines the mutuality, and interdependence inherent to these relationships. Hence, this dynamic has a potential to devalue or undermine those identities which are salient to the individual, family member or friend, casting them instead into a role revolving around disability and the assumptions inherent to it. As is discussed previously in chapter three, Knox and Bigby's (2007) findings suggest that family relationships are iterative, negotiated,

and fluid roles adopted by entire family systems, in an effort to maintain wellbeing and support all family members. Participants in their study spoke of negotiating care-related tasks, noting that these familial relationships are characterised by interdependence, and mutuality. A key finding from this study was the concept of Family Business, the notion that families get on with daily tasks, and activities, that are important for their family unit, rather than perceiving their roles as caregivers or inherently related to disability. Findings from this study suggest that familial care relationships are complex and dynamic, and cannot be accurately reduced to care-recipient-care-provider dyads.

### **5.6.3 Summary.**

Themes identified at the Social Causal layer of understanding, include; 'Just get them into groups', 'Mainstreamers versus Ed-support', and 'As a Carer'. The theme 'Just get them into groups' reflects a dynamic within social systems and structures to construct alternative settings for individuals who live with the label intellectual disability which serves to legitimise one's identity as "intellectually disabled". The subtheme 'Mainstreamers versus Ed-support' presented the Australian education system as an example of setting within which alternative settings manifest, and fixed identities are ascribed. The theme 'As a Carer' reflects the complexities and tensions inherent to informal and formal systems of care surrounding individuals living with the label intellectual disability. The notion that sister, mother, or friend could swap their personal role for that of a carer, is perhaps a reflection of the assumptions and myths which underpin the construction of intellectual disability, those who surround so-labelled individuals.

The dynamics and social processes identified at this layer of understanding are the tangible manifestation of myths, assumptions and rhetoric identified at the Myth Metaphor and Worldview Discourse layers of understanding. Assumptions of incompetency, vulnerability, and rhetoric of protection provide a foundation for social systems which are congregative, and subject individuals labelled with intellectual disability to high levels of surveillance. Organising individuals labelled with intellectual disability into "groups" is presented as a solution to the problem of intellectual disability. These social systems emerge as problematic and paradoxical as, rather than promoting access, equality, and normality, these systems and models of care appear to promote difference. This paradox resembles that which is identified

at the Myth Metaphor layer of understanding within the theme 'The Intellectual Disability Paradox'.

### **5.7 Litany Layer**

The Litany layer of understanding within a causal layered analysis reflects the way that problems or issues are commonly described or explained. The themes presented within the Litany layer emerge through the stories told, and are evident in the ways that individuals commonly describe and explain their experiences. Issues identified at the Litany layer tend to represent an explicit or overt manifestation of the implicit assumptions and understandings identified at other layers of understanding. Themes presented and deconstructed at the Litany layer (see Figure 6), include; 'To be important, with someone' and 'I can go out with whoever I want!' Each of these themes is explored in depth in the following sections. Some of the quotes provided to justify claims made at this layer have been used to evidence dynamics, tensions and phenomena at preceding layers of the analysis. At the Litany layer, quotes are understood at a more surface level than at the deeper layers of analysis, where symbolism, metaphor, and values may be deconstructed and understood.

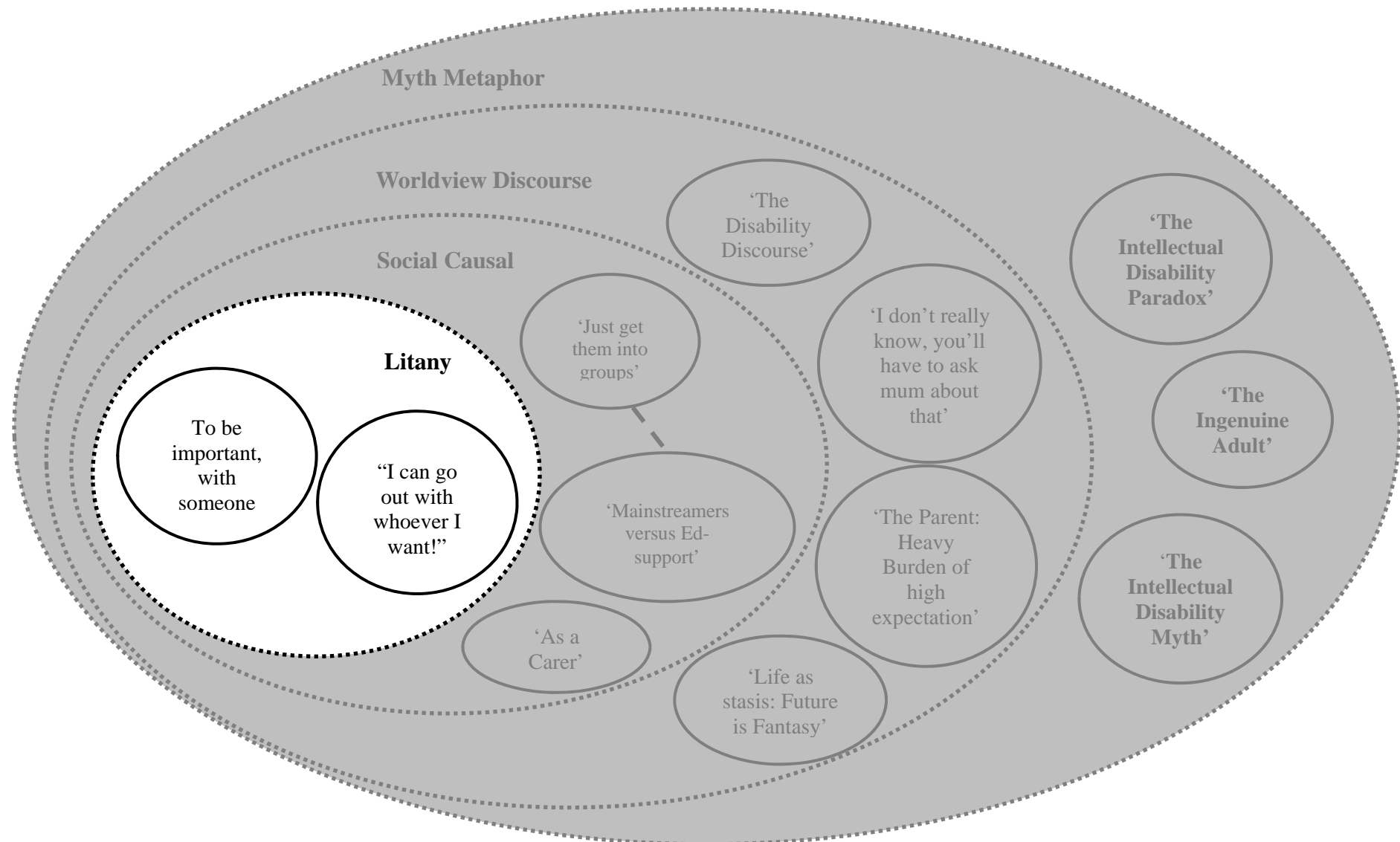


Figure 6. Thematic map of findings with emphasis on Litany layer of causal layered analysis.

### 5.7.1 'To be important, with someone'.

The theme 'To be important, with someone' captures a discourse surrounding intimacy, belongingness, and connectedness within participants' stories. Six participants labelled with intellectual disability identified as being single, while the remaining 10 participants labelled with intellectual disability identified as being in a relationship. Some participants were in long term relationships, some participants were happily single, and other participants identified as single, and expressed that they would like to have a boyfriend or a girlfriend. Participants also reflected on the deep connections they experienced in their friendships, and with their family members. These relationships, and the pursuit of a relationship, were characterised by the notion of providing, and receiving care and support. For example, one participant explains:

Participant: *...I need somebody, though, that cares about me more sometimes, though. Like, for example, I need a girl, though, to hang around with me, just to hang around, enjoy, have a bit of, have a bit of a connection between us.*

Emily: *Yeah.*

Participant: *Just share, just sharing our, just sharing ourselves.*

The participant describes the kind of relationship he would like to have, one characterised by a shared connection, and a sense that each individual is "there for one another". Participants also reflected on their plans and hopes for the future, including leaving their long term relationship to meet new people, to get married, to perhaps have children, and live with friends or a partner, for instance:

Emily: *...So in your- you were saying that in your future you were thinking about maybe marriage?*

Participant: *yeah, marriage, yeah*

Emily: *yeah*

Participant: *living independently*

Emily: *living independently*



Participant: *have our own house*

Participants described plans for the future involving their close friends and family. For example, two participants in a long-term relationship shared their plans to live with mutual friends when their parents die:

Emily: *so when do you guys think you might move out?*

Participant one: *one day*

Participant two: *one day I think, yeah. I'm not really sure...*

Emily: *do you think you're ready to move out now or you have to wait?*

Participant one: *you have to wait*

Participant two: *you have to wait, that's all, you have to wait, you have to wait with my mother, my mum and my dad will be gone one day*

Emily: *ok*

Participant one: *yeah*

Participant two: *so, yeah, that's what happens*

Participant one: *and then my parents, same thing too*

Participant two: *yeah, [participant one's] parents the same thing and they'll be gone one day*

While several participants in this study shared their experiences of engaging in relationships, and of experiencing the love, care, and support of another, some participants reflected on a deep longing, an unmet desire, for this kind of connection. For example:

Participant: *...that's why I like to be attached to a bloke and be important with a bloke....Yeah I want that more than anything [crying].*

Emily: *So that's very important?*

Participant: *I want a bloke that's like my dad, like, always there, that kind of, that kind of feeling. Yeah.*

Some participants shared this sense of longing, and expressed an unmet desire to engage in a close intimate relationship with another. When discussing what would be good or important about having a partner, one participant noted:

Participant: ...*I just want a boy who loves to be my friend*

Emily: *ok, what would that be like?*

Participant: *good*

Emily: *and what would you do with a boy who's your friend?*

Participant: *umm... talk to each other on the mobile phone*

The participant explains that they would like to have a friend who is a boy, and imagines that they would enjoy speaking to one another over the phone. The everyday activity of talking on a mobile phone symbolises intimacy and closeness for the participant. The theme, 'To be important, with someone' captures the complexity, and diversity, inherent to all human relationships. A key aspect of this theme is the value attached to being close with someone, having an opportunity to experience love, loss, rejection and support, on a mutual and reciprocal basis.

The theme 'To be important, with someone' highlights a collective desire; shared by all, to be connected with others in a meaningful way. The content of this theme may not be remarkable. What is remarkable, however, is that hopes and experiences regarding relationships are punctuated by a rhetoric of disability, and the notion that the right to have children, get married, move out and express sexuality is contingent upon being affixed with the label intellectual disability. This dynamic is noted in chapter three, when literature and research on the experiences of individuals labelled with intellectual disability is presented and discussed. A key argument raised in chapter three is that the desire to engage in relationships, and to be connected to others, is not remarkable; it is a collective desire inherent to humanity.

The desire shared by individuals labelled with intellectual disability to be connected to others, and to engage in close relationships, is well-recognised within the research literature (Azzopardi-Lane & Callus, 2014; Knox & Hickson, 2001) (Bane et al., 2012; Yacoub & Hall, 2008). Similarly, as is highlighted in the findings of this study, previous research has found that many individuals labelled with

intellectual disability share an unmet desire to engage in relationships and intimacy (Johnson et al., 2002; Knox & Hickson, 2001; McVilly et al., 2006b), sometimes, as a function of the socio-cultural value attached to the label. As Hollomotz and the Speakup Committee (2008) argue, some people will navigate life without having an intimate or close relationship, however, individuals labelled with intellectual disability appear not to have the same level of choice, control, and autonomy over opportunities to engage with others in intimate and close relationships. This dynamic is reflected in the findings of this study, where individuals seem to have their choices and experiences filtered through the social construction of intellectual disability.

### 5.7.2 'I can go out with whoever I want!'

The theme 'I can go out with whoever I want!' captures the tensions, and complexities, inherent to the process of negotiating relationships and intimacy in the context of living with the label intellectual disability. When discussing relationships, desires, and intimacy, some participants spoke of intellectual disability, and how this label may influence their opportunities, or the way that other individuals view their relationships. At the Litany layer, participants reflect on their personal experiences of being evaluated, and of being informed as to their own rights, and responsibilities as an individual living with the label intellectual disability. One participant shared her and her partner's experiences of being bullied on the basis that they both live with the label of intellectual disability, and that they are in a relationship together:

*Participant: ...It's like, we always get judged at the same time. It's like, oh, you're going out with a short girl, and I get called, oh, you're going out with a tall guy. And I don't care, it's my, my choice. It's like, oh, I said to the person that said it, it's not up to you who I decide to go out with, it's what I decide who to go out with. Yeah.*

*Emily: So it's about doing what you want to do, and what's good for you, and not what other people say that you should do.*

*Participant: Yeah. So you can't tell me, judge between what us, we do, and stuff. It's like, oh you judge between us, and it's like oh, I told them to stop judging us, because we have disability and they didn't. So they're saying "...you've got a disability. You can't be here. You're not allowed in here."*

Emily: *So what's that about? Why do you think it matters if you have a disability?*

Participant: *Um, it doesn't really matter, but it depends on how, like, Mainstream treated us as well. Because we get pushed around by Mainstreams, saying, "...oh, you aren't worth going out with anyone else that's better." Because, at the moment, my ex-boyfriend, he wants me back, but I've moved on...and I said to him "I've moved on" over Facebook. I've told him "I can go out with whoever I want". It's like I've decided I'm going out with another guy. So it's like, "I can't go out with you, because I've moved on.*

Here, it seems that the participant is confronted by other's expectations of them and of individuals living with the label intellectual disability. The participant suggests that those individuals who bully them about their relationship believe that individuals living with the label intellectual disability do not have a right to engage in intimate relationships. The participant goes on to elaborate on her interactions with these individuals:

Participant: *...I asked him, I asked him why do you think me and him aren't perfect together? Because we have a disability? "Oh, because if you and he decide to get married and have kids"—and I'm not going to do that—but he's telling me, "if you're going to have a kid together"—and I'm not, that's not going to be happening for a while—"that means your kid's going to have a disability". I'm like, "no, it doesn't mean that. It's gonna mean that our child won't have a disability, because that won't go through, so...*

Emily: *Because the genetics don't....*

Participant: *...connect and stuff.*

The participant outlines an experience of having to defend their right to have children. The participant explains that the decision to have children is their own, and that no one else is responsible for telling them what they are allowed to do in this regard. It is suggested that it is not remarkable that individuals who live with the label intellectual disability will have children; however, it does seem remarkable that individuals who live with this label should form a target for this kind of rhetoric.

Perhaps it is also remarkable that individuals, such as the participant, should have to defend their right to have children. This theme is perhaps underpinned by implicit assumptions on intellectual disability, the myth of 'The Ingenuine Adult', and 'The Intellectual Disability Myth'. The participant's experience of defending their right to have children, is reflected in research findings, which suggest that within dominant Australian Western culture, individuals labelled with disability are not expected to, or actively discouraged from, having children (Dotson et al., 2003). The rhetoric here reflects that identified by Brown (1994) and Bernert and Ogletree (2013) that sexuality and intimacy for individuals labelled with intellectual is often suppressed or repressed, rather than promoted.

While some participants' experiences highlight how myths and assumptions can manifest in explicit ways, provoking negative evaluations from others, another participant shared her own views toward the label Down syndrome, and what this means in the context of relationships:

Participant: *I don't want to have, I don't want to be Down syndrome, I want to be normal*

Emily: *ok, and a boyfriend, you want your boyfriend to be normal too?*

Participant: *yes, he is normal (laughs)*

Emily: *so... so how come you, you don't want to have Down syndrome? Why do you want to be different?*

Participant: *I just want to be normal*

Emily: *hmm... and what does normal mean?*

Participant: *I just want to be normal because I need a normal boyfriend that I can kiss*

The participant seems to suggest that because they live with the label Down syndrome, they cannot have a normal boyfriend. Perhaps the participant's reflections on their opportunity to pursue a relationship reflect the internalisation of myths, and assumptions, surrounding intellectual disability. For example, the participant may subscribe to the notion that individuals living with the label intellectual disability are

asexual, and do not have a right to intimacy, closeness, and the positive expression of sexuality. These are not just worldviews/thoughts that the participant has about individuals living with the label intellectual disability, these are thoughts and worldviews the participant has for themselves. Essentially, the participant is stating that they do not want to be “who they are”, because “who they are” is someone who is not allowed to have a meaningful relationship. At a Litany layer, this is perhaps the known truth about individuals who live with the label intellectual disability. This truth is not necessarily enforced upon an individual, and met with resistance, rather, this truth may be internalised and accepted by the individual as a part of their identity. The internalisation of such beliefs about oneself, is perhaps what Shakespeare identifies as a dynamic where one’s sexual self-esteem is lowered (Shakespeare, 2000), and exploration of one’s sexual identity is unexplored (Bernert & Ogletree, 2013; Eastgate, 2008; Fitzgerald & Withers, 2013). Findings from this research resemble those generated from Fitzgerald and Wither’s study, who found that women labelled with intellectual disability often had little or no concept of themselves as sexual beings. With regard to the participant’s experiences, the internalisation of the view that individuals’ with Down syndrome may not have a boyfriend is particularly problematic; the participant is effectively disqualified from this aspect of the human experience.

The theme ‘I can go out with whoever I want!’ captures the tension inherent to considering relationships and sexuality in the context of intellectual disability. This theme captures the tensions that the social construct of intellectual disability provokes in this domain of the human experience. Participants in this study highlighted how the label influences their experiences, and opportunities to engage in close relationships. ‘The Disability Discourse’ featured heavily in participants’ discussions and reflections on close relationships. A key feature of this theme is the resistant voice, a voice which challenges the dominant cultural assumption that individuals labelled with intellectual disability should experience relationships in particular ways as a function of this label. This resistant voice is evident in findings from other research studies, where individuals rejected the notion that access to relationships, intimacy, sexuality, reproductive rights, choice, and control should be contingent upon living with the label intellectual disability (Bane et al., 2012;

Bernert, 2011; Fitzgerald & Withers, 2013; Healy et al., 2009; Rushbrooke et al., 2014a).

### **5.7.3 Summary.**

Themes identified at the Litany layer of understanding include; 'To be important, with someone' and 'I can go out with whoever I want!'. The theme 'To be important, with someone' is reflective of the desire to engage meaningfully with others, to be connected, and experience intimacy with others. The theme 'I can go out with whoever I want!' captures a tension which seems to be inherent to negotiating, and pursuing relationships, in the context of living with the label intellectual disability. Both of these themes relate to a fundamental part of the human experience, that is, to be connected to others, and to experience belonging. This desire is not remarkable, and is not "special"; it is considered part of human nature. This desire appears to become remarkable, however, when presented in context of intellectual disability. Participants explained how the label intellectual disability influences their rights and opportunities to engage in close relationships and explore sexuality.

A key feature of the findings at the Litany layer of understanding is the presence of two, seemingly competing, voices. The theme 'To be important, with someone' captures a desire to be intimate, to explore one's sexuality and to engage in relationships. Conversely, the theme 'I can go out with whoever I want!' is an explicit commentary on how living with the label intellectual disability influences the opportunities to enact this desire.

## **5.8 Vignette: Reconstructing the issue**

This chapter commenced with the presentation of a vignette, titled "Rhiannon's story", which represented a compilation of experiences and reflections of various participants. Rhiannon's story was presented as a first person account of the tensions and complexities associated with living with the label intellectual disability. In concluding this findings chapter, in order to reconstruct and make sense of the findings emerging from the causal layered analysis it is useful to revisit Rhiannon's story from a different perspective. A key message emerging from the findings is that the label intellectual disability takes on meaning and significance depending on how others conceptualise or construct this label. Participants identified that this label

impacted on their lives, opportunities, and experiences; however, this label was largely constructed by participants as a problem for other people. This key message subverts dominant discourse and rhetoric surrounding intellectual disability as a problem of the individual. As such, in reconstructing the key message from the analysis, I am going to move away from an introspective account of what it means to live with this label; rather, I will attempt to capture the social-cultural construction of the label intellectual disability. The following vignette is a reflection on Rhiannon's life from the perspective of Rhiannon's mother. This vignette is presented as an attempt to make sense of, reconstruct, and contextualise the findings emerging from this study.

### **5.8.1 My daughter, Rhiannon.**

*My daughter, Rhiannon, is 24 years old now, she lives at home with us, her brother, sister and father. I guess when Rhiannon was born (she was our second child) we really didn't know that anything was out of the ordinary. Normal pregnancy, normal birth... it wasn't until she was a few years old that we started to notice some little things, some funny things. She took a little longer to walk, and perhaps didn't pick up so many words as her sister had for her age, but she was a happy baby, nothing was 'wrong', as such. I guess when I look back on it now, that was a very blissful time. I think of it, kind of like, the 'calm before the storm'. Sometimes I wonder 'what it would be like for us all to live in that time again?' a time without doctors, without support-workers and service-providers, when Rhiannon could just be herself, be normal. We knew nothing of intellectual disability then.*

*Of course, the 'storm' came when Rhiannon began at kindergarden, and her teacher let us know that Rhiannon was a little behind her classmates, she had trouble picking her name on the whiteboard, and working with the coloured counters. She recommended that we see our GP, who then referred us to the children's hospital, for some tests. The thing is, they couldn't name 'it', they couldn't tell us 'what was wrong', just that she wasn't quite developing like other children her age. And that's when we registered with the Disability Services Commission, we were trying to work out how best to support our daughter, who we had been told had an intellectual disability. It was hard at that time, very disorienting. So many programs, and*



*systems, terminology - it was like a whole different world for people with intellectual disability.*

*I guess everything was kind of regular until Rhiannon began schooling, at that point, we had to decide, do we put her into Mainstream schooling or Ed-support? The teachers recommended that she enter into Ed-support, they said that she would make friends more easily there. They also said that the teachers would be better able to support her in their classrooms, that they would have more time for her. Rhiannon made some lovely friends in primary school, mostly in Ed-support, some of whom she is still very close to today. Rhiannon also had some hard times in school, I know the Mainstream kids used to tease her a bit, it really upset me, I just wanted to protect her from all of that. Things got a little bit better in high school; she started attending more extra-curricular activities, going to TAFE, dancing, drama and basketball. Rhiannon's group of friends kind of travelled together for their schooling, now we are all very close, all of us mothers, and our sons and daughters.*

*Rhiannon has a job now, she managed to get it through her employment assistance provider, she packs shelves at our local grocery store. It's good because the staff all know her there, they understand about her, and what she needs. They look after her well there. Rhiannon's pretty busy at the moment, and I'm pretty busy too! Driving her to and from all of her different activities and groups. We have spoken about public transport, but I just worry that something might happen to her. It's hard though, hard to explain to her, when she sees her younger brother catching trains, and I have to tell her that she can't. She has lots of things to do though; she goes to basketball and bowling every week. I know that she loves bowling because she gets to see her boyfriend there. He lives quite far away from us, I know she'd like to see him more, but it's a real struggle to make it happen. She often asks about going to dinner with him, wants more time alone with him.*

*So bowling is good, seeing him once a week is at least once a week. And it's good that his mum and I are such good friends, it means that we can help them when they have little fights, or organise for them to catch up. I think it would be even harder if I didn't know Rhiannon's boyfriends parents. And he comes over every now and then for dinner. They go into her room to watch a DVD, I do worry about them getting a bit carried away together, but I think Rhiannon is a bit scared-off the whole*

*sex thing. She says she wants to wait until she is married. And I know they do talk about marriage, having kids, the whole lot. I think it could happen one day, but not just now. Rhiannon's been working hard with her carer to learn cooking, cleaning, washing, that kind of thing. She's pretty good at taking care of herself, but she's got a way to go I think before she's ready for independent living. I mean, I know she, her father and I won't always be here for her, that kind of worries me. I know that her brother and sister will always keep an eye on her, and take care of her. And I know that there are government programs, independent living, and all that. But I don't want her to end up alone, or in one of those nursing homes for old people. It's not right. I'd like her to live a normal life, get married, be an aunty, live independently. I guess that what we're all working towards for her, together*

### **5.9 Conclusion**

In this chapter, findings generated from a causal layered analysis of interviews were presented. A range of strategies have been employed to present the themes emerging from the analysis, including vignettes, a thematic map (see Figure 1), a summary of themes at each layer (see Table 5), and a written explanation of each theme in detail. Themes at each layer of understanding were presented, commencing with the Myth Metaphor layer of understanding, and concluding with the Litany layer of understanding. Several key messages, dynamics, and paradoxes emerged within and between the layers of understanding.

Within the Myth Metaphor layer of the analysis, several themes were identified, including: 'The Intellectual Disability Myth', 'The Intellectual Disability Paradox', and 'The Ingenuine Adult'. Themes at the Myth Metaphor layer of understanding suggest that there are some meta-processes and paradoxes associated with the label intellectual disability. For example, that intellectual disability is paradoxically identified as a social construct, but also an undeniable and inherent feature of the individual. 'The Intellectual Disability Paradox' reflects a dynamic where the pursuit of normality, seems to carry one further away from an ordinary existence. The myth of the ingenuine adult symbolised individuals labelled with intellectual disability as child-like, incompetent, vulnerable, and in need of protection. These myths perhaps contribute to a socio-cultural context where relationships, sexuality, parenthood, and independence are seen as remarkable in the context of intellectual disability.

Several themes were identified at the Worldview Discourse layer of understanding, including; 'The Disability Discourse', 'I don't really know, you'll have to ask mum about that', 'The Parent: Heavy burden of high expectation', and 'Life as Stasis: Future is fantasy'. Themes identified at this layer are embedded within 'The Intellectual Disability Paradox' (Identified at the Myth Metaphor layer). Notions of pursuing a normal life, being ready for the future, and a strong discourse which served to other individuals labelled with intellectual disability were prevalent. Themes at this layer touched on the roles and expectations ascribed to parents of individuals labelled with intellectual disability, and highlighted how parents are expected to negotiate and assume responsibility for facilitating, and also protecting, their son or daughter in the context of close relationships and sexuality. Of interest at this layer of understanding are the power imbalances, and the expectations placed on individuals labelled with intellectual disability, and their parents, support-workers, and others.

Themes identified at the Social Causal layer of understanding, included; 'Just get them into groups', subtheme 'Mainstreamers versus Ed-support', and 'As a carer'. The dynamics and social processes identified at this layer of understanding are the tangible manifestation of myths, assumptions and rhetoric identified at the Myth Metaphor and Worldview Discourse layers of understanding. Assumptions of incompetency, vulnerability, and rhetoric of protection provide a foundation for social systems which are congregative. Organising individuals labelled with intellectual disability into groups is presented as a solution to the problem of intellectual disability. These social systems emerge as problematic and paradoxical as, rather than promoting access, equality, and normality, these systems and models of care appear to promote difference. This paradox resembles that which is identified at the Myth Metaphor layer of understanding within the theme 'The Intellectual Disability Paradox'. For example, services arranged around the central principle of intellectual disability may subscribe to assumptions and myths, such as the myth of 'The Ingenuine Adult'. Further, systems predicated on these myths and assumptions are not conducive to promoting choice, control, independence, privacy or spontaneity. In these, often disability-specific, settings, so labelled individuals may experience little opportunity to engage in relationships, and to explore sexuality.

Themes identified at the Litany layer of understanding include; 'To be important, with someone' and 'I can go out with whoever I want!' A key feature of the findings at the Litany layer of understanding is the presence of seemingly competing voices. The theme 'To be important, with someone' captures a desire to be intimate, to explore one's sexuality and to engage in relationships. Conversely, the theme 'I can go out with whoever I want!' is an explicit commentary on how living with the label intellectual disability influences the opportunities to enact this desire. The universality of the desire to engage in relationships and intimacy sits in stark contrast to rhetoric where one's access is contingent upon the label intellectual disability. At this layer of understanding, one is left with a distinct sense that just because something is desired, wanted for, or needed, that does not mean it will or can be enacted.

This chapter reflected an attempt to attend to the primary aim of this research, to explore what it means to negotiate relationships and sexuality while living with the label intellectual disability. The following chapter, chapter six, is an extension of the findings chapter, and reflects an integration of feedback obtained from the community on key messages emerging from the research (as per phase three of the research, outlined in chapter four) with findings emerging from a causal layered analysis of interviews with participants. Findings from the current chapter, the following chapter, and chapter seven (the process chapter), will be synthesised and explored further in chapter eight, the discussion chapter.

## **Chapter six: Inviting feedback from the community**

### **6.1 Introduction**

In this chapter, the findings from phase three of the research are presented. As is outlined in chapter four, phase three of the research occurred as an iterative process, overlapping with the data collection, analysis, and writing up phases of the research. Communicating findings to, and inviting feedback from the community, occurred via two processes; via workshops, seminars, and conferences, and, via a circulating a summary of findings to community groups, organisations, and stakeholders within the community. The details of these processes are outlined in full in chapter four. The findings from each of these formats will be presented in turn, commencing with the findings that emerged from my engagement in workshops, seminars, and conferences. Subsequently, I will summarise commentary provided by the community on the summary of findings document. At the conclusion of this chapter, I will consider the findings emerging from phase three in context of those emerging from causal layered analysis of the interviews with participants.

### **6.2 Feedback from the community obtained via seminars, workshops, and conferences**

Over the course of the research I attended a range of local, national, and international seminars, workshops on conferences where issues related to disability, sexuality, and relationships were considered and discussed (details outlined in chapter four). The target audience of these settings was diverse, some were attended by advocates, self-advocates, parents, family members, support-workers, health professionals, researchers, disability service-provider representatives, students, and others in the community. In order to meaningfully interpret the findings emerging from these settings it is necessary to reflect that discussions were more often *about* individuals labelled with disability, rather than intentionally targeted to audiences of individuals who identified as so-labelled. It is reasonable to suggest, however, that it is not possible to know exactly who was in the audience. To suggest that so-labelled individuals were or were not identifiable and so were or were not present would be antithetical to this enquiry. However, over the course of attending these various workshops, seminars, and conferences a pattern emerged where voices of so-labelled individuals were not as prevalent as the voices of those who spoke *about* so-labelled individuals. In fact, several of the seminars and workshops I attended were framed as

not appropriate for, or explicitly did not extend invitation to, individuals labelled with intellectual disability. This formalised distinction between individuals labelled with intellectual disability, and others in the community who are constructed as well-positioned to discuss issues related to disability (e.g., parents, family, support-workers, and so on) is evident in the anecdote which opens the introduction to this thesis. That is, at that workshop, parents attended a morning session, while their sons and daughters attended a separate afternoon session.

An overwhelming message that emerged across seminars, workshops, and conferences was the notion that disability, sexuality, and relationships are complex, and problematic for a range of individuals, including so-labelled individuals, family members, support-workers, disability service-providers, and others. Seminars, workshops, and conferences were attended by a range of individuals who appeared to share a collective desire to know more information on this topic. This desire to know more, and to seek information was foregrounded in a sense that very little is known on the topic, and that individuals, groups, and stakeholders within the community do as best they can to navigate the complexities associated with disability, sexuality, and relationships. The prevailing sentiment within these settings was that sexuality and relationships should be accessible to all. Conversations on disability, sexuality, and relationships were influenced by rhetoric about safety, protection, risk, human rights, historical treatment of so-labelled individuals, stigma, stereotyping, and myths of disability and sexuality held by the community. This rhetoric was accompanied by a strong level of uncertainty and concern around exactly what could be done to promote access, and to support so-labelled individuals to engage in sexuality and close relationships.

Attendees to seminars, workshops, and conferences who identified as being employed in a disability support-worker role, or as disability service-provider representatives spoke to the influence that formal systems and role expectations had on their experiences of disability, sexuality, and relationships. While some individuals and service-provider representatives noted that their employers engaged a formal policy on sexuality for service-users, most suggested that no such formal policy or direction existed within their workplaces. A lack of explicit information on how to manage and respond to issues pertaining to sexuality and relationships meant that many processes, rules, and procedures manifested informally, and were not

necessarily sanctioned by the employer or service-provider. Support-workers spoke to the challenges associated with a lack of clarity regarding what they could or couldn't, or should or shouldn't do. At the various workshops, seminars, and conferences, some individuals (support-workers, individuals labelled with intellectual disability, and others) noted that efforts to facilitate opportunities for service-users to express or explore their sexuality occurred covertly, and were not integrated as a formal component of service delivery. For example, several support-workers spoke of intentionally leaving service-users alone at particular points during the day so that they may engage in sexual self-exploration if they so desired. Some individuals noted that individual values, such as religious beliefs, heavily impacted on how support-workers dealt with issues pertaining to sexuality and relationships. Stories were told of particular support workers who would purposefully restrain or prevent service-users from opportunities to engage in masturbation, consuming pornography, or engaging in other forms of sexual expression.

Some support-workers spoke of risking their jobs via intentionally subverting (formal and informal) rules they felt violated service-users rights to engage in sexual expression and close relationships. For example, several support-workers recounted instances where they had assisted service-users to arrange to engage in services with sex-workers, despite explicit instruction that this was not permitted according to the policy of the service-provider. Myths surrounding the legality associated with sexual expression and accessing sex-workers seemed rife within the community, with many individuals explaining that they had been misinformed that individuals labelled with intellectual disability, categorically, were not legally allowed to engage in sexual activity. These stories, anecdotes, and discussions suggest that support-workers are placed in a difficult position where they must assume personal responsibility, at times risking employment, to promote what they perceive as the basic right of sexual expression, intimacy, and relationships. My impression from engaging with the community across various workshops, seminars, and conferences was that efforts to promote rights to sexual expression and close relationships must be undertaken "under the radar", as a kind of covert rebel operation.

Concerns associated with systems, procedures, and policies were constructed as barriers to engaging in close relationships and sexuality. For example, one individual

spoke of a married couple who were not permitted to live together in a group home<sup>15</sup> due to occupational health and safety concerns. Service-providers and others cited concerns that sleeping in the same bed may lead to physical harm due to medical issues experienced by the service-users. Other individuals cited a reduction in pension following marriage as a barrier to individuals labelled with intellectual disability being married.

Some seminars, workshops, and conferences were educative in nature, providing information, resources, and guidance to teachers, support-workers, and service-providers on issues pertaining to disability, sexuality, and disability. Within these forums, it became apparent that while educative resources did exist (for teachers, individuals labelled with intellectual disability and others), they were under-utilised. A particular problem identified by educators was the fact that individuals could pick and choose how they delivered and used educative resources. For example, individuals may not personally agree with, or feel comfortable discussing particular issues (e.g., masturbation, pregnancy, pap smears), as such, this component of the program might not be delivered. Educators and program facilitators suggested that individuals labelled with intellectual disability experienced a lack of sexual education, particularly compared with children, young adults, and adults who do not live with this label. By extension, educators suggest, fears around the personal safety of so-labelled individuals were realised by a lack of understanding, education, and protective behaviours. Concerns around protection, safety and risk-management are perhaps legitimated by an endemic lack of sexual education for individuals labelled with intellectual disability.

A prevailing theme across settings was the notion of safety, protection, and risk. Conversations on disability, sexuality, and relationships were commonly accompanied by a discussion of managing risk, promoting safety, and equipping so-labelled individuals with protective behaviours. While some posited education as a key to promoting safety and sexual expression, it seemed that safety was also managed in other ways. For example, many individuals spoke of strategies to prevent opportunities for sexual expression, or close relationships. For example, one parent

---

<sup>15</sup> The term 'group home' refers to a shared supported residential setting. Group homes are characterised by multiple residents, who receive some level of formal or informal support from a disability service-provider or funding body.



noted that they hoped telling their adult child labelled with intellectual disability that they had to wait until they were married to have sex might prevent them from having sex. This and other similar strategies did not seem to offer a great deal of comfort or certainty for parents, and seemed to be born out of uncertainty on how to navigate the complexities associated with sexuality and close relationships.

Another key message to emerge out of these settings was the sentiment that individuals labelled with intellectual disability shared a collective unmet desire to engage in sexual expression, and engage in close relationships. While this sentiment does not capture the experiences of all individuals, a large section of those attending the seminars, workshops, and conferences spoke to the lack of, yet hope for, opportunities for so-labelled individuals to engage in sexual expression and close relationships.

### **6.3 Findings from the community obtained via circulation of key findings to key stakeholders**

I received feedback from community members on the summary of findings document via telephone and via email. The individuals who made contact with me shared their experiences associated with relationships, sexuality and intellectual disability. All individuals who made contact with me occupied formal roles within disability service-providers or research communities, or identified as family members of individuals labelled with intellectual disability. Some individuals provided feedback directly to me, while others offered to circulate the information on to others who they felt might be interested in providing commentary. A key message to emerge from this commentary was the value of exploring issues pertaining to sexuality and relationships in the context of intellectual disability. Some suggested that the findings provided were consistent with their experiences surrounding sexuality, relationships, and intellectual disability. Others emphasised the complexity of working to address the concerns raised within the summary of findings document. One community member reflected a sense of sadness upon reading the findings, and suggested that there is a tendency for issues around sexuality and relationships to be “pushed under the carpet”.

One community member emphasised that there is a lack of access to information on sexuality and relationships for individuals labelled with intellectual disability.

This community member reflected that many individuals labelled with intellectual disability do not have access to sexual education as they develop. The community member suggested that a lack of access to information and sexual education positioned individuals labelled with intellectual disability as vulnerable to risk and exploitation. This community member advocated that access to information and education would promote opportunities to make informed decisions about relationships and sexuality. Some suggested that individuals labelled with intellectual disability could be engaged in social programs that promote assertiveness and education around sexuality and relationships. Another community member reflected that often there is a strong emphasis on risk, fear, and control surrounding relationships, sexuality, and intellectual disability. This community member advocated for engaging parents of individuals labelled with intellectual disability in educative programs on sexuality and relationships while their children were of a young age. The implication being that such programs might socialise parents away from engaging in practices which are over-protective and undermined the needs and rights of their children.

Each of the community members who made contact with me to provide their feedback on the findings, in some form or another, asked for my commentary on issues pertaining to relationships, sexuality, and intellectual disability. One community member asked explicitly how I anticipated the sexual rights of individuals labelled with could be supported. Others extended invitations for me to communicate further with their service-users, and organisations, on issues related to sexuality, relationships, and intellectual disability. A pattern emerging from these interactions is an enthusiasm within the community for information, discussion, and development on what appear to be shared concerns regarding relationships, sexuality, and intellectual disability. Some community members extended opportunities for organisational support to engage with their service-users, or organisational community.

#### **6.4 Integrating feedback from community with findings from interviews with participants**

There are commonalities in the key messages and issues emerging from the seminars, workshops, and conferences, and the feedback provided by the community on the summary of findings document. A strong theme emerging from these

processes is an acknowledgement that living with the label intellectual disability somehow compromises opportunities to express one's sexuality and engage in close relationships. This theme is congruent with findings emerging from the causal layered analysis of interviews with participants (such as 'The Intellectual Disability Myth' at the Myth Metaphor layer), where opportunities to engage in close relationships and express sexuality were constructed as contingent upon intellectual disability. Participants in this research, attendees at seminars, workshops, and conferences, and community members who provided feedback on the findings summary, acknowledged that many individuals labelled with intellectual disability experienced unmet desires, and limitations in choice and independence, surrounding close relationships. Attendees and community members, as did participants in this research (e.g., in the theme 'I can go out with whoever I want!'), reflected that all individuals have a right to engage in relationships and express their sexuality.

Commonalities may be drawn between the structure and dominant foci of the seminar, workshop, and conference settings, and the findings emerging at the Worldview Discourse layer of analysis. For example, discussions at seminars, workshops, and conferences on sexuality, relationships and intellectual disability were punctuated by discourses of risk, vulnerability, safety, and protection. These discourses were also evident in themes such as 'The Ingenuine Adult' at the Myth Metaphor layer, 'I don't really know, you'll have to ask mum about that' and 'The Parent: Heavy burden of high expectation' at the Worldview Discourse layer. These myths and discourses were reflected in seminar, workshop, and conference settings, which often placed strong emphasis on protecting individuals labelled with disability, and engaging in discussion *about* rather than *with* so-labelled individuals. The construction of parents as responsible for facilitating and managing their adult child's relationships, social contact, and sexual expression identified at the Worldview Discourse level of analysis was apparent in seminar, workshop, and conference settings, where emphasis was often placed on what parents could do to support and protect the sexual rights and relationships of their sons and daughters. It was apparent in these settings, and in the commentary provided by the community on the findings summary, that parents and others are constructed as playing an active role in promoting the sexual rights and relationships of individuals labelled with intellectual disability.

Themes identified at the Social Causal layer of analysis (such as 'Mainstreamers versus Ed-support', subtheme 'Just get them into groups', and 'As a Carer') were reflected in the ways that community members posed strategies for addressing issues related to relationships and sexuality. For example, solutions to problems and challenges faced by individuals labelled with intellectual disability and their parents, and, family members were often presented as interventions, training programs or clubs for individuals labelled with intellectual disability. These clubs and programs were characterised by being disability-specific, focusing on skill development, and were facilitated by parents, family members, support-workers or service-providers. These systems and structures resemble those which were noted by participants in this research, for example, social clubs, independent living skills programs, and so on. It is speculated that this approach to "solving" issues pertaining to relationships, sexuality, and intellectual disability is reflective of dominant ideologies, myths, and assumptions surrounding the nature of intellectual disability.

While patterns, dynamics, and processes were similar in the findings from interviews with participants, and feedback on the findings from the community, there were also notable differences. For example, within the seminar, workshop, and conference settings, issues pertaining to sexuality and sexual expression were frequently discussed. Conversations on relationships were often associated with discussions on sexuality. This dynamic was not so apparent within interviews with participants. Sexuality, and sexual expression, seldom emerged as a topic for discussion during interviews. While this could be because I didn't explicitly raise sexual expression as a topic with participants, it is interesting to note that sexuality, sexual expression and sexual intimacy was not so commonly discussed with participants. My sense is that sexuality as a topic would not have been so prevalently discussed in seminars, workshops, and conferences if conversations were *with* rather than *about* individuals labelled with intellectual disability. I speculate that this dynamic is underpinned by the taboo surrounding sexuality in context of intellectual disability; where sexuality is constructed as a topic inappropriate for discussion *by* individuals labelled with intellectual disability.

## **6.5 Conclusion**

In this chapter, the findings from phase three of this research project were presented and discussed. The chapter commenced with a summary of key messages

emerging from my engagement in a range of seminars, workshops, and conference pertaining to intellectual disability. Subsequently, I considered key messages emerging from commentary provided by the community on the research findings. Key to the process of inviting community members to comment on the findings (in seminar, workshop, and conference settings, and on a specific findings summary document) is to consider this commentary in context of the findings emerging from the analysis. In doing so, it is apparent that patterns, dynamics, systems, and structures emerging from the research findings that serve to construct sexuality, relationships, and intellectual disability as problematic, hold meaning and relevance to the wider community. The feedback, contributions, and commentary attained from the community give a richness and depth to the kinds of assertions that might be made regarding the core research aim. The research findings, feedback from the community, and my reflections on the research process (to be outlined in the following chapter, chapter seven) inform the interpretations and claims outlined in chapter eight, the discussion chapter.

## Chapter seven: Reflections on process

### 7.1 Introduction

In this chapter, I present a critical reflection on some of the complex issues and dynamics which have emerged throughout the research process. These issues are presented in terms of my personal reflections and recollections, and in terms of observations made in the role of participant-conceptualiser (as previously outlined in chapter four; K. K. Smith, 1983). There are two aims associated with this chapter – to contribute to the transparency of the research process, and in so doing, the trustworthiness of the research findings and to contribute to a critical and progressive discourse surrounding what it means to attempt to engage in participatory research. An account of the various decisions made throughout the research process is provided, in an effort to elucidate the complex ethical tensions, and moral obligations involved in the research. The dynamics, challenges, and issues which emerged are considered in terms of a broader, collective socio-cultural, and research context. Issues which present as ethical or moral dilemmas are important, as they may reveal nuances inherent to the very topic of the research enquiry.

This chapter is presented in two broad sections. Initially, I present Michelle Fine's (1992) notion of *intellectual surprises* as a conceptual framework to make sense of the key tensions emerging from the research process. Subsequently, I critically examine each of the key intellectual surprises emerging from the research processes, using personal examples and theory to understand the tensions, dynamics, and paradoxes.

### 7.2 Intellectual surprises

Oliver (1992) suggests that it is inappropriate to deny, or neglect, the politicised nature of disability studies. He and others (Walmsley & Johnson, 2003; Zarb, 1992) suggest that the role of the participatory and emancipatory researcher is to disrupt the status quo and challenge existing power relations. Michelle Fine (1992, p. 220) describes various stances that a researcher may assume, suggesting that the *participatory activist* is one who self-consciously embraces subjectivity and meaning-making, and seeks to “...*unearth, interrupt, and open new frames for intellectual and political theory and change*”. In this stance, researchers are engaging

in inherently political works and so share a responsibility to “... *assess critically and continually our own and as well as informants' changing positions*” (Fine, 1992, p. 220). This kind of critical examination is a mechanism through which researchers open themselves up to experience intellectual surprises (Fine, 1992). Intellectual surprises are those insights gained when social and cultural contexts are critically examined and phenomena are understood as a product of those contexts. These insights are surprising to the extent that they take on a new meaning when they are decontextualised and revealed as a product of the culture which produces them. In the following, I will discuss a series of tensions and dilemmas, which I posit as intellectual surprises emerging from the research process.

### 7.3 Reflexivity

Reflexivity is a tool for generating a new perspective, for revealing nuances, complexities, and tensions inherent to the phenomena under study (L. Finlay, 2002; Sultana, 2007). Reflexivity is commonly understood as “...*thoughtful, conscious self-awareness...*” (L. Finlay, 2002, p. 532), and can be engaged on multiple levels (Northway, 1998). At a surface level, reflexivity identifies researcher-bias and so can contribute to the apparent trustworthiness and rigor of the research process (L. Finlay, 2002). At a deeper-level, it is a meta-analytic process (L. Finlay, 2002), a way of grounding the research in a social, cultural, historical, and political context. The strategies I engaged to promote reflexivity (Berger, 2013; Morrow, 2005) throughout this research project, included reflexive journaling, engaging in critical discourse with a research team and with members of the community, engaging in multiple interviews with an individual, member-checking and creating an audit-trail of decisions made throughout the course of the research.

A contextualist approach acknowledges that knowledge can only ever be generated within a social, cultural, political, temporal, and historical context (Jaeger & Rosnow, 1988). Reflexivity is the active engagement in a discourse of what can, and cannot be, achieved within a particular context (Sultana, 2007). Reflexive processes can reveal complexities and tensions within contemporary systems and so an inherently politicised process (L. Finlay, 2002; Scott, 1997). In fact, Finlay (2002, p. 544) reflects that coming out through reflexive processes is “...*ultimately a political act*”. Reflexivity offers the opportunity to challenge pre-existing power

relations, and is tool to safeguard against the unconscious perpetuation of these oppressive dynamics (Northway, 2000).

The nature of research is contextual, and as researchers, we are inevitably embedded in the cultural contexts which we aim to explore, deconstruct, and make sense of. Reflexivity offers a mechanism to foster awareness of one's own position, biases and assumptions, in attempt to avoid perpetuating existing power dynamics and oppressive structures (Elwood, 2007; Guilleman & Gillam, 2004). Reflexivity forms part of a broader discourse surrounding epistemology, ontology, axiology, and knowledge (Berger, 2013). Where research is embedded in a social constructionist and contextualist approach, the research findings are understood as inevitably constructed by the researcher's own understandings and assumptions of the world (L. Finlay, 2002).

The knowledge gained from explorative enquiry is constructed iteratively via the subjectivity of the researcher, the participants and the milieu of the broader social context (Guilleman & Gillam, 2004). To this extent, the researcher through their own subjective interpretations of data, constructs the knowledge which is gleaned through the research process (Guilleman & Gillam, 2004). To use an analogy, the researcher will adopt a particular lens through which to understand and interpret phenomena. Reflexivity reveals the nature of this metaphorical lens and how the researcher may influence the research findings, and research process. Reflexivity is transformative, offering opportunity for insight, generation of knowledge, and an understanding of how the phenomena under study may be evident within the research process (L. Finlay, 2002; Northway, 2000; Scott, 1997).

#### **7.4 Intellectual surprise #1: Enculturation**

The first of the intellectual surprises I will consider relates to enculturation and reflexivity. Reflexivity allowed me to recognise and make sense of a key intellectual surprise within the research process – my own enculturation around intellectual disability. My interactions with individuals and the community highlighted my underlying prejudices, assumptions, and values. On reflection, it is clear that, at times, my decisions, interactions, comments, and expectations were directed by myths and misconceptions of what it means to have an intellectual disability. For example, on one occasion I was interviewing an individual who I had known for a number of years. We were sitting at her kitchen bench, talking about her search for



employment, about her partner and her friends. The following is an extract from the interview, in which we discuss time spent with friends:

Emily: *and when you talk about like, you go to each other's houses... is that like, just a bunch of friends that you org-....*

Participant: *me, [friend]...*

Emily: *.... Organise it?*

Participant: *... [Friend], [friend] and [friend]*

Emily: *yep*

Participant: *we go, just have a meeting like, what we should do and this and that and each umm... umm... public holiday...*

At this point, I remember feeling surprised that this individual and her friends organised themselves in this way. My surprise is reflected in my subsequent question:

Emily: *yeah. And does anyone, like, do you get any help with that? Or do you guys, do you just do that like, informal, like as a bunch of friends?*

Participant: *just us guys.*

Emily: *that's really cool that you set it all up and...*

My response here is patronising, I am subscribing to the expectation that this individual, and her friends, would not be capable of organising themselves without assistance. I am operating on the assumption that individuals who live with the label intellectual disability are only able to socialise and have friendships in the context of formal service-settings. Our conversation continued, as the individual outlines how she and her friends organise their time together:

Participant: *and then we umm.... Whoever doesn't have the phone numbers, like, [friend], [friend], my friends, other friends like, [friend] and [friend] don't have [friend's] phone number...*

Emily: *ok*

Participant: *...and [friend's] mum wants [friend] to go out with us and all that, so I umm.... said I'll ring the people who you don't have phone numbers with...*

Emily: *hmmm*

Participant: *.... So we split up the phone number ringing.*

Emily: *oh yep. That's a, umm.... A good system... so umm...*

Participant: *and we have to get times, dates and all that, see if it's open, not open, you know?*

Emily: *so how... do you have a name for the group? Or you just...?*

Participant: *just...*

Emily: *do it?*

Participant: *just do it.*

Here, I am reflecting my assumptions surrounding the capacities and expectations of the participant and her friends, I cannot let go of the notion that socialisation must occur within some formal context; I even go so far as to ask if the group has a name. I would never think to ask the same question of a similarly-aged individual who did not live with the label intellectual disability. In this case, however, I assume there is a formal structure to the group, and I assume that the participant and her friends must have assistance to organise their time together. At the time, I remember feeling as though this friendship-group was unique and unusual. I was impressed that individuals labelled with intellectual disability were organising themselves independently and also impressed because I assumed that the parents of these individuals had allowed this to take place. My assumptions here seem to reflect a dominant approach to understanding, and attempting to remedy, issues constructed around relationships, sexuality, and intellectual disability. A key pattern which emerged during my engagement in seminar, workshop, and conference settings (outlined in chapter six) was the assumption that disability-specific, formalised and chaperoned service, programs and clubs were most valuable for promoting relationships for individuals labelled with intellectual disability. Here, I am subscribing to a dominant worldview that the relationships of so-labelled individuals must be facilitated on their behalf in formalised ways.

On reflection, reading back over our conversation, I feel really silly. To me, the friendship group was remarkable, whereas, in reality, it is not. It only seemed remarkable to me because of the assumptions and expectations I held toward individuals labelled with intellectual disability. My own assumptions and biases were reflective of findings which emerged from the causal layered analysis and findings. For example, my assumptions were reflective of those evident in the themes of 'The Intellectual Disability Myth', 'The Intellectual Disability Paradox', 'The Ingenuine Adult', and 'Just get them into groups'. This exchange suggests that despite being mindful of these assumptions, I am in no way immune to them.

This level of enculturation around the social construction of intellectual disability is illustrated on another occasion, when I was talking with one participant about his plans for the future. In this exchange, the participant and I were discussing his plans to move out of their family home. The participant had previously mentioned to me that he wanted to get an apartment, but did not want to move out of the family home at that point in time. The following is an extract from our conversation:

Emily: *Ok, so, when you're a bit older you want to get an apartment or now?*

Participant: *yep, yep, but not yet*

Emily: *not yet*

Participant: *but I still live with my parents, I still love them*

Emily: *ok*

Participant: *yep*

Emily: *so how will you know when you're ready to move into an apartment?*

I assume that the participant does not want to move out because he does not feel he is "ready". I know that I would not have asked this question of similarly-aged individual who was not labelled as having an intellectual disability as the notion of being ready would not have crossed my mind. Because the participant lives with this label, I assume that he will need to be ready before he can move out, that he will need to develop their competencies. I am assuming that the participant is unlike other similarly-aged adults, that he will need to be ready for independent living. The nature of my question restricts the participant's response options, encouraging agreement

that he needs to be ready before he can leave home, that he is not yet competent. I do not give the participant the opportunity to disagree with my assumptions:

Participant: *first I have to look after myself first*

Emily: *ok, do you think you can do that now or?*

Participant: *not yet, I need a bit more practice, practice, practice (laughs)*

Emily: *ok*

When the participant agrees with me, and explains that they have to learn to “look after” themselves, I accept his statement, and do not ask for elaboration. This would have offered a good opportunity for me to ask the participant: *can you tell me what you mean by ‘look after yourself’?* I did not ask the participant to elaborate, however, because I assumed I knew what they meant. Our conversation continued:

Participant: *something like, washing my own clothes, handing the, wait, something that the apartment does... like umm... cooking your own foods...*

Emily: *yeah, can you do those things now?*

Again, I am reinforcing my assumption that the participant is incompetent, and that they must reach a level of competency before they can move out. I would not have asked this kind of intrusive and patronising question of a similarly aged individual, but I felt it was ok to ask the participant:

Participant: *umm... getting there, but not yet, bit more teaching (laughs)*

Emily: *Is that what you learn at [disability service-provider]?*

Participant: *well I can, I can cook sausages*

My interaction with the participant here reveals my own biases and assumptions in operation. I am also reinforcing the notion that individuals labelled with intellectual disability require special treatment, intervention, and development to engage in various day to day activities. I assume that the participant is learning these skills deliberately, and in a specific and formal setting. This may or may not be the case, but my handling of the questions allows the participant very little opportunity to respond in a way that does not confirm my own assumptions about their life. My line of questioning is a good example of how stigma, myths, and stereotypes may be perpetuated in the research context. Reflexive journaling allowed me to pay attention

to these biases. My biases reflect findings identified in the research; themes such as, 'The Ingenuine Adult' and 'Life as Stasis: Future is fantasy'.

Looking back over interview transcripts, I identified several occasions where my interactions, questions, and tone was distinctly patronising. On these occasions, I was assuming the role of the expert, and assuming that I had some form of ultimate understanding about individual's lives. For example, on one occasion, a participant was discussing with me how he sometimes finds their partner irritating:

Participant: *yes, I was with her, umm... watching DVD just enjoying myself and [participant's girlfriend] was acting... distracting (Laughs)*

Emily: *oh*

Participant: *repeats the words*

Emily: *repeating the words?*

Participant: *yes, of the TV but I try to relax.*

Emily: *oh, were you finding it annoying?*

Participant: *yeah.*

Emily: *Do you think that that happens in relationships? That people will get annoyed with each other?*

The participant explains to me that he finds it irritating when his partner reads the subtitles of movies aloud. Rather than responding empathically, or allowing space for the participant to reflect on this experience, I undermine the participant's experiences and feelings. I suggest to the participant that perhaps this happens in all relationships. In this instance, I am patronising the participant because I am assuming a position of authority, and I am *telling the participant how it is*. Implicitly, I am encouraging the participant not to worry about this experience. Of course, this is not the position which I should assume during interviews. At the time, I remember wanting to make the participant feel better, to protect them from feeling annoyed, irritated or disappointed, to make sure they didn't worry. I know that I would not have felt this way toward any other similarly aged individual. I was trying to protect the participant, and so was perpetuating assumptions surrounding vulnerability, incompetence, and the myth of the 'The Ingenuine Adult'. This kind of interaction

does not promote equality, or minimise power distance. Rather, my role as the researcher here reinforced the traditional researcher-researched power difference.

Embedded within the dominant Western cultural context, researchers are afforded positions of power and control, and are not immune to the influence of social-cultural values within research practices. Researchers operating under participatory action research paradigms must not fall foul of the assumption that disability can be "...abstracted from the social world which produces it" (Oliver, 1992, p. 101). The notion that research can never be divested of ideology is a tension inherent to research practices.

A contemporary trend within the research community is to explore the relativism of the label intellectual disability. How this label can shape identities, opportunities to engage in aspects of day to day life, and to pursue aspirations. This trend reflects a new understanding, where intellectual disability is viewed as fluid, and contextual (Goodley, 2013), as opposed to a fixed, inherent, and pervasive aspect of one's character (Goodley, 1998). Despite this new understanding, and the emergence of new participatory and emancipatory research paradigms there is a process of cultural lag (Cocks, 1998; Goodley, 1998), where remnants of historically appropriate myths and stigma toward disability remain embedded within current social cultural values and social practices. While there is a tendency to consider various paradigms in disability research as taking hold in a sequential, and absolute fashion, these shifts reflect underlying trends in the approach to research, and the conceptualisation of disability (Oliver, 1992). It is possible to act according one paradigm, while thinking in another, as Oliver (1992, p. 106) reflects, while a new "...paradigm has changed the rules, in reality it has not changed the game."

### **7.5 Intellectual surprise #2: Ethics-in-practice**

The second intellectual surprise which I will consider is the negotiation of ethics-in-practice, in the face of emerging ethical tensions and moral obligations. Ethics in practice, also referred to as *virtue ethics* or *participatory ethics*, reflects the notion of a moral responsibility within research practices (Waterman, 1998). Exercising principles of ethics-in-practice offers an opportunity to extend beyond the commitments, guidelines, and standards outlined by formalised procedural ethics, to negotiate the complex tensions and dynamics which emerge as a result of actively engaging in research processes (Elwood, 2007). The tensions associated with

negotiating principles of ethics-in-practice in the context of more formalised institutional procedural ethics is oft-cited by those working with the participatory, action, and qualitative research domains. The various assumptions which underpin procedural or institutional ethics are said to be, at times, at odds with the principles set out by ethics-in-practice. For example, procedural ethics are those which are typically enforced by institutional bodies, and rest on the assumption that ethical dilemmas can be anticipated, and prevented, outside of the context of the research process (Elwood, 2007). Often, researchers and institutional boards and bodies are the only participants in formalised ethics procedures, which typically present research participants as passive, vulnerable, and in need of protection from harm (Elwood, 2007).

Formalised notions of ethical practice in research can be traced back to the Nuremberg trials of World War II, an historical event which is seen to have sparked the development of formalised procedural ethical codes and standards (Guilleman & Gillam, 2004). These ethical codes and standards were born out of a desire to prevent such atrocious violations of human rights in future research endeavours (Elwood, 2007). The value of formalised ethical procedures, guidelines, and principles cannot be understated; they form a foundation for ethical scrutiny of research, providing standards by which research may be deemed as ethical (Elwood, 2007). It is argued, however, that institutional ethics cannot prevent ethical dilemmas (Elwood, 2007; O'Neil, 1989). The very nature of the research process is fluid, and complex ethical tensions emerge, and must be negotiated actively, throughout the research process (Sultana, 2007). As such, there are challenges associated with negotiating ethics-in-practice, in the context of procedural ethical expectations (Elwood, 2007). For example, the universal and fixed nature of procedural ethical principles can restrict opportunities to engage in collaborative, participatory, and exploratory research processes. Core principles of inclusive and participatory research (e.g., that community play an active role in the research process) may be overtly disallowed by expectations set out by institutional ethics boards.

According to principles of ethics-in-practice, researchers have a responsibility to extend beyond what is formally required of them, to engage in constructive dialogue to work through unanticipated and complex ethical issues as they emerge. As Sultana (2007, p. 383) reflects, "...*the very conduct of fieldwork is always contextual,*

*relational, embodied and politicized*". Engaging in ethics-in-practice is an iterative, reflexive, and dialectical process which requires active negotiation of "...*identities, group membership (or exclusion), and power relations*"(Elwood, 2007, p. 331) which may be reflective of the very phenomena under study. Ethics-in-practice offers a framework for complementing fixed codes for ethical conduct, and fostering a move "...*toward moral and mutual relations with a commitment to conducting ethical and respectful research that minimises harm*" (Sultana, 2007, p. 377)

Ethics-in-practice offers opportunities to re-negotiate power relations necessary for working toward the often emancipatory or social justice imperatives within participatory and action research (Elwood, 2007; Waterman, 1998). For example, engaging ethics-in-practice procedures offers opportunities to re-negotiate traditional power relations between the researcher and the researched. Ethics-in-practice reflects the moral responsibility that researchers assume when engaging in action research to exercise cultural competency, and sensitivity, within the research process. Researchers have a responsibility to be mindful of "... *histories of colonialism, development, globalization, and local realities, to avoid exploitative research or perpetuation of domination and control*" (Sultana, 2007, p. 375). Researchers also have a responsibility to critically examine the ethical dilemmas and junctures within the research process, to report on important ethical decisions and intentions (Waterman, 1998). This kind of critical reflection on *ethically important moments* (see Guilleman & Gillam, 2004) may reveal the complexities of the phenomena under study, and create a space to engage more appropriate research practices in future.

### **7.5.1 Ethically important moments.**

One of the key concerns which emerged from the research process was gaining access to participants. It was clear to me that the individuals with whom I wished to speak were embedded in settings which would make it difficult for me to contact them directly. This presents an ethical dilemma, as many of the individuals who participated in the research were legally able to give informed consent, and should be afforded the proper level of anonymity and confidentiality in doing so. The following is an extract from my reflexive journal, in which I consider the ethical and moral dilemmas which emerged during the recruitment process.



*At the time I started recruiting, intuitively, my first point of contact was with the parents of the individuals that I wanted to speak to. I would speak to parents face to face if I saw them at events, I would make a phone call, or I would email. I did not have the direct contact details for the individuals who I hoped to interview. My sense is, even if I had these contact details, I would not have used them; I would have gone through mum or dad first. If I had engaged directly with sons and daughters, without speaking with parents first, I would have caused offence, and likely would not have been able to speak with anyone. Speaking with parents first was tantamount to seeking permission to speak with their son or daughter. This process presented some tensions, as most of the individuals who I wanted to interview were not appointed a legal guardian, and so for many there was no legal requirement that I sought permission from a parent prior to speaking with them. Morally, culturally, and ethically, however, I felt the distinction was not so clear. I felt there was an expectation, within the community, that I would go through parents first, check with them, before speaking with their son or daughter.*

My sense is that this recruitment process was acceptable to the community in which I was engaged, to parents, and to the individuals who I interviewed. My sense is that parents and their sons and daughters alike expected that this would be the process of engagement. In context, this recruitment process was not unusual or remarkable to me. This process does become remarkable, and reflect an intellectual surprise, when it is decontextualised. In any context other than this, it would be ill-advised, inappropriate or downright unethical to approach parents, in lieu of consenting adults, to indirectly recruit participants. My reflections continue and I consider the power processes at play:

*This dynamic placed parents in a position of power. Effectively, I was asking permission to speak with their adult son or daughter, and they had the opportunity to say yes, or no. The very first participant I intended to approach about the study never heard about it, as their mum informed me that she did not think it was a good idea as she and her son had a lot going on at that time. I remember feeling frustrated, as the study did not rely on her involvement, and more to the point, her son should have been in a position to make the decision. In contrast, I spoke with some parents who were enthusiastic to have their son or*

*daughter take part. I spoke with one woman who assured me that her son would not have a problem, and that he would definitely take part. While I appreciated her enthusiasm, I was very concerned that her son may feel pressured, or as though he didn't have a real choice to say no.*

I was perpetuating a dynamic which has since emerged as a major theme within the research findings. This dynamic seems to be underpinned by an expectation that parents, service-providers, and others are responsible for their adult son or daughter with an intellectual disability. These expectations were reflected in the commentary and feedback provided by the community on the research findings (outlined in chapter six). Inherent in the commentary from the community was a strong discourse that parents, support-workers, and others had a responsibility to facilitate and promote relationships and sexuality on behalf of individuals labelled with intellectual disability.

Throughout the recruitment process I was acutely uncomfortable. I knew that the processes were contrary to the social justice aims of the study. This dynamic is a reflection of the dominant social-cultural context, one in which I had to act with cultural sensitivity. These power relations were internalised by the individuals with whom I spoke, who seemed to internalise the level of power afforded to them by virtue of the label intellectual disability. Not only were these power relations evident in the recruitment process, they were evident throughout the research process:

*I arrived at a participant's house to conduct an interview. The participant's mother answered the door, and pulled me aside to tell me all about the participant's recent break-up with her partner. She said that she wanted to let me know, just in case the participant didn't want to talk about relationships on that day. After our interview, I recall that her mother, as did others, asking me if I "...got what I needed..." from the interview. I found this interaction difficult. While it is not unusual for participants to ask this question post-interview, it is unusual for a parent of an adult participant to do so. In my mind, of course I got what I needed! I was privileged to have their son or daughter share their stories with me. I felt I was being cast into a particular role, and a power distance between me and the participants was apparent. Despite my experience of interviews as conversational, and organic, power differences became evident immediately outside of the interview context. I came to resent, and dread, the*

*obligatory post-interview conversation with mum or dad. Of course, I maintained confidentiality, and privacy, and tried to politely deflect questions. But I was acutely aware that I was committing a betrayal. Again, here I was, contributing to the existing social relations, where individuals labelled with intellectual disability are constructed as incompetent, unknowing and lacking sensitivity to the social nuances.*

This dynamic reveals the potential for systems, structures, and individuals, including myself as the researcher, to perpetuate the existing power relations and oppression of individuals labelled with intellectual disability. According to my procedural ethics approval, I was following stated procedures. It was clear, however, that this dynamic presented a tension for engaging ethics-in-practice. The other key issue raised by this ethical and moral dilemma was my role as the researcher, and my connection to the community. At times, I felt like an ally, and a traitor, to the community. When I engaged with parents I felt like I was betraying individuals labelled with intellectual disability. I was conforming to and perpetuating oppressive power structures. This feeling of betrayal was pervasive, and complex, and followed me throughout the research process, for example:

*I feel so awful. I have taken people's stories, I have had door-handle conversations with parents, and I have stood politely and nodded, acknowledged the difficulties they speak of.... And then I sit in supervision and discuss how these dynamics are oppressive, perhaps overprotective, and unfair to sons and daughters. As a sibling and family member, as a support-worker, I share some of these concerns. I know why parents feel the way they do, I know why they sometimes take over, make decisions, expect to be consulted. As a sibling, in many cases, I would expect this too. How can I sit here and judge these individuals. It is like I am taking this privileged information, and decontextualizing it so it seems bad. In many ways, I feel like a traitor. There is a distinct sense that I have to 'pick sides'. Who I am an ally to? Parents, or their adult sons and daughters? I fear I am committing a betrayal to all. Of all people, I should know why things are the way they are, yet I sit here and critically examine things, pull them apart, and presume a higher-order understanding of what is really going on. This is the intersection between honouring lived experiences, and judging them. Who can say what is right, and who really knows*

*what it is like to live with the label intellectual disability, or to feel responsible for someone who is so-labelled? Of all people, I feel I should not be judging, yet I am.*

This reflection raises some interesting questions: *who is the community? Whose interests are being served? Who benefits from the research?* There are various issues associated with being a researcher who is embedded within the community. Connection to the community can give the researcher credibility, and afford a level of unearned trust and respect (Berger, 2013). Being embedded can also blur the lines of participation, and pose challenges to how the information is processed. I reflect on this in my reflexive journal:

*This research process has been deeply personal for me, where findings directly relate to my experience of the world, and my own family context. Researchers embedded within the community must grapple with competing alliances, assumed truths and understandings of the way things are. For me, the ultimate act of betrayal is taking these experiences, and information (to which I have privileged access), decontextualising them from within the community, and placing them in the public domain. I feel intensely protective of the stories and findings generated from the research, because I am personally invested in them, and would hate for them to be misinterpreted. This fear is underpinned by a sense that these findings may not be beneficial to the community. They may not be constructive, they may serve to further promote blame, and the sense that individuals in the community are misinformed, or simply not doing things right.*

My sense is that notions of betrayal, being an ally, or a traitor, are connected to the inherently politicised nature of participatory and emancipatory research (Oliver, 1992; Sultana, 2007). Engaging in reflexivity is ultimately a political act (L. Finlay, 2002). Where there is a social justice imperative underpinning the research, findings are not merely findings, they have the potential to be transformative. Sultana (2007, p. 378) refers to being embedded as doing research at "home". She reflects on the complexities of being embedded, that one may be simultaneously, and variously, considered an insider or an outsider. Reflecting on the research process, I can identify with the notion of being an insider and an outsider. Perhaps the tension is in negotiating these perceived alliances on a personal level, while also pursuing a commitment to the emancipatory aims inherent to participatory action research

processes. I echo Sultana's (2007, p. 378) reflection that one must be "...*faithful to the relations in that space and time, and to the stories that were shared and the knowledge that is produced during the research*" The research findings must be represented in their entirety, but also contextualised so that the stories and dynamics do not lose meaning, or take on a meaning which is counterintuitive to progressive social change. The research process has been punctuated by a series of ethically important moments which, at every turn, must be addressed by principles of ethics-in-practice. The very nature of ethics-in-practice, perhaps, means that one cannot necessarily "get it right".

### **7.6 Intellectual surprise #3: Ideals versus reality**

Another key intellectual surprise to emerge from the research process is the tension inherent to negotiating the ideals of participatory, action, and inclusive research, with the reality of research practice. These ideals and the reality of research practice can create tensions in the research process. In the following, I will consider the participatory and action ideals which are inherent to participatory, action, and inclusive research paradigms. Using examples from this study, I will discuss and critically examine how these ideals play-out in practice and may impact on the research process.

#### **7.6.1 The participatory ideal.**

One of the ideals of inclusive, participatory, and emancipatory research is that it should comprise a participatory element. Participatory research paradigms (as are detailed in chapter four) emerged from a culmination of various socio-political factors, such as the pre-eminence of social role valorisation theory (Wolfensberger, 2000) and the social model of disability (Oliver, 1996b). Participatory research paradigms emphasise the value of lived experiences, and are an acknowledgement of the historical tradition of research as a means to legitimise continued oppression and marginalisation of individuals labelled with intellectual disability (Walmsley, 2001). While there are specific principles associated with each domain of participatory research (e.g., applied research, inclusive research, and participatory action research), they share common assumptions and principles. Within the participatory research paradigm, individuals who are the focus of the research should own the research problem, and should exert a level of control over the research process and outcomes,

and research should be conducted with a view to affecting commitment to social change (Walmsley & Johnson, 2003).

Key to participatory, emancipatory, and action research paradigms is a reconceptualisation of the traditional roles of researcher and the researched, and the renegotiation of power. At the outset of this project, I found myself in a position where I had the power to decide the terms on which individuals would engage with the project, as participants, informants, collaborators or co-researchers. I found myself deciding how I would bestow my inherent power as a researcher to others. One of the ways which I considered I could engage individuals in participatory and collaborative roles was to establish a reference group. I imagined the reference group would form a formal advisory committee, a group of individuals who I consult on the research process and dilemmas as they emerged. For a period of time I grappled with this idea, and eventually, did not take any action. While it is not common for researchers to outline those relationships and collaborations that do not eventuate (Bigby & Frawley, 2010; Sultana, 2007), I feel that the decision not to establish a reference group is worth reflection; it reveals a significant tension inherent to participatory action research processes.

On engaging principles of ethics-in-practice, Waterman (1998) suggests that sometimes the only moral way to act may be not to take any action at all. Action may be counterproductive to ethical practice and the aims of the enquiry. My sense is that a reference group may have perpetuated existing power structures, undermining the aims of this research project. I was mindful that a formalised reference group would have been tokenistic, as it would have served the purpose of legitimating my claim that individuals were engaged in particular collaborative roles, but may not have constituted genuine participation. My supervisory team advised that individuals may be engaged in more informal advisory roles. This strategy represented a move away from the practice of colonising individuals labelled with disability to suit the purposes of those holding a position of power (Opie, 1992). This decision represented an important ethical moment (Guilleman & Gillam, 2004) within the research process, this informal approach to engaging participatory practices also reflects a tension within the research process.

I was grappling with the paradox of empowerment, and tensions around what constituted genuine participation. The decision not to establish a formalised reference

group is an example of my power, and my exercise of that power, over the research process. At one point, I reflected on the tensions associated with recruiting individuals who are not in activated or formalised advocacy structures in my reflexive journal:

*In the inclusive research studies I have read about, often, participants and interviewees are recruited through self-advocacy/advocacy networks, or service-providers. Very rarely, it seems, are participants recruited on an individual basis, from a community sample. Perhaps then, participants in other studies were in positions of empowerment and were already activated. On reflection, the recruitment processes were not ideal, but they were a means to gain access to individuals who would not otherwise have an opportunity to share their stories. In the name of meeting the ideals of inclusive or participatory research, should we only aim to speak with those who are already activated?*

Critique of participatory research is commonplace, and it is common practice for researchers to engage in critical analysis on the extent to which a research project may be considered truly participatory. A review of the literature highlights the complex challenges and difficulties associated with meeting the ideals of participation in practice (e.g., Bigby & Frawley, 2010; Harrison et al., 2001; Povee et al., 2014).

Principles of participatory research paradigms largely emerged out of the British Disability movement. As such, participatory principles presuppose a range of conditions which may not be so prevalent within the Australian context. For example, much of the literature and practices of inclusive research is produced within the context of the British disability movement, which is host to a strong self-advocacy movement (Goodley, 1998). In Australia, the same strong traditions of self-advocacy are not so predominant (Bigby & Frawley, 2010), and so the conduct of research within this context can present a set of unique challenges. The self-advocacy movement is considered a mechanism by which individuals labelled with intellectual disability can gain access to citizen participation (Frawley & Bigby, 2011), and has been identified as a "...prerequisite for generating the types of experiences and skills that equip individual self-advocates to participate in any type of inclusive research" (Bigby et al., 2014, p. 10). In their critical reflection on the "Making life good in the community" study Bigby and Frawley (2010, p. 54) reflect

on the unique nature of Australian culture, and suggest a “...*need to explore the ways people with intellectual disability in Australia can be involved in research without the presence of many of the supportive contextual factors...*” inherent to the principles of undertaking inclusive research.

There is a tension inherent to attempting to conduct inclusive and participatory research within the Australian context, and perhaps other social, cultural, and political contexts. Despite an acknowledgement that the ideals of participation have been produced within the British context, these ideals are avidly pursued within the Australian context. In this regard, the ideals of participatory research seemed to be underpinned by an assumption that they are universal, and context-independent. Operating under this assumption, the researcher is positioned to either compromise the application of ethics-in-practice, or, they must concede that they have not met the ideal, and so have not truly undertaken inclusive or participatory research. For example, when I decided against establishing a formal reference group, on the basis that I did not feel it was ethically or morally appropriate, my concern was: *how will this research be judged as inclusive or participatory?* I can reflect that I felt pressure to provide formalised exemplars of participation and collaboration, so that the research might be considered as truly participatory or inclusive. On reflection, I can see that this formalised structure would likely not have been empowering, and rather, would have served my purposes as a researcher seeking to claim trustworthiness and rigor in the research processes. In my pursuit of a formal example of the participatory ideal, the outcome could have been antithetical to the core aims of participatory and inclusive research.

Perhaps this tensions serves to explain why there is a dearth of candid accounts of inclusive and participatory research processes, difficulties, and challenges (Bigby & Frawley, 2010; Sultana, 2007). It may be the case that researchers share my concerns and fear that the absence of formalised inclusion might undermine their claim to having conducted genuine forms of participatory, inclusive or emancipatory research. These participatory ideals and the issues they present for engaging in ethics-in-practice are concerning, particularly as the integrity of research participation for individuals labelled with intellectual disability historically and contemporarily is questionable. Frawley and Bigby (2011) reflect on this tension, and go so far as to suggest that citizen participation is often a means to merely legitimise,



rather than inform, policy. Similarly, participatory ideals in research may serve to legitimise research findings, rather than challenge the power structures and social issues under exploration.

It is perhaps worthwhile to consider more closely what is meant by genuine participation. Arnstein (1969) addresses the notion of genuine participation using the analogy of a *ladder of participation*. The author rejects what she terms a *misleading rhetoric* of absolute control arguing that no individual has ultimate control (Arnstein, 1969, p. 216). Rather, Arnstein suggests that there are various levels of citizen participation. At the bottom rungs of the ladder individuals are subject to manipulation and theory or non-participation. At the top rungs of the ladder, individuals are engaged in delegated power and citizen control, where the “have-not” citizens attain full managerial control. The value of Arnstein’s ladder of participation is her acknowledgement of the fluidity of participation, that it is progressive, and holds value in various forms. A key criticism of Arnstein’s ladder of participation, however, is that the hierarchical structure and emphasis on power undermines the complexity and chaos which is inherent to social change processes (Tritter & McCallum, 2006). A key assumption of Arnstein’s ladder is the assertion that there is a finite amount of power available to citizens (Rocha, 1997). There is a concern that framing participation in this way is threatening, and has the potential to recreate the “tyranny of the majority”.

These criticisms have led some to advocate for a more nuanced model of citizen participation (Tritter & McCallum, 2006). Reinders (2002) suggests that affording individuals organisational, institutional or formalised access to participation may not engender genuine citizen participation. He, as do Frawley and Bigby (2011), advocates that there are contextual preconditions which must work in tandem with institutional access, to promote genuine citizen participation. For example, in their exploration of the experiences of individuals labelled with intellectual disability on government disability advisory bodies in Australia, Frawley and Bigby found that attitudes and values toward board members labelled with intellectual disability were integral for promoting genuine participation. This tension seems to echo the tensions articulated by Oliver (1997), who suggests that emancipatory aims can only be achieved if social relations have already been transformed. He suggests that mere access to resources and formal opportunity is not sufficient.

While the approach and the design engaged for this research is more exploratory than that initially proposed, the paradox inherent to systems is still evident. Where, as researchers, we subscribe to language such as inclusivity, or participatory, or refer to research as disability research, we place the research process, and participants, in the realm of the remarkable and exceptional. This can lead to a dynamic where individuals labelled with intellectual disability are held to a higher standard of participation than other involved parties. In their reflections on the previously outlined "Living Safer Sexual Lives project" Harrison et al. (2001) address this tension. The authors reflect that "...*self-advocates* [labelled with intellectual disability] *did not chair the reference group although efforts were made to establish a rotating chair position. It should be said that people without an intellectual disability also resisted acting as chair*" (Harrison et al., 2001, p. 62). Here, the authors are acknowledging the potential for participation in participatory, inclusive, and action research, to be interpreted through a lens of intellectual disability, and to be attributed greater significance on the basis of associated assumptions.

Perhaps what is offered by the participatory ideal is the formalised opportunity to participate, the public statement of intent to engage individuals in genuine participation. This public statement is perhaps not sufficient, if the assumptions, values, and worldviews are not conducive to genuine participation. My sense is that there is great value in transparent, honest, and candid accounts of participation in research; perhaps these accounts more closely resemble genuine attempts to engage individuals in genuine participation.

### **7.6.2 The action ideal.**

Participatory, action, and inclusive research almost always includes an emancipatory element, and a drive for social change and justice. The rhetoric is often that one is "doing" emancipatory research. It might be argued that empowerment, citizenship and participation are an experience (Reinders, 2002), rather than something that one "does" in static terms. The nature of empowerment and emancipation suggests, however, that this kind of research only takes place as an organic outcome of organic process. In meeting the "action ideal", researchers are positioned to give evidence of formalised examples of action. This pressure is perhaps compounded by the pre-emptive requirements inherent to institutional ethics, where researchers are expected to outline the research project from start to finish,

pre-empting the action component of the process. The extent to which this project, or any participatory project (Oliver, 1997), can be said to have affected social change, however, is unclear. Those who took part in or who are the focus of the research are perhaps the only individuals who are well-positioned to make this judgement (Harrison et al., 2001).

#### ***7.6.2.1 Sexuality and intellectual disability as a problem to be solved.***

On reflection, I can see how my approach to this research project was influenced by an eagerness to meet the action ideal inherent to participatory, inclusive, and action research. In pursuing this ideal, I found myself in a position where I had arrived at the answer before I had explored the issues at hand. This struggle to negotiate ambiguity and uncertainty can hold significance for the way in which the phenomena under study is conceptualised and explored. The following is an extract from my reflexive journal, at a point where I reflect on my initial inspiration and plan for this project:

*My initial concept for a PhD project was to create a dating agency for individuals living with the label intellectual disability. I had been inspired with this idea having watched a TV documentary called "Truly, madly, deeply"<sup>16</sup> which followed the experiences of several individuals accessing the UK dating agency 'Stars in the Sky'. Watching this documentary was like a revelation; I had never considered that such a service existed for individuals labelled with intellectual disability. I was struck that individuals living with the label were just 'having a go', like everyone else. Some individuals experienced connection, others frustration and heartbreak, and to me, the dating agency was the vehicle through which these experiences could be had. I was invigorated with this idea, and approached my supervisors with a project which would involve the development, trial and evaluation of a dating agency for individuals labelled with intellectual disability. At this stage, I viewed this agency as a kind of solution to a problem. I saw it a necessary and radical move which would promote the sexual and human rights of individuals labelled with intellectual disability.*

*I was excited, and so when I met with one of my supervisors Professor Errol Cocks, I couldn't really understand why he didn't share my feelings. He asked me*

---

<sup>16</sup> Channel 4. (2005). Truly, madly, deeply: Channel 4.

*a question along the lines of: Why do you think this is a good idea? He could see what I could not; that I had prematurely assumed a course of action without exploring the experiences, needs and wants of the community. Up to that point, I had been socialised (formally and informally) as a researcher who had knowledge to share, someone with good ideas and with an inherent power and authority to enact my ideas. It took me a little while, and I recall being resistant to a change in focus, but I began to understand why my proposed research project was unwise. Reflecting now on my reactions, rationale and logic, I can identify several issues and various dynamics emerging from the notion of a dating agency...*

My reflection on my initial approach outlines the struggle to which Northway (1998) alludes, the struggle to embrace ambiguity, to relinquish control, and to engage in a truly exploratory project. My initial approach to this project highlights my reluctance to relinquish the control that comes with conceptualising, defining, and solving a problem. This reluctance might be re-framed as, in fact, reflective of a reluctance to engage in the re-distribution of power which precedes genuine participation and change (Arnstein, 1969). Being embedded within the dominant logical-positivist, Western bio-medical culture (Breen & Darlaston-Jones, 2010) facilitated my construction of sexuality and intellectual disability as a “problem to be solved”. The construction of sexuality and intellectual disability as a problem to be solved pathologises sexuality and disability, and locates the focus of intervention at the individual level. Locating processes for social change at the organisational and individual level, and de-emphasising the collective and cultural levels, potentially undermines opportunities for genuine action. For example, Cocks and Cockram (1995, p. 27) reflect that the organisational level may not represent an effective site for social change, on the basis that “...*formal human services, in many instances, constitute one of the important social mechanisms through which social devaluation is mediated.*” Endeavours to engage in inclusive and participatory methods perhaps become a way to legitimise the research outcomes, limiting opportunities for meaningful participation and social change (Frawley & Bigby, 2011).

Historically and contemporarily, intellectual disability has been conceptualised more-so in terms of an individual or medical model, than in terms of a critical perspective (Goodley, 2013). Social problems are often conceptualised at the

individual level, and solutions enacted at the individual level via social and systemic means (Oliver, 1992). An historical perspective on the disability rights movement suggests that oppression of so-labelled individuals is often perpetuated via services and structures which were framed as promoting rights and justice for individuals labelled with intellectual disability. The structures and systems which are designed to provide care and support are often paradoxical in nature. As Taylor (2000) suggests in his exploration of family networks and social identity, the more an individual becomes enmeshed in systems which aim to promote development and deal with the "problem" of intellectual disability, the more the individual becomes a target for negative stigma, and negative evaluation.

My sense is that my initial research proposal, to establish a dating agency for individuals labelled with intellectual disability, could have constituted an example of this paradox. The assumptions inherent to the dating agency structure I had in mind (e.g., that individuals labelled with intellectual disability should only date other so-labelled individuals) would have perpetuated myths surrounding intellectual disability and, ultimately, would have been contrary to the aims and purpose of the enquiry. Without critical reflection, and the benefit of supervision, I would not have been cognisant of this ethical dilemma.

#### **7.6.2.2 *What constitutes action?***

There is a suggestion that the interviewing process itself can be transformative. Finlay (2002) suggests that the interview process is not passive, that interviews do not just capture meaning, they can alter it. The strength of conversational interviewing is that it allows space for interviewees to tell their story and for novel themes and ideas to emerge (Burgess-Limerick & Burgess-Limerick, 1998). Interviews are an inherently reflexive process, and so can become a transformative experience for both interviewee and interviewer. The process of engaging in repeated conversational interviews provides opportunity for more than consultation. This approach allows shared meaning-making, where assumptions and understandings can be challenged and refined, so as to form a kind of informal and organic member-checking procedure. At one point, I reflect on my experience of interviewing:

*Initially, I found that the unstructured nature of conversational interviewing challenging. I was uncomfortable with not knowing what I was going to ask, or what we were going to cover. As I have engaged in more and more interviews, I see the value of this format. Presenting to an interview without any pre-defined questions forces me into the role of the naïve enquirer, I have to listen, and try to understand the experiences of the individuals who are sharing their stories. While I can't ever really know if it is the case, I feel like the interview experience is enjoyable for the individuals who are sharing their stories. I feel like it is rare for anyone to take time to deliberately reflect on our experiences, hopes and aspirations. It seems a very reflexive process, and sometimes I think that individuals I speak with look forward to our time together. I have had interviews in parks, sitting on a rug, under a tree. Individuals have taken me around their homes, showing me items of value and sentiment. I have sat and had coffee, and scones, at kitchen benches and in cafes. I can say with certainty that this process has been transformative for me, perhaps it may also have been for participants...*

Since concluding the interviewing process, I have had incidental contact parents at forums and workshops on disability and sexuality. It may be the case being involved with this project has, for some, opened up or contributed to a dialogue surrounding issues of sexuality and disability. Since beginning the project, I have had conversations with parents, support-workers and others, enquiring on progress and about the sexuality and disability as topic generally. The very existence of the project has opened up new avenues and opportunities for dialogue perhaps bringing the topic of disability and sexuality to the table for some individuals in the community.

I also note, however, that the challenges associated with gaining access to individuals to participate in the research, pose difficulties for disseminating research findings, and promoting the action ideal. For example, as outlined in chapter four, I have had the opportunity to present on the research process and findings in public and academic forums on disability and sexuality. Attendees at these forums include individuals labelled with disability, parents, family members, teachers, disability service-provider representatives, health professionals, and professionals working in the sex industry, members of ministerial committees, academic researchers, and students. Individuals labelled with intellectual disability are less-often in attendance at these forums.

At a recent event, I spoke with a group of mothers who indicated that they were “*unsure whether the forum would be appropriate*” for their adult sons and daughters, and so had attended without them. The mothers said that they wish they had brought their adult sons and daughters along, and hoped to do so in future. It could be argued that these forums and events are often targeted to parents and service-providers, rather than being for individuals labelled with intellectual disability. At these kinds of events it appears that parents, service-providers, and others are positioned as gatekeepers, the conduit for providing information on sexuality to their adult sons and daughters and clients. This dynamic presents a challenge to the action ideal. It seems that the very phenomenon under study (the social construction of sexuality of individuals labelled with intellectual disability) is the very barrier which undermines participatory action research as a mechanism for social change.

Toward the end of the research process, I reflected on the action component of the research project, contrasting the outcome and reality with my initial aspirations:

*In the planning of the project, and throughout, I always felt as though the ‘action component’ would reveal itself. In reality, this has not happened. At the end of the project, there is no clear pathway forward for ‘action’. I think this difficulty has emerged from the nature of the findings from the research. It is clear from speaking with individuals labelled with disability, that they should not be the target of change. Rather, those who surround the individual, and broader social-cultural structures, need to change. How does one design an action strategy to target global culture? Grappling with these uncertainties, at times I have felt hopeless, and overwhelmed. This truly is a complex problem, one which resembles other amorphous cultural problems (such as racism, sexism, prejudice against gender diversity, and so on). My sense is that it would naïve to think such macro-level social change can be deliberately achieved. What can be done as a tangible, and valuable, outcome of this project? Maybe, the outcome of the project is another step toward a slow progression of social change, a process which will only reveal itself in retrospect.*

My reflection illustrates the tensions which seem to pervade the pursuit of participation, empowerment, and inclusion in research. These tensions reflect a negotiation of formality and informality, procedure and practice, and institution and

culture. These tensions are evident at multiple levels, and research provides a rich microcosm to critically reflect on these tensions.

### **7.7 A key intellectual surprise: Getting it 'right'**

The final key intellectual surprise I will consider is the notion of "getting it right". The value of engaging in reflexive processes within disability research practices cannot be understated. A retrospective analysis of disability research traditions reveals a long history of othering, perpetuating existing power structures, and failing to conduct research which benefits individuals who are labelled with disability (Cocks & Cockram, 1995; Oliver, 1992, 1997). Reflexivity is a tool to "...*decolonise the discourse of the other...*" and engage in mindful, iterative, and transformative research practices (Berger, 2013, p. 3). Engaging ethics-in-practice, and reflexivity, offers a framework to subvert traditional research paradigms and processes, and to re-negotiate the social and material relations of research production (Oliver, 1997; Zarb, 1992). Research may be considered a microcosm which is reflective of the broader social discourses, social cultural values, and social practices surrounding disability within the wider community. The interactions between researcher-researched, conceptualisation of the research question and various other aspects of research are a reflection of the wider dominant social and cultural context (Oliver, 1992). Even in instances where researchers aim to explore and challenge stigma embedded within social-cultural contexts, a lack of reflexive practice can lead to the production of knowledge which perpetuates the oppression associated with the labelling process. A retrospective analysis of disability research traditions reflects this dynamic, where rather than promote social change, research has historically perpetuated the alienation, individualisation, and isolation of individuals labelled with disability (Oliver, 1992).

As researchers within a dominant logical-positivist Western bio-medical context, we are socialised into a set of power relations, where researchers are traditionally positioned as experts, and so reside in positions of power and control (Cocks & Cockram, 1995). As Northway (2000) suggests, researchers are socialised into a particular research culture. Within this culture, perhaps, there is a phenomena of being socialised into a kind of methodological individualism (Lukes, 1972) encouraged to identify problems, and to fix these problems, typically, via some kind of intervention. Inherent to this paradigm, is the idea of doing things the right way



(Dokecki, 1996), of pursuing objectivity and embracing formal procedures and process (Northway, 1998). These principles are reinforced at multiple levels, in terms of an emphasis on the value of particular research methods in tertiary settings, and in terms of procedural institutional ethics which must be engaged in order to conduct research (Sultana, 2007). Northway (1998) reflects on the tensions associated with conducting participatory research in settings which promote the value of institutional ethics procedures. The author suggests that within this traditional research culture, researchers can struggle to negotiate the ambiguity and uncertainty which accompanies renegotiating traditional power relations within research.

Researchers such as Zarb (1992) and Oliver (1997) challenged whether research can ever truly meet emancipatory aims on the basis that the researcher inhabits the ultimate position of power. Oliver (1997) argues that empowerment cannot be achieved when those with power decide to bestow power onto others. This is not an empowering process as the choice to distribute or relinquish power maintains the pre-existing power structure. Zarb (1992) argued that the relations of disability research production could only be changed if the material and social relations of research production were transformed. Oliver (1997) extends beyond this, to suggest that research can only be considered emancipatory where the social relations of research production have already been transformed. This tension is echoed by Reinders (2002), who suggests that basic values of rights-based rhetoric, and institutional inclusion, is not sufficient for securing the "good life" for individuals labelled with intellectual disability. Much like Oliver, Reinders advocates for an emphasis on transforming politics of culture, the moral and social milieu surrounding the social construction of intellectual disability. Reinders (2002, p. 4) suggests that, programmes to "*...secure their rights effectively must be appropriately funded, but the newly created space for action must be inhabited in particular ways in order to make the changes a lasting success*".

Embedded within the dominant logical-positivist, Western, and individualistic culture (Breen & Darlaston-Jones, 2010), the value of psychological research is often judged against adherence to principles of institutional ethics, research paradigms, and processes. Within the dominant cultural context, less emphasis is placed on the value of practice, process, and iterative-generative reflexive practice (Bishop et al., 2002). Likewise, problems, solutions, interventions, and strategies are often commonly

framed at the individual and organisational, rather than at collective, cultural or macro levels. Hence, this cultural context presents a challenge to conducting research with emancipatory or social justice aims. This cultural context does not promote the value of reflexivity, ethics-in-practice or genuine participation within research enquiry.

While research endeavours may reflect the intention to engage in emancipatory and empowering processes, research is inevitably embedded in oppressive power structures (Oliver, 1997). Oliver suggests that researchers are inevitably on the side of the oppressors. My sense is that these boundaries are not so simply drawn, that the issue is more complex than is reflected in a dichotomy of the oppressed and the oppressors. Often, research is framed in terms of what researchers "ought to do" (e.g., the ideal), yet, the reality often falls short of these ideals. Where participation or ideals are not met, researchers are positioned to ask the question: *what didn't I do right?* At the conclusion of the research project, I ponder at *what I didn't do right*. While I can see many opportunities to have made different decisions, to have responded differently to ethically important moments, I cannot clearly see where I went "wrong" or determine with any certainty what I would have done differently. It would be naïve to judge the success of a research project on the extent to which social change has been affected; real-world social change processes are often not directed by intentional or deliberate effort, nor are they necessarily revealed in immediate or overt ways. Perhaps, there simply is no right or wrong; rather, research processes are merely faithful to the temporal, historical, social, cultural, political contexts in which they take place.

## 7.8 Conclusion

This chapter attends to one of the objectives of this research project, to develop an understanding of inclusive processes in research with individuals labelled with intellectual disability, their family members, support-workers, and others. Michelle Fine's (1992) notion of intellectual surprises provides a conceptual framework to make sense of the key tensions emerging from the research process. Issues arising from the research process were often paradoxical, and seemed to mirror those tensions and complexities which impact upon the relationship experiences of individuals labelled with intellectual disability. Using my personal reflections, experiences, and theory, these paradoxes and complexities have been explored and

critically discussed. It would seem that a key tension underpinning applied and inclusive research paradigms is the negotiation of procedural ethics and virtue ethics, the negotiation of ideals and reality. The tension here seems to be underpinned at a deeper level by a need to get things right, which, paradoxically, undermines the contextualist, social constructionist, and pragmatist episteme which underpins this form of research. This chapter is followed by chapter eight, the discussion chapter, in which findings from the research will be integrated with feedback from the community, my reflections on the research process and theory and research literature, to provide key findings, outcomes, and opportunities for alternative discourses.

## **Chapter eight: Discussion**

### **8.1 Introduction**

Within this chapter, the findings generated from the research project are discussed and explored in light of literature and theory. The aim of this research project was to explore what it is like to pursue close relationships, in the context of living with the label intellectual disability. The specific objectives were to:

- Explore close relationships as they are experienced by adults labelled with intellectual disability; and;
- Explore inclusive processes in research with individuals labelled with intellectual disability, their relationship partners, friends, family members, support-workers, and others

This discussion chapter reflects an attempt to consider critically the key messages emerging from the research findings. I will draw upon research findings generated from a causal layered analysis of interviews with participants, feedback attained from the community on the findings, and upon my reflections in engaging inclusive research processes; integrating these understandings with research literature and theory. At the conclusion of this chapter, the parameters within which the research findings can be meaningfully interpreted are considered, and implications and directions for future research endeavours posed.

### **8.2 Reconstructing the issues**

Performing a reconstruction of the issues is the final phases in conducting a causal layered analysis (Inayatullah, 2004). While the earlier analytical phases of the analysis reflect a deconstruction of the issues, this last phase allows for an appreciation of phenomena in terms of cultural and historical contexts, giving rise to new understandings, and presenting opportunities for posing of alternative futures. In reconstructing the issue, the key messages and understandings emerging from the analysis are conveyed (Bishop & Dzidic, 2014). The key messages emerging from this research relate to findings generated from a causal layered analysis of interviews with participants (outlined in chapter five), feedback from the community (outlined in chapter six) and also to my reflections on engaging inclusive research processes (outlined in chapter seven).

### 8.2.1 Reflecting on the research findings.

Several key messages and understandings have emerged from this research. At the Myth Metaphor layer of analysis the conceptualisation of intellectual disability as a social construct emerged as in contest with intellectual disability as an undeniable truth, or feature, of the individual. A range of qualities emerged as central to this concept of disability, including the notion that one is incompetent, vulnerable, and in need of protection. These qualities are symbolised by the metaphor of the ingenuine adult, where the individual labelled with intellectual disability is ascribed the role of child, with no genuine prospects of transforming this role. Symbolised as the ingenuine adult, the individual with intellectual disability is constructed as persistently “so close yet, so far” from leading a normal life. At the Myth Metaphor layer of understanding, it became apparent that individuals labelled with intellectual disability represent an approximation of an adult person, rather than an actual adult person. The symbolic ingenuine adult is particularly problematic in the context of relationships and sexuality, as the child identity sits in contest with exploring, developing, and experiencing sexuality. At this layer of understanding, a key meta-process emerged, termed ‘The Intellectual Disability Paradox’. The ‘The Intellectual Disability Paradox’ reflected socio-cultural pressure to manoeuvre the individual labelled with intellectual disability evermore close to representing an actual human person, to leading a normal life. This imperative is paradoxical and problematic, as in so doing, the so-labelled individual is established as inherently different.

‘The Intellectual Disability Myth’, the symbolic ingenuine adult, and ‘The Intellectual Disability Paradox’ seemed to serve as a foundation for a range of assumptions about what life should be like for individuals who are labelled with intellectual disability. The filtering-down of myths and metaphors into the Worldview Discourse layer of understanding is apparent. For example, the identified discourse surrounding disability was marked by notions of difference, and of othering, of individuals labelled with intellectual disability as being less than perfect, and individuals living without this label represented as perfect. The qualities assumed of an individual labelled with intellectual disability (e.g., vulnerability, incompetency), and the symbolism of the ingenuine adult, were evident in the power relationships, and role expectations ascribed to so-labelled individuals and those who surround them (e.g., family members, parents and siblings). For example, individuals

labelled with intellectual disability seemed to have their power, control, and choice over a range of day-to-day and more executive areas of their lives compromised as a function of the label. Power and responsibility seemed to be located with parental figures, who seem to be charged with the interminable task of protecting one's son or daughter from, and simultaneously promoting access to, a normal life. Here, the social processes were observed as disempowering for all involved as all individuals are pressured to surrender to collective myths, metaphors and assumptions surrounding intellectual disability. At this layer of understanding, the influence of assumptions of incompetency, vulnerability and child-like qualities seemed to play a role in the expectations that an individual labelled with intellectual disability could feasibly have of life. Individuals labelled with intellectual disability are subjected to high standards for proving normality and competency, and one's access to the human experience may be contingent upon meeting this high standard. Discourses and worldviews were concerned with difference, notions of normal, and protection. Paradoxically, efforts to protect, and normalise, perhaps perpetuate a lack of opportunity to experience the depth and breadth of human experience, to explore one's sexuality, and to have relationships.

The dynamics and social processes identified at the Social Causal layer of understanding are the tangible manifestation of myths, assumptions, and rhetoric identified at the Myth Metaphor and Worldview Discourse layers of understanding. Assumptions of incompetency, vulnerability, and rhetoric of protection provide a foundation for social systems which are congregative, and subject individuals labelled with intellectual disability to high layers of surveillance. At the Social Causal layer, the problem of vulnerability is attended to via the presence of a formal or informal carer. It seemed that this carer role could be assumed ahead of relational or familial roles. The ever-present carer is consistent with discourses and power-relations identified at the Worldview Discourse layer of understanding. Organising individuals labelled with intellectual disability into groups is presented as a solution to the problem of intellectual disability, where the problem is constructed within dominant Western culture as within the individual. These social systems emerge as problematic and paradoxical. Rather than promoting access, equality, and normality, these models of care appear to promote difference. For example, the segregation of individuals labelled with intellectual disability into Ed-support settings appears to

serve as a systemic legitimization of the myths which establish individuals labelled with intellectual disability as inherently different. The school system emerged as a platform for stigma and discrimination toward individuals labelled with intellectual disability, and also seemed to reinforce an internal view that one is different.

A key feature of the findings at the Litany layer of understanding is the presence of two, seemingly competing, voices. One voice reflects a discourse surrounding relationships, the notion that all humans share a desire to be intimate, to feel connected and important to others. In competition with this voice is another that forms an explicit commentary on how living with the label intellectual disability influences opportunities to enact this desire. Community members explained how the label intellectual disability influences their rights and opportunities to engage in close relationships and explore sexuality. At the Litany layer, a strong tension emerged between access to sexuality and relationships as a human right, and access to sexuality and relationships as contingent upon intellectual disability.

### **8.2.2 Identifying key dynamics, discourses, and processes.**

Reflecting on the dynamics, discourses, and processes highlighted at each, and between, the layers of understanding, it is possible to speculate that there are several key issues at play which construct relationships, sexuality, and intellectual disability as a wicked problem (Bishop & Dzidic, 2014). It is apparent that the myths and metaphors which underpin intellectual disability establish an identity which is pervasive, permanent and offers little opportunity for mobility. Intellectual disability may be considered an infallible social construct to the extent that the element which is supposed to undermine scientific basis stigma and discrimination (e.g., ability to demonstrate competence and intelligence) is the very element which qualifies an individual as having an intellectual disability. Intellectual disability seems to be accepted as forming the fabric of an individual's character, and so undermines one's personhood, and opportunities to forge an ordinary life.

Once cast as an individual with intellectual disability, the individual is ascribed the role of the eternal child, and expected to be vulnerable, incompetent, and deferent. Complementary to this role, those surrounding the so-labelled individual are placed in difficult positions. Parents are expected to become accountable for their adult son or daughter, to create opportunities, and to protect from harm. In this way, I

speculate that individuals labelled with intellectual disability, and those who surround them, are equally disempowered by deep-level collective understandings of intellectual disability.

Systems which operate on a congregative care model appeal to the assumption that intellectual disability is a master status, and present as a natural solution to the problem of intellectual disability. Individuals who share this identity can be kept together for safety and protection. These settings are problematic and paradoxical for engaging choice, control, spontaneity, and exploring relationships and sexuality. These settings, dynamics, and discourses set up a context in which individuals labelled with intellectual disability are restricted from exploring sexuality, and engaging in relationships. In some ways, these settings are self-fulfilling; they necessitate, and are necessitated by, the definition of intellectual disability as a social category.

The sheer complexity and endemic nature of these settings and contexts gives rise to a sense of hopelessness, a sense that what should be possible, is simply not because individuals have an intellectual disability. Deconstructing, and then reconstructing, the issues, however, allows for new understandings, which are not bound by hegemonic interpretations, to emerge. Performing this last phase of the causal layered analysis supports the assertion that it is the label, rather than the individual, which establishes these conditions. This is a cultural problem, not a problem of the individual.

These key dynamics, discourses, and processes have been synthesised into a series of key messages emerging from this research, including; the problematic nature of lived realities versus myths, the enduring nature of logical positivism, contesting the myth of disability, the paradoxical nature of the construct of intellectual disability, negotiating complex socio-cultural settings, disability as culture, and the current state of affairs regarding opportunities to explore sexuality, and engage in close relationships. Each of the aforementioned key dynamics, discourses, and processes emerging from this research will be discussed below, with reference to relevant literature and theory.



### 8.3 Lived realities versus myths

One of the key tensions to emerge from the findings of this research is in relation to the ways myths associated with the label intellectual disability are constructed within dominant Western culture. Myths may be likened to cultural scripts or civilisational codes (Inayatullah, 2004) which serve a purpose of maintaining the status quo, and reinforcing the cultural hegemony. Scripts, codes, and myths reflect collective understandings and experiences of the world. Key scripts that have emerged from this research relate to normalising ideologies, the notion that one should aspire to lead a normal life, that individuals labelled with intellectual disability should or cannot explore their sexuality or engage in close relationships, that parents of so-labelled individuals must assume responsibility for their adult son's and daughter's lives, that intellectual disability reflects an inherent quality of the individual, and that individuals labelled with intellectual disability approximate adult children or ingenuine adults. The scripts are symbolic and metaphorical to the extent that they represent assumption; however, they are also tangible to the extent that they reflect a lived reality for individuals labelled with intellectual disability. These scripts appear to govern rhetoric surrounding intellectual disability and the ways that interventions are established and strategies engaged to address the problem of intellectual disability at social and systemic levels.

The scripts and myths might be understood, acknowledged, identified, disrupted, and challenged at various levels, and in various settings. Regardless of how these scripts are dealt with, however, they still exist to form a part of the milieu of the socio-cultural context. The way that these myths are dealt with seems rather problematic. For example, I refer to the myth of the ingenuine adult, identified at the Myth Metaphor layer of the causal layered analysis. The myth of the ingenuine adult refers to the symbolic representation of individuals labelled with intellectual disability as existing in suspended development, child-like and without hope of attaining those markers which indicate maturation and adulthood. While the myth is symbolic, it is also manifest in overt ways at various layers. For example, some participants and community members who took part in this research appeared to internalise the myth of the ingenuine adult, referring to themselves as "*teenage adults*". It seems that while a rhetoric of being an adult, and having rights, pervades the lives of individuals labelled with intellectual disability, for individuals

participating in this study this rhetoric was at times undermined by the myth of the ingenuine adult, to the extent that, in reality, they were positioned to assume roles of deference and passivity in their own lives. This dynamic was evident in the theme 'I don't really know, you'll have to ask mum about that' identified at the Worldview Discourse layer of analysis. The findings from this study are reflected in those of other studies, where adult participants labelled with intellectual disability identified as teenagers, and where parents are constructed as responsible and accountable for their adult sons and daughters (Bane et al., 2012; Bernert, 2011; Fitzgerald & Withers, 2013; Hollomotz & The Speakup Committee, 2008; Rogers, 2010; Tepper, 2000). The myth of the ingenuine adult seems to prevail even when supposed markers of adulthood (e.g., holding a job, having an intimate partner or living out of the family home) are met. The myth of the ingenuine adult is not fantasy, for the individual labelled with intellectual disability, this myth becomes lived reality. As was the case for individuals participating in this research, the myth of the ingenuine adult reflected reality, a lived experience of being treated similarly to a child or teenager. Referring to myths is somewhat problematic as this implies fantasy, and undermines the significance of this lived experience for participants in this research, and individuals labelled with intellectual disability within the wider community.

We might speculate that, within dominant Western culture, considering myth as fantasy and as holding no truth value beyond an outdated cultural relic is perhaps comforting. In this sense, myths are transported from the realm of collective understanding, to the realm of the individual. For example, at surface layers (e.g., Litany and Social Causal layers) the value or relevance of the ingenuine adult myth might be rejected, however, this myth prevails at the deeper Worldview Discourse and Myth Metaphor layers of understanding. This dissonance may reflect a lag in the structures enacted to deal with the problem of intellectual disability, and the ways that intellectual disability is constructed and conceptualised. For example, it is possible to speculate that social practices which appeal to the myth of the ingenuine adult (e.g., participants in this research refer to an unmet desire to spend private time their partner without the surveillance of a carer or parent) are not challenged and attended to. Shuttleworth (2007) suggests that there is a discrepancy between explicit values surrounding sexuality and disability, which embrace a human rights and social justice perspective, and the enactment of social policy and pragmatic promotion of

sexuality for individuals labelled with disability. Perhaps this dissonance between values and systems reflects a reluctance to accept that there exists a dominant cultural context where, at a deep level, there is a collective subscription to the myth of the ingenuine adult. Where these mythologies are manifest, enacted or visible at the surface level, these assumptions are located with particular individuals.

This dynamic seems to have emerged in my reflections on my own behaviour and actions in engaging inclusive research processes, outlined in chapter seven. For example, in reflecting on my interactions with participants, I identify several occasions where I tend to protect, patronise or presume incompetency in terms of the interview setting, and in terms of the dynamics of participation (e.g., approaching parents prior to participants labelled with intellectual disability). One of the things that I struggle with in these reflections is blaming myself as an individual for being short-sighted, naïve or particularly prejudiced. I experience a pressure to attribute this prejudice as an inherent part of my character. In doing so, I fail to recognise that I am embedded within a cultural context which promotes these behaviours, myths, and scripts. I am a person, embedded within a cultural context which promotes these assumptions and ideologies and permits these actions. To emphasise the collective nature of myths is not to relinquish personal responsibility for enacting these myths, rather, placing myths in a collective realm allows space to progress beyond rhetoric which blames, finds fault, or determines what is right or wrong. Rather than engage these binaries of understanding, a more sophisticated way to deal with myths seems to be an acknowledgement that myths are accessed by all as a means to make sense of the world. It is perhaps the responsibility of the individual person to identify where these myths operate, and to examine these settings critically, in order to attempt to disrupt or challenge them. Of course, I do not believe that individuals labelled with intellectual disability are child-like, but, I exist within a context where I am encouraged to engage so-labelled individuals as though they are children.

Acknowledging some ownership and culpability for deeply rooted myths and ideologies promotes a culture of reflexivity, and critical examination of how we, as researchers, are engaging with communities. Where, as researchers, we all admit some level of prejudice, we are all pressured to engage more thoughtfully, reflexively, in these settings. This collectivist worldview seems to sit in contrast to the prevailing individualistic worldview which is deeply-rooted within dominant

Western culture and the discipline of psychology (van Uchelen, 2000). van Uchelen (2000, p. 67) emphasises that an individualistic approach to the exploration of complex relational and cultural issues can result in “...*incomplete, inaccurate, and insensitive representations of the phenomena of interest*”. The predominance of individualism within dominant Western culture determines that it is difficult to challenge, and to adopt more collectivist means of interpretation. Sarason (1981) suggested that the endurance of individualistic and asocial thinking within psychology can be attributed to the order, structure, and legitimacy this worldview affords what has historically, and perhaps contemporarily, been considered a form of philosophy. It is possible to draw links between the predominance of individualism, and the tensions surrounding myth as fantasy or lived reality. Where individualistic interpretation is relied upon, the significance of myths for the lived experiences of individuals labelled with intellectual disability and those who surround them is undermined. For example, rather than understanding heightened vulnerability to sexual exploitation amongst individuals labelled with intellectual disability as a symptom of long-standing lack of access to sexual education, an individualistic interpretation determines that individuals labelled with intellectual disability are simply inherently vulnerable to such exploration. It is suggested that individualistic interpretations must be challenged in order to progress to a more nuanced understanding of close relationships, sexuality, and intellectual disability.

#### **8.4 The enduring nature of logical-positivism: Following the party-line**

Reflecting on the research findings, research processes, and the body of research literature, the endurance of logical-positivism as a framework for understanding the nature of intellectual disability becomes clear. In this sense, it would seem that a collective devotion, not to a particular model of disability, rather, to an episteme (e.g., logical-positivism) sets a frame of reference for understanding the experiences of individuals labelled with intellectual disability. At the conclusion of chapter two I consider how the concepts of governmentality (Foucault, 1991), normalising ideologies (Ashby, 2010) and power give language and means to understand meta-processes in the construction of intellectual disability. It would seem that the findings generated from this research highlight the governing power of science and the logical-positivist episteme within dominant Western culture.

It seems that the hegemonic understandings of intellectual disability constructed by Western bio-medicine are manifest in the lived experiences of individuals labelled with intellectual disability. Some suggest that science is the means by which power is regulated and located within dominant Western culture (Jenkins, 1998; Kauffman, 1999). Findings emerging from this study give credence to this view, as, even when we, as researchers, claim to subscribe to social constructionist episteme, we do so under the principles of logical-positivism. For example, reflecting on my engagement in inclusive research processes, it became clear to me that I was subscribing to deeply-rooted assumptions of intellectual disability, my role as a researcher, and the nature of research more broadly. My initial approach to the research (e.g., wanting to establish a dating agency), although cloaked in a social constructionist episteme (e.g., where I understood intellectual disability as a socially constructed identity), reflected a logical-positivist stance. We may claim to be disrupting and challenging cultural hegemony via participatory action research endeavours, however, to use Kauffman's (1999, p. 268) analogy, perhaps we, as researchers, are doing no more than following "*...another party line...*" Fine (1992) notes that disrupting and challenging the status quo via critical examination of dominant power structures allows for insight, and intellectual surprises. The intellectual surprise which emerges here is that, despite an active resistance and awareness, we are collectively governed by a need for certainty and truth. This manifestation of a need for certainty and truth is reflected in the experiences of participants in this study who exist in congregative settings, and, based on the Australian Education system, may have their identities reduced to the label Ed-support within and beyond the duration of their schooling experience. It may be speculated that this need for certainty and truth is the mechanism that relegates individuals labelled with intellectual disability to lead a life contingent upon intellectual disability.

### **8.5 Contesting the myth of intellectual disability**

Intellectual disability may be considered mythological, on the basis that it only derives meaning in the context of normal. Disability is the antonym to normal, perhaps the antonym to humanity, as Goodley (2013, p. 640) suggests "*...when disabled people ask, who am I, they risk being hit with the mirror of the abled self.*" It might be suggested that disability exists in the negative space surrounding the ideals of normality. Normality gains shape and meaning in context of disability, and

vice versa. For example, participants in this research suggested that individuals from the Mainstream might be considered perfect and normal, while individuals labelled with intellectual disability, or those who are Ed-support, "...*need to get a little bit more push*"... The theme 'The Disability Discourse', identified at the Worldview Discourse layer, highlighted that individuals labelled with intellectual disability are constructed as diametrically opposed to those individuals who do not live with this label. We can acknowledge that the ideal of normality is a social construct which shifts depending on social, cultural, and historical context, and it seems paradoxical that disability is constructed as fixed and objective quality.

There is an apparent dissonance in the way that disability is understood at multiple levels. The fallacy is that we, as researchers, academics or community members, claim, at any point, to understand what it is. It would seem, however, that the form, qualities, and nature of disability are subject to interpretation within dominant Western culture. The fluid quality of the social construction of intellectual disability is reflected in the succession of various models and paradigms of disability, each of which aim to carve out an alternative way of understanding this construct. In chapter two of this thesis, I outline and critically consider the various models of intellectual disability, progressing from the individual model of disability (Oliver, 1996b), to consider the social model of disability (Oliver, 2013), and then on to an embodied ontology of disability (Shakespeare & Watson, 2001), and critical disability studies (Goodley, 2013). These models are often represented as a linear progression toward ever more sophisticated ways of understanding disability. Cocks and Allen (1996) pose a challenge to these assumptions, and suggest that the attainment of a perfect truth or understanding is unattainable. Rather, what is perceived to be accurate, meaningful, and appropriate is constructed by context. There seems to be a paradox inherent to the assumption that these models and paradigms might form a mechanism to move toward a better understanding of disability, and away from a conceptualisation which is oppressive and othering. For example, within disability studies it is claimed that more recent models of disability, underpinned by social constructionism and pragmatism, represent a shift away from the individual model of disability and from a logical-positivist understanding of disability as an inherent quality of the individual. Rather than achieve this aim, the models provide new means for the labelling and identification of disability,

seemingly in more socially appropriate terms. Perhaps, this dynamic is exemplified by the appropriation of the terms Ed-support and Mainstream as a contemporary means to identify individuals who are labelled with intellectual disability. While these terms are born out of a system which seeks to be respectful of othering processes, and promote educative support for all, these terms seem to perpetuate the experience, as was the case for some participants in this research, of being othered. Similarly, in defining the nature and terms of disability, models, and paradigms perhaps serve to perpetuate difference and exceptionality.

Perhaps it is important to examine more closely the need to subscribe to a model or paradigm at all. These models are based on an assumption that disability is a construct, to be named, defined, and understood. For example, it might be argued that labels (e.g., for disabilities) are useful as they grant access to resources and support, thus fostering opportunities for individuals to engage in ideal ways (e.g., normality). It might also be argued, however, that these labels serve to construct difference, and can be othering (e.g., where individuals are identified or objectified in terms of that label). To draw a parallel to models and paradigms of disability, I suggest that rather than normalise the experience of disability, these models serve to highlight disability as difference, a social category to be thought of in particular and right ways. To appeal to a fluid definition of disability poses a challenge to dominant Western culture, as it deviates from certainty (as previously discussed in regard to 'Lived realities versus myths'). The way the construct of intellectual disability is dealt with, even in social constructionist and pragmatist settings, seems rather positivist. That is, to deny the relevance of one model in favour of another is to appeal to a logical-positivist episteme, even if the model which is subscribed to is social constructionist in nature. At a broader level, it is possible to speculate that dominant Western culture does not support pluralism or support the level of tolerance and ambiguity central to accepting that various models of disability hold value, at various levels of understanding.

The enduring predominance of logical positivism over collective ways of thinking and establishing truth-value is evident in the discourse surrounding the value of the social model. As is outlined in chapter two, the social model of disability was challenged on the basis that this model could not account for the lived experience of impairment (Oliver, 1996a), and on the basis that the model implied

that if all disabling barriers could be removed, then the construct of disability would no longer hold relevance (Shakespeare, 2004). In this instance, it seemed that the failure of the social model to account for all aspects of the experience of disability gave rise to the understanding that it is an inadequate means to articulate the experience of disability. This kind of reasoning, despite being embedded in rhetoric of social constructionism, seems to appeal to a logical-positivist episteme. This example highlights a meta-process which seems to be operating at the deeper levels of understanding. It is speculated that a lack of skill in dealing with pluralism and fluidity gives rise to the endurance of logical-positivism as a primary means to understand the ways we understand the construct of disability.

The enduring nature of logical positivism filters into various levels of understanding, represented in the findings from this research with regard to myths and metaphors, worldviews, and discourses, social systems and in terms of surface level explanations on the issue of intellectual disability, relationships, and sexuality. For example, at the deeper-levels of understanding, intellectual disability is constructed as inherent difference, and as a master status of the individual. This pattern is manifest in terms of discourses surrounding disability, and in terms of conforming to expectations of normality. This rhetoric is reinforced at Social Causal and systemic levels, in the ways that individuals with, and without, disability inhabit distinct social and cultural spaces (e.g., participants in this research attended disability-specific sports clubs, alternative to employment services and often experienced social contact only within disability-specific settings). The social structures and systems which perpetuate the disabled/non-disabled binary legitimise disability as an ultimate ontological truth, as opposed to a social category. For example, intellectual disability is established as a rhetorical construct where individuals must have an intellectual disability to enter into an Ed-support program, and must have an intellectual disability because they are identified as Ed-support. These social systems serve to legitimate the label intellectual disability as an inherent quality, a master status. Social structures surrounding so-labelled individuals necessitate, and are necessitated by the assumptions of homogeneity and inherent-ness of intellectual disability. The enduring influence of logical-positivism was also evident in terms of the processes observed in this research. For example, in chapter seven I outline the pressure to conform to ideals of participation and action in



research, and the pressure to get it right. Across both the content and process domains of this research it is apparent that uncertainty and ambiguity are rejected in favour of assumed truths, the pursuit of normality and certainty.

While discourses about intellectual disability promoted within contemporary literature, and within service models, appeal to a social constructionist perspective, it would appear that at various levels the conceptualisation of intellectual disability as an inherent, individual quality prevails. For example, in chapter seven, I suggest that this research project is antithetical the social justice aims of the enquiry (e.g., by its very nature, this project highlights that relationships and sexuality are “special” in the context of intellectual disability). It could be suggested that models of disability function similarly. For example, despite the content of the model, the existence of the model itself suggests that disability still retains a tangible quality. Perhaps, however, more contemporary models of disability, such as the critical disability studies approach, subscribe to a relativist approach, and conceptualise disability as fluid and nothing if not entirely contextual.

### **8.6 The Intellectual Disability Paradox**

The intellectual disability paradox refers to a dynamic or process which has been observed within the research findings of this study and in terms of the broader body of research literature. Key to the construction of intellectual disability within dominant Western culture is the assumption that intellectual disability is problematic. For example, intellectual disability diagnosed on the basis of perceived deficits in cognitive and adaptive functioning. Intellectual disability as a construct, within this research, is reflected as abnormality, incompetence, vulnerability and as an enduring feature of the individual. I speculate that intellectual disability is constructed as both problematic and a problem to be solved. For example, the creation of intellectual disability as a diagnostic category creates a space where services may be tailored to support, assist and remedy those deficits experienced by so-labelled individuals. This dynamic is problematic; however, as in attempting to solve the problem of intellectual disability, arguably, a problem or problems are created. Shakespeare (2000) suggest that the problem of intellectual disability is not inevitable, rather, the socio-cultural context surrounding the so-labelled individuals constructs barriers to sexual expression and relationships. The ultimate paradox is that in constructing the social category and in attempting to correct or compensate for those impairments

which have been objectively identified, individuals with intellectual disability are othered and positioned outside the realm of normality, and perhaps humanity.

### **8.6.1 The pursuit of a normal life.**

Evident within the findings of this research is the assumption that being labelled with intellectual disability necessarily precludes one from leading a normal life. The notion of a normal life might extend to leading a life where one is safe and engages in various aspects of the human experience. This assumption is evident in the myths surrounding disability, the discourses which establish Mainstreamers as perfect and those in Ed-support as abnormal, and reflected in a dynamic evident in the experiences of participants in this study, who must be ready or prove their competencies prior to engaging in a range of experiences (e.g., moving out of the family home, having sex, etc.). It might be speculated that these various assumptions are underpinned by normalising ideologies. Normalising ideologies, or the notion that one should pursue a normal life, are considered the mechanism which constructs the problem and directs the solution to the problem of intellectual disability. Normalising ideologies may form a structure of governmentality (Foucault, 1991) within dominant Western culture, creating boundaries and conditions for the right, preferred or acceptable way of doing things (Ashby, 2010).

It seems that there is a pressure within dominant Western culture to engage in a normal way of doing things. There is an inherent assumption that individuals labelled with intellectual disability are not living socially meaningful lives (Klotz, 2004; Rapley, 2004). It would seem that formal and informal systems and structures surrounding individuals labelled with intellectual disability are embedded in a collective aim to compensate for intellectual disability and promote a normal life. For example, as is evident in the experiences of individuals who participated in this research, in an effort to promote opportunities for engagement, while also protecting individuals, parents, and carers may accompany their adult child as a carer to various events and activities. Equally, formalised independent living programs are structured around an idea that one must train to be ready to move out of home, to engage in an ordinary life. Within these settings, individuals labelled with intellectual disability may be expected to live up to particularly high standards of normality. For example, bad language or behaviours determined as abnormal or less-than perfect may be used as evidence for incompetency and, access to the community once granted, may be

relinquished by governing structures (May & Simpson, 2003). This dynamic is problematic, as often, behaviours are pathologised or considered problematic in the context of intellectual disability (Dotson et al., 2003; Fine & Asch, 1988). For example, swearing may be tolerated among adults within the wider dominant Western culture, but seen as an inappropriate form of expression for individuals labelled with intellectual disability.

It seems that individuals labelled with intellectual disability are subjected to a higher standard of behaviour, that they must prove themselves as more normal than normal people (Goodley, 2001). Corbett (1994) establishes that there is a collective pursuit of a false normality, and suggests that normality by definition is unattainable. A strong discourse emerging from the findings of this research is that individuals labelled with intellectual must prioritise safety, and “...*practice, practice, and practice*” to be ready to engage in the future. Where individuals labelled with intellectual disability are perceived not to meet standards for behaviour, they may be precluded from engaging in aspects of the human experience. Individuals may be precluded from a normal life in favour of, as was the case in findings emerging from this research, and within previous research studies (May, 2000; Rogers, 2010; Todd & Shearn, 1997) an imagined, metaphorical and fantastical future which is seen to protect the individual from experiencing the “perceived pain” of intellectual disability. This dynamic is paradoxical, as Todd and Shearn (1997, p. 363) highlight that this process, “... *while protecting people from toxic experiences, confirm the stigma of their identities.*” Perhaps this dynamic is evident in the experiences of participants in this research who fantasise about a pretend life. It is possible that this pretend life, and the unrealised dream of having a partner and children, is preferable to leading a life where, in reality, the dream while pursued is not achieved. Similarly, this kind of pretend life may offer a level of comfort and safety for those who are constructed as accountable for individuals labelled with intellectual disability. For example, as outlined in chapter six, one parent shared with me that she had told her adult child that sex comes after marriage, in the hope that her child may not engage in sex as prospects for marriage were unlikely.

As previously mentioned in chapter two, this pressure to be more normal than normal people may be understood in context of Goffman's (1963) concept of passing and the construction of intellectual disability as a spoiled identity. In an effort to

compensate for a spoiled identity, individuals labelled with intellectual disability are subjected to high standards to prove their normality and competencies. Where competency is considered axiomatic for most, individuals labelled with intellectual disability are placed in a difficult position of having to prove their competencies. As outlined in chapter two, Rapley (2004, p. 202) suggested that "... *(in)competence is negotiated and constructed locally, and for local purposes, by local means*". This observation seems to capture the dynamic evident in the findings from this research, where normalising ideologies and constructs of competence serve to legitimate the exercise of power and control at various levels.

The assumption inherent to this dynamic is that there is a truth-value in normality, and that there is a right or preferred way of doing things. This social pressure is considered to reflect ableist attitudes (Ashby, 2010). Ableism is the embodiment of the culturally hegemonic pressure to conform to normality, and reflects a presumption that all individuals aspire to achieve a level of normality. As outlined in chapter two, principles of normality have heavily influenced the direction and progress of the disability movement, as the normalisation principle set the scene for deinstitutionalisation, employment opportunity and the pursuit of an ordinary life. The normalisation principle, and social role valorisation theory, has come under criticism for this emphasis on the pursuit of normality. While these theories opened up a dialogue for the re-imagining of the lives of individuals labelled with intellectual disability, it could be argued that these models merely provided a different means by which dominant Western cultural ethnocentrism could be enacted. Ethnocentrism is determined by Levine and Campbell (1972, p. 8) to reflect "...*ingroup-outgroup polarization and the self-centred scaling of all values in terms of the ingroup folkways.*" It is possible to suggest that ableism is manifest via ethnocentrism, where dominant cultural values assert that the normal way of doing things is the right way of doing things. It is suggested that notions of normality are inextricably linked with social norms and dominant cultural values. Ethnocentrism is strongly linked with prejudice, as individuals tend to evaluate the experiences of others with regard to their own cultural values and assumptions (Matsumoto & Juang, 2008). As such, individuals who do not conform to notions of normality are constructed as abnormal and leading meaningless lives. I speculate that the pressure to conform to normality, captured in ableist attitudes, reflects a form of

ethnocentrism. Perhaps the concept of ethnocentrism can be used to explore how the role of the researcher is constructed within participatory action research. That is, one must conform to a traditional ideal of a researcher in order to occupy this role. Equally, perhaps ethnocentric attitudes are present in the discourses of needing to be ready prior to engaging in a range of experiences, such as moving out of the family home. In all instances, there is an enduring assumption that there is a right way of doing things.

This form of ethnocentric evaluation frames the experience of individuals who are constructed as existing outside the threshold of normal as squarely abnormal. Within dominant Western culture there is a prevailing assumption that all individuals wish to be normal, to be more like the constructed dominant ingroup culture. Perhaps the concept of ethnocentrism gives a means to articulate the collective, socio-cultural pressure placed on individuals labelled with intellectual disability to pursue a normal life. Perhaps the concept of ethnocentrism also gives weight to the notion that all individuals, labelled with intellectual disability or not, are trapped and restricted by notions of a normal life. For the individual labelled with intellectual disability, as was evident in the experiences of participants in this research, this pressure to pursue a normal life seems to navigate one ever further away from leading an ordinary life characterised by choice, control, independence, mistakes, regret, and experiential learning.

### **8.6.2 Solving the problem of intellectual disability: Alternative settings.**

The constructing of a normal life is evident in the formal social systems in which individuals labelled with intellectual disability are embedded. These settings perhaps construct a self-conscious version of a normal life where at all points the discourse reflects questions on how normal this life is, how this life could be made more normal. As outlined previously, a key discourse to emerge from the findings of this research is that intellectual disability is constructed as inherently problematic, and that active efforts must be engaged to embed some normalcy in the lives of individuals labelled with intellectual disability. At the Social Causal layer, findings from this research suggest that individuals labelled with intellectual disability are engaged in alternative settings as a means to solve the problem of intellectual disability. For example, for several participants in this research, primary social contact, and hobbies, took place in disability-specific settings. The means to promote

access to relationships and connectedness to others is via models of congregative care, or, as one participant labelled with intellectual disability states “...*just get them into groups*”.

These alternative settings perhaps represent a tangible manifestation of the disability paradox, as these settings are characterised by the label intellectual disability, and by assumptions of intellectual disability. It is in these settings that messages around needing to be ready to engage in the future, needing protection, suppressed sexuality and deferring to others are promoted. A key dynamic emerging from the findings of this study is that these alternative disability-specific settings seem to be necessitated by, and necessitate, the construction of intellectual disability. This dynamic seems to resemble that outlined by Finlay and Lyons (2005) in their exploration of the socio-cultural construction of the label intellectual disability. As previously outlined in chapter two, the authors found that for so-labelled individuals the label intellectual disability represented an administrative category, rather than an inherent characteristic of the individual. The implication of this finding, for Finlay and Lyons, was that intellectual disability represented an administrative construct. The notion of intellectual disability as administrative construct reinforces the notion that the label is both constructed by, and constructs, social, and systemic settings. This same dynamic was observed by Rosenhan (1973) in his famed experiment where he explored the experience of being “sane in insane places”. As outlined in chapter two, Rosenhan argued that pseudo-patients were stigmatised, labelled, disempowered, and disadvantaged by settings in which people were presumed insane, inadequate or incompetent. He argued that these settings reinforced the experience of insanity, suggesting that individuals have no choice other than to react in bizarre ways to bizarre settings. Similarly, the lack of sexuality education provided to individuals labelled with intellectual disability is widely-reported (Johnson et al., 2002; Lafferty et al., 2013; Williams et al., 2014), and is perhaps fostered by congregative settings (such as the Ed-support classroom), where students may not receive adequate sex education. Claims that individuals labelled with intellectual disability are vulnerable, and need protection, are legitimated by this lack of knowledge. As Rosenhan suggests, individuals in settings which are based on assumptions disadvantage the individual, fostering behaviours and dynamics which necessitate the setting.

Taylor and Bogdan (1980), as noted in chapter two, outline how institutions operate via a range of legitimating myths. For example, disability-specific settings operate on the basis of homogeneity, vulnerability, surveillance, and protection. These settings, in turn, may create environments where individuals labelled with intellectual disability experience little opportunity to exercise choice, control, and spontaneity, and perhaps internalise these assumptions of their capacity and character. For example, as emerged from the findings of this research, one participant suggested that as they have Down syndrome, they cannot expect to have a normal boyfriend. This individual seemed to believe that intellectual disability undermined their right to have a boyfriend or girlfriend, or engage in sexual expression. In this sense, the myths observed at deeper-layers of understanding (e.g., that individuals labelled with intellectual disability are child-like, vulnerable or incompetent) were also evident at surface layers of understanding (e.g., the notion that one could or should not have an intimate partner because of intellectual disability). These enduring understandings, and surface and deeper-levels of understanding are perhaps precipitate and are reinforced by the illusion of the institution, and the legitimating function of social structures.

The governing power of systemic and administrative structures perhaps reflects a tendency to think and operate in legalistic and systemic terms within dominant Western culture. It is speculated that systems and structures can provide socially-appropriate means of legitimising segregation and othering. For example, findings from this research highlight the legitimating function of the Australian education system in pigeonholing students as either Mainstream or Ed-support, and thus providing a structural means to enact socio-cultural assumptions, stigma, and discrimination against individuals labelled with intellectual disability. For example, participants spoke to the ways in which they felt "pushed around by" individuals in the Mainstream, and how Mainstream individuals looked down upon individuals from the Ed-support. Employing legalistic and structural frameworks to justify and permit treatment of labelled individuals undermines unfairness, stigma, and prejudice which construct those systems. It would seem that formal and informal systems which serve to protect, normalise and serve the interests of individuals labelled with intellectual disability represent structures of governmentality (Foucault, 1991), or socially-condoned means to maintain the status quo.

### 8.6.3 Paradoxes of empowerment, normality, and participation.

Shakespeare (2000, p. 163) challenges ableist attitudes and normalising ideologies, encouraging individuals labelled with disability to reflect on whether they are trying to gain access to Mainstream conceptualisations of sexuality, or, aiming to “...*challenge the ways in which sex and sexuality are conceived, expressed and limited in modern societies...*”. Shakespeare appears to advocate for a disruption to these dominant cultural assumptions as a means to re-define the boundaries which determine individuals labelled with intellectual disability cannot lead meaningful sexual lives, or engage in close relationships. The tension which Shakespeare appears to touch on relates to the assumption that normality, or a normal life, can ever be granted. It is suggested that the concept of normality bears similarity to notions of participation. Often, it seems that the same rhetoric is employed surrounding the extent to which one engages in a normal life, and the extent to which one participates meaningfully in various aspects of life. Here, it is speculated that the concepts of normality and participation are problematic. I suggest that parallels may be drawn between the paradox of empowerment (Rappaport, 2002), and paradoxes of normality and participation.

To further explore this argument, I will refer to the participatory ideal outlined in chapter seven, wherein I discuss the ways in which notions of inclusion and participatory research may be problematic, and antithetical to the aims of research inquiry. For example, where participation or inclusion is formalised in research processes, paradoxically, these research processes may become exclusionary, or construct participation as a special feature of the research inquiry and perhaps a remarkable role for the individual labelled with intellectual disability. I suggest that in conforming to the participation ideal, we, as researchers, may be creating settings where participation is ingenuine and token. One of the key difficulties associated with conducting emancipatory, participatory or action research is achieving the often desired outcome of social change and empowerment. For example, in recent years there has been a shift toward research which is participatory, inclusive and promotes action and social change. The structural features of research have transformed, with the implication that so too will roles adopted by community members and opportunities for participation and empowerment. While these structural features may change, this transformation is argued as insufficient for facilitating genuine



participation and empowerment among community members. For example, citizen participation may be promoted and espoused as a means to legitimise, rather than inform, policy (Frawley & Bigby, 2011). It is suggested that a necessary condition for emancipatory outcomes and social change is a transformation of the social relations alongside the material relations of research production (Zarb, 1992). That is, the underlying socio-cultural values associated with research participation, and perhaps intellectual disability, must change in order for real emancipatory outcomes and genuine citizen participation (Frawley & Bigby, 2011; Reinders, 2002).

Research paradigms may be cloaked in rhetoric of participation, and inclusion, however, the governing structures may remain largely unchanged. For example, in chapter seven I reflect on the challenges associated with conducting participatory action research in a university setting, where formalised processes and ethical procedures limit opportunities for fluid and exploratory engagement with the community. To refer to Taylor and Bogdan's (1980) illusion of institutions, the institution of research may transform, but is perhaps still operating on the same legitimating myths (e.g., formally trained researchers are the experts, and should occupy traditional research roles) which maintain the status quo. While participation may be pursued and promoted, where participation is not genuine, research enquiry may reproduce, rather than challenge or disrupt the status quo. It seems that there is common thread or process operating with regard to concepts of normality, participation, and empowerment. Each of these concepts seems to hold a paradoxical quality in practice. For example, where participants in this research were being made ready, or getting ready, to live independently, they were, in fact, perhaps missing out on the ordinary experience of living out of home, of making mistakes, and learning from those mistakes. The notion that independence can be gifted emerged as a discourse within the findings of this research, several participants spoke of the idea of being permitted, authorised, allowed to do things, or given independence. Where independence, and by extension, a normal life, is the domain of others to give, paradoxically, opportunities for a normal life may be undermined. The greater emphasis placed on constructing a normal life, or attempting to be inclusive, or encouraging participation, on the basis of the label intellectual disability; so-labelled individuals appear to experience greater levels of exclusion, othering, and non-participation.

When reflecting on the participatory ideals of participatory action research, I consider the paradox of empowerment, the notion that empowerment by definition cannot be granted or gifted as this reflects merely another process by which dominant structures choose to distribute power. The argument I outline in chapter seven is that attempting to empower marginalised parties can be an inherently disempowering process. It is speculated that processes of normality and participation operate in a similar fashion. That is, the more one attempts to construct a normal life, or to promote participation, the further one is from leading a normal life or engaging genuine participation. In the same way the gifting power is inherently disempowering, granting normality and participation is inherently exclusionary. Herein lays the nature of the disability paradox. It is argued that at various levels the label intellectual disability, the assumptions associated with the label, and the systems in place to address the problem of intellectual disability, serve to other individuals who are located within this social category.

### **8.7 Negotiating close relationships and sexuality within a complex socio-cultural context**

In the earlier sections of this discussion chapter, I outline some of the key dynamics, discourses, and processes which have emerged from the findings of this research, and my reflections on engaging in inclusive research processes. In so doing, I hope to have impressed upon the reader the sheer complexity and endemic nature of the settings and contexts which construct intellectual disability, relationships, and sexuality as a wicked problem. One of the key messages outlined in the earlier stages of this chapter is the construction of this wicked problem as a cultural problem, rather than a problem to be understood and addressed at the individual level. It is speculated that within this culture, particular individuals are expected to take on particular roles, and occupy fairly difficult positions. For example, a finding to emerge from this research is the construction of a parent as bearing a "heavy burden of high expectation", expected to negotiate issues related to relationships and sexuality on behalf of their adult child labelled with intellectual disability. It is also suggested that often these roles and responsibilities are not considered within cultural context, rather, they tend to be evaluated in a de-contextualised manner, at the individual level. For example, as is outlined in previous chapters, parents may run the risk of being scrutinised as a bad parent, as irresponsible or discriminating

against their own child. Parents and family members are traditionally portrayed as holding ableist attitudes and being overprotective of their family member labelled with intellectual disability (Neely-Barnes et al., 2010). Findings emerging from this research, however, support the view that this understanding is somewhat oversimplified and does not reflect the complex cultural context in which family members, and individuals labelled with intellectual disability, are embedded. For example, in this research, parents seemed to be positioned as to protect their adult children from a perceived negative reality surrounding capacities and competencies for certain activities, goals, and tasks (e.g., riding a motorbike, having sex, getting married). Findings from this research suggest that the myths and worldviews associated with intellectual disability construct roles and responsibilities for so-labelled individuals and their family members at multiple levels. The parent-child dynamic extends beyond the bounds of the family, and seems to be captured within broader social systems and structures in which individuals labelled with intellectual disability are embedded. For example, as noted in chapter six, conversations on sexuality, relationships, and disability were more often had *about* so-labelled individuals, as opposed to being *targeted to and facilitated by* so-labelled individuals.

A key dynamic to emerge from the research findings, and my reflections on the research process, is the complexity of the role that parents, siblings, and family members play in the lives of their sibling, son or daughter labelled with intellectual disability. For example, as previously outlined in chapter seven, my contact with participants labelled with intellectual disability was mediated by parents. In order to gain access to potential participants labelled with intellectual disability, it was culturally appropriate for me to first make contact with parents and family members. This presented as an ethically important moment within the research process and seems to reflect the nuanced, complex, and fluid family dynamics captured by Knox and Bigby (2007) in their research on notions of midlife care for individuals labelled with intellectual disability. The authors found that notions of care reflected a mutual, reciprocal, and negotiated process, to promote independence from formalised service settings, and to resist ableist assumptions and discrimination within the wider community (Neely-Barnes et al., 2010). For example, findings from this research

study suggest that siblings and parents may take on the role of a carer when and as needed.

It seems that parents are placed in a difficult position, expected to maintain a balancing act between assuming the role of protector, and facilitator. Parents are constructed as simultaneously responsible for ensuring their son or daughter experiences a good life, while also protecting them from harm (Rushbrooke et al., 2014b). Findings from the research suggest that this harm may be anticipated, rather than experienced. For example, participants in this research indicated that limitations to their independence may preclude the opportunity to learn through doing, or through making mistakes. The role of parents in granting independence was also acknowledged and discussed by participants. It seems that parents and support-workers are expected to pursue competing goals; they must protect their son or daughter, while also empowering and supporting them to engage in close relationships and express their sexuality (Dupras & Dionne, 2013). Where parents are seen to fail at this task, they may come under scrutiny for being bad, irresponsible, overprotective, and discriminatory (Almack et al., 2009; C. A. Hamilton, 2009; Knight, 2013). Yet, parents have little guidance as to how to take on this role, and execute their ascribed responsibilities.

It is speculated that the experiences of parents of individuals labelled with intellectual disability are often not placed within a socio-cultural or political context. Rather, their actions are evaluated on an individual level, which tends to individualise their experiences, and leave them subject to negative evaluations (Knight, 2013). It seems as though parents, support-workers, and family members risk condemnation for failing to strike a balance between two apparently irreconcilable aims, protection, and empowerment (Almack et al., 2009; Ryan & Runswick-Cole, 2008). Parallels may be drawn here between the experience, and construction of parent of a son or daughter with intellectual disability, and other individuals who may endure scrutiny of their role, and actions in presumed care-giving relationships. Rosenhan (1973), in reflecting on his study of pseudo-patients in psychiatric hospitals, noted that it would be a mistake to consider that staff at the hospitals were acting with malice, or stupidity, in their dealings with pseudo-patients. The author suggests that the staff were also a product of the environment, and that their behaviours, likewise to their patients, "...were being controlled by the situation,

*rather than malicious deposition...*" (Rosenhan, 1973, p. 257). Rosenhan's reflections hold relevance for the construction of parents, he cautions against performing an individualised analysis of these complex settings. In neglecting to acknowledge the complexities, and tensions, faced by family members and support-workers in their constructed roles, perhaps there is a danger of placing parents in an equally disempowered position as individuals labelled with intellectual disability.

### **8.7.1 Disability as culture.**

As a researcher engaging in these settings, I have come to understand that I am engaging in a complex and unique socio-cultural context. As a researcher I was ascribed a particular role, and experienced pressure to conform to the culture and conventions of the community I was immersed in. Reflecting on the research process, I can see that my actions in moments I would consider as ethically important were guided by a sense of what was culturally appropriate. In the same way that I was positioned to adopt particular roles and responsibilities within this cultural context, so too are community members, individuals, families, support-workers, and others. To evaluate the roles, actions, and responsibilities assumed by parents at an individual level seems to undermine the cultural context in which these individuals are embedded. Rather, it is argued that there is value in reflecting on the nature of disability as culture, and means and ways to honour and work within cultural contexts associated with the experience of intellectual disability.

Often, considerations of culture are limited to ethnicity, religion, age, race, gender and sexuality (Eddey & Robey, 2005; Schrader et al., 2013), failing to account for the role of various other socio-political identities, such as disability (Nehring, 2007). Eddey and Robey (2005, p. 707) posit that a culture of disability needs to be considered and honoured, and is characterised by "*...both a group and personal identity based on common experience, a shared resilience in coping with a world that may be oppressive, and a unique body of tangible artifacts (e.g., art, music, literature) derived from this shared experience.*" The authors also argue that any definition of a culture of disability should extend to include those who form the network of the individual labelled with disability (e.g., parents, family members, and others). Considering a culture of disability corresponds with the minority group model of disability (Eddey & Robey, 2005), previously outlined in chapter two. In the same way that individuals who form part of the queer community share a culture,

identities, experiences with interacting with the dominant culture, values, attitudes, and cultural artefacts, so too do individuals who form part of the disability community (Schrader et al., 2013).

Recognition of a culture of disability places responsibility on individuals engaging within this community to develop and exercise cultural competencies, or cultural capabilities (Edey & Robey, 2005). A point of contention within the literature on cultural competency is the extent to which such competency can be developed, or achieved (Duignan, 2006). It is speculated that developing cultural competencies and capabilities reflects an ongoing process of discovery of oneself, and others (Stephenson, 2000). Reflecting on my role as a researcher in this study I speculate that my consideration of ethically important moments, and engagement in reflexivity (outlined in chapter seven), represented an attempt to develop and conduct myself in ways which I perceived as culturally competent, capable, and sensitive. It is suggested that a reflection on shared histories, contemporary, and historical experiences of oppression, colonisation, and interaction with dominant culture is necessary in order to produce research which does not replicate, but rather, challenges, existing power relations (Sultana, 2007). To this end, I would suggest that reflexivity offers a valuable tool for developing an appreciation of the research and cultural context and for engaging communities in mindful and ecologically meaningful ways. To continue the trend and position parents, and others who form the network surrounding individuals labelled with intellectual disability, as misinformed, overprotective, irresponsible or discriminatory does not contribute to a progressive discourse.

### **8.8 The current state of affairs: Possibilities versus realities**

In posing the key messages and findings which have emerged from this research, I feel a pressure to provide some commentary on the current state of affairs on the extent to which individuals labelled with intellectual disability experience opportunity to engage in close relationships, and explore their sexuality. To provide a definitive evaluation of this issue, and the experiences of so-labelled individuals, would be inevitably inadequate and antithetical to the epistemological and ontological foundations of this inquiry. There is no means or rationale for me to comment in any definitive way on what it means to live with the label intellectual disability and to negotiate close relationships and sexuality. What I might do,

however, is attempt to draw out some impressions I have developed based on findings generated from the research, and my reflections on engaging in the research process.

A discrepancy in desire to engage in relationships, and incidence of relationships, for individuals labelled with intellectual disability is widely reported within the research literature (Johnson et al., 2002; Knox & Hickson, 2001; McVilly et al., 2006b). This finding does not correspond entirely with the findings emerging from this research. Many of the individuals labelled with intellectual disability with whom I spoke indicated that they were engaged in close relationships. Several participants had boyfriends or girlfriends, spoke of future plans to get engaged and married, have children, and move out of the family home to live with an intimate partner. The diversity in these experiences, aspirations, and desires is reflective of the diversity reported within the research literature, where individuals labelled with intellectual disability, as was the case in this research, shared a range of expectations and aspirations for relationships (Azzopardi-Lane & Callus, 2014; Knox & Hickson, 2001). Some participants in this research, as in previous research studies (Bane et al., 2012; Yacoub & Hall, 2008), explain that they are happily single, or not currently interested in engaging in a close relationship. It is the case that some individuals expressed a deep unmet desire to be in a relationship, and to feel connected and important with someone else. The nature and diversity of these experiences is not remarkable, and perhaps reflects the diversity of human experiences.

Despite this diversity, and the fact that a substantial proportion of the individuals who I spoke with were in relationships, something seems to be amiss, to suggest that there are some complex issues in negotiating relationships and sexuality while living with the label intellectual disability. Throughout this research project I often experienced a sense of hopelessness, or helplessness, and a sense that there was something deeper going on below the surface. While individuals were engaged in relationships, spoke of boyfriends, girlfriends, and future plans, there seemed to be a distinct lack of opportunity for individuals to enact these plans, to be spontaneous, exercise choice, control, and independence. The topic of sexuality, and physical intimacy was notably absent from my conversations with individuals labelled with intellectual disability. Perhaps this is because I didn't ask, yet, it didn't really come up. Sexuality came up in conversations before and after interviews, and in social and

community-based settings, with parents who would tend to present sexuality as a problem to be managed or dealt with, a tricky issue. My sense is that for many individuals labelled with intellectual disability, for multiple reasons, exploring one's sexuality is simply not possible.

There seemed to be multiple barriers, and multiple levels, which influenced the nature of relationships, and opportunities to engage in relationships. For example, as identified in this study, and previous research studies (McVilly et al., 2006a; F. Sullivan et al., 2013), at a systemic level, congregative models of care limited spontaneity, alternative settings constructed around disability were predicated on assumptions of disability and so were characterised by surveillance, caregiver-care recipient relationships and a lack of privacy. Informal and formal settings appeared to place emphasis on protection, and external parties seemed to take on the role of managing and mediating close relationships. While there was a critical voice of resistance, a suggestion that individuals labelled with intellectual should be afforded independence, and experience control on their own lives, this voice of resistance was not particularly loud.

It is possible to speculate on how and why the relationships and sexuality of individuals labelled with intellectual disability are constructed as remarkable. For example, the notion that so-labelled individuals can have intimate relationships seems to subvert myths of disability, and so is considered unusual or extraordinary (Azzopardi-Lane & Callus, 2014). While I fundamentally disagree with this assertion, on the basis that these are myths and assumptions, I speculate that perhaps relationships had by so-labelled individuals are somewhat remarkable. I would argue that these relationships are remarkable based on the cultural and social barriers which must be negotiated, subverted, challenged, and disrupted in order for such relationships to flourish. The remarkable nature of these relationships is not based on qualities and expectations of the individuals who engage in the relationships, rather, they are remarkable as a function of the socio-cultural context in which they must thrive and develop.

Reflecting on the research findings, and my experiences engaging in the research process, my sense is that these issues could be summed up in the following sentiment; *just because something is possible, this doesn't mean that it can or will*



*happen*. In other words, technically, individuals labelled with intellectual disability do and can engage in relationships and explore their sexuality. I would suggest, however, that below the surface, one might challenge the extent to which these relationships, and opportunities to explore sexuality, characterised by choice, control, independence, spontaneity, and privacy. It seems that for many individuals, the nature of close relationship experiences, and sexuality, is heavily contingent upon the socio-cultural assumptions which correspond with the label intellectual disability. As previously discussed in chapter three, it is true that many people will navigate life without having met “the one”, without having children, or getting married, that many individuals will experience heartbreak, loneliness, and love unrequited. The fundamental issue, it seems, is not that individuals labelled with intellectual disability are at risk of experiencing unmet desire, or unmet relationship aspirations, rather, the fundamental issue is that is that individuals labelled with intellectual disability seem to experience difficulties, and challenges, in negotiating close relationships, on the basis of this label.

### **8.9 Parameters of the research inquiry**

It is necessary with any form of research inquiry to reflect upon and critically consider the parameters within which research findings can be meaningfully interpreted. One of the parameters for this research inquiry is the nature of the community and the participants I engaged to share their experiences of close relationships and sexuality. All of the individuals labelled with intellectual disability who I interviewed were living within the family home, and were aged in their early, mid and late twenties. It is speculated that lived experiences and relationship experiences would vary for individuals who perhaps reside in different settings (e.g., living out of the family home, cohabiting with a partner or living in supported accommodation) and who reflect a different age profile. Experiences may be different on the basis of different developmental and life stages, but also as a function of living in different temporal contexts (e.g., individuals who are now in their late adulthood have experienced some particular structural, formal and informal factors related to the construct of intellectual disability). The extent to which the findings from this study are transferable or hold relevance for individuals in similar or dissimilar cultural, historical, and temporal contexts should be determined with caution. The unique profile of community members who participated in this study is

also considered a strength of the research. It is uncommon for the experiences of individuals in their twenties, living within the family home, specifically within Australia, to be represented within the research literature. Findings from this research offer insight into the experiences of individuals embedded within these settings.

An additional boundary within which the research findings must be considered is the notable absence of an action component within the research process. As is outlined in my reflections on the research process, on chapter seven, I commenced this research project with every intention to affect some kind of social change, and engage participants actively in the research process. The nature of the research process, and the lack of an action component to this study, sets parameters around the extent to which this research might be evaluated as truly reflecting participatory or action research, and the extent to which this project can be judged as having affected social change. As previously discussed in chapter seven, opportunities to engage in exploratory research which challenges traditional researcher-participant dynamics and aims to affect social change is not easily conducted within institutional settings which demand procedural and ethical certainty (Elwood, 2007) .

Having completed the study, and reflecting on the process, I can identify that I grappled with the tensions surrounding ethics-in-practice and procedural ethics. I now see that my intention to engage a participatory action research project was ambitious given the resources, time, and the expectations of the institutional setting I am embedded in. In this process, I feel as though I was challenged to maintain principles of ethics-in-practice, in favour of the participatory or action ideals inherent to this form of research. These reflections, and my experience of the research process, hold great personal and professional value for me. I hope that my reflections on the research process represent a strength of this research, perhaps holding relevance for or resonating with others engaged in similar research endeavours.

An additional parameter within which the research findings can be meaningfully interpreted relates to the notion that this research inquiry could be considered as replicating and perpetuating those dynamics under exploration. A key tension which has emerged from the research literature, and the findings of this research, is that relationships and sexuality are often presented as remarkable, extraordinary or unusual in the context of intellectual disability. In chapter three, I critically evaluate

how previous research studies exploring sexuality, relationships, and disability perhaps contribute to this discourse. The very nature of this inquiry presents relationships and sexuality in the context of intellectual disability as a special phenomenon. To this extent, it is important to acknowledge the potential of this inquiry to replicate the dynamic under study, and to undermine the aims of the inquiry. As noted previously, I speculate that some paradoxes are inevitable. Perhaps the value of this research inquiry is that I have engaged in active examination, reflection, and consideration of this paradox, and have interpreted the research findings and process in light of this dynamic. I hope that in doing so I have managed to disrupt or challenge this discourse, and contribute to a progressive understanding of the complexities which underpin this issue.

### **8.10 Implications and opportunities for further exploration**

There are a multitude of practical and theoretical implications to be realised from this research which hold relevance for practical and theoretical domains. One of the key practical implications of this research is the contribution that the research findings offer to a progressive discourse surrounding close relationships, sexuality, and intellectual disability. This research inquiry is embedded in a contextualist approach, which acknowledges the value of space, time, and history in constructing contemporary lived experiences (Jaeger & Rosnow, 1988). As such, the findings generated offer insight to the lived experiences of individuals labelled with intellectual disability, living within the family home, within the dominant Western Australian context. The experiences shared by participants offer educative value for the wider community, research community, and those in the community who are policy-makers and who exercise political influence. I advocate that future research studies also engage an exploratory and collaborative approach, capturing lived experiences as a means to generate and interpret findings which hold ecological value for the community.

The findings generated suggest that progress has been made from historical conditions surrounding close relationships, sexuality, and intellectual disability. The findings also suggest, however, that contemporary experiences of this issue are governed by enduring ideologies and mythologies of disability. Taylor and Bogdan's (1980) work on the notion of defending the illusion of the institution suggests that while surface level structures may transform, the deeper-level myths, ideologies, and

assumptions may prevail leaving opportunities to engage in close relationships and explore one's sexuality relatively unchanged. Findings from this research reinforce a need to exercise tenacity, reflexivity, and critical awareness in how we, as researchers and community members, engage in future endeavours to affect social change in the domain of close relationships, sexuality, and intellectual disability.

A key implication of practical and theoretical relevance to emerge from this research is the paradoxical nature of processes and concepts which construct discourses surrounding intellectual disability, and lived realities for individuals who are so-labelled. For example, in this discussion chapter, the paradoxical nature of pursuing a normal life, of empowering the disempowered, and aiming to be inclusive and participatory are considered. These paradoxes hold relevance for the ways in which future endeavours in this domain are engaged, or for how issues related to intellectual disability, close relationships, and sexuality are framed. For example, I argue that there is great value in critically reflecting on how language surrounding difference (e.g., Mainstreamers and Ed-support) operates and is integrated into discourses of intellectual disability. Critical awareness of the symbolic, and tangible, ramifications of these labels may influence understandings of intellectual disability at other levels. It is speculated that perhaps the paradoxes identified are unavoidable, and form part of dominant Western culture. Perhaps, critically examining, commenting, and reflecting on these paradoxical meta-processes allows for some level of negotiation of the construct and lived experience of intellectual disability. It is advocated that future research endeavours adopt a contextualist and multi-levelled and ecological approach to exploring issues in this domain.

One of the key theoretical implications to emerge from this research relates to the ways in which the truths of the world are processed, understood, challenged, and disrupted. A recurring pattern which emerged from the research findings and, research process and which is evident in the research literature is the enduring nature of logical-positivism, and the significance this episteme holds for the ways close relationships, sexuality, and intellectual disability are considered. I speculate that the enduring nature of logical-positivism, and the privileged position afforded to science, seems to direct and constrain attempts to reconcile, manage, and address close relationships, sexuality, and intellectual disability.

This research reflected an attempt to critically examine existing power structures and to deconstruct those contextual and cultural settings which construct intellectual disability, sexuality, and close relationships as fundamentally problematic. This approach, supported via the analytical framework of causal layered analysis (Inayatullah, 1998) has been valuable for uncovering and highlighting the nuances and complexities pertaining to intellectual disability, close relationships, and sexuality. The findings from this research highlight a tendency to appeal to binaries, certainty, and truth as a means to make sense of the world. Findings from this study also suggest that this logical-positivist or individualised framework is not sufficient for capturing the nuances and complexities of the issues at hand. For example, as outlined in chapter three, the roles of those who form part of the network surrounding individuals labelled with intellectual disability are often evaluated as overprotective or discriminatory. This individualised, rather than collectivist and contextual, exploration of the dynamics at hand seems to undermine the true complexity, and deeper-level issue, which maintain intellectual disability, sexuality, and close relationships as problematic. This contextualist approach sets the target of change away from the individual, redirecting the focus of change toward the broader cultural context.

It is apparent that we, as researchers, are not particularly skilled at taking a pluralistic approach. It is speculated that further exploration of issues surrounding relationships, sexuality, and disability would be well-supported by a pluralistic approach, and an appreciation that various issues, barriers, assumptions, and realities manifest at multiple layers of understanding. The intent of this inquiry is not to privilege one form of episteme or way of understanding over another; rather, the intent is to argue that various epistemologies and frameworks open up different contexts, and different levels of understanding. For example, rather than conceptualising various models of disability in a linear fashion and as more or less sophisticated than each other, I advocate, in concordance with Shakespeare and Watson (2001), that various models of disability could be located at different levels of understanding. That is, the individual model offers value in some contexts, as does the embodied ontology or critical disability studies approach to disability.

This line of reasoning could be extended to hold relevance for the means by which research in this domain is executed. A key tension outlined in chapter seven is

the pressure exerted upon participatory action and inclusive researchers to get it right. As previously discussed, this pressure to get things right perhaps carries one further away from a place where ambiguity and fluidity is appreciated, hegemonic structures may be disrupted and challenged. A practical implication of this reflection is the value of taking a contextualised, and cultural sensitive approach to research context. In this discussion chapter I discuss the value of considering disability as culture, and respecting and working within the cultural values, systems and mores of the community. Concepts of ethic-in-practice (Elwood, 2007) and processes of reflexivity (Northway, 2000) offer valuable tools for encouraging culturally sensitive engagement with communities, and create a space for my role as researcher to be renegotiated, and for dominant cultural power structures to be examined, challenged, and disrupted.

Integrating findings generated from research processes, and observations from engaging inclusive research processes using the participant-conceptualiser model (K. K. Smith, 1983), have allowed for an exploration of frame-talk, and for dynamics and processes to emerge at multiple levels of understanding. These meta-processes and dynamics (such as the paradoxical nature of normality and participation considered in this discussion chapter) “... *offer guidelines for navigating the avowedly uncertain future course an intervention might take*” (Elias, 1994). Reflecting on the research process, and integrating these reflections with the research findings, contributed a richness, depth, and complexity to the overall messages which could be drawn from the research inquiry. The power dynamics, and paradoxes, evident in the lives of individuals labelled with intellectual disability, and those who surround them are complex. These dynamics are not only available for study; they are also inherent to research processes. These dynamics are presented within, and perpetuated by research. We, as researchers, aim to explore the close relationships of individuals labelled with intellectual disability, but perhaps unwittingly perpetuate the marginalisation of individuals who are so-labelled. As researchers, we too are embedded within particular cultural contexts, and must engage in active consideration of how we co-construct the findings which emerge from the enquiry. It is advocated that future research endeavours integrate reflections on research process, with research findings. Doing so not only contributes to the depth and

richness of research findings, but also constructs an accurate portrayal of what it means to conduct participatory, action, and inclusive research in practice.

There is currently a lack of candid accounts of inclusive and participatory research processes (Bigby & Frawley, 2010; Sultana, 2007) and so myths and ideals of participatory, action and inclusive research, and the notion of getting it right, tend to prevail. As the integrity of research participation for individuals labelled with intellectual disability historically and contemporarily is questionable, candid accounts of barriers, challenges, and difficulties experienced in the research process are particularly valuable within the disability research community. Candid accounts and reflections on the research process are valuable for debunking myths surrounding the ideals of research and for fostering greater transparency within the research community.

To propose with any certainty a clear direction for future research endeavours would be antithetical to the epistemological, methodological, and theoretical underpinnings of this research. In contemplating a direction for future research, beyond those outlined above, it is valuable to refer to Sarason's (1996) barometers of change theory (outlined in chapter two). With regard to predicting and anticipating change, Sarason posits that collectively, we are not very skilled at it, and challenges the assumption that there is a logical next step. In the spirit of Sarason's views on the nature of change, it is not possible to suggest with certainty a direction for future research which might generate social change. Perhaps, however, it is possible to speculate at some endeavours which are less likely to replicate or perpetuate the dynamics which have emerged from the findings and processes of this research. As such, the following points are advocated for future research endeavours in this field:

- Taking a multi-levelled and contextualist approach to the research inquiry has highlighted the complexity and nuances of the issues at a deeper-level;
- Exploring the lived experience of individuals labelled with intellectual disability, and those within their networks, as a means to honour community members as experts, and challenge traditional modes of power and research production;

- Attending to research process and culture for embedding the inquiry in a broader collective context, and shifting the focus of change or intervention away from the individual; and
- Engaging exploration, as is advocated by Shakespeare and Watson (2001), in specific and situated contexts. A move away from meta-theory, and intense focus on models of disability, allows for understanding of how specific experiences are constructed by the label intellectual disability.

Conceiving of a path for further exploration, for moving forward, is difficult. On forecasting social change, Sarason (1996) reflects that we run the risk of becoming ideologues that effectively enact a self-fulfilling prophecy, seeing what we want to see, and forging change predicated on notions of what the future should look like. To reiterate, Sarason (1996, p. 31) encourages us to acknowledge that “... *the present is not pregnant with a future, it is pregnant with many futures*”. In current discourses of disability and sexuality, we, as researchers and academics, run the risk calculating a particular future, at the expense of various others futures. Perhaps the focus should turn toward understanding the potential for various, alternative, futures, rather than pursuing any one future. In moving forward, perhaps there is a responsibility to understand, and explore the “...*interactions among change processes*” (Sarason, 2000).

There is collective reflexivity in the research community, a notion that we have moved on, and that there is a need to continue to develop understandings. It might be suggested that sexuality, and the label intellectual disability are understood on some levels, and not others. For example, the sexual rights of individuals labelled with intellectual disability may be legally recognised, but culturally and morally individuals are refused these rights. Pursuing social transformation, and various particular outcomes, is perhaps a reflection of a collective short-sightedness, of a collective subscription to the illusion of transformation as destination (Day, 2007). Perhaps it is necessary to conduct exploration in ways that acknowledge the transiency of this wicked problem (Bishop & Dzidic, 2014), an approach that acknowledges the ecological, multi-levelled, and multi-faceted nature of the issues. While the lack of certainty, and clarity around these pursuits may be unnerving, there



is perhaps comfort in the notion that "...*the very act of travelling confirms that there will be a transforming element to the activity*" (Day, 2007, p. 40).

### 8.11 Conclusion

At the end of this thesis, it seems entirely appropriate to return to where it began. The thesis commenced with a reflection on a workshop I had attended on disability, relationships, and sexuality. During the course of the workshop, one young man posed the question: *How do I get a girlfriend?* While myths, assumptions, and strategies were discussed at the workshop, at the end of the one-day session, this simply-posed question remained unanswered. It is reasonable to suggest that this research was an attempt to answer this kind of question, and other broader questions pertaining intellectual disability, sexuality, and close relationships. Using a qualitative research design, embedded in principles of contextualism, I engaged community members in conversational interviews to reflect on their close relationship experiences. In accordance with the model of participant-conceptualiser, findings from a causal layered analysis of these interviews were integrated with my reflections on the research process, feedback from the community, and my experiences of being immersed within the community. At the conclusion of this thesis the question *how do I get a girlfriend?* remains unanswered.

Findings from this research suggest that the close relationship experiences of individuals labelled with intellectual disability are very much governed by expectations, discourses, and assumptions surrounding what it means to be so-labelled. Individuals labelled with intellectual disability, and those surrounding them, exist in complex socio-cultural settings that establish sexuality and relationships, in the context of intellectual disability, as fundamentally problematic. The formal and informal structures that surround individuals labelled with intellectual disability are grounded in an assumption that things can be made "right" or "okay" *for* individuals who are so-labelled. Systems and structures present a series of paradoxes in the lived experiences of so-labelled individuals, paradoxes which are negotiated, challenged, and challenging for individuals labelled with intellectual disability, and those who surround them. This complex socio-cultural setting undermines access to a life characterised by choice, independence, and intimacy; the kind of life to which all individuals *should* have an uncontested right.

The label 'intellectual disability' does not, in itself, preclude the ability to answer the question *how do I get a girlfriend?* I suspect that this question is just as difficult to answer, just as amorphous, for individuals who are not so-labelled. The fundamental issue, perhaps, is that this question is posed so prevalently within the community of so-labelled individuals. This research suggests that responsibility for answering the question *how do I get a girlfriend?* is often located with those *who surround* the individual labelled with intellectual disability, rather than *with the individual*. It seems that living with the label 'intellectual disability' compromises the right and opportunities to pursue relationships, express sexuality, and, ultimately, meet a desire which is central to the human experience - the desire to *be important, with someone*.

## References

- Abberley, P. (1987). The concept of oppression and the development of a social theory of disability. *Disability, Handicap & Society*, 2, 5-19. <http://dx.doi.org/10.1080/02674648766780021>
- Abbott, D. (2012). Nudge, nudge, wink, wink: Love, sex and gay men with intellectual disabilities - a helping hand or a human right? *Journal of Intellectual Disability Research*, <http://dx.doi.org/10.1111/j.1365-2788.2012.01642.x>
- Abbott, D., & Burns, J. (2007). What's love got to do with it?: Experiences of lesbian, gay, and bisexual people with intellectual disabilities in the United Kingdom and views of the staff who support them. *Sexuality Research & Social Policy*, 4, 27-39. <http://dx.doi.org/10.1525/srsp.2007.4.1.27>
- Abbott, D., & Howarth, J. (2007). Still off limits? Staff views on supporting gay, lesbian and bisexual people with intellectual disabilities to develop sexual and intimate relationships? *Journal of Applied Research in Intellectual Disabilities*, 20, 116-126. <http://dx.doi.org/10.1111/j.1468-3148.2006.00312.x>
- Abbott, S., & Mcconkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities*, 10, 275-286. <http://dx.doi.org/10.1177/1744629506067618>
- Albrecht, G. L. (2002). American pragmatism, sociology and the development of disability studies. In C. Barnes, M. Oliver & L. Barton (Eds.), *Disability studies today* (pp. 23-86). Cambridge, United Kingdom: Blackwell Publishing.
- Almack, K., Clegg, J., & Murphy, E. (2009). Parental negotiations of the moral terrain of risk in relation to young people with intellectual disabilities. *Journal of Community & Applied Social Psychology*, 19, 286-298. <http://dx.doi.org/10.1002/casp.992>
- Altman, I., & Rogoff, B. (1987). World views in psychology: Trait, interactional, organismic, and transactional perspectives. In D. Stokols & I. Altman (Eds.), *Handbook of environmental psychology* (Vol. 1, pp. 7-40). New York, NY: John Wiley & Sons.
- American Psychiatric Association. (2013). *The Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Washington, DC: Author.
- Appleby, Y. (1994). Out in the margins. *Disability & Society*, 9, 19-32. <http://dx.doi.org/10.1080/09687599466780021>
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55, 469-480. <http://dx.doi.org/10.1037//0003-066.55.5.469>
- Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, 35, 216-224. <http://dx.doi.org/10.1080/01944366908977225>
- Ashby, C. (2010). The trouble with normal: The struggle for meaningful access for middle school students with developmental disability labels. *Disability & Society*, 25, 345-358. <http://dx.doi.org/10.1080/09687591003701249>
- Aunos, M., & Feldman, M. A. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 285-296. <http://dx.doi.org/10.1046/j.1468-3148.2002.00135.x>

- Australian Psychological Society. (2007). *Code of ethics*. Melbourne, Australia: Author.
- Azzopardi-Lane, C., & Callus, A. (2014). Constructing sexual identities: People with intellectual disability talking about sexuality. *British Journal of Learning Disabilities, 43*, 32-37. <http://dx.doi.org/10.1111/bld.12083>
- Bane, G., Deely, M., Donohoe, B., Dooher, M., Flaherty, J., Iriarte, E. G., . . . Wolfe, M. (2012). Relationships of people with learning disabilities in Ireland. *British Journal of Learning Disabilities, 40*, 109-122. <http://dx.doi.org/10.1111/j.1468-3156.2012.00741.x>
- Barnartt, S. N. (2010). Disability as a fluid state: Introduction. In S. N. Barnartt (Ed.), *Disability as a fluid state* (Vol. 5, pp. 1-22). Bingley, United Kingdom: Emerald Group Publishing Limited.
- Barnes, C. (1991). *Disabled people in Britain and discrimination: A case for anti-discrimination legislation*. London, United Kingdom: C. Hurst & Company.
- Beecher, H. K. (1966). Ethics and clinical research. In J. M. Humber & R. F. Almeder (Eds.), *Biomedical ethics and the law* (pp. 193-205). New York, NY: Plenum Press.
- Berger, R. (2013). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research, 13*(4), 468-494. <http://dx.doi.org/10.1177/1468794112468475>
- Bernert, D. J. (2011). Sexuality and disability in the lives of women with intellectual disabilities. *Sexuality and Disability, 29*, 129-141. <http://dx.doi.org/10.1007/s11195-010-9190-4>
- Bernert, D. J., & Ogletree, R. J. (2013). Women with intellectual disabilities talk about their perceptions of sex. *Journal of Intellectual Disability Research, 57*, 240-249. <http://dx.doi.org/10.1111/j.1365-2788.2011.01529.x>
- Bigby, C., & Frawley, P. (2010). Reflections on doing inclusive research in the "Making Life Good in the Community" study. *Journal of Intellectual and Developmental Disability, 35*, 53-61. <http://dx.doi.org/10.3109/13668251003716425>
- Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 27*, 3-12. <http://dx.doi.org/10.1111/jar.12083>
- Biklen, D., & Burke, J. (2006). Presuming competence. *Equity and Excellence in Education, 39*, 166-175. <http://dx.doi.org/10.1080/10665680500540376>
- Biklen, D., & Kliewer, C. (2006). Constructing competence: Autism, voice and the 'disordered' body. *International Journal of Inclusive Education, 10*, 169-188. <http://dx.doi.org/10.1080/13603110600578208>
- Bishop, B. J., & Dzidic, P. L. (2014). Dealing with wicked problems: Conducting a causal layered analysis of complex social psychological problems. *American Journal of Community Psychology, 53*, 13-24. <http://dx.doi.org/10.1007/s10464-013-9611-5>
- Bishop, B. J., Sonn, C. C., Drew, N. M., & Contos, N. E. (2002). The evolution of epistemology and concepts in an iterative-generative reflective practice: The importance of small differences. *American Journal of Community Psychology, 30*, 493-510. <http://dx.doi.org/10.1023/A:1015855801188>
- Björnsdóttir, K., & Svendsdóttir, A. S. (2008). Gambling for capital: learning disability, inclusive research and collaborative life histories. *British Journal of Learning Disabilities, 36*, 263-270. <http://dx.doi.org/10.1111/j.1468-3156.2008.00499.x>

- Blatt, B. (1999). *The collected papers of Burton Blatt: In search of the promised land*. Washington, DC: American Association on Mental Retardation.
- Bogdan, R., & Taylor, S. J. (1982). *Inside out: The social meaning of mental retardation*. Toronto, Canada: University of Toronto Press.
- Booth, T. (2003). In the frame: Photovoice and mothers with learning difficulties. *Disability & Society, 18*, 431-442.  
<http://dx.doi.org/10.1080/0968759032000080986>
- Box, M., & Shawe, J. (2014). The experiences of adults with learning disabilities attending a sexuality and relationship group: "I want to get married and have kids". *Journal of Family Planning and Reproductive Health Care, 40*, 82-88.  
<http://dx.doi.org/10.1136/jfprhc-2012-100509>
- Boxall, K., & Ralph, S. (2009). Research ethics and the use of visual images in research with people with intellectual disability. *Journal of Intellectual and Developmental Disability, 34*, 45-54.  
<http://dx.doi.org/10.1080/13668250802688306>
- Braddock, D. L., & Parish, S. L. (2001). An institutional history of disability. In G. L. Albrecht, K. D. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 11-68). Thousand Oaks, CA: Sage.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology 3*, 77-101.  
<http://dx.doi.org/10.1191/1478088706qp063oa>
- Breen, L. J. (2009). Early childhood service delivery for families living with childhood disability: Disabling families through problematic implicit ideology. *Australasian Journal of Early Childhood, 34*(4), 14-21. Retrieved from <http://www.earlychildhoodaustralia.org.au/our-publications/australasian-journal-early-childhood/>
- Breen, L. J., & Darlaston-Jones, D. (2010). Moving beyond the enduring dominance of positivism in psychological research: Implications for psychology in Australia. *Australian Psychologist, 45*, 67-76.  
<http://dx.doi.org/10.1080/00050060903127481>
- Breen, L. J., & O'Connor, M. (2014). From consultation to participation in public health research: Reflections on a community-based research partnership. *BMC Research Notes, 7*, 936. <http://dx.doi.org/10.1186/1756-0500-7-936>
- Brickman, P., Rabinowitz, V. C., Karuza, J., Coates, D., Cohn, E., & Kidder, L. (1982). Models of helping and coping. *American Psychologist, 37*, 368-384.  
<http://dx.doi.org/10.1037/0003-066X.37.4.368>
- Brown, H. (1994). An ordinary sexual life?: A Review of the normalisation principle as it applies to the sexual options of people with learning disabilities. *Disability & Society, 9*, 123-124.  
<http://dx.doi.org/10.1080/09687599466780181>
- Burgess-Limerick, T., & Burgess-Limerick, R. (1998). Conversational interviews and multiple-case research in psychology. *Australian Journal of Psychology, 50*, 63-70. <http://dx.doi.org/10.1080/00049539808257535>
- Burke, A., McMillan, J., Cummins, L., Thompson, A., Forsyth, W., McLelan, J., . . . Wright, D. (2003). Setting up participatory research: A discussion of the initial stages. *British Journal of Learning Disabilities, 31*, 65-69.  
<http://dx.doi.org/10.1046/j.1468-3156.2003.00183.x>
- Burns, J., & Davies, D. (2011). Same-sex relationships and women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 24*, 351-360. <http://dx.doi.org/10.1111/j.1468-3148.2010.00609.x>

- Bussey, M. (2009). Causal layered pedagogy: Rethinking curricula practice. *Journal of Future Studies*, 13(3), 19-32. Retrieved from <http://www.jfs.tku.edu.tw/>
- Cambridge, P., & Forrester-Jones, R. (2003). Using individualised communication for interviewing people with intellectual disability: A case study of user-centred research. *Journal of Intellectual and Developmental Disability*, 28, 5-23. <http://dx.doi.org/10.1080/136682503100008687>
- Cambridge, P., & McCarthy, M. (1997). Developing and implementing sexuality policy for a learning disability provider service. *Health & Social Care in the Community*, 5, 227-236. <http://dx.doi.org/10.1111/j.1365-2524.1997.tb00118.x>
- Campaign, R., & Wilson, E. (2010). *Food court friends: Building relationships through research*. Melbourne, Australia:
- Chadwick, A. (1996). Knowledge, power and the disability discrimination bill. *Disability & Society*, 11, 25-40. <http://dx.doi.org/10.1080/09687599650023308>
- Chappell, A. L. (2000). Emergence of participatory methodology in learning difficulty research: Understanding the context. *British Journal of Learning Disabilities*, 28, 38-43. <http://dx.doi.org/10.1046/j.1468-3156.2000.00004.x>
- Chappell, A. L., Goodley, D., & Lawthorn, R. (2001). Making connections: The relevance of the social model of disability for people with learning difficulties. *British Journal of Learning Disabilities*, 29, 45-50. <http://dx.doi.org/10.1046/j.1468-3156.2001.00084.x>
- Clark, L., & Marsh, S. (2002). *Patriarchy in the UK: The language of disability*. Retrieved from <http://disability-studies.leeds.ac.uk/files/library/Clark-Laurence-language.pdf>
- Cocks, E. (1998, May). *Vision, values and strategies for the future: Time to return to basics*. Paper presented at the Council of Intellectual Disability Agencies Conference, Melbourne, Australia
- Cocks, E., & Allen, M. (1996). Discourses of disability. In E. Cocks, C. Fox, M. Brogan & M. Lee (Eds.), *Under blue skies: The social construction of intellectual disability in Western Australia* (pp. 282-318). Perth, Australia: Centre for Disability Research and Development, Faculty of Health and Human Sciences, Edith Cowan University.
- Cocks, E., & Cockram, J. (1995). The participatory research paradigm and intellectual disability. *Mental Handicap Research*, 8. <http://dx.doi.org/10.1111/j.1468-3148.1995.tb00140.x>
- Corbett, J. (1994). A proud label: Exploring the relationship between disability politics and gay pride. *Disability & Society*, 9, 343-357. <http://dx.doi.org/10.1080/09687599466780381>
- Cornish, F., & Gillespie, A. (2009). A pragmatist approach to the problem of knowledge in health psychology. *Journal of Health Psychology*, 14, 800-809. <http://dx.doi.org/10.1177/1359105309338974>
- Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.
- Davies, C. A. (1998). Constructing other selves: (In)competences and the category of learning difficulties. In R. Jenkins (Ed.), *Questions of competence: Culture, classification and intellectual disability* (pp. 102-124). Cambridge, United Kingdom: Cambridge University Press.
- Day, S. (2007). A reflection on PostModernism and the transformation of failure in learning disability services within the independent public sector at the

- beginning of the 21st century. *British Journal of Learning Disabilities*, 35, 38-42. <http://dx.doi.org/10.1111/j1468-3156.2006.00389.x>
- Devlin, R., & Pothier, D. (2006). Introduction: Toward a critical theory of dis-citizenship. In D. Pothier & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 1-24). Vancouver, Canada: UBC Press.
- Dewey, J. (1938). *Logic: The theory of enquiry*. Oxford, United Kingdom: Holt.
- Disability Services Commission. Services, supports and eligibility. Retrieved from <http://www.disability.wa.gov.au/services-support-and-eligibility/services-supports-and-eligibility-new/eligibility/>
- Dokecki, P. R. (1996). *The tragi-comic professional: Basic considerations for ethical reflective-generative practice*. Pittsburgh, PA: Duquesne University Press.
- Dotson, L. A., Stinson, J., & Christian, L. (2003). People tell me I can't have sex. *Women & Therapy*, 26, 195-209. [http://dx.doi.org/10.1300/j015v26no3\\_02](http://dx.doi.org/10.1300/j015v26no3_02)
- Duignan, P. (2006). *Educational leadership: Key challenges and ethical tensions*. Cambridge, United Kingdom: Cambridge University Press.
- Dupras, A., & Dionne, H. (2013). The concern of parents regarding the sexuality of their child with a mild intellectual disability. *Sexologies*, 23, 79-83. <http://dx.doi.org/10.1016/j.sexol.2013.09.002>
- Eastgate, G. (2008). Sexual health for people with intellectual disability. *Salud Pública de México*, 50, 255-259. <http://dx.doi.org/10.1590/S0036-36342008000800019>
- Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. In C. Wilig & W. Stainton-Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (pp. 179-194). London, United Kingdom: Sage.
- Eddey, G. E., & Robey, K. L. (2005). Considering the culture of disability in cultural competence education. *Academic Medicine*, 80, 706-712. Retrieved from <http://journals.lww.com/academicmedicine/pages/default.aspx>
- Edgerton, R. B. (1993). *The cloak of competence: Stigma in the lives of the mentally retarded* (Rev. ed.). Berkeley, CA: University of California Press.
- Elias, M. J. (1994). Capturing excellence in applied settings: A participant conceptualizer and praxis explicator role for community psychologists. *American Journal of Community Psychology*, 22, 293-318. <http://dx.doi.org/10.1007/BF02506868>
- Elwood, S. (2007). Negotiating participatory ethics in the midst of institutional ethics. *ACME: An International E-Journal for Critical Geographies*, 6, 329-338. Retrieved from [http://www.acme-journal.org/vol6/SE.pdf?origin=publication\\_detail](http://www.acme-journal.org/vol6/SE.pdf?origin=publication_detail)
- Emerson, E., & McVilly, K. R. (2004). Friendship activities of adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Applied Research in Intellectual Disabilities*, 17, 191-197. <http://dx.doi.org/10.1111/j.1468-3148.2004.00198.x>
- Etherington, K. (1997). Research methods: Reflexivities- Roots, meanings, dilemmas. *Counseling and Psychotherapy Research*, 4, 46-47. <http://dx.doi.org/10.1080/14733140412331383963>
- Evans, D. S., McGuire, B. E., Healy, E., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part 2: Staff and family carer perspectives. *Journal of Intellectual Disability Research*, 53, 913-921. <http://dx.doi.org/10.1111/j.1365-2788.2009.01202.x>

- Fine, M. (1992). Passions, politics, and power: Feminist research possibilities. In M. Fine (Ed.), *Disruptive voices: The possibilities of feminist research* (pp. 205-231). Ann Arbor, MI: The University of Michigan Press.
- Fine, M., & Asch, A. (1988). Disability beyond stigma: Social interaction, discrimination, and activism. *Journal of Social Issues, 44*, 3-21. <http://dx.doi.org/10.1111/j.1540-4560.1988.tb02045.x>
- Finkelstein, V. (1980). *Attitudes and disabled people: Issues for discussion*. New York, NY: World Rehabilitation Fund.
- Finlay, L. (2002). "Outing" the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research, 12*, 531-545. <http://dx.doi.org/10.1177/104973202129120052>
- Finlay, W. M., & Lyons, E. (2005). Rejecting the label: A social constructionist analysis. *Mental Retardation, 43*, 120-134. [http://dx.doi.org/10.1352/0047-6765\(2005\)43<120:RTLASC>2.0.CO;2](http://dx.doi.org/10.1352/0047-6765(2005)43<120:RTLASC>2.0.CO;2)
- Fitzgerald, C., & Withers, P. (2013). 'I don't know what a proper woman means': What women with intellectual disabilities think about sex, sexuality and themselves. *British Journal of Learning Disabilities, 41*, 5-12. <http://dx.doi.org/10.1111/j.1468-3156.2011.00715.x>
- Foley, S. (2012). The UN Convention on the Rights of Persons with Disabilities: A paradigm shift in the sexual empowerment of adults with Down Syndrome or more sound and fury signifying nothing? *Sexuality and Disability, 30*, 381-393. <http://dx.doi.org/10.1007/s11195-012-9279-z>
- Ford, R. (1966). Quite intelligent. In P. Hunt (Ed.), *Stigma: The experience of disability* (pp. 31-43). London, United Kingdom: Geoffrey Chapman.
- Foucault, M. (1991). Governmentality. In G. Burchell, C. Gordon & P. Miller (Eds.), *The Foucault effect: Studies in governmentality* (pp. 87-104). Chicago, IL: University of Chicago Press.
- Frankfurt, H. G. (1958). Pierce's notion of abduction. *The Journal of Philosophy, 55*, 593-597.
- Frawley, P., & Bigby, C. (2011). Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia. *Journal of Intellectual and Developmental Disability, 36*, 27-38. <http://dx.doi.org/10.3109/13668250.2010.549465>
- Frawley, P., & Bigby, C. (2014). "I'm in their shoes": Experiences of peer educators in sexuality and relationship education. *Journal of Intellectual & Developmental Disability, 39*, 167-176. <http://dx.doi.org/10.3109/13668250.2014.890701>
- Gallagher, E. (2002). Adult clients with mild 'intellectual disability': Rethinking our assumptions. *Australian and New Zealand Journal of Family Therapy, 23*, 202-210. <http://dx.doi.org/10.1002/j.1467-8438.2002.tb00518.x>
- Garbutt, R. (2008). Sex and relationships for people with learning disabilities: A challenge for parents and professionals. *Mental Health and Learning Disabilities Research and Practice, 5*, 266-277. <http://dx.doi.org/10.5920/mhldrp.2008.52266>
- Gelb, S. A. (2002). The dignity of humanity is not a scientific construct. *Mental Retardation, 40*, 55-56. [http://dx.doi.org/10.1352/0047-6765\(2002\)040<0055:TDOHIN>2.0.CO;2](http://dx.doi.org/10.1352/0047-6765(2002)040<0055:TDOHIN>2.0.CO;2)
- Gerber, D. A. (1990). Listening to disabled people: The problem of voice and authority in Robert B. Edgerton's *The cloak of competence*. *Disability, Handicap & Society, 5*, 3-23. <http://dx.doi.org/10.1080/02674649066780011>



- Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American Psychologist*, 40, 266-275. <http://dx.doi.org/10.1037/0003-066X.40.3.266>
- Gilmore, L., & Chambers, B. (2010). Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees. *Journal of Intellectual & Developmental Disability*, 35, 22-28. <http://dx.doi.org/10.3109/13668250903496344>
- Giorgi, A., & Giorgi, B. (2008). Phenomenology. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 26-52). London, United Kingdom: Sage.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Harmondsworth, United Kingdom: Penguin Books.
- Gold, R. L. (1958). Roles in sociological field observations. *Social Forces*, 36, 217-223. Retrieved from <http://sf.oxfordjournals.org/>
- Gomez, M. T. (2012). The S words: sexuality, sensuality, sexual expression and people with intellectual disability. *Sexuality and Disability*, 30, 237-245. <http://dx.doi.org/10.1007/s11195-011-9250-4>
- Goodley, D. (1998). Supporting people with learning difficulties in self-advocacy groups and models of disability. *Health & Social Care in the Community*, 6, 438-446. <http://dx.doi.org/10.1046/j.1365-2524.1998.00136.x>
- Goodley, D. (2001). 'Learning difficulties', the social model of disability and impairment: Challenging epistemologies. *Disability & Society*, 16, 207-231. <http://dx.doi.org/10.1080/09687590120035816>
- Goodley, D. (2013). Dis/entangling critical disability studies. *Disability & Society*, 28, 631-644. <http://dx.doi.org/10.1080/09687599.2012.717884>
- Goodman, N. (1978). *Ways of worldmaking* (pp. 91-107). Indianapolis, IN: Hackett Publishing Company.
- Greenwood, D. J., & Levin, M. (1998). *Introduction to action research: Social research for social change*. Thousand Oaks, CA: Sage
- Gresham, F. M. (1986). On the malleability of intelligence: Unnecessary assumptions, reifications, and occlusion. *School Psychology Review*, 15, 261-263. Retrieved from <http://psycnet.apa.org/psycinfo/1986-21705-001>
- Grieve, A., McLaren, S., Lindsay, W., & Culling, E. (2008). Staff attitudes towards the sexuality of people with learning disabilities: A comparison of different professional groups and residential facilities. *British Journal of Learning Disabilities*, 37, 76-84. <http://dx.doi.org/10.1111/j.1468-3156.2008.00528.x>
- Guilleman, M., & Gillam, L. (2004). Ethics, reflexivity and, "ethically important moments" in research. *Qualitative Inquiry*, 10, 261-280. <http://dx.doi.org/10.1177/1077800403262360>
- Hamilton, C. (2002). Doing the wild thing: Supporting an ordinary sexual life for people with intellectual disabilities. *Disability Studies Quarterly*, 22(4), 40-59. Retrieved from <http://dsq-sds.org/article/view/371/489>
- Hamilton, C. A. (2009). 'Now I'd like to sleep with Rachael': Researching sexuality support in a service agency group home. *Disability & Society*, 24, 303-315. <http://dx.doi.org/10.1080/09687590902789461>
- Harrison, L., Johnson, K., Hillier, L., & Strong. (2001). Nothing about us without us: The ideals and realities of participatory action research with people with an intellectual disability. *Scandinavian Journal of Disability Research*, 3, 56-70. <http://dx.doi.org/10.1080/15017410109510776>

- Haverkamp, B. E. (2005). Ethical perspectives on qualitative research in applied psychology. *Journal of Counseling Psychology, 52*, 146-155. <http://dx.doi.org/10.1037/0022-0167.52.2.146>
- Healy, E., McGuire, B. E., Evans, D. S., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part 1: Service-user perspectives. *Journal of Intellectual Disability Research, 53*, 905-912. <http://dx.doi.org/10.1111/j.1365-2788.2009.01203.x>
- Hollomotz, A., & The Speakup Committee. (2008). 'May we please have sex tonight?': People with learning difficulties pursuing privacy in residential group settings. *British Journal of Learning Disabilities, 37*, 91-97. <http://dx.doi.org/10.1111/j.1468-3156.2008.00512.x>
- Hughes, B. (2007). Being disabled: Towards a critical social ontology for disability studies. *Disability & Society, 22*, 673-684. <http://dx.doi.org/10.1080/09687590701659527>
- Inayatullah, S. (1998). Causal layered analysis: Postconstructuralism as method. *Futures, 30*, 815-829. [http://dx.doi.org/10.1016/S0016-3287\(98\)00086-X](http://dx.doi.org/10.1016/S0016-3287(98)00086-X)
- Inayatullah, S. (2004). Causal layered analysis: Theory, historical context and case studies. In S. Inayatullah (Ed.), *The causal layered analysis (CLA) reader: Theory and case studies of an integrative and transformative methodology* (pp. 8-49). New Taipei City, Taiwan: Tamkang University Press.
- Jaeger, M. E., & Rosnow, R. L. (1988). Contextualism and its implications for psychological enquiry. *British Journal of Psychology, 79*, 63-75. <http://dx.doi.org/10.1111/j.2044-8295.1988.tb02273.x>
- Jenkins, R. (1998). Culture, classification and (in)competence. In R. Jenkins (Ed.), *Questions of competence: Culture, classification and intellectual disability* (pp. 1-24). Cambridge, United Kingdom: Cambridge University Press.
- Jenner, P., & Gale, T. M. (2006a). A relationship support service for people with learning difficulties. *Tizard Learning Disability Review, 11*(3), 18-25. <http://dx.doi.org/10.1108/13595474200600015>
- Jenner, P., & Gale, T. M. (2006b). The relationship support service: An update. *Tizard Learning Disability Review, 11*(4), 38-42. <http://dx.doi.org/10.1108/13595474200600036>
- Jingree, T., & Finlay, W. M. (2012). 'It's got so politically correct now': Parents talk about empowering individuals with learning disabilities. *Sociology and Health & Illness, 34*, 412-428. <http://dx.doi.org/10.1111/j.1467-9566.2011.01378.x>
- Johnson, K., Frawley, P., Hillier, L., & Harrison, L. (2002). Living safer sexual lives: Research and action. *Tizard Learning Disability Review, 7*(3), 4-9. <http://dx.doi.org/10.1108/13595474200200022>
- Johnson, K., Hillier, L., Harrison, L., & Frawley, P. (2001). *People with intellectual disabilities living safer sexual lives*. Melbourne, Australia: Australian Research Centre in Sex Health and Society. Retrieved from <http://apo.org.au/node/8657>
- Jones, C. (2009). Friendship, romance and possibly more. *Learning Disability Practice, 12*(2), 8-13. <http://dx.doi.org/10.7748/ldp2009.03.12.2.8.c8197>
- Jones, C., & Wilson, C. (2009). Defining advantage and athletic performance: The case of Oscar Pistorius. *European Journal of Sport Science, 9*, 125-131. <http://dx.doi.org/10.1080/17461390802635483>
- Kauffman, J. (1999). The role of science in behavioral disorders. *Behavioral Disorders, 24*, 265-272. Retrieved from <http://www.jstor.org/stable/23889066>

- Kelly, G., Crowley, H., & Hamilton, C. (2009). Rights, sexuality and relationships in Ireland: 'It'd be nice to be kind of trusted'. *British Journal of Learning Disabilities*, 37, 308-315. <http://dx.doi.org/10.1111/j.1468-3156.2009.00587.x>
- Kennedy, E. M. (1968, June 8). Tribute to Robert F. Kennedy [Audio Recording]. St. Patrick's Cathedral, NY City. The John F. Kennedy Presidential Library and Museum, Boston.
- Kliwer, C., Biklen, D., & Kasa-Hendrickson, C. (2006). Who may be literate? Disability and resistance to the cultural denial of competence. *American Educational Research Journal*, 43, 163-192. <http://dx.doi.org/10.3102/00028312043002163>
- Klotz, J. (2004). Sociocultural study of intellectual disability: Moving beyond labelling and social constructionist perspectives. *British Journal of Learning Disabilities*, 32, 93-104. <http://dx.doi.org/10.1111/j.1468-3156.2004.00285.x>
- Knight, K. (2013). The changing face of the 'good mother': Trends in research into families with a child with intellectual disability, and some concerns. *Disability & Society*, 28, 660-673. <http://dx.doi.org/10.1080/09687599.2012.732540>
- Knox, M., & Bigby, C. (2007). Moving towards midlife care as negotiated family business: Accounts of people with intellectual disabilities and their families "Just getting along with their lives together". *International Journal of Disability, Development and Education*, 54, 287-304. <http://dx.doi.org/10.1080/10349120701488749>
- Knox, M., & Hickson, F. (2001). The meanings of close friendship: The views of four people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 14, 276-291. <http://dx.doi.org/10.1046/j.1468-3148.2001.00066.x>
- Koch, T., & Harrington, A. (1998). Reconceptualising rigour: The case for reflexivity. *Journal of Advanced Nursing*, 28, 882-890. <http://dx.doi.org/10.1046/j.1365-2648.1998.00725.x>
- Kuhn, T. S. (2012). *The structure of scientific revolutions: 50th anniversary edition with an introductory essay by Ian Hacking* (4th ed.). Chicago, IL: The University of Chicago Press.
- Lafferty, A., McConkey, R., & Taggart, L. (2013). Beyond friendship: The nature and meaning of close personal relationships as perceived by people with learning disabilities. *Disability & Society*, 28, 1074-1088. <http://dx.doi.org/10.1080/09687599.2012.758030>
- Levine, R. A., & Campbell, D. T. (1972). *Ethnocentrism: Theories of conflict, ethnic attitudes and group behavior*. Oxford, United Kingdom: John Wiley and Sons.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Löfgren-Martenson, L. (2004). "May I?" About sexuality and love in the new generation with intellectual disabilities. *Sexuality and Disability*, 22, 197-207. <http://dx.doi.org/10.1023/B:SEDI.0000039062.73691.cb>
- Löfgren-Martenson, L. (2009). The invisibility of young homosexual women and men with intellectual disabilities. *Sexuality and Disability*, 27, 21-26. <http://dx.doi.org/10.1007/s11195-008-9101-0>
- Lukes, S. (1972). *Individualism*. Oxford, United Kingdom: Basil Blackwell.

- Lund, T. (2005). The qualitative-quantitative distinction: Some comments. *Scandinavian Journal of Educational Research*, 49, 115-132. <http://dx.doi.org/10.1080/00313830500048790>
- Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, 91, 1-20. <http://dx.doi.org/10.1348/000712600161646>
- Mall, S., & Swartz, L. (2012). Sexuality, disability and human rights: Strengthening health care for disabled people. *South African Medical Journal*, 102, 792-793. Retrieved from <http://www.samj.org.za/index.php/samj>
- Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum: Qualitative Social Research*, 11(3), Online publication. Retrieved from <http://www.qualitative-research.net/index.php/fqs/index>
- Matsumoto, D., & Juang, L. (2008). *Culture and psychology* (4th ed.). Belmont, CA: Thomson Higher Education.
- May, D. (2000). Becoming adult: School-leaving, jobs and the transition to adult life. In D. May (Ed.), *Transition and change in the lives of people with intellectual disabilities* (pp. 75-96). London, United Kingdom: Jessica Kingsley.
- May, D., & Simpson, M. K. (2003). The parent trap: Marriage, parenthood and adulthood for people with intellectual disabilities. *Critical Social Policy*, 23, 25-43. <http://dx.doi.org/10.1177/026101830302300102>
- McCarthy, M. (2014). Women with intellectual disability: Their sexual lives in the 21st century. *Journal of Intellectual and Developmental Disability*, 39, 124-131. <http://dx.doi.org/10.3109/13668250.2014.894963>
- McCarthy, T. (1984). *The critical theory of Jurgen Habermas*. Cambridge, MA: The MIT Press.
- McClimens, A. (2003). The organization of difference: People with intellectual disabilities and the social model of disability. *Mental Retardation*, 41, 35-46. [http://dx.doi.org/10.1352/0047-6765\(2003\)041<0035:TOODPW>2.0.CO;2](http://dx.doi.org/10.1352/0047-6765(2003)041<0035:TOODPW>2.0.CO;2)
- McConkey, R., & Ryan, D. (2001). Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability. *Journal of Intellectual Disability Research*, 45, 83-87. <http://dx.doi.org/10.1111/j.1365-2788.2001.00285.x>
- McDonald, K. E., Keys, C. B., & Henry, D. B. (2008). Gatekeepers of science: Attitudes toward the research participation of adults with intellectual disability. *American Journal of Mental Retardation*, 113, 466-478. <http://dx.doi.org/10.1352/2008.113:466-478>
- McDougall, K. (2006). 'Ag shame' and superheroes: Stereotype and the signification of disability. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider & M. Priestley (Eds.), *Disability and social change: A South African agenda* (pp. 387-400). Cape Town, South Africa: Human Sciences Research Council.
- McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. (2006a). Self-advocates have the last say on friendship. *Disability & Society*, 21, 693-708. <http://dx.doi.org/10.1080/09687590600995287>
- McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. M. (2006b). I get by with a little help from my friends: Adults with intellectual disability discuss loneliness. *Journal of Applied Research in Intellectual Disabilities*, 19, 191-203. <http://dx.doi.org/10.1111/j.1468-3148.2005.00261.x>
- Meaney-Tavares, R., & Gavidia-Payne, S. (2012). Staff characteristics and attitudes towards the sexuality of people with intellectual disability. *Journal of*

- Intellectual and Developmental Disability*, 37, 269-273.  
<http://dx.doi.org/10.3109/13668250.2012.701005>
- Meekosha, H., & Shuttleworth, R. (2009). What's so 'critical' about critical disability studies? *Australian Journal of Human Rights*, 15(1), 47-75. Retrieved from <http://www.austlii.edu.au/au/journals/AJHR/>
- Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society*, 24, 47-62.  
<http://dx.doi.org/10.1080/09687590802535410>
- Mirza, H. S. (1998). Race, gender and IQ: The social consequence of a pseudo-scientific discourse. *Race Ethnicity and Education*, 1, 109-126.  
<http://dx.doi.org/10.1080/1361332980010108>
- Moghaddam, F. M. (1990). Modulative and generative orientations in psychology: Implications for psychology. *Journal of Social Issues*, 46(3), 21-41.  
<http://dx.doi.org/10.1111/j.1540-4560.1990.tb01932.x>
- Montero, M. (2000). Participation in participatory action research. *Annual Review of Critical Psychology*, 2, 131-143. Retrieved from <http://www.discourseunit.com/annual-review/arcp-2-action-research/>
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology*, 52, 250-260.  
<http://dx.doi.org/10.1037/0022-0167.52.2.250>
- Munger, K. M., Gill, C. J., Ormond, K. E., & Kirschner, K. L. (2007). The next exclusion debate: Assessing technology, ethics, and, intellectual disability after the human genome project. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 121-128.  
<http://dx.doi.org/10.1002/mrdd.20146>
- National Health and Medical Research Council. (2007). *National statement on ethical conduct in human research 2007* Canberra, Australia: Commonwealth of Australia. Retrieved from <https://www.nhmrc.gov.au/guidelines-publications/e72>
- Neely-Barnes, S. L., Graff, C. J., Roberts, R. J., Hall, H. R., & Hankins, J. S. (2010). "It's our job": Qualitative study of family responses to ableism. *Intellectual and Developmental Disabilities*, 48, 245-258.  
<http://dx.doi.org/10.1352/1934-9556-48.4.245>
- Nehring, W. M. (2007). Cultural considerations for children with intellectual and developmental disabilities. *Journal of Paediatric Nursing*, 22, 93-102.  
<http://dx.doi.org/10.1016/j.pedn.2006.07.007>
- Northway, R. (1998). Engaging in participatory research: Some personal reflections. *Journal of Intellectual Disabilities*, 2, 144-149.  
<http://dx.doi.org/10.1177/146900479800200305>
- Northway, R. (2000). Disability, nursing research and the importance of reflexivity. *Journal of advanced nursing*, 32(2), 391-397.  
<http://dx.doi.org/10.1046/j.1365-2648.2000.01488.x>
- O'Neil, P. (1989). Responsible to whom? Responsible for what? Some ethical issues in community intervention. *American Journal of Community Psychology*, 17, 323-341. <http://dx.doi.org/10.1007/BF00931040>
- Oliver, M. (1992). Changing the social relations of research production? *Disability, Handicap & Society*, 7, 101-114.  
<http://dx.doi.org/10.1080/02674649266780141>

- Oliver, M. (1996a). Defining impairment and disability: Issues at stake. In C. Barnes & G. Mercer (Eds.), *Exploring the divide: Illness and disability* (pp. 29-54). Leeds, United Kingdom: The Disability Press.
- Oliver, M. (1996b). *Understanding disability: From theory to practice*. New York, NY: St Martin's Press.
- Oliver, M. (1997). Emancipatory research: Realistic goal or impossible dream? In C. Barnes & G. Mercer (Eds.), *Doing disability research* (pp. 15-31). Leeds: The disability press.
- Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society*, 28, 1024-1026. <http://dx.doi.org/10.1080/09687599.2013.818773>
- Opie, A. (1992). Qualitative research, appropriation of the 'other' and empowerment. *Feminist Review*, 40, 52-70. Retrieved from <http://www.jstor.org/stable/1395277>
- Osburn, J. (2006). An overview of social role valorization theory. *The SRV journal*, 1, 4-13. Retrieved from <http://www.socialrolevalorization.com/articles/journal/>
- Parsons, C. (2008). The dignity of risk: Challenges in moving on. *Australian Nursing Journal*, 15(9), 28. Retrieved from <http://search.informit.com.au/browseJournalTitle;res=IELHEA;issn=1320-3185>
- Pepper, S. C. (1942). *World hypotheses: A study in evidence*. Los Angeles, CA: University of California Press.
- Perske, R. (1972). The dignity of risk and the mentally retarded. *Mental Retardation*, 10(1), 24-27. Retrieved from <http://psycnet.apa.org/psycinfo/1972-23551-001>
- Pfeiffer, D. (1994). Eugenics and disability discrimination. *Disability & Society*, 9, 481-499. <http://dx.doi.org/10.1080/09687599466780471>
- Pham, D. N. (2012). *The voices unheard: Exploring how young people with disabilities view and experience their growing up as sexual beings. A case study in Akshay Prathisthan, New Delhi, India*. (Master's dissertation, International Institute of Social Studies), The Hague, The Netherlands. Retrieved from <http://thesis.eur.nl/pub/13286/>
- Pilnick, A., Clegg, J., Murphy, E., & Almack, K. (2011). 'Just being selfish for my own sake...': Balancing the views of young adults with intellectual disabilities and their carers in transition planning. *The Sociological Review*, 59, 303-323. <http://dx.doi.org/10.1111/j.1467-954X.2011.02006.x>
- Pitt, V., & Curtin, M. (2004). Integration versus segregation: The experiences of a group of disabled students moving from mainstream school into special needs further education. *Disability & Society*, 19, 387-401. <http://dx.doi.org/10.1080/09687590410001689485>
- Polkinghorne, D. E. (2005). Language and meaning: Data collection in qualitative research. *Journal of Counseling Psychology*, 52, 137-145. <http://dx.doi.org/10.1037/0022-0167.52.2.137>
- Povee, K., Bishop, B. J., & Roberts, L. D. (2014). The use of photovoice with people with intellectual disabilities: Reflections, challenges and opportunities. *Disability & Society*, 29(893-907) <http://dx.doi.org/10.1080/09687599.2013.874331>
- Pownall, J. D., Jahoda, A., & Hastings, R. P. (2012). Sexuality and sex education of adolescents with intellectual disability: Mothers' attitudes, experiences and support needs. *Intellectual and Developmental Disabilities*, 50, 140-154. <http://dx.doi.org/10.1352/1934-9556-50.2.104>

- Priestley, M. (1998). Constructions and creations: Idealism, materialism and disability theory. *Disability & Society*, 13, 75-94.  
<http://dx.doi.org/10.1080/09687599826920>
- Priestley, M. (1999). *Disability politics and community care*. London, United Kingdom: Jessica Kingsley.
- Prilleltensky, I., & Fox, D. (1997). Introducing critical psychology: Values, assumptions, and the status quo. In Authors (Ed.), *Critical psychology: An introduction* (pp. 1-20). London, United Kingdom: Sage.
- Race, D., Boxall, K., & Carson, I. (2005). Towards a dialogue for practice: Reconciling social role valorisation and the social model of disability. *Disability & Society*, 20, 507-521.  
<http://dx.doi.org/10.1080/09687590500156196>
- Rapley, M. (2004). *Social construction of intellectual disability*. Cambridge, United Kingdom: Cambridge University Press.
- Rappaport, J. (2002). In praise of paradox: A social policy of empowerment over prevention. In T. A. Revenson, A. R. D'Augelli, S. E. French, D. L. Hughes, D. Livert, E. Seidman, M. Shinn & H. Yoshikawa (Eds.), *A Quarter Century of Community Psychology* (pp. 121-146). New York, NY: Kluwer Academic/Plenum Publishers.
- Reason, P., & Riley, S. (2008). Cooperative enquiry: An action research practice. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 207-235). London, United Kingdom: Sage.
- Reinders, J. S. (2002). The good life for citizens with intellectual disability. *Journal of Intellectual Disability Research*, 46, 1-5. <http://dx.doi.org/10.1046/j.1365-2788.2002.00386.x>
- Rembis, M. A. (2010). Beyond the binary: Rethinking the social model of disabled sexuality *Sexuality and Disability*, 28, 51-60.  
<http://dx.doi.org/10.1007/s11195-009-9133-0>
- Riedy, C. (2008). An integral extension of causal layered analysis. *Futures*, 40, 150-159. <http://dx.doi.org/10.1016/j.futures.2007.11.009>
- Rittel, H. W. J., & Webber, M. M. (1973). Dilemmas in a general theory of planning. *Policy Sciences*, 41, 155-169. <http://dx.doi.org/10.1007/BF01405730>
- Rocha, E. M. (1997). A ladder of empowerment. *Journal of Planning Education and Research*, 17, 31-44. <http://dx.doi.org/10.1177/0739456X9701700104>
- Rogers, C. (2010). But it's not all about the sex: Mothering, normalisation and young learning disabled people. *Disability & Society*, 25, 63-74.  
<http://dx.doi.org/10.1080/09687590903363365>
- Rorty, R. (1982). *Consequences of pragmatism: Essays, 1972-1980*. Minneapolis, MN: University of Minnesota Press.
- Rosenhan, D. L. (1973). On being sane in insane places. *Science*, 179, 250-258.  
<http://dx.doi.org/10.1126/science.179.4070.250>
- Rushbrooke, E., Murray, C., & Townsend, S. (2014a). The experiences of intimate relationships by people with intellectual disabilities: A qualitative study. *Journal of Applied Research in Intellectual Disabilities*, 27, 531-541.  
<http://dx.doi.org/10.1111/jar.12091>
- Rushbrooke, E., Murray, C. D., & Townsend, S. (2014b). What difficulties are experienced by caregivers in relation to the sexuality of people with intellectual disabilities? *Research in Developmental Disabilities*, 35, 871-886.  
<http://dx.doi.org/10.1016/j.ridd.2014.01.012>

- Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: Mothers, disabled children and disability studies. *Disability & Society*, 23, 199-210. <http://dx.doi.org/10.1080/09687590801953937>
- Saaltink, R., Mackinon, G., Owen, F., & Tardif-Williams, C. (2012). Protection, participation and protection through participation: Young people with intellectual disabilities and decision making in the family context. *Journal of Intellectual Disability Research*, 56, 1076-1086. <http://dx.doi.org/10.1111/j.1365-2788.2012.01649.x>
- Sanders, K. Y. (2006). Overprotection and lowered expectations of persons with disabilities: The unforeseen consequences. *Work: A Journal of Prevention, Assessment and Rehabilitation*, 27, 181-188. Retrieved from <http://iospress.metapress.com/content/7x044pcgney9kvuv/>
- Sarason, S. B. (1981). *Psychology misdirected*. New York, NY: The Free Press.
- Sarason, S. B. (1996). *Barometers of change: Individual, educational, and social transformation*. San Francisco, CA: Jossey-Bass.
- Sarason, S. B. (2000). Barometers of community change: Personal reflections. In J. Rappaport & E. Seidman (Eds.), *Handbook of community psychology* (pp. 919-929). New York, NY: Kluwer Academic/Plenum Publishers.
- Saxe, A., & Flanagan, T. (2014). Factors that impact support workers' perceptions of the sexuality of adults with developmental disabilities: A quantitative analysis. *Sexuality and Disability*, 32, 45-63. <http://dx.doi.org/10.1007/s11195-013-9314-8>
- Schrader, S., Jones, N., & Shattell, M. (2013). Mad pride: Reflections on sociopolitical and mental diversity in the context of culturally competent psychiatric care. *Issues in Mental Health Nursing*, 34, 62-64. <http://dx.doi.org/10.3109/01612840.2012.740769>
- Schriner, K. (2001). Disability and institutional change: A human variation perspective on overcoming oppression. *Journal of Disability Policy Studies*, 12, 100-106. <http://dx.doi.org/10.1177/104420730101200207>
- Scotch, R. K., & Schriner, K. (1997). Disability as human variation: Implications for policy. *Annals of American Academy of Political and Social Science*, 549, 148-159. Retrieved from <http://www.jstor.org/action/showPublication?journalCode=annaameracadpoli>
- Scott, D. (1997). The researcher's personal responses as a source of insight in the research process. *Nursing Inquiry*, 4, 130-134. <http://dx.doi.org/10.1111/j.1440-1800.1997.tb00086.x>
- Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 48-56. <http://dx.doi.org/10.1002/mrdd.20093>
- Shakespeare, T. (1998). Choices and rights: Eugenics, genetics and disability equality. *Disability & Society*, 13, 665-681. <http://dx.doi.org/10.1080/09687599826452>
- Shakespeare, T. (2000). Disabled sexuality: Toward rights and recognition. *Sexuality and Disability*, 18, 159-166. <http://dx.doi.org/10.1023/A:1026409613684>
- Shakespeare, T. (2004). Social models of disability and other life strategies. *Scandinavian Journal of Disability Research*, 6, 8-21. <http://dx.doi.org/10.1080/15017410409512636>
- Shakespeare, T., Gillespie-Sells, K., & Davies, D. (1996). *The sexual politics of disability: Untold desires*. New York, NY: Cassell.



- Shakespeare, T., & Watson, N. (1997). Defending the social model. *Disability & Society, 12*, 293-300. <http://dx.doi.org/10.1080/09687599727380>
- Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? *Research in Social Science and Disability, 2*, 9-28. [http://dx.doi.org/10.1016/S1479-3547\(01\)80018-X](http://dx.doi.org/10.1016/S1479-3547(01)80018-X)
- Sherry, M. (2004). Overlaps and contradictions between queer theory and disability studies. *Disability & Society, 19*, 769-783. <http://dx.doi.org/10.1080/0968759042000284231>
- Shildrick, M. (2007). Contested pleasures: The sociopolitical economy of disability and sexuality. *Sexuality Research & Social Policy, 4*, 53-66. <http://dx.doi.org/10.1525/srsp.2007.4.1.53>
- Shuttleworth, R. (2007). Introduction to special issue: Critical research and policy debates in disability and sexuality studies. *Sexuality Research & Social Policy, 4*, 1-14. <http://dx.doi.org/10.1525/srsp.2007.4.1.01>
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 53-80). London, United Kingdom: Sage.
- Smith, K. K. (1983). A role for community psychologists: As participant-conceptualizers. *Australian Psychologist, 18*, 143-160. <http://dx.doi.org/10.1080/00050068308256249>
- Soder, M. (2009). Tensions, perspectives and themes in disability studies. *Scandinavian Journal of Disability Research, 11*, 67-81. <http://dx.doi.org/10.1080/15017410902830496>
- Special Olympics Australia. (n.d.). Special Olympics Australia. Retrieved from <http://www.specialolympics.com.au/>
- Spina Bifida Association of WA Inc. (2007). *Supporting disability support workers: A self-paced learning guide workbook*. Retrieved from IdeasWA website: <http://www.ideaswa.net/upload/editor/files/downloads/SupportingDisabilitySupportWorkers-CoordinatorManual.pdf>
- Stephenson, J. (2000). Corporate capability: Implications for the style and direction of work-based learning (Working paper No. 99-14). Retrieved from University of Technology, Sydney, Research Centre for Vocational Education and Training website: <http://www.voced.edu.au/node/14908>
- Stoffelen, J., Kok, G., Hospers, H., & Curfs, L. M. G. (2013). Homosexuality among people with a mild intellectual disability: An explorative study on the lived experiences of homosexual people in the Netherlands with a mild intellectual disability. *Journal of Intellectual Disability Research, 57*(3), 257-267. <http://dx.doi.org/10.1111/j.1365-2788.2011.01532.x>
- Stringer, E. T. (2007). *Action research* (3rd ed.). Thousand Oaks, CA: Sage.
- Strnadová, I., & Cumming, T. M. (2014). People with intellectual disabilities conducting research: New directions for inclusive research. *Journal of Applied Research in Intellectual Disabilities, 27*, 1-2. <http://dx.doi.org/10.1111/jar.12075>
- Strnadová, I., Cumming, T. M., Knox, M., & Parmenter, T. R. (2014). Building an inclusive research team: The importance of team building and skills training. *Journal of Applied Research in Intellectual Disabilities, 27*, 13-22. <http://dx.doi.org/10.1111/jar.12076>
- Sullivan, C. (2010). Theory and method in qualitative research. In M. A. Forrester (Ed.), *Doing qualitative research in psychology* (pp. 15-38). London, United Kingdom: Sage.

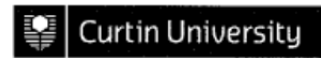
- Sullivan, F., Bowden, K., McKenzie, K., & Quayle, E. (2013). Touching people in relationships: A qualitative study of close relationships for people with an intellectual disability. *Journal of Clinical Nursing*, 22, 3456-3466. <http://dx.doi.org/10.1111/jocn.12375>
- Sultana, F. (2007). Reflexivity, positionality and participatory ethics: Negotiating fieldwork dilemmas in international research. *ACME: An International E-Journal for Critical Geographies*, 6(3), 374-385. Retrieved from <http://www.acme-journal.org/vol6/FS.pdf>
- Taylor, S. J. (2000). "You're not a retard, you're just wise": Disability, social identity, and family networks. *Journal of Contemporary Ethnography*, 29, 58-92. <http://dx.doi.org/10.1177/089124100129023828>
- Taylor, S. J., & Bogdan, R. (1980). Defending illusions: The institution's struggle for survival. *Human Organization*, 39, 209-218. Retrieved from <http://www.sfaa.net/>
- Tepper, M. (2000). Sexuality and disability: The missing discourse of pleasure. *Sexuality and Disability*, 18, 283-290. <http://dx.doi.org/10.1023/A:1005698311392>
- Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability & Society*, 19, 569-583. <http://dx.doi.org/10.1080/0968759042000252506>
- Tiefer, L. (1987). Social constructionism and the study of human sexuality. In P. Shaver & C. Hendrick (Eds.), *Sex and gender* (pp. 295-324). Thousand Oaks, CA: Sage.
- Todd, S., & Shearn, J. (1997). Family dilemmas and secrets: Parents' disclosure of information to their adult offspring with learning disabilities. *Disability & Society*, 12, 341-366. <http://dx.doi.org/10.1080/09687599727218>
- Tregaskis, C. (2002). Social model theory: The story so far... *Disability & Society*, 17, 457-470. <http://dx.doi.org/10.1080/09687590220140377>
- Tritter, J. Q., & McCallum, A. (2006). The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy*, 76, 156-168. <http://dx.doi.org/10.1016/j.healthpol.2005.05.008>
- Union of the Physically Impaired Against Segregation. (1976). *Fundamental principles of disability*. London, United Kingdom: Author.
- United Nations General Assembly. (2006). *Convention on the Rights of Persons with Disabilities*. Available from United Nations Retrieved from <http://www.un.org/disabilities/convention/conventionfull.shtml>
- van Hilvoorde, I., & Landeweerd, L. (2008). Disability or extraordinary talent: Francesco Lentini (three legs) versus Oscar Pistorius (no legs). *Sport, Ethics and Philosophy*, 2, 91-111. <http://dx.doi.org/10.1080/17511320802221778>
- van Uchelen, C. (2000). Individualism, collectivism, and community psychology. In J. Rappaport & E. Seidman (Eds.), *Handbook of community psychology* (pp. 65-78). New York, NY: Kluwer Academic/Plenum Publishers.
- Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, 16, 187-205. <http://dx.doi.org/10.1080/09687590120035807>
- Walmsley, J. (2004). Involving users with learning difficulties in health improvement: Lessons from inclusive learning disability research. *Nursing Inquiry*, 11, 54. <http://dx.doi.org/10.1111/j.1440-1800.2004.00197.x>

- Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures*. London, United Kingdom: Jessica Kingsley.
- Waterman, H. (1998). Embracing ambiguities and valuing ourselves: Issues of validity in action research. *Journal of Advanced Nursing*, 28, 101-105. <http://dx.doi.org/10.1046/j.1365-2648.1998.00763.x>
- Watzlawick, P., Weakland, J., & Fisch, R. (1974). *Change: Principles, problem formation and problem resolution*. New York, NY: Wiley.
- Weschler, D. (2003). *Wechsler intelligence scale for children—Fourth Edition (WISC-IV)*. San Antonio, TX: The Psychological Corporation.
- Wicker, A. W. (1989). Substantive theorizing. *American Journal of Community Psychology*, 17, 531-547. <http://dx.doi.org/10.1007/BF00922630>
- Williams, F., Scott, G., & McKeachie, A. (2014). Sexual health services and support: The views of younger adults with intellectual disability. *Journal of Intellectual and Developmental Disability*, 39, 147-156. <http://dx.doi.org/10.3109/13668250.2014.899326>
- Wilson, N. J., Parmenter, T. R., Stancliffe, R. J., & Shuttleworth, R. P. (2011). Conditionally sexual: Men and teenage boys with moderate to profound intellectual disability. *Sexuality and Disability*, 29, 275-289. <http://dx.doi.org/10.1007/s11195-011-9203-y>
- Winges-Yanez, N. (2014). Why all the talk about sex? An autoethnography identifying the troubling discourse of sexuality and disability. *Sexuality and Disability*, 32, 107-116. <http://dx.doi.org/10.1007/s11195-013-9331-7>
- Wolfensberger, W. (2000). A brief overview of social role valorization. *Mental Retardation*, 38, 105-123. [http://dx.doi.org/10.1352/0047-6765\(2000\)038<0105:ABOOSR>2.0.CO;2](http://dx.doi.org/10.1352/0047-6765(2000)038<0105:ABOOSR>2.0.CO;2)
- Wolfensberger, W. (2002). Social role valorization and, or versus, "empowerment". *Mental Retardation*, 40, 252-258. [http://dx.doi.org/10.1352/0047-6765\(2002\)040<0252:SRVAOV>2.0.CO;2](http://dx.doi.org/10.1352/0047-6765(2002)040<0252:SRVAOV>2.0.CO;2)
- Wolpert, J. (1980). The dignity of risk. *Transactions of the Institute of British Geographers* 5, 391-401. Retrieved from <http://www.jstor.org/action/showPublication?journalCode=traninstbritgeog>
- World Health Organisation. (2006). *Defining sexual health: Report of a technical consultation on sexual health, 28-31 January 2002, Geneva*. World Health Organisation. Retrieved from [http://www.who.int/reproductivehealth/publications/sexual\\_health/defining\\_s\\_h/en/](http://www.who.int/reproductivehealth/publications/sexual_health/defining_s_h/en/)
- Yacoub, E., & Hall, I. (2008). The sexual lives of men with mild learning disability: A qualitative study. *British Journal of Learning Disabilities*, 37, 5-11. <http://dx.doi.org/10.1111/j.1468-3156.2008.00491.x>
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 235-251). London, United Kingdom: Sage.
- Young, R., Gore, N., & McCarthy, M. (2012). Staff attitudes towards sexuality in relation to gender of people with intellectual disability: A qualitative study. *Journal of Intellectual & Developmental Disability*, 37, 343-347. <http://dx.doi.org/10.3109/13668250.2012.704983>
- Young, S. (2011, May 6). Changing the climate of disability Re: Ramp up [Web log message]. Retrieved from <http://www.abc.net.au/rampup/articles/2011/05/06/3210043.htm>

- Young, S. (2014, April). *I'm not your inspiration, thank you very much [Video file]*. Retrieved from [http://www.ted.com/talks/stella\\_young\\_i\\_m\\_not\\_your\\_inspiration\\_thank\\_you\\_very\\_much?language=en](http://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much?language=en)
- Zarb, G. (1992). On the road to Damascus: first steps towards changing the relations of disability research production. *Disability, Handicap & Society*, 7, 125-138. <http://dx.doi.org/10.1080/02674649266780161>

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

## Appendix A



## Memorandum

<b>To</b>	Associate Professor Clare Roberts, Psychology and Speech Pathology
<b>From</b>	Mrs Mandy Downing, A/Manager Research Ethics
<b>Subject</b>	<b>PROTOCOL APPROVAL – EXTENSION HR133/2011</b>
<b>Date</b>	18 October 2013
<b>Copy</b>	Emily Castell, Psychology and Speech Pathology Associate Professor Brian Bishop, Psychology and Speech Pathology

Office of Research and Development  
Human Research Ethics Committee

TELEPHONE 9266 2784

FACSIMILE 9266 3793

EMAIL hrec@curtin.edu.au

Thank you for keeping us informed of the progress of your research. The Human Research Ethics Committee acknowledges receipt of your progress report for the project *"Growing relationships: meanings, experiences and aspirations of people with intellectual disability."*

Approval for this project is extended to **04/10/2015**.

Your approval has the following conditions:

- (i) Annual progress reports on the project must be submitted to the Ethics Office.

Your approval number remains **HR133/2011**. Please quote this number in any further correspondence regarding this project.

Yours sincerely

Mrs Mandy Downing  
A/Manager Research Ethics

## Appendix B

### **Here is some information about stage one of a study called:**

---

“Growing relationships: Meanings, experiences and aspirations of people with intellectual disabilities”

### **You might know someone who wants to take part in this study.**

---



- I am the researcher
- My name is Emily Castell
- I am a student at Curtin University

### **What is the study about?**

- This study has lots of parts. This information tells you about the first part.
  - I want to find out how people with intellectual disability feel about their relationships.
  - This study will help people learn about the friends, partners, boyfriends and girlfriends of people with intellectual disability.
  - The things I learn might help other people with intellectual disability with their relationships
- 

### **Taking part in this study**

- I want to talk to people with intellectual disability about their relationships and feelings
- I will only talk to people who are 18 years of age or older, and who are able to talk
- I will talk to each person on their own, in a comfortable place
- I will audio-record what we talk about so that I can remember
- I would like to meet and talk with each person more than once
- Each time, we will talk for less than one hour
- We can take as many breaks as each person wants



When **this part of the study is done**, I will ask each person if they would like to do other parts.

When **all parts of the study are done**, I can tell people what I found out.

---

### **Keeping things safe**

- The things I learn in this part of the study will help me with other parts of the study
- I will keep all information safe and secret
- The only people who will know this information are Emily and the people who help her at university



**If I think that a person is being hurt, or is hurting someone else I will have to tell someone about it.**

---

### **Taking part in this study**

- Anyone doing this study can stop at any time
- If they stop, nothing will happen to them or to me
- Everyone doing this study must read an information sheet and sign a consent form
- For legal reasons, if a person has a guardian, their guardian must also sign the consent form
- If you are upset or worried about the study you can talk to my supervisor, Clare Roberts on XXXX XXXX.



### **Talking about the study**

- If you want to know more about the study, you can call Emily on XXX XXX XXX, or email Emily at [emily.castell@postgrad.curtin.edu.au](mailto:emily.castell@postgrad.curtin.edu.au)



---

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 133/2011). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning XXXX XXXX or by emailing [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au).

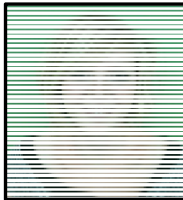
## Information – Stage one

---

### This study is called:

“Growing relationships: Meanings, experiences and aspirations of people with intellectual disabilities”

---



- I am the researcher
  - My name is Emily Castell
  - I am a student at Curtin University
- 

### About this study

- I want to find out how people with intellectual disability feel about the people they are close to.
  - This study has lots of parts. I am asking you to do the first part.
  - **To do this study, you must be 18 years of age or older and be able to talk.**
- 

### What will happen if you take part?

- I will talk to you about your feelings and the people you know
- I will talk to you in a quiet place
- I will audio-tape what we talk about so I can remember
- We will talk for less than one hour
- You can have a rest when you want to
- I would like to talk with you more than once
- When this part of the study is done, I will ask if you want to do other parts.
- When all the parts of the study are done, I can tell you what I found out.



### Keeping things safe

- The things we talk about will be used in other parts of the study
- The only people who will know what you say are Emily and the people who help her at university
- I will not tell other people your name
- I will choose a different name for you so that no-one knows what you say
- I will keep your information safe and secret





**If I think someone is hurting you or you are hurting someone else I will have to tell someone about it.**

---

### **Do you want to take part?**

- You do not have to do this study if you don't want to
- You can stop at any time
- If you stop, nothing will happen to you or me
- If you want to take part, please sign the consent form



### **Things for you to think about**

- If you take part, you will help others understand more about people with intellectual disability and their friends, boyfriends, girlfriends and partners
- I don't think anything bad will happen if you take part
- If you are upset or worried about the study you can talk to my supervisor, Clare Roberts on XXXX XXXX.



### **Talking about taking part**

- If you want to talk about the study, you can call Emily on XXX XXX XXX, or email Emily at [emily.castell@postgrad.curtin.edu.au](mailto:emily.castell@postgrad.curtin.edu.au)



**If you want to do the study, please talk about it with a friend, someone in your family or another person who you know. This may help you make a decision.**



**Emily will give you another sheet of paper about the study for you to show to people who want to know more.**



**For legal reasons, if you have a guardian, they will also have to sign a consent form before you take part.**



---

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 133/2011). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning XXXX XXXX or by emailing [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au).

### Consent form – part one

---

**This is a consent form for a study called:**

“Growing relationships: Meanings, experiences and aspirations of people  
with intellectual disabilities”

---

**Please read this sheet. If you like, you can talk about it with someone.**

**After reading each line, please circle the  or the **

---

- I have read information about the study  or 
- I am at least 18 years old  or 
- I can talk  or 
- If I am not sure about the study, I have asked  
Emily questions  or 
- I don't have to take part if I don't want to  or 
- I can stop taking part when I want  or 
- My information will be kept safe and secret  or 
- I am ok with Emily audio-recording what I say to her  or 
- If Emily thinks that someone is hurting me, or I am hurting someone, she  
will have to tell someone about it  or 
- I want to take part in this study  or 

---

**If you have circled all of  the, please write your name, phone  
number and your signature:**

**Name:** \_\_\_\_\_

**(Please print)**

**Contact number:** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

---

---

**If you have a guardian, they will need to read this consent form and agree for you to take part in the study. If you are a guardian for the consenting person, and you agree with this form, please fill out this section:**

**Name:** \_\_\_\_\_

**(Please print)**

**Contact number:** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

### Verbal Consent Protocol

---

**Title of project:** "Growing relationships: Meanings, experiences and aspirations of people with intellectual disabilities"

**Researcher:** Emily Castell, PhD student, School of Psychology and Speech Pathology, Curtin University

---

**Prior to administering the verbal consent protocol:**

The researcher will seek permission from the expert to audio-record the verbal consent procedure. The researcher will inform the expert that no identifying information will be used within this recording.

**Verbal consent protocol**

1. The researcher will state the code number of the expert, for record-keeping
2. The researcher will read the information sheet aloud to the expert, throughout, the researcher will pause and ask the expert:
  - a. *"Do you have any questions?"*
3. The researcher will discuss the details of the project with the expert, paraphrasing the content contained within the information sheet.
4. Subsequently, the researcher will ask the expert:
  - a. *"Are you interested in taking part in this project?"*

If the expert responds "Yes", the researcher will continue with the consent protocol.

---

5. The researcher will ask the expert the following questions, and circle the response given:
  - a. *"Are you able to talk?"* (Yes / No)
  - b. *"Are you 18 years of age or older?"* (Yes / No)

If the expert responds "yes" to both questions, then the researcher will continue with the consent protocol.

6. The researcher will then state each of the following sentences (ticking that each statement has been said):
  - If you do not want to do (the activity), this is fine, let me know
  - If you want to stop talking at any time, this is fine, let me know
  - I will keep your information safe and secret
  - If I think that you are being hurt, or you are hurting someone else, I will have to tell someone

- Nothing bad will happen if you decide not to take part
- I will audio-record the things we talk about, is this ok? (Yes / No)
- Do you want to take part in this project? (Yes / No)

7. Once all statements have been said, and provided that the expert answers "yes" to the last two statements, the research activity will proceed.
8. If the expert answers "No" to the either of the last two statements, the researcher will arrange for the individual to return to their home/the location they were transported from.

---

**Verbal consent obtained (circle one):** Yes / No

Researcher name and signature: \_\_\_\_\_ Date: \_\_\_\_\_

Expert code number: \_\_\_\_\_ Expert contact details: \_\_\_\_\_

---

**Consent for participation from legal guardian**

The researcher will find out whether the expert has a legal guardian.

If the expert has legal guardian, the researcher will provide them with an information sheet for stage one and ask them to sign below to consent for the expert to take part in the study.

If you are a legal guardian for the consenting person and you have read and agreed with the information sheet that Emily has provided you, please fill out this section:

Name: \_\_\_\_\_ (Please print)

Contact number: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Pictures to be used in conjunction with verbal consent protocol**

---

**Title of project:** "Growing relationships: Meanings, experiences and aspirations of people with intellectual disabilities"

**Researcher:** Emily Castell, PhD student, School of Psychology and Speech Pathology, Curtin University

---

NOTE: Pictures will be printed, laminated and presented individually as visual aids for experts throughout administration of the verbal consent protocol.

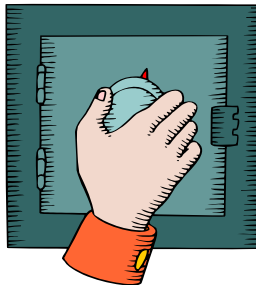
- I. A picture of the researcher:



- II. With reference to interviews:



- III. Keeping things safe and secret:



- IV. Using the telephone/talking to Emily:



V. Talking things over with someone else:



VI. Thinking about the study:



VII. Asking a guardian to sign the consent form:





### **Subsequent Verbal Consent Protocol**

---

**Title of project:** "Growing relationships: Meanings, experiences and aspirations of people with intellectual disabilities"

**Researcher:** Emily Castell, PhD student, School of Psychology and Speech Pathology, Curtin University

---

**Prior to administering the verbal consent protocol:**

The researcher will seek permission from the expert to audio-record the verbal consent procedure. The researcher will inform the expert that no identifying information will be used within this recording.

**Verbal consent protocol**

1. The researcher will state the code number of the expert, for record-keeping
  2. The researcher will explain the activity the expert is about to engage in (e.g., an interview or "have a chat")
  3. The researcher will ask:  
     *"Do you have any questions?"*
  4. The researcher will then state each of the following sentences, ticking that each statement has been said:
    - If you do not want to have a chat today, this is fine, let me know
    - If you want to stop talking at any time, this is ok, let me know
    - I will keep your information safe and secret
    - If I think that you are being hurt, or you are hurting someone else, I will have to tell someone
    - Nothing bad will happen if you decide that you don't want to have a chat today
    - I will audio-record the things we talk about
    - Do you want to have a chat today?
  5. Once all statements have been said, and provided that the expert answers "yes" to the last statement, the research activity will proceed.
  6. If the expert answers "No" to the last statement, the researcher will arrange for the individual to return to their home/the location they were transported from.
- 

**Verbal consent obtained (circle one):** Yes / No

Researcher signature: \_\_\_\_\_ Date: \_\_\_\_\_

Expert code number: \_\_\_\_\_

### Appendix C

Hello,

My name is Emily Castell, and I am doing my PhD in Psychology at Curtin University.

I have been doing a project on the close relationships and sexuality of adults with 'intellectual disability'. I have spoken to community-members with intellectual disability, family members, service-providers, support-workers and others about close relationships, sexuality and 'intellectual disability'.

The project is now coming to an end, and I would like to ask people from the community for their thoughts about the research findings. Finding out how community-members feel about the findings will let me know how useful they are to the community.

Below are some of the things that people have shared with me. It would be great if you could take time to read them, and let me know what you think.

If you know anyone else who might be interested to read and share their ideas on these findings, please pass this on to them.

#### Key Findings

What community members with intellectual disability told me:

Some had a boyfriend, girlfriend or partner. Some wanted to get married, move out with a partner and have children.

Some were happy to be single. Others really wanted to have a boyfriend, girlfriend or partner.

They spoke about the value of feeling important to and sharing life with someone.

Some spoke about spending time with friends, family members and others at clubs and programs for people with disability.

Some said that they were often joined by a carer, brother or sister, parent or support-worker when out with friends.

Some said that it would be good to have more time alone in private with friends, boyfriends, girlfriends and partners.

Some said that when out at social events, kissing and hugging were not allowed or could get them into trouble.

There are some people who do not think they should have children, or get married, just because they have an 'intellectual disability'.

They should have a right to be in a relationship, to have privacy and choice in day-to-day life. Intellectual disability is not a good reason to deny these rights and choices.

Parents of people with intellectual disability were expected:

To make good decisions for their adult son or daughter.

To protect, and also support, their son or daughter to have a relationship and express sexuality.

At the moment it seems that while some are able to have relationships, others are not. Attitudes about intellectual disability stop some people from having relationships and expressing sexuality.

Thank you for reading these findings. I would love to know your ideas and thoughts on them.

If you would like to share your thoughts with me, you can get in touch by 13<sup>th</sup> February 2015

Email: [emily.castell@curtin.edu.au](mailto:emily.castell@curtin.edu.au)

Telephone on XXXX XXX (between 10am-4pm, Monday, Wednesday, Thursday and Friday)

If you know anyone who might also like to read this information, and share their ideas, please pass it on to them.

Thank you for your time and efforts,

Emily Castell