

**PUBLIC POLICY AND SERVICES:  
RETHINKING THE APPROACH TO  
CARERS AND THEIR DEPENDANTS.**

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# ABSTRACT

Unpaid carers perform a vital role in supporting the lives of dependent people with disabilities. This load is borne at significant personal cost and many carers are entrapped in extended, possibly lifetime, obligations. The severe physical, mental and material impact of caring is well documented in qualitative and quantitative research.

Carers are represented in government policy, but the focus there is to ensure carers can continue to care. Thus commitments by the Australian government, particularly new funding commitments under the Disability Care Framework, assume a lifetime commitment by carers to the care and management of their dependent family members with disabilities. This approach does not consider the treatment or opinion of carers to being so committed.

This thesis explores whether carers are treated fairly in theory and policy and finds that prevailing theories and policy permit carer entrapment. It derives a new fair care theory, asks whether this theory resonates with carers, and demonstrates how this new theory could be implemented in policy.

Three analytical methods are used. The first draws from Bacchi's "What's the Problem Represented to be" (WPR) method of policy analysis, which asserts that all policy is framed to fix a problem, and how a problem is represented determines the ensuing policy. Bacchi's method is derived from Foucault's concepts and some critiques of Foucault validate the use of complementary methods to extend the reach of Foucauldian approaches. To include the absent voices of carers, qualitative interviews with carers are used as a second method. To pursue alternative problematisations, this thesis then employs a third approach drawn from ideal political theories and models.

These combined methods allow prevailing voices, theories, and policy problematisations to be disrupted by alternative voices, theories and problematisations. To develop an alternative theoretical solution, the thesis investigates Kittay's care constructs alongside Rawls's theory of justice and so constructs an alternative new fair care theory. The policy and theoretical analysis and the interviews with carers affirm that the new fair care theory addresses carer entrapment, resonates with the majority of carers interviewed, and could be employed to reframe care policy and attain the fair treatment of carers.

# 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.

Part of the research for this thesis was conducted in accordance with ethics approval, reference number: 5201000516.



Michelle Dellagiacoma

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# Chapter 1 – Introduction and Background

## 1.1 Introduction

Choose to be a carer? No with a capital N. Loss of control of own life, caring lasts a life span even with supported care, I'd still be a carer, still his advocate, still overseeing the emotional and administrative side plus being the in-between person resolving things. (Maria);

When I'm home with Izzy in the house, I just feel trapped, in a prison, another universe, not a normal person. Sometimes I have to escape to the front lawn to feel air and breathe. (Sue); and

(As a carer I] feel excluded from others your age and other family members, can't go to lots of places. (Barbara).

These were the views of three of the carers interviewed; they were responding to the question: "Would you choose to be a carer?" This thesis will argue that Carers <sup>1</sup> of dependent people are constrained by their caring role. Some, like the three carers quoted above, feel excluded and entrapped.

This thesis explores whether carers are treated fairly in theory<sup>2</sup> and policy, and finds that prevailing theories and policy do not consider carers' views, and permit carer entrapment. To address carer entrapment this thesis derives a new fair care theory, asks whether this theory resonates with carers, and demonstrates how it could be implemented in policy.

This chapter introduces the thesis, briefly outlining carers' situations, international trends in care and the background to the carer interviews. This thesis spans political theory, public policy and interviews with carers. This is because, in my community and

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<sup>1</sup> For the purposes of this thesis, the term carer refers to the unpaid person who has the primary care of a dependent person with a disability.

<sup>2</sup> I use the term 'theory' to refer to the ideal models specified in the fields of disability, care and political philosophy because experts in these fields refer to their models and approaches as 'theory'; for example the prominent political philosopher Rawls refers to his ideal model as a Theory of justice.

policy work I observed the direct line between disability self-advocacy, disability theory and disability policy and compared this with the apparently limited carer self-advocacy, carer theory and policy.

I am a carer. In the early 2000s, I was a member of the Disability Advisory Council of New South Wales (NSW), hereafter referred to as the Council. The Council is a legislated state government advisory council<sup>3</sup>. In this period, I was also a member of the board of Carers NSW, a peak state advocacy board, and founder of a carer support group. I have multiple positions with the subject area of the thesis. For the last 20 years I've worked in policy in state government. I am also a carer. This background means that I am positioned as an insider for much of this thesis via my affinity with carers and the interview participants and a practical appreciation of the political and policy process. These positions mean I have the sympathy for carers which is partially balanced by an understanding of the limits and constraints of the policy process.

The Council's members are interviewed by its Chair and appointed by the NSW Government for a fixed term. The Council seeks to be representative of the disabled population. Accordingly, its membership primarily comprises people with a variety of physical disabilities, with the remainder of the Council consisting of researchers, practitioners, generally one person with a mild intellectual disability, and a few carers of disabled people. The Council is supported by a government-funded secretariat. In my six years attending Council meetings I often observed both members and staff refer to disability theory and the "social model of disability" as central to instructing the treatment of people with disabilities. Council members often remarked on how a policy or initiative had missed the point or somehow misunderstood the application of disability theory. It struck me that adherence to disability theory was seen as essential in directing disability policy. When Council members referred to carers, they reflected the assumption in disability theory that family carers provide an integrated (meaning typical familial) environment for their disabled family member.

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<sup>3</sup> The Council was established under the Community Welfare Act 1987, its enabling legislation was transferred under Clauses 15 to 19 of the Disability Inclusion Act 2014 on 3 December 2014

Carers NSW is a community organisation that provides input to carer policy and administers government-funded carer support and counselling programs. In my 7 years attending board meetings, there was no mention of a carer theory to instruct policy. Many of the carers in my carer support group expressed intense frustration with their caring role whilst disability theory and policy assume carers embrace this role. I consequently wondered what theory or rationale directed the treatment of carers in policy and what would constitute a fair approach to carer treatment.

To explore what constitutes fair carer treatment, both theory and policy are examined as I contend that all policy is based on the theoretical premise which underlies it. Care and disability theories and policy are linked, in that the design and provision of disability services reduces or removes carers' workload; hereafter this will be referred to as the carer-disability link. Therefore, this thesis analyses policy and theories associated with justice, care and disability.

This theory-policy nexus draws from Carol Bacchi's "What's the Problem Represented to be" (WPR) method of policy analysis<sup>4</sup> which asserts that all policy is framed to fix a problem, thus how a problem is represented determines the ensuing policy (Bacchi 2009: iii).

Bacchi's WPR approach will be used to analyse policy relevant to carers. According to Bacchi, much policy analysis is erroneously based on an understanding that policy is reactive, thus a problem exists and policy is enacted to 'fix' the problem. In contrast, Bacchi's approach seeks to question how a problem is represented or framed in the first place. She asserts that this problem representation directs the ensuing policy. By interrogating the problem representation, Bacchi is highlighting that problems are not fixed, and their definition or representation reflects particular presumptions that indicate the government's underlying approach to specific groups of people.

This is evident in the way disability theory represents the problem of disability and consequently directs the policy that addresses it. The primary disability theory is the

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<sup>4</sup> A full explanation of Carol Bacchi's WPR method is outlined in Chapter 2

social model theory of disability which says that people are not intrinsically disabled; rather, the problem is represented as the disabling environment which hinders their integration. The social model is complemented by the principle of Normalisation and Social Role Valorisation which promulgates disabled people attaining the same valued social roles as their same-aged peers. The social model theory of disability, promoted by Disability Advisory Council members, directs the formulation of policy to address the disabling environment by the provision of wheelchair ramps and tasking others to provide adequate personal support to feed, toilet, and shelter people with disabilities.

This thesis employs three different analytical methods, a policy analysis, carer interviews and an analysis of ideal political theories. Bacchi's WPR method, explained in section 2.5, directs the policy analysis (Bacchi 2009, Bacchi and Eveline 2010).

According to Bacchi, the WPR method "signals an interest in forms of rule ... and involves the study of the thinking behind different forms of rule" (Bacchi 2009: 47). For this reason, Bacchi's approach interrogates 'practical texts'<sup>5</sup> (Bacchi 2009: xxii, 34, 112, 233, 297) via a series of questions which identify policy problematisations and thereby probe the premise and 'presumed truth' behind the institutional response. As Bacchi observes, Foucault discussed a similar logic as a way of questioning what appears to be self-evident and in this way "to dissipate what is familiar and accepted, to re-examine rules and institutions and on the basis of this reproblematisation ... to participate in the formation of a political will" (Foucault 1988: 265 in, Bacchi 2009: 46).

Foucault's concepts and governmentality studies (Foucault 1980, Foucault 1988) are used by Bacchi as the basis for her WPR method. To understand the limits of Bacchi's approach I sought critiques of Bacchi; finding none, I looked for critiques of her progenitor, Foucault, and the post-structuralist movement he is categorised in. There are a number of critiques of Foucault and post-structuralism which are discussed in

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<sup>5</sup> Bacchi's phrase 'practical text' follows Foucault's definition of 'practical texts' and refers to all documents and relevant commentary from government that together direct government action, including media releases, budgets, policy documents and legislation - see Bacchi *Why study problematizations? Making politics visible*, 2011

more detail in the policy analysis in Part 2. They are outlined here as these critiques explain why other analytical methods are employed alongside Bacchi's WPR method.

Foucault analyses the practical texts of government. Critics argue that this approach does not incorporate the views of testers, particularly absent testers, nor does it presume underlying theory or truths nor proffer ideological solutions. Whilst some critiques present these observations as fatal flaws, three contextualise them as an argument to use Foucault's analytics alongside other approaches. Mitchell Dean, Patricia Harris and Hillyard and Watson (Hillyard and Watson 1996, Harris 2001, Dean 2015) critique Foucault's and post-structuralism's scope. These critiques all refer to the use of additional methods and approaches to complement or extend the reach of Foucault and post-structuralism.

Mitchell Dean (Dean 2015) sets the scene for employing other complementary methods when he discusses Foucault's legacy in the context of the post-war welfare state and argues that perceptions of Foucault should shift from him constituting the: "unsurpassable horizon of critical thought to acknowledged classical thinker, with strengths and limitations" (Dean 2015: 389). In this way Dean moves away from the for-against critiques of Foucault, arguing that these are irrelevant as it is not a "matter of attacking or defending him" (2015: 389) but rather recognising his strengths and limitations. In framing Foucault in this way, Dean then explains how Foucault's analytics "might not be the monolith some would like" (2015: 400) but Foucault's work provides one understanding of the "different forms of power and domination ... [which] ... can be elaborated within a Foucauldian vocabulary but could also go further afield" (Dean 2015: 400). Dean points to other methods which can articulate Foucault's work with "more elaborate ways of understanding practice" (Dean 2015: 401) so that Foucault becomes "the starting, not the end, point for coming to grips with the problems and problematizations of our present" (Dean 2015: 403). Thus, Dean re-contextualises Foucault as providing a useful analytical method, which can be complemented by other methods.

Following Dean's logic, in order to extend Bacchi's Foucauldian analysis, I employ other methods. Hillyard and Watson suggest the need to move forward and extend the "insights of post structuralism ... [by including] ... the voices and theories of those who are 'other' - may well give us new directions for moving forward" (Hillyard and Watson 1996: 342). To include the largely absent voices of carers, qualitative interviews with

carers are employed. The scope of these interviews is outlined at the end of this chapter. The material impact of government policy on carers is evident in these interviews and challenges the problem representations of government policy and legislation which is uncovered in Bacchi's WPR analysis. The findings of the interviews will be recorded alongside relevant issues throughout the thesis.

In exploring the criticism that Foucault does not advocate universal theory, Hillyard and Watson claim that "Foucault is not saying here that the idea of justice should never be involved in political struggle but that the basic metaphor is not conversation but battle" (Hillyard and Watson 1996: 340). Dean observes that whilst Foucault did not endorse truths or particular ideologies there is a Gramscian reading of Foucault that "allows us to reconnect an analytics of government with the critique of ideology" (Dean 2015: 401).

Dean, and Hillyard and Watson note that insights drawn from theory and justice can extend the reach of Foucauldian approaches. Bacchi's WPR approach works back from the policy to uncover "What the Problem is Represented to be" and, in uncovering the problem indicates the theory that inspired the particular problem representation. Following these critiques, Bacchi's WPR is employed to identify problematisations, and uncover the ideology around carer treatment. It will thereby identify the negative exercise of power, legitimised by theoretical premise, which entraps carers. This process will allow prevailing theories, presumptions, and policy to be disrupted, in battle as it were, by alternative theories and policy.

Patricia Harris discusses how "post structuralism assists in this struggle to challenge and disrupt orthodoxy and thus make way for other alternatives" (Harris 2001: 346). Here, Harris conceives of post-structuralism "assisting", not directing.

Making way for a third approach that comes from, as Dean says, "further afield" (Dean 2015: 400), namely from ideal political theories and models. These, combined with the insights from the carer interviews, provide Hillyard and Watson's "new directions moving forward" (Hillyard and Watson 1996: 342).

Because of the disability-carer link, both disability and carer theories are analysed. As demonstrated in Chapter 6, disability theory primarily springs from the advocacy movement which effected a commitment to the deinstitutionalisation and integration of all people with disability in the community. It promulgates two key approaches. First is

the social model theory of disability that is summarised by one of its key proponents as a model which:

does not deny the problem of disability, but locates it squarely within society ... It is not individual limitations of whatever kind, which are the cause of the problem, but society's failure to provide appropriate services. and adequately ensure the needs of disabled people are fully taken into account in social organisation (Oliver 1996: 32).

The second key approach in disability theory are the concepts of Normalisation and Social Role Valorisation which were primarily applied to intellectually disabled people, with a goal of enabling them to acquire similar roles as their same aged peers. Thus, Social Role Valorisation and Normalisation promote the integration of all people with disabilities with the community (i.e. in education, employment and lifestyles). The way these theories arose and were disseminated and defended is described in detail in Chapter 6. For dependent, generally intellectually disabled people, integration in the community is translated to a lifetime living in the family home with family carers obligated to support them. Bacchi's WPR analysis shows that disability theory implicitly presumes carers are servicing and providing an environment for disabled people.

The analysis of carer theory in Chapter 7 shows that from its beginnings in the feminist movement (Rossi 1970a, Brennan and Pateman 1979, Davis 1984) which viewed care as a burden, care theory shifted to primarily examining the role of the function of care as a verb not the treatment of persons (noun) who are carers. Many care theorists develop ideas around an ethic of care which centralises the importance to society of care or care relations (Gilligan 1982, Noddings 1984, Tronto 1993, Barnes 2006). Within this approach some theorists acknowledge carers as people impacted by their caring role, and propose acknowledgement of the impact and suggest ideas involving a caring society supporting carers. Eva Feder Kittay proposes the most comprehensive schema which promotes the centrality of carer-dependant relationships within a model that she calls "doulia". This model envisages the continuance of carer-dependant relationships within encircling societal support.

Kittay's doulia concept echoes aspects of those models which promote the continuation of carer-dependant relationships (this includes aspects of disability theories/models, and the ethic of care). Importantly Kittay's doulia concept, will be shown, in Chapters 4, 7 and 8, to most closely reflect government policy, which presumes ongoing carer-dependant relationships. I critique Kittay's scheme and find that whilst Kittay argues for

government support of carer-dependant relationships and emphasises the importance of care in the context of a relationship, she does not fully address the entrapment of carers in such relationships.

Although Kittay and other care theorists are sympathetic to the impacts on carers, none address the ideal, or just, treatment of carers. To address carer entrapment and propose a just ideological solution for the treatment of carers, I draw from the political theory of John Rawls, particularly his seminal work *The Theory of Justice*. Rawls's Theory of Justice proposes a scheme which guarantees the ideal treatment of citizens.

Rawls's theory prioritises liberty and provides care for the least advantaged. Rawls does not address carers but I show how, given careful alterations and justification, Rawls's theory provides a useful basis for deriving an alternative and just theory for carers.

Rawls's theory is "designed so it can be implemented, via constituent power ... (which) ... is to be suitably institutionalised in the form of a regime" (Rawls 2003: 146). I derive a new Rawlsian-based theory that addresses the just and fair treatment of carers, calling it the "fair care theory" and proposing this theory as a solution which can be implemented in policy to ensure the fair treatment of carers.

In summary, Bacchi's WPR approach scrutinises the representation of problems in government policy and relevant documents, looking at both the context of the problem as well as the presentation of the problem itself. For example, government research on carer impact forms the factual context. This research consistently indicates that carers experience high levels of exhaustion and impoverishment; Bacchi's WPR analysis identifies that the policy response to this research chooses to represent the problem as a deficit in carer resilience. This is based on the premise of integrated ongoing familial care embedded in disability theories. The consequent solutions to this problem representation are then framed around how to help carers to continue to care by addressing the 'problem' of carer resilience. The logical policy solution is then limited to providing methods to enhance carer resilience. Bacchi's WPR analysis allows me to go beyond a program evaluation of the policy, to analyse whether stated government policy achieves the outcome of carer resilience. It leads to questioning whether the premise of continued provision of care by carers, and its resultant problem representation of lack of carer resilience, is an appropriate goal in the context of background research, carer interviews and alternative theoretical frames.

Bacchi's WPR analysis enables a reflexive questioning of a government's own paradigms, allowing a more explicitly honest appraisal of a government's intent. As Hillyard and Watson assert, such post structuralist approaches, disrupt issues locked in particular problem frames and open up new possibilities when seen in other frames. The fact of carer impact could draw from a different theoretical premise, such as the new fair care theory. On this premise, strategic policy would instead read 'carers, as citizens, are entitled to just and fair treatment' and result in different problem representations such as an unfair carer entrapment, which would lead to different solutions around how best to address carer entrapment. The resultant policy solutions would consequently be framed to assure liberty for carers by relieving them of their entrapping care obligations and urgently providing a range of supports for dependants, ranging from accommodation to respite. This is a very different problem representation to the one represented in care policy, namely a deficit in carer resilience.

## **1.2 Why this thesis is important**

This thesis is urgent, relevant and timely for three reasons. Firstly, because of the large number of carers – in Australia 2.7 million, or almost 12 percent (ABS 2016) of the Australian population, are carers. Secondly, because the severity of carer impact and entrapment warrants urgent attention. Thirdly, because increased Australian funding for dependants means there is scope to devise policy and direct funding to permit the fair treatment of carers.

This thesis will seek to demonstrate that many carers are locked into an exploitative caring role extending through their entire lives (50 years or more). It is hoped this research will assist in redressing this injustice by contributing to the theoretical approach to care and the reframing of government policies that support carers and dependants.

This research is significant because it analyses government policy, legislation and texts, explores carers' choices and derives a new fair care theory. This new theory can provide a just and logical platform on which to develop a new approach to carers, in policy and practice, both within Australia and internationally.

### **1.3 Thesis structure**

This thesis is divided into two parts bookended by the introductory and concluding chapters. Part 1 explores relevant policy that affects carers within the state of New South Wales (NSW), Australia. NSW was selected as it is the most populous and demographically diverse state in Australia. Examining policy in the state of NSW can serve as a case study for the policy treatment of carers in Australia and other liberal democracies. This part applies Bacchi's WPR method to analyse the problematisation and underlying premise of the relevant practical texts of government (public policy, legislation and government texts). A full explanation and critique of this method is outlined in Chapter 2 of Part 1 prior to applying the WPR method to international, Commonwealth and NSW State care and disability texts. This analysis finds that these texts are focused on the needs of people with disabilities and do not address fair carer treatment. Part 2 explores key theories that affect carers, critically analysing care and disability theories. It compares the trajectory of disability theory to direct rights-based disability policy, compared with how the emphasis on carer-dependant relationships in carer theories permits policy which emphasises carer-dependant relationships and effectively permits carer entrapment. Chapter 8 in this part derives an alternative theoretical solution. It examines Kittay's care constructs alongside John Rawls's theory of justice to construct a new fair care theory. Chapter 9 concludes the thesis elucidating its key findings and overarching themes and affirming that the new fair care theory can address carer entrapment, resonates with the majority of carers interviewed and with carers providing evidence to the Carer Inquiry<sup>6</sup> and could be employed to reframe care policy.

### **1.4 Who are carers? Profile and situation of carers in Australia**

Australia's implementation of the policy of deinstitutionalisation of dependants (primarily psychiatrically- and intellectually disabled people) since the 1980s has effected a substantial shift towards increased provision of unpaid (usually familial) care, to enable the survival of dependants in the community. Unpaid carers perform a vital role in supporting the lives of dependent people with disabilities. This load is borne at

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<sup>6</sup> The 2009 Parliamentary Inquiry produced the report: 'Who Cares? Report on the inquiry into better support of carers'. Henceforth it will be referred to as the Carer Inquiry.

significant personal cost and means many carers are entrapped for decades. It is not clear whether carers are happy with this obligation to care, and to what extent they have the ability to exercise choice in undertaking this obligation.

The severe physical, mental and material impact of caring is well documented in qualitative and quantitative research (Glendinning 1983, Harrington 1999, Edwards, Higgins et al. 2007, A.I.F.S 2008, Lin, Hu et al. 2009). In terms of cost, “research from both Australia and overseas demonstrates that the indirect costs of care are significant. Carers are less likely to be employed ... [there is]... extensive evidence on the ... costs of care, which may have long-term effects on informal carers financial security, social participation and health” (Hill T 2011: 53,55). Carers save the Australian Government an estimated \$60.3 billion annually (Deloitte Access Economics 2015)<sup>7</sup> . Given that carers represent such substantial savings to government, as Chapter 3 demonstrates, there is a strong financial imperative for government policy to address care and carers.

According to the Australian Institute of Health and Welfare “the role of informal carers ... cannot be underestimated ... [their] ... need for assistance ... is the focus of government policy ...” (AIHW 2015). However, this focus is not for carers themselves but how best to ensure carers can be “assisted” to continue to provide care. Recently the Australian Government has committed to a new tax levy to fund the National Disability Insurance Scheme. This levy commenced in July 2014. The new funding generated is administered under the Disability Care Framework and presumes a lifetime commitment by carers to the care and management of their dependent family members. This approach does not consider the treatment or opinion of carers to being so committed.

In Australia, there is a strong interest in carers which is heightened by a growing unease about the ability of society to adequately provide care for its increasing aged and disabled population. As noted in a media release by Australia’s (then) chief statistician:

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<sup>7</sup> Access Economics is a branch within private company Deloitte; they were commissioned by Carer’s Australia to report on the economic aspects of care. This finding refers to “the replacement value of informal care ... If all hours of informal care provided in 2015 are replaced with services purchased from formal care providers.”(Deloitte Access Economics 2015: iii) .

Carers not only make a huge contribution to the lives of the people that they care for, but they are also essential in supporting the formal care system in Australia (ABS 2013)

The Australian Institute of Health and Welfare (AIHW), and national and state carer advocacy organisations, Carers Australia and Carers NSW, predict an imminent 'carer crisis', where the number of people requiring care increases disproportionately to those available to care (A.I.F.S 2008, ABS 2008).

In 2015, 2.7 million people in Australia were identified as carers of people with a 'core activity limitation'. Of these 856,100 identified as primary carers (ABS 2016). For the purpose of the survey, the ABS defines people with core activity limitations as those who need assistance in their day-to-day lives with core activities listed as self-care, body movements or communication. The group identified as caring for someone with a severe or profound core limitation includes carers aged from 15 years to older than 85 years. The majority of carers however are aged between 25 and 64 years. Whilst both men and women were carers, more women were primary carers (68.1%), almost double that of male primary carers (ABS 2016). In Australia in 2012, of the approximately 440,100 people with intellectual disability, most were supported by informal carers (344,100 people) (ABS 2014).

One of the most extremely affected carers are the parents (particularly the primary carers) of those with profound-to-moderate intellectual disabilities. This carer subgroup may be in an obligatory care situation for up to 60 years, and due to the severity of the disabling condition, are often involved in the longest hours of care and the widest range of care tasks. Those with severe-to-moderate intellectual disabilities not only need their physical/bodily needs taken care of, as those with physical disabilities do, but they also require ongoing management, shepherding and supervision. I refer to those within this group as *dependants* because I consider that they represent the most dependent subgroup of all those with disabilities. In addressing this subgroup, carers of those who are less dependent are also addressed.

## **1.5 Background – interviews with carers**

Bacchi's WPR analysis of policy indicates an absence of carers' views in policy and a critical silence on the fair treatment of carers. As the 'imprint' of carers is largely absent in policy, to include carers' views I interviewed eleven carers. The methodology of these

interviews is described here. As explained earlier, the voices and insights of the carers interviewed occur as relevant, throughout the thesis.

Semi-structured interviews were held with the primary, unpaid carer, all of whom were parents of a dependent person with a disability. All those interviewed had been carers for a minimum of nine years with dependants ranging in age from nine to 35 years. I interviewed ten women and one man.

Given the limitation in the size and range of the sample interviewed, it cannot be claimed that the interviews were representative of carers in general or particular carer subgroups (grouped by, for example, ethnicity, circumstance or religion). Following others, such as Marion Barnes, whose book *Caring and Social Justice* (2006) was largely based on her interviews with twelve carers, I contend that my interviews with eleven carers allows an insight to carer views on choice, lifestyle, and services. It will also provide a sense of whether the Rawlsian-based new fair care theory resonates with carers.

All carers interviewed were self-nominated; the survey, inviting participants, was advertised in a NSW-based carers' newsletter and via metropolitan-based carer organisations. The facilitators of carer support groups and metropolitan-based carer organisations assisted by informing their members of the survey and encouraging them to contact me. The Carer interviews were held in a café in Central Sydney; they were approximately 1½ to 2 hours in length with all interviews transcribed. The transcript was then coded to enable a thematic analysis.

All the interviews were conducted within the guidelines of the approval granted by the Macquarie University ethics committee. These included the exchange of explanatory consent and information letters and links to support/counselling if required.

The interviews are significant for two reasons, firstly because, Arksey and Glendenning's extensive review of carer research found limited research on carer choice (Arksey and Glendenning 2007), and these interviews research carer choice and lifestyle. Secondly, the interviews exposed carers' subjective feelings of entrapment, which indicates that further research on carer choice warrants urgent attention.

Cognisant of the Arksey and Glendinning study (2007), the interview questions explored carers' views on carer choice, lifestyle, ties to their dependants and policy and services. A copy of the interview questions is provided in Appendix 1.

To maintain confidentiality, where carers and dependants are quoted or referred to, they are identified by pseudonym. The carers interviewed are listed by pseudonym in the table following with a brief profile of their dependent child<sup>8</sup>, and family situation.

Carer's Pseudonym	Description of dependent child	Carer's family situation
Catherine	Karen, 15 years old with severe intellectual and physical disabilities.	Married with three teenage children. Karen is the youngest child.
Joan	Mark, 35 years old with moderate intellectual disabilities and severe physical disabilities.	Married with three children in their 20s and 30s. Mark is the middle child.
Cristina	Jack, 11 years old with moderate intellectual disabilities and severe behavioural issues.	Married with four children of which Jack is the youngest.
Maria	Tom, 18 years old with moderate intellectual disability.	Married with two children. Tom is the youngest.
Anne	Liam, 35 years old with severe physical and intellectual disability.	Married with two children. Liam is the youngest.
Barbara	Luke, 16 years old with moderate/severe intellectual disabilities and behavioural issues.	Married with three children. Luke is the middle child.
Steve	Sarah, 15 years old with intellectual disabilities.	Married with three children of which Sarah is the eldest.

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<sup>8</sup> I use the word child to refer to the relationship between the parent-carer and the child-dependant. As seen in the table, the age of the dependants ranged from 9 to 35years.

Carol	Kate, 15 years old with moderate intellectual disability.	Kate is the eldest of three children. Carol is married.
Sue	Izzy, 17 years old with severe intellectual and physical disabilities.	Izzy is the eldest of three children.
Luk	Ming, 18 year old girl with a moderate intellectual disability.	Ming is the eldest of three children. Luk is married.
Fozia	11-year-old twins severely physically and intellectually disabled.	Married with twin disabled children.

The interview began by encouraging carers to reflect broadly on their life by first posing “what if” questions, asking carers to reflect on what constitutes “a good life”<sup>9</sup>, and what their lives would have been like had they not become carers. When necessary, prompts were used to elicit responses on different aspects of life (career, home environment, social life, community engagement, relationships, health, leisure and interests) prior to exploring carers’ thoughts on carer choice, fair carer treatment, and care and disability services.

All carers interviewed expressed strong opinions. The format of semi-structured open-ended questions allowed carers to reflect and develop their opinions which often ranged beyond the focus of the questions. Out of respect to these carers, and in order to candidly portray their views, I have usually relayed their full response as they reflected on each question. Carers’ deliberations in formulating responses often explained their reasoning or the underlying premise of their views. This provided a more comprehensive picture of how well the fair care theory resonated with these carers.

The responses had a distinct pattern; carers were typically hesitant when commenting on carer choice and definitive and immediate on issues around disability and carer services. Carers’ hesitancy in answering questions on carer choice and lifestyle was striking. All carers started to answer and paused to revise, think and formulate, or

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<sup>9</sup> The policy analysis in Chapter 4 explains that the concept of living the ‘good life’ is referred to as a goal in policy for disabled people.

reformulate their responses. Many carers asked to return to questions on choice, in order to revise, clarify or expand their responses. It was clear that most carers did not have a ready answer to questions on carer choice and lifestyle entitlements. This pattern of response raises questions why these apparently articulate carers all responded hesitantly.

Possible hypotheses are simply that carers have rarely been asked questions on their lifestyle and choices. Arksey and Glendenning's study (2007) empirically shows that carer choice is rarely addressed in research. Given that most research is government funded, it is logical to deduce that government does not want to explore carer choice. As they have rarely been asked or told about carer choice, carers do not have ready responses to such questions.

As well as responding hesitantly, many carers struggled to express their thoughts. It appeared that they were grappling to reconcile their relational ties to their dependants with their own needs and choices. As such, carers struggled to resolve their internal conflict, formulate their views, and find the words to express them. This struggle indicates that society has scant theoretical framework, language and acceptable phraseology developed around carers' rights and choices and has not provided the means or opportunity for carers to explore, develop or voice such choices.

Developing this hypothesis further in light of the WPR approach, it seems logical to deduce that care and disability policy and legislation have created a particular institutional normality where family carers are obliged to provide ongoing support for dependants. Carers' initial inability to answer questions on their lifestyle and choices reflects the institutionalisation of this particular normality. The process of the interviews, in asking carers questions on their lifestyle and choices, effectively helps disrupt this institutionalised presumption. By the end of their interviews, most carers resolved their internal conflicts, shook off the adopted institutional normality and, asking to return to earlier questions on choice in lifestyle, assertively stated that carers should have a right to choose and to pursue their dreams, careers and lifestyle opportunities.

### **1.5.1 Carer responses**

Six key themes emerged in the interviews. The first three themes relate to care and disability policy and services, particularly accommodation, and are discussed in Part 1 alongside Bacchi's WPR analysis of relevant government texts.

The last three themes relate to ideal treatment of carers around the meaning of 'the good life', carer choice, lifestyle and opportunities. These are explored in Part 2 which discusses the ideal theoretical treatment of carers.

In undertaking these interviews and examining the theoretical and policy treatment of carers of dependants, this thesis addresses carers in general. However, the analysis will particularly focus on carers of dependants because, to employ Kittay's rationale, it is not that "I assume it to be the most typical case, but because it is the case most in need of consideration if one is asking about the social responsibility to the carer" (Kittay 1999: pxiii). Whilst I focus on the case of carers of dependent disabled people, I borrow Kittay's rationale (Kittay 1999) in claiming that by focusing on these extreme cases, lesser cases are swept up in the consideration.

In focusing on carers of dependants, this thesis outlines an alternative theoretical framework, the new fair care theory. This new theory addresses the extreme subset of the most affected carers, carers of those with severe to moderate intellectual disability, as, to borrow Kittay's rationale (Kittay, 1999), I claim that by focusing on these extreme cases, lesser cases are swept up in the consideration. I hope this new theoretical framework can inform public policy and potentially improve the treatment of all carers.

# **PART 1. CARERS IN PUBLIC POLICY**

This part will use Bacchi's WPR approach to analyse the treatment of carers in policy, focusing on the case of carers in the Australian state of New South Wales (NSW).

As explained earlier, carer treatment is closely linked to the services provided to their disabled dependant, therefore both disability and carer policy are analysed. Some international, national and state policy affects the treatment of carers in NSW. This policy analysis is not exhaustive; it will focus on those policies which are particularly critical to the treatment of carers at each of these levels.

This part comprises an explanatory chapter and three chapters which each analyse a different level of policy.

## **Chapter 2 – The Policy Context of Care and Bacchi's WPR Approach**

This chapter will briefly overview broad international and Australian trends in family care; provide Australian examples which illustrates the debate; explain and critique Carol Bacchi's "What's the Problem Represented to Be?" approach; provide a sense of the Australian policy context; and list the key policies which will be analysed.

### **2.1 International trends in caring: From family care to institutional care and back**

It is useful to position the policy analysis in the context of international policy trends. The socio-economic structure of Western democracies is described by Esping-Andersen as a welfare regime which comprises an "inter-causal triad of state, market and the family ...[it]... can be defined as the ... interdependent way in which welfare is produced and allocated between states, markets, and family" (Esping-Andersen 1999: 35). These three components together manage welfare risk. Care is a significant social and economic component of this welfare, which enables and contributes to a functioning society.

According to Esping-Andersen, the welfare regime which unfolded between 1930 and 1960 was "an attempt to rewrite the social contract between government and citizenry"

(Esping-Andersen 1999: 33) enabled by the development of government administration structures which allow the collectivisation of social risks. Pooling social risks was justified as “welfare regimes are built around effecting egalitarian ideals and risk profiles” (Esping-Andersen 1999: 5) where social risks were defined as matters for collective state action. The state assumption of social risks was only possible in 20th-century society as “until the twentieth century ... the infrastructure of public administration, statistical bookkeeping, and taxation remained inadequate to the task of collectivising social risks on a mass scale” (Esping-Andersen 1999: 36).

The German socio-economic theorist, Max Weber outlines the ideal and typical traits of bureaucratic organisation whose growth he linked with the expansion of capitalism. The professionalisation of the state in turn led to a professional, more generic approach to issues of society (Weber, Roth et al. 1978). Where care is supported by the State, it results in the collectivisation of risk, wherein society recognises these risks as warranting co-ordinated, centrally pooled public consideration. The collectivisation of risks was complemented by the growth and professionalisation of the bureaucracy. Thus, the enactment of social policy was enabled by the bureaucratic approach which codified this action in government policy, service delivery and increasing care by government institutions.

Government policies and institutions which provide care outside the family “lessen individuals’ reliance on the family ... [and] ... maximise an individual's command of economic resources independently of familial or conjugal reciprocities” (Esping-Andersen 1999: 44). In contrast, where governments assign maximum obligations to the household, the provision of care leads to “the entrapment of families in internationally heavy caring burdens” (Esping-Andersen 1999: 67). “In other words, female<sup>10</sup> independence necessitates de-familializing<sup>11</sup> welfare obligations” (Esping-

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<sup>10</sup> Esping Andersen is referring to Britain mirroring Europe in obliging family to provide high levels of care. He notes that post-war British Labour policy held that married women should be regarded as occupied with vital unpaid work in the household, which supported their husbands to obtain paid work and thereby support the nation; females were recognised as undertaking the majority of familial welfare.

<sup>11</sup> ‘defamilialization’ is a term used by Esping- Andersen to refer to policies which reduce the welfare obligations to the household (and primarily to women) by shifting the provision of care outside the family unit. It is opposite then to ‘familialization’ where welfare obligations – primarily the obligation to care – occur within the family household.

Andersen 1999: 45) to facilitate universal individual autonomy and social and economic independence.

Since the 1990s, there has been an increased demand for care beyond the sphere of the family (Lewis, Bernstock et al. 1995, Esping-Andersen 1999, Daly 2002) . The continuing demand for de-familialization is linked to broad trends in the advancement of women, particularly their increasing level of education. “Compared to the 1960s, however, women today are dramatically more educated ... and ever more women demand economic independence and permanent integration in working life” (Esping-Andersen 1999: 69). These trends are accompanied by changes in family character, particularly the increasing destabilisation of family structures, and population ageing. Such broad shifts have altered traditional patterns of care, requiring an adjustment in government’s policy response.(Daly and Lewis 2000, Pascall and Lewis 2004, Fine 2007).

So powerful is the unmet demand for de-familialization of welfare that economists refer to it as the welfare-state crisis. To address the crisis requires firstly a recognition that the family–welfare state nexus which underpinned the so called golden age no longer exists and that this threatens not only the state but in affecting the behaviour of families, threatens the very stability of society:

Contemporary welfare states can no longer count on the availability of housewives and full-time mothers .... at the macro level, it implies a waste of human capital, lower levels of paid female employment mean also a smaller tax base; and lower fertility now threatens the basic financial viability of welfare states future.” (Esping-Andersen 1999: 70).

Daly and Lewis and pinpoint the crisis:

Concern about the supply of female labour renders care a central concern for both welfare states and societies. ... practically all welfare states are experiencing a crisis of care as a result of population ageing and the decreasing availability of private unpaid care (Daly and Lewis 2000: 291).

Daly and Lewis emphasise the importance of recognising the: “significance of care as a category of welfare state analysis ... it is impossible to understand the form and nature

of contemporary welfare states without a concept like care ... [we] ... make the case that the redefinition of public policies around care is central” (Daly and Lewis 2000: 283).

Carers of dependants are a subgroup of care. None of the broad welfare/care-activity discussions specifically addresses this subgroup. Daly and Lewis seek to defragment distinctions in care and combine all carer activity, regardless of situation or character of the carer (relational/unpaid/paid) and care receiver (old/young/disabled). Their primary focus in establishing the meta concept of “social care”<sup>12</sup> is to enable an examination of the distribution of the activity or labour of care at the macro level. This elevates care as a meta concern and defines it as an activity of care (on the level of welfare-state activity) which can presumably be structurally addressed at a macro policy level; “care is one and the same time of growing concern for welfare states and an even more frequent object of social policy” (Daly and Lewis 2000: 288). This approach has its analytical benefits as a meta tool to inform macro-political change. It is the context to the particular oppression of sub groups such as carers.

Socio/economic theorists note the impacts of existing meta trends on carers. Daly and Lewis note that the shift away from state responsibility for care, towards family and private care, is “prompting more compulsory altruism on the part of family carers” (Daly and Lewis 2000: 292). They argue that this affects universal citizen rights:

The changes which are being introduced in contemporary welfare states has the potential to alter the nature of social rights (social citizenship) quite substantially. ... social care has ... rarely amounted to citizenship based entitlements” (Daly and Lewis 2000: 294).

Pascall and Lewis also note the convenient sleight of hand undertaken by the state where “political reworking of the work--welfare relationship into active welfare has individualised responsibility ... and challenges the structures that support care in state and family” (Pascall and Lewis 2004:373).

The current shift in the treatment of care, by welfare states, appears to be a rationalisation that justifies deinstitutionalisation and decreasing state responsibility

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<sup>12</sup> For a full explanation of Daly and Lewis’s concept of social care, see their table: ‘Elaborating the Concept of Social Care’ (Daly and Lewis 2000: 287).

and increasing familialization of care. It is unclear whether this shift is based on an explicit theory or underlying principle. The shift has been characterised “from the mid-1980’s ... [by] ... a stampede to emphasise obligations, rather than rights, which has been translated into policy in respect of the direct enforcement of parental responsibilities and more indirect encouragement of responsibility for the care of elderly relatives” (Daly and Lewis 2000: 295).

## **2.2 A Snapshot of Australian carers, politically and personally.**

Media articles capture the variety of interests, opinion and societal forces that surround carers politically and personally. A 2007 newspaper article entitled: “An angry breed: handle with care” (Horin 2007) describes the conflicting views of care- and disability advocates about the ideal accommodation model for dependent disabled people. Most marked in the discussion is that the conflicting groups are arguing at different levels. Disability advocates argue at the level of the ideal theoretical treatment of people with disabilities, while carer advocates argue from the point of their lived experience.

Implementation of disability theory and advocacy in Australian policy occurred in the early 1980s. It resulted in the policy endorsement of the integration of all people with disabilities in the community. Chapter 6 discusses disability advocacy, theory and its insistence on deinstitutionalisation and integration. This mandated the closure of many large government-funded institutions and the housing of disabled people in the community, primarily with their birth families. Currently, the majority of dependent disabled people live with, and are supported by, their families; very limited government-supported housing is available. For example, in 2011 in NSW, 90%, or 230,000 dependent disabled people lived with, and were cared for by, their families, whilst the government supported approximately 7% or 7000 dependent people in smaller, ‘group home’ accommodation. In 2002 the Australian Institute of Health and Welfare (AIHW) estimated that there was an unmet demand for 12,500 accommodation places (AIHW 2002 ). Proportionally, the supply of accommodation was less than half the unmet demand for accommodation. Provision of government-supported accommodation means carers are not obliged to care for dependants in the family home.

The 2007 newspaper article describes three carers, all women in their 40s and 50s, who object to their obligation to provide care for their adult dependent children, and the consequent absence of choice in their personal lives:

Brown, 51, is divorced with three adult children who have left home. She lives with [dependent 21-year-old] Tess on a government benefit ... 'we are the first generation,' Brown says, 'who not only kept the kids at home but did so when other women were in the workforce. I'm ageing without assets or superannuation. Families chose whether they wanted to care before. Now there is no choice' (Horin 2007).

The conflict between disability- and carer-rights advocates arises because government-supported housing in small group settings is expensive, and the alternative, possibly more efficient, congregate care models are not regarded as acceptable to disability advocates. Further, while some carers may choose not to live with and support their (perhaps adult) dependants, these dependants may choose to live with their parents. Established disability- rights advocates therefore object to both the shift in focus to carer rights, and the freedom of carers to express any negative personal feelings in regards to providing ongoing care in the family home. This is because such comments do not accord with disability theories' precepts of positive familial care for dependent disabled people:

The newcomers represent a backlash. They threaten to shift the focus of the rights of people with disabilities to the interests of carers. 'In the battle to focus on rights of people with disabilities, we've lost 30 years of ground.' says Matthew Bowden, co-chief executive of People with Disabilities, an advocacy group ... The way newcomers framed the debate offends many long-time disability advocates. For example, an angry submission by the National Carers Coalition to a Senate enquiry to disability funding ... talks of 'families saddled with this burden unaided', 'lifelong suffering', and 'servitude', and urges the government to examine the 'sham that is the community inclusion rhetoric'. ... a spokeswoman for [disability advocacy] ... says: 'I find it very offensive to have issues represented in this way' (Horin 2007).

The second example concerns a family with three children in which the 17-year-old daughter is dependent, with a severe intellectual and physical disability. She is unable to speak, and requires full personal care including nappy changes, feeding, removal of saliva and behavioural control. The dependent daughter has attended two nights of out-of-home respite and is due to return to her family from school. In her school communication book, her classroom teacher writes:

Hi Mum and Dad,

Isabella was happy to know that today is going home day. She has been a bit sad, of late. Respite did not appear to have brushed her hair this morning and I feel that [respice's provision of] one round of jam sandwiches ... is not enough food to sustain her all day.

17/10/12 - Teacher X

Upon return to the familial home, Isabella cried and hit herself with her own fist, causing her jaw and mouth to swell and become bloodied. To stop her self-mutilation, her mother had to stop helping her other children with their homework and spend one hour struggling to apply arm restraints and trying to feed Isabella, who kept spitting out her dinner. Was Isabella happy to be at home? The private sphere of the home is rarely visible to the public sphere. The schoolteacher could not observe Isabella's behaviour at home.

The certainty and presumption in the school note is disturbing and itself raises questions about the underlying premise of familial care. As Isabella has limited communication, did Isabella know she was going home? Was she happy to be going home? How do mum and dad feel about receiving Isabella home? This story highlights some of the critical dilemmas in the debate. Whilst society, as represented by the concerned schoolteacher, may feel the dependent disabled person is best cared for by the family carer, and may extrapolate their personal opinions as an opinion expressed by a dependant, this extrapolation could be inaccurate. Isabella may, or may not, have preferred home to government respite.

Isabella has a substantial impact on her family carer, as do the adult dependants of other carers, but there is no acknowledgement in either story, of the feelings or choices of these carers. The primary concern of society (as represented by the schoolteacher), and disability advocacy, is that, ideally, dependent disabled people should be cared for by their families. Further, disability advocacy seeks to curtail any negative expression by carers, effectively seeking to police carers' feelings about their own caring situation.

Finally, the October 2016 murder-suicide of a Sydney family of four comprising mother, father and two autistic children, was reported in print media with headlines such as *Caring to Death* (Ballantine 2016). These deaths are a sobering reminder of the extreme desperation experienced by some carers that must warrant urgent moral attention.

## 2.3 Critiques of Bacchi's Foucauldian approach.

Bacchi's "What's the Problem Represented to be" approach (WPR), explained in full in Section 2.5, is largely derived from Foucauldian and post-structural theories. Bacchi codifies her WPR method in her 2009 book *"Analysing policy: What's the problem represented to be?"* A decade before Bacchi employed a "what's the problem" interrogation to women's policy (Bacchi 1999). In this earlier analysis she distinguishes between examining "problems" as distinct from "problematizations" citing Foucault's work which conceives problematizations as "discursive practices that introduce something into play of true and false and constitute it as an object for moral reflection, scientific knowledge or political analysis" (Foucault 1988: 257,265 cited in Bacchi 1999: 2).

In later work, Bacchi explains the basis of her WPR method referring to Foucault's interviews from 1972 to 1977 (Foucault 1980) which identify the social understanding of knowledge and Foucault's "recognition of a power– knowledge nexus in which power is involved in producing forms of knowledge ... in which knowledges exercise power or influence in shaping people's lives" . Bacchi explains how Foucault's power–knowledge nexus forms the "central theoretical premise in the book." (Bacchi and Eveline 2010: 118). Bacchi notes her method also draws on Foucault's governmentality studies and two other theoretical sources, namely social construction which highlights that knowledge is formed not fixed, and feminist body theory which, Bacchi says, refers to the material impacts of policy on actual bodies: "Policy representations therefore affect socially embedded bodily possibilities, often with life and death effects" (Dean 2006 in Bacchi 2010: 119).

Bacchi explains that in using Foucault's concept of knowledge and power the political subject is emergent, not fixed. Thus, the "WPR approach works from the premise that the discursive constitution of problem representations produces political subjects of particular types (gendered, ... (dis)abled, and radicalised .) through eliciting certain subject positions ... [And thus exerting political control by] ... stigmatising some, exonerating others, and keeping alterations ... within limits ... [thus constituting certain

groups] ... as 'different' and needing forms of 'special treatment'<sup>13</sup> (Bacchi and Eveline 2010:118-119).

Bacchi employs Foucault's understanding of hidden and assumed power: "for a critical theorist such as Foucault, power relations are evident through their capacity to 'produce' the truths we live by." (Bacchi 2012: 145) The recognition of uncovering and scrutinising hidden power, seeing its effect on carers, and disrupting its assumed institutionalised 'truths', are essential to my policy analysis to both unmask hidden power and to provide opportunity to disrupt its otherwise inevitable entrapment of carers. Bacchi's WPR analysis can uncover how some assumptions such as 'family carers should provide care for dependents for their lifetime' is really an example of how "the normalizing effects of power are most insidiously employed ... to make a particular action appear obvious and inevitable" (Bacchi 2012: 144).

Bacchi's WPR approach is based on Foucault's governmentality studies and also analyses a range of practical texts of government in order to scrutinise their institutional truths which exert control on certain groups:

"Governmentality studies, associated with Foucault, broaden our understanding of government to include the full array of institutions, agencies and 'knowledge' ... [the] ... WPR approach takes policies ... as the entry point for analysis, it understands government ... in this broader sense ... [therefore scrutinising] the political significance of the concepts and categories they... adopt and deploy, and the need to scrutinise reflexively the nature and effects of these categorical creations" (Bacchi and Eveline 2010:119).

In a 2012 article, Bacchi further elucidates how Foucault's key conceptualisations inform her WPR method: the "problematization in Foucauldian-inspired post structural analysis ... opens up innovative research strategies that make politics, understood as the complex strategic relations that shape lives, visible" (Bacchi 2012: 1).

Bacchi's WPR approach has a number of supporters (Bletsas 2012, Pereira 2014, Söderström Skott, Line et al. 2015) who demonstrate the practical applicability of her

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<sup>13</sup> Bacchi is referring to examples drawn from her analysis of gendered policy in which women are treated as different; the analysis could readily apply to the 'special' treatment of carers.

approach on a “world scale” (Pasha 2010) and in uncovering truths to enable both broad and specific policy change (Pereira 2014). However to justify my use of Bacchi’s WPR approach it is necessary to examine its detractors, as mentioned in Chapter 1. As I did not find critiques of Bacchi, I have looked to those of her progenitor and therefore examined critiques of Foucault and post-structuralism.

Both Foucault’s supporters and detractors acknowledge that Foucault is seen as the epitome of post-structural analysis (Harris 2001 , Villadsen and Karlsen 2012, Dean 2015). Dean describes how Foucault's legacy is perceived as an “unsurpassable horizon” in governmental studies (Dean 2015 : 389), whilst Villadsen and Karlsen state that “Foucault is often counted as *the* poststructuralist thinker on power” (Villadsen and Karlsen 2012 : 139).

Foucault and post-structuralism have been criticised for not addressing particular societal aspects or having a limited approach. In using Bacchi’s WPR, Foucauldian-based method I acknowledge that it, as with any approach, has its benefits and limitations. As I argue in Chapter 1, it is the case of using the right “theoretical practical” (Villadsen and Karlsen 2012) method for the question posed. Following Dean’s contention that Foucault is not the “unsurpassable horizon” who must be defended, Bacchi’s Foucauldian method is employed alongside other methods.

However, some commentators argue that the selection of a post-structural- or Foucauldian approach is so limited as to be an ineffective method in policy analysis, so rather than defend Foucault’s approach as an unsurpassable horizon, I’ll apply Dean’s reasoning and address these critiques to explain why I’ve employed Bacchi’s Foucauldian method alongside other methods to address the fair treatment of carers.

This thesis explores a discrete question, specifically the treatment of carers in theory and public policy. It is not examining the policy process nor focusing on the political actors and contesters and the way they participate in the process, nor does it focus exclusively on the role of the state or its interactions, or measure impacts of policy, or question the effects of broad political themes such as the effect of capitalism. In order to justify the use of Bacchi’s WPR approach as the main method in the policy analysis, I will address core criticisms of Foucault. Key criticisms of Foucault’s concepts or post-structuralism include that they:

- Do not recognise the primary power of the state, or an established power hierarchy with the state as the central seat of power;
- Ignore recognised factors and class categories;
- Are too concerned with micro-analysis and so obscures “big-picture” issues, large ideals or macro trends such as the effect of capitalism;
- Draw from certain “practical texts” and so does not examine outputs from other contesters;
- Are predicated on uncovering the negative, and so incapable of advocating solutions or positive theories.

Many critics combine these criticisms to paint a more complete picture of Foucault's/poststructuralists' inadequacy. To enable a clear exploration I have discussed each criticism separately and then, so that my discussion does not lose sight of the big picture, discussed the combined criticisms.

### **2.3.1 Ignores the primacy of the state**

Critics claim that in ignoring the primary power of the state, Foucault's analysis leads to the “rejection of the identification of government with the state, understood as the centralised locus of rule” (O'Malley, Weir et al. 1997: 501) and an “emphasis on the declining significance of the nation-state fits with the renewed interest in localism and decentralised administration ... [which] ... denies the significance of broad developments and substitutes a language of particularism and diversity” (Taylor-Gooby 1994: 388). Concomitant with a reduction in state significance is the recognition of other power entities: “Post structuralism dismembered the state, emphasising the various and inconsistent practices which shape its manifold components. Its position as the main feature power is accordingly downgraded, and it emerges as one part of a broader ‘capillary’ of power relations involving professionals, bureaucracies, schools, families, leisure organisation and so forth. For Foucault ... there is no central point of power” (Harris 2001: 304).

Some critics (notably Dean and Harris) note that Foucault and other poststructuralists did not assume the central power of the state in order to distinguish their analysis from Karl Marx's philosophy. In his overarching analysis of Marx's legacy, Simon Choat argues that Foucault's work had similarities to Marx's investigation into power, in that Foucault examined the exercise of power and its misuse in relations of domination. I

note that Foucault's, and in turn, Bacchi's WPR approach, whilst they don't begin with a presumption of dominant state power, focus on the principal holders of power, which in many instances identifies the state as a key power holder and typically the primary power holder, whilst identifying the other holders of power such as professionals, advocates and bureaucracies. Thus those who criticise Foucault for reducing or dismembering state power do not adequately allow Foucault's ability to uncover the state-dominated power hierarchy within the context of other power relations.

My analysis of care policy in Chapters 3,4 and 5, will demonstrate that whilst the state is a critical power, it is not the only power. Power is also distributed to international bodies, such as the UN (with its influential treaties), disability advocacy, academia, research and bureaucracy which together affect the treatment of dependants and carers. By not prescribing the dominance of the state, Bacchi's Foucauldian approach permits an analysis that can expose the reality of multiple agents including the state, or as Harris puts it, exposing the "capillary of power relations", that together allow a more complete scrutiny of the circumstances of carer treatment and the adequacy and underlying rationale of policy.

### **2.3.2 Foucault ignore recognised factors and class categories**

Most critics note that in the same way that Foucault does not begin with the state, he also does not acknowledge, or dilutes the importance of, key factors such as economics or recognised class categories such as race, and gender (Taylor-Gooby 1994, Harris 2001, Villadsen and Karlsen 2012). For example, Harris notes the post-structuralist approach may pose "a risk that economic factors may now become overly washed out the account. Even if capital does not determine history, it certainly has a profound effect" (Harris 2001:338). Harris states that ignoring of class categories is limiting as "there are instances when global categories remain necessary ... where they (male/female, black/white, working-/middle-class) represent *actual* systems of thought with *real* effects" (Harris 2001: 343).

Critics note that as Foucault and poststructuralists don't identify broad movements and class categories their approach may result in a "perhaps unwarranted restriction of the kinds of power that could be analysed" (Villadsen and Karlsen 2012: 143) and permitting only a "partial vision" (Taylor-Gooby 1994: 402) which is so fragmented that

it does not recognise trends and developments in recognised factors and class categories.

I claim that not staying rigidly within known class categories such as race or gender means that Bacchi's WPR analysis is flexible enough to allow other subgroups, such as carers, to be identified for attention. Further, the WPR approach allows subgroups of recognised categories to be identified. For example the identification of dependent disabled people within the established category of people with disability.

I note that the WPR analysis, whilst it does not insist that one begin with known categories, does not prohibit an examination of such categories. This openness to both new and recognised categories means Bacchi's WPR approach is open to identifying the specific trends and underlying rationale that apply to known categories, new categories and new subgroups; this means it can uncover the more obscure, hidden or unpalatable rationales that govern these groups.

Bacchi's WPR approach can similarly uncover critical factors. For example in employing the WPR to analyse the Carer Inquiry (Commonwealth of Australia 2009), In section 5.1, this thesis will provide evidence that in considering the option of full economic support for dependants and commensurately removing the obligation on carers to support dependants, the Carer Inquiry states that such an approach could not be countenanced as it resulted in an unfair burden on the taxpayer. These statements and associated gaps and tensions throughout the Carer Inquiry are readily uncovered in applying Bacchi's WPR approach and highlight how resultant carer policy is influenced by critical factors such as economic rationalism.

I do acknowledge that the WPR approach, by not presuming known categories and factors, means that the broad structural identification around such factors, and the ability to identify evolving historical trends around known categories and factors, is less likely. Further, the identification of broad themes may rely on an amalgamation of critical issues uncovered during the analysis.

### **2.3.3 Foucault is too concerned with micro analysis**

Linked with a recognition of the centrality of the state, Foucault it is noted, was "less apt to study the broad structures" (Villadsen and Karlsen 2012: 140), focusing instead on discrete areas and micro politics. This included not recognising broad movements, such

as capitalism, or any “totalising system of propositions” (Harris 2001: 338), and functioning “as an ideological smokescreen, preventing us from recognising some of the most important trends in modern social policy” (Taylor-Gooby 1994: 385).

As Taylor-Gooby scathingly remarks, post-structuralism’s decreased emphasis on broad themes and the focus on “a cloud of detail, may ignore the wood through enthusiasm for bark-rubbing” (Taylor-Gooby 1994: 389) and can “cloak developments of considerable importance” (1994: 403).

I acknowledge that Foucault and poststructuralists do not begin with broad themes, or the premise that they must be found. There are other analytical methods that begin with these themes. However, although they do not begin with broad themes, Foucauldian analyses are open to discovering them.

O’Malley et al.’s criticism elucidates the structural-schematic effect of Foucauldian analysis:

While it is inescapable that we engage in a degree of hypostatization, idealisation and reification of rationality and programs in order to even talk of them, the cumulative effects of the problematic features of governmentality work arguably create an insular and *episodic* vision of rule (O’Malley, Weir et al. 1997: 512) .

I acknowledge that Foucault’s, and in turn Bacchi’s, analyses of “practical texts” are potentially episodic and do not presume fixed or known rationales, or the evolution of policy resulting from building on cumulative understandings of known categories.

I concede that there is an absence of continuity, of examining the trajectory and developments of known factors and categories using the same definitions, which permit a sense of the cumulative and historical development of such factors, and categories. I also acknowledge the risk that in not prescribing a broader view, the broader view can be missed. Foucault and in turn Bacchi, rely on the application of their approach to a well-conceived ‘corral’ of texts. In short, without prescription and heft of knowledge pertaining to establish categories, it is left to the researcher who applies Bacchi’s Foucauldian method to get the most appropriate “corral” of texts and follow, with enough vigour, an investigation and uncovering of the paths such analysis leads to. Whilst Bacchi does not prescribe a particular broad view, she leads the researcher to consider the broader contextual analysis in asking: How has this representation of the problem come about?” see section 2.5 (Bacchi, 2009: 3).

In my case, following the path of Bacchi's WPR analysis leads back to the underlying theoretical construction of disability, and forward from the policy "silence" on the fair treatment of carers to political theories that could ensure fair liberty for carers. In asserting this approach I follow Dean's premise that Foucault [and in turn Bacchi's WPR approach] can validly be employed as one of the approaches alongside other approaches, in this case care and political theories to address fair carer treatment.

Bacchi's WPR analysis does not assume broad themes but relies on how the analysis and its findings are amalgamated, interpreted, applied and extrapolated. For example, when I applied Bacchi's WPR approach to analysing the range of "practical texts" it resulted in consistent findings that carers were rarely identified as the object of need, and there was an absence of fair treatment or rights espoused for carers. This led me to amalgamate this consistent finding in public policy which I then interpreted and coalesced into a statement that pointed to the broader theme that policy does not address the fair treatment of carers but assumes carers have an ongoing obligation to care for dependants. By not adhering to established, or known, themes, Bacchi's WPR analysis permits a creative uncovering, definition and amalgamation of new findings which can capture new broad themes. In my case, the analysis uncovers the theme of carer obligation. This makes Bacchi's WPR analysis an important method for examining carer treatment.

### **2.3.4 Foucault does not examine the process and outputs of other contesters**

A number of critics note that by focusing on the "practical texts" of government, Foucault and post-structuralists ignore the players, organisations and processes of contestation. O'Malley et al. remark on how exclusion of contesters ignores both those outside government and also voices within government, thereby losing "conceptualisations of politics as relations of contest or struggle which constitute chief of government" (O'Malley, Weir et al. 1997: 503). O'Malley et al. then go on to describe how the effects of ignoring such a critical aspect of government, namely contestation, effectively ignores different aspects of policy analysis associated with agency, arguing that:

The subordination of contestation to rule at the analytical level, leaves little space for theorising the *productive engagement* between them. ... [Arguing that apart from government texts, a ]... broader range of social institutions and actors needs to be accepted as sources; (O'Malley, Weir et al. 1997: 511-513).

O'Malley et al. note that “in evacuating social relations from its analysis of the political ... in the exclusion of contestation and diversity among the governed, much of the governmentality work seemed to short-circuit its capacity to contribute to the formulation of progressive post social politics” (O'Malley, Weir et al. 1997:513 ).

Harris succinctly summarises the multiplicity of effects observing that “contest, for O'Malley et al., is constitutive of political rationality not just an obstacle to it ... [Noting that political rationality] ... is a product of particular contestation between for example business, labour, welfare and political government. Any alternative politics will similarly carry the imprint of contestation and difference” (Harris 2001: 339).

Harris's observation constitutes my defence of Foucault and post-structuralism; I acknowledge that indeed Bacchi's WPR analysis does not examine the processes or products of agency but by containing or capturing the “imprint” of such contestations in the practical texts analysed, captures much of the resultant effect of such contestations. This is because whilst these practical texts are drawn from government, they result from the social and political relationships and contestations arising both within and outside of government and can be seen as the primary result of these contestations and relations. Bacchi's direction to identify critical silences within the practical texts speaks to those contestations and agents who are less powerful and largely absent in the texts.

Bacchi's WPR analysis identifies a critical silence on the treatment of carers. This silence indicates that carers are less powerful testers who do not leave an ‘imprint’ on policy. For this reason, the method of qualitative interviews with carers is used to ensure the absent carer-testers are considered.

### **2.3.5 Foucault is negative and not solution oriented**

Most of Foucault's critics say Foucault's analysis is predicated on uncovering the negative and therefore does not extend to solutions or positive theories as he is “too concerned with critique” (Wickham 2008: 41). Instead of positive power and solutions, Foucault and post-structuralist's focus on critical or negative power. For example, O'Malley et al. argue that in focusing on ideological critique post-structuralism

gives itself the task of unmasking ‘disguised’ ideological interests ... [and thus assumes a] ... negative theory of power: power as prohibitory rather than inciting. The texts of criticism, it is argued, neglect the possibility of government operating through the formation of subjects, a positive form of power (O'Malley, Weir et al. 1997: 506).

Wickham concurs, stating that “Foucault's account of modern positive power has been dissected and found wanting ... being all too ready to turn negative at the drop of a hat, being infected with the urge to social critique the urge that leads to so much of the aforementioned hat dropping” (Wickham 2008: 41).

Yeatman also notes the lack of solutions or positive themes. Yeatman extols Hegel's conception of government obligation to institutionalise positive rights in order to actualise positive ideals around freedom and rights of the person: “for Hegel ‘the state’ is an ideal, and the question centres on how this ideal is actualised in thought and institutional practice” (Yeatman 2004: 412). For both Yeatman and Hegel the intent of policy is to achieve positive outcomes framed around ideals; not only to fix problems.

Harris claims “the normative position of post structuralists remains concealed ... the theoretical task ... is to discover the conditions which give rise to particular regimes of truth. Ideals such as social justice are themselves treated as discursive constructs subject to genealogical inquiry” (Harris 2001: 344). Harris notes however that “post structuralism *does* have a normative component. At the very least this relates to the desire to disrupt orthodoxy” (Harris 2001: 344).

In line with his assessment that post-structuralists focus on local micro politics to the detriment of observing a broader view, Taylor-Gooby notes this focus means the broader approach of universalism and larger themes for human betterment are lost. Whilst he acknowledges some of the strengths of the post-structuralist approach used, Taylor-Gooby concludes that this focus on the local and particular interest means that “post-modern approaches are seriously flawed in some aspects of the social analysis” (Taylor-Gooby 1994: 399).

It may seem that framing social issues as “problems” casts only a negative role for policy, to fix problems. It seems reasonable to ask how the problem representation approach assesses positive policy, that is, policy that is framed to achieve universally agreed positive goals and ideals.

Dean's recasting of Foucault's writing within its historical context provides a softer interpretation, arguing that Foucault was not opposed to ideology but “sought to distinguish an analytics of government from ideology critique ... to try to specify the originality of [Foucault's work] rather than build a wall between it and other, existing critical analysis” (Dean 2015: 401).

Bacchi's WPR analysis can capture the scope of government policy in both its setting of positive goals and its framing of problems. Government policy is framed to identify positive outcomes, and then to outline strategies to achieve these outcomes. These strategies involve altering the factors which result in a deficit of the achievement of said outcomes. In other words, a government's representation of the problem is caused by its very framing of a positive ideal and the reasoning surrounding the deficit from this ideal; the framing of the problem is therefore contextualised by the positive ideal which is not being realised.

A key question is that, whilst poststructuralism indeed takes a close view, identifying new groups, sub groups and particular interests, is it able to coalesce these micro-discussions and develop a macro view? Can the findings of Bacchi's WPR approach be amalgamated sufficiently to reveal the broad miss-steps and absences that affect particular subgroups, such as carers, and then propose positive solutions? Harris's observation that poststructuralists' normative component comprises the "desire to disrupt orthodoxy" (Harris 2001: 344) means that, in the case of carers, truths and ideals which assume carer obligation can be disrupted. Whilst this disruption doesn't automatically propose an alternative positive ideal, it leaves new space for one to be proposed. Indeed, Bacchi invites a solution in asking: "can the problem be thought about differently? (Bacchi, 2009:3)

I follow Dean, on viewing Foucault and consequently Bacchi's WPR as one method complemented by other methods. The WPR method reveals carer entrapment and points to critical silences on carer liberty. I then need to draw on other methods outside of Bacchi's Foucauldian analysis, to find possible solutions. Bacchi's WPR doesn't claim to encompass ideals and truths nor does it negate such truths. It allows other methods to provide truths and solutions. In this case I draw on the method of political philosophy of John Rawls's theory of justice to derive a solution and frame an ideal premise to fill the gap identified by Bacchi's Foucauldian based analysis.

## **2.4 Why I use Bacchi's WPR approach**

Carol Bacchi's "What's the problem represented to be" (WPR) approach will be used to analyse policy relevant to carers. According to Bacchi, much policy analysis is erroneously based on an understanding that policy is reactive, thus a problem exists and policy is enacted to 'fix' the problem. In contrast, Bacchi's approach seeks to

question how a problem has been represented or framed in the first place calling this the problematisation of the problem. She asserts that it is this problematisation that directs the ensuing policy. By interrogating the problematisation Bacchi uncovers the underlying theoretical orientation of government opening up issues to alternative theories, problematisations and policies.

To summarise the reasons for employing Bacchi's WPR Foucauldian approach, my primary justification relies on Dean's assertion that Foucault is "not the 'unsurpassable horizon' of critical thought ... [but rather an] ... acknowledged classical thinker, with strengths and limitations" (Dean 2015: 389). This describes the context in which I apply Bacchi's WPR Foucauldian approach as a critical component of analysis which can be employed alongside other methods, in my case methods from political models and theories, and qualitative interviews with carers.

Within this context of being an invaluable method for policy analysis, this section acknowledges that Bacchi's Foucauldian approach has its limitations and recognition of these limitations indicates and justifies the other complementary methods that I employ. For example, I utilise the method of qualitative interviews with carers to address Bacchi's limited ability to include contesters who are silent in policy. Albeit, I argue that the need to include contesters applies only to those contesters who do not leave an imprint or are absent or silent, in policy. This critique also demonstrates that Bacchi's approach has strengths which are particularly relevant in analysing the treatment of carers, in policy.

A robust critique of the strengths of Foucauldian and poststructuralist analysis comes from its critics. Harris acknowledges that poststructuralism provides "insight into the ways in which professionals govern behaviour through patterns of professional discourse" (Harris 2001:341). In exploring the negatives of post-modernism Taylor-Gooby also acknowledges its contribution, particularly noting that post-modern themes go beyond traditional class and social factors "to include needs based on age, gender, ethnicity, sexuality and disability" (Taylor-Gooby 1994: 399). As noted previously, Foucauldian approaches allow new classes and issues such as disability, dependency and carers to be closely explored.

The example of economic rationalism evident in the Carer Inquiry, as noted previously, demonstrates that by being able to clearly identify the critical factors such as

economics, Bacchi's WPR approach is a robust analytical method that can probe known factors.

Harris quotes Dean's assertion that Foucault provides a "methodical problematisation of the given" (Dean 1990 in Harris 2001: 336). Harris notes that in this way poststructuralist theory can destabilise existing orthodoxies and frame or define "the limits we may go beyond" (Foucault 1992 cited in Harris 2001 : 336). I acknowledge that Foucault does not propose solutions or universal theories; however, in destabilising existing paradigms or orthodoxies, his approach allows space for new paradigms, theories and solutions, such as the fair care theory, to be proposed. Indeed Foucault's defining of new limits and frames identifies not only the absence of theories but can also prescribe or frame the space which a new theory should fill.

I follow Harris's argument regarding the

importance of challenging the entire neo-liberal frame and its consequences for economically and socially subordinated groups ... that critical poststructuralism assists in this in the struggle as it allows one to stand back, deconstruct, suggest alternatives, relativise, question and refuse. It is simultaneously a *practical* and *theoretical* tool deployable across agency and university well into the political arena. (Harris 2001: 346).

It is this potential to disrupt accepted paradigms that is necessary in the case of carer treatment.

Villadsen and Karlsen assert "if Foucault's thinking was never a monolithic whole but rather a series of strategic engagements with specific historical problems in specific social contexts there is no reason why elements from his analytical toolbox could not be mobilised in conjunction with the concepts or tools from other sources" (Villadsen and Karlsen 2012: 146).

Some critics concede that poststructuralism, when combined with other methods provides:

Insights ... particularly those which have been influenced by feminism and post-colonialism as well as the voices and theories of those who are 'Other' - may well give us new directions the moving forward (Hillyard and Watson 1996: 342).

Thus Bacchi's WPR Foucauldian-based approach can disrupt accepted paradigms and identify new categories, thereby exposing obligations which entrap carers and silences

on carers' liberty. As such, Bacchi's WPR approach constitutes a critical method to uncover new population categories for attention, such as carers and a new subgroup of the disabled, such as dependants, and provides a frame for new concepts and ideologies based on the new fair care theory - a theory which is derived from Rawls's theory of justice and contextualises carers as citizens of society. A society that, as Yeatman says is geared towards improvement of and for its citizens: "The universal development of modern society ... is the type of society that is oriented to freedom. ... The development of the state on a universal scale ... requires us to develop a fully secular ideal of the state that can actualise a universal conception of right" (Yeatman 2004: 403). The fair care theory prescribes a positive and universal conception of the fair treatment for carers, which can be a solution to the silence on carers and occupy the space identified in the WPR analysis and disruption of prevailing policy.

## **2.5 Bacchi's "What's the Problem Represented to be" method.**

Bacchi specifies three propositions which are central to her WPR approach:

1. We are governed through problematisations.
2. We need to study problematisations (through analysing the problem representations they contain), rather than 'problems'.
3. We need to problematise (interrogate) the problematisations on offer through scrutinising the premises and effects of the problem representations they contain. (Bacchi 2009: 47)

Based on Foucault's logic of questioning the presumptions underlying texts, and opening these up to disruption and new ideas (Foucault 1980, Foucault 1983, Foucault 1988), Bacchi proposes six questions:

1. What's the problem represented to be in a specific policy?
2. What presuppositions or assumptions underlie this representation of the 'problem'?
3. How has this representation of the 'problem' come about?
4. What is left unproblematic in the problem representation? Where are the silences? Can the 'problem' be thought about differently?
5. What effects are produced by this representation of the 'problem'?
6. How has this representation of the 'problem' been produced, disseminated and defended? How could it be questioned, disrupted and replaced? (Bacchi 2009: 3)

Bacchi's WPR approach is a method that enables the critical interrogation of public policy. Its framework systematically questions the underlying accepted truths (Bacchi, 2011) which determine how the problem is represented in policy. This exposes the problematisation in policy to critical analysis. The policy analysis aims to uncover the underlying rationale and beliefs of government and particularly, how this indicates the underlying theoretical framework of government in regards to carers. Bacchi's Question 2 interrogates policy to uncover the underlying assumption which directs/explains the preferred problematisation, and in turn, the underlying theory.

The identification of alternative problematisations that are opposed in the policy document may be explicitly opposed in the text in defence of the preferred problem or theory. Bacchi addresses this in Question 6, which refers to the defence of the preferred problematisation. Such explicit opposition may refer to some ideas as too idealistic or unfeasible, for example, the Carer Inquiry says that it is unfeasible for the taxpayer to provide all supports for dependants. In dismissing taxpayer support as "unfeasible", the "problem" of carer entrapment and policy guaranteeing liberty for carers is also dismissed, because to truly guarantee carers' liberty, I argue, one must be able to guarantee alternative, primarily taxpayer- funded, support, particularly out-of-home accommodation, for dependants. This rationale illustrates how problematisation and underlying theories, in reality both lead, and are led by, each other, depending on the circumstances and political context in which they occur. Thus, certain problematisations are cast which lead policy to explicitly or implicitly 'prefer' certain theories or underlying assumptions which are feasible for policy to enact.

Thus Bacchi's premise that problematisations are not fixed but are constructed to justify the policy, legislation, action or inaction of government. Bacchi's method involves working backwards from policy to problematisation. This method also leads the analysis forwards to the direct line between underlying rationales and theories to problematisations and to policy.

In Question 4 – 'What is left unproblematic or silent in the problem representation? – Bacchi says that opposition to an idea may be implied by the absence of, or silence on, an idea. The recognition of opposition-in-absence is apparent when one looks for a theme and marks its absence. It is also apparent in the recurrent 'strained' issues/concepts, those where policy advances a problematisation and resultant solution where an alternative more logical problematisation and solution seems indicated. For

example, the WPR analysis will demonstrate that the Carer Inquiry and carer policy and legislation, promote problematisations such as carer resilience and carer recognition and their consequent solutions of carer training and acknowledgment; although alternative problematisations which address carer entrapment seem more logical. These strained issues are useful in identifying the government's underlying ideology on carers. Bacchi's approach provides a robust method of determining a government's underlying theoretical framework, particularly where this is implicit rather than explicit.

The thesis employs an integrated, rather than a systemic, application of Bacchi's policy analysis by selecting and combining some of her critical questions depending on their applicability to particular policy. Bacchi's method calls this an integrated, rather than a systemic approach, which is more suitable when analysing complex and multifaceted policy. Bacchi notes the integrated analysis is more common as it enables the application of "specific questions ... where the analysis occasions their use" (Bacchi 2009: 128). This approach is less repetitive and enables comparisons between documents.

Bacchi's integrated approach is used with one adjustment: to recognise, where relevant, the policy document as a whole and within the policy framework presented by government. Most government policy is written with a specific hierarchical structure beginning with general and strategic statements and moving on to logical groupings of more specific policy and direction. It is therefore more useful to analyse policy within the context of the document as a whole and in the contextual framework of other relevant policy.

This 'holistic policy framework' approach will recognise the document as a whole, within a contextual grouping of relevant government policy. This contextualisation should allow me to track the thread of government policy development, and permit an insight into the rationale and, ultimately, the theoretical underpinning of government policy. For example, tracking an issue from its emergence in government discussion in the form of research, community forums or government inquiries, to subsequent reports and final policies/statements, permits a picture of what ideas surrounding the issue have been shed and what ideas have solidified. The Carer Inquiry allows a telling insight on the theoretical premise underpinning care policy in Australia. It will be analysed in an attempt to track whether the issue of carer choice, listed in the terms of

reference for the Carer Inquiry, arose in the information gathering, public submission and research phase, and how it was addressed through the refinement of the reporting phase, and in the final stage of government implementation via policy and legislation. How the Carer Inquiry responded to carer choice directly relates to how closely a government's rationale supports carer choices and addresses carer entrapment.

In order to address carer treatment, this part uses Bacchi's WPR approach to analyse a range of "practical texts" which address carers either directly or indirectly. Practically, carer policy and services appear in two forms: direct carer services (such as payments, counselling and privileges) and services to people with disabilities which reduces the care-load, referred to as the carer-disability services link (such services include respite, special child care support, short- and long term accommodation). Carer policy also occurs at different levels of government. Policy impacting carers in NSW resides at the international, national and state levels. Hence, the policy review will involve an analysis of relevant carer and disability policy, legislation and commentary at the international, Commonwealth and NSW State government levels.

It is hoped that this analysis, by clarifying the government's rationale for silences around carer treatment and identifying the 'shape' of this silence, will indicate both the scope and the place where a ideal care solutions can reside and can provide a springboard for carer grounded ideal theories.

## **2.6 The Australian policy framework.**

The Australian Government operates within a system in which the federal government and each state government have specific areas of power, responsibility and access to revenue. This federal system means that authority is constitutionally divided between central (federal) and regional (state) governments (Gillespie in Brett 1994).

The Commonwealth Constitution of 1901 outlines the administrative structures and role of the Commonwealth Government. The Commonwealth Constitution does not specify human rights in the manner found in the American Constitution. Without a Bill of Rights, the rights of Australian citizens are defined by common law and interpretations derived from decisions of the courts and laws made by parliament. As Chapter 3 will show, Australia is also committed to various rights-styled obligations under the UN treaties it has ratified.

Generally, the Commonwealth has authority over income tax revenue streams and direct welfare payments. The state government administers the majority of direct government services, with the majority of funding sourced from the Commonwealth Government. The distribution of funding to the states by the Commonwealth Government is conditional; generally funding is 'tied' to specific purposes or outcomes. This financial control means the Commonwealth Government, via its tied financial grants, broadly directs policy, whilst state government is usually responsible for direct detailed policy and the administration of services.

Much has been written about the impacts of federalism on Australian policy and the administration of welfare (Castles, Uhr et al. 2005). Castles et al. note that the division of power has the effect of ratcheting the pace of reform and relying on negotiated agreements between states and the central Commonwealth Government (Castles and Uhr 2007).

Australia has an idiosyncratic wage-based welfare model which is distinct from the European rights-based welfare model. In Australia the bulk of welfare is delivered through means tested wage supplementation or substitution (pensions) rather than institutional welfare programs. Researchers have commented on Australia's comparatively low expenditure on welfare services in comparison with other Western democracies (Brennan in Brett 1994, Castles and Uhr 2007). Australia's care and disability funding is a mixture of direct payments to the person with disabilities, financial subsidies to carers and state government support services. Section 2.7, below, and Chapter 4 outline how Australia's new National Disability Insurance Scheme (NDIS) represents a shift away from state government services towards increased funding to disabled people to enable them to purchase services from private organizations and individuals.

## **2.7 Brief outline of Australian disability and care policy.**

Australian policy development reflected international trends. The 1960s to early 1970s saw an increase in government support which peaked under Whitlam, whose approach was "akin to the European social democratic model in which services are seen as the right of all citizens ... under Whitlam there was an explosion of activity in the field of social policy" (Brennan cited in Brett 1994: 284).

Following Whitlam, the shift away from institutional care towards the familialization of care mirrors the shift towards familialization observed internationally. From 1975 to 1983, the Fraser government embarked upon a program of reducing public expenditure and reducing services administered by government. The reduction in welfare provision had the effect of limiting welfare to provision of a safety net for the poor and working “to promote the role of the unpaid care provided by family members as alternative to State-provided services and supports” (Brennan cited in Brett 1994: 286).

Parallel to broad trends in familialization was an assertion of independence and rights for people with disabilities. In 1981 the United Nations raised international awareness of the rights of people with disabilities; its Declaration of Rights of Disabled People marked a shift away from separation to social inclusion and equal rights. In Australia the policy shift emphasised the end of segregation and support for integration and social inclusion following key disability theories including, the social model of disability (SM) and the principles of normalisation (N) and social role valorisation (SRV)<sup>14</sup> which were largely developed in the 1970s and 1980s. In the 1980s the Australian Government reviewed services for people with disabilities, and in 1986 replaced the *Handicapped Persons Assistance Act 1974* with the *Commonwealth Disability Services Act 1986*. The primary object of this Act was to deinstitutionalise disability services and to increase the types of services which support integration in the wider community, particularly supporting people with disabilities to gain employment in the public sphere and in typical settings.

In NSW, the shift away from institutional care accelerated with the release of the report on the Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled, in 1983. The report is named after David Richmond who chaired the inquiry and it will be referred to as the ‘Richmond Report’ (Richmond 1983). The Richmond Report advocated deinstitutionalisation and support for clients in typical community environments. The *NSW Disability Services Act 1993*, represented the realisation of the Richmond Report. This Act outlined the scope of new disability services, prescribing

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<sup>14</sup> For ease of analysis, in the policy analysis acronyms will be used to refer to these disability theories.

services which support the normalisation and integration of people with disabilities. Again, this involved a shift from institutional care to support in the community, primarily within the family home.

In 2006 the United Nations endorsed the Covenant of the Rights of Persons with Disability [CRPD] which was ratified by 111 countries. Australia ratified the CRPD in 2008. The CRPD builds on the rights espoused by advocates of the social model of disability and is informed by principles of normalisation and social role valorisation. The CRPD specifies how the rights of people with disability apply in all situations including accommodation, education, and employment within the 'natural unit' (United Nations Commission 2009) of the family.

Published in 2011, the Productivity Commission reported on the National Disability Long-Term Care and Support Scheme. It documented the unmet needs of disabled people and recommended a National Disability Insurance Scheme (NDIS) (Browning, Browning et al.) to provide ongoing national funding. This report's findings were substantially adopted by the Commonwealth Government. On the 7th December 2012, the NDIS received intergovernmental agreement by the Council of Australian Government. The NDIS represents a significant change in the support of disability, giving rise to sweeping new policy and legislation at both the national and state levels. It will replace all current national and state disability support systems.

In terms of overarching policy trends, the NDIS marks a significant shift in federalist arrangements. Previously the Commonwealth negotiated agreements with each Australian state, making state government responsible for administration and delivery of services. Under the NDIS, the administration of funding is directed by national legislation which circumvents the function of state agencies in the delivery of disability services. Instead funding will be provided directly to disabled people, or in the case of dependent-disabled people, their families, via private community agencies.

There is limited policy directed solely at the carer; much care policy is embedded in disability policy. The table below outlines relevant government documents which affect the treatment of carers; these are listed by status. The status of documents is critical as it indicates the extent to which the document represents agreed government policy. High status policy directs government action and either frames its funding and services or enforces certain practices. Status is also accorded depending on the extent to which

the document is written in a prescriptive and enforceable manner; a policy which is written in general terms, outlining broad goals, without specific measurable outcomes or funding, has lower status than one with specific goals and legislatively enforceable obligations. For example, a policy which discusses the benefits of carers having choices and opportunities is of less status than one which affords carers rights and funds support services to realise such rights.

The list is also coded in terms of whether the document has a short-, medium- or long-term period of influence, and by document type, that is, whether the document is legislation, a government inquiry, a statement of government policy, or a document describing operational and practical arrangements. Key to document types:

- L** Legislation
- I** Inquiry
- P** Policy
- R** Research
- AO** Arrangements/Operational (possibly including financial allocation).

Status	Disability Policy	Carer Policy
HIGH Long Term	<b>L</b> - Disability Services Act 1986 (Commonwealth) <b>L</b> - NSW Disability Services Act 1993 [repealed by the NSW Disability Inclusion Act 2013] <b>L</b> - NSW Disability Inclusion Act 2013 <b>L</b> - NSW – National Disability Insurance Scheme (NSW Enabling) Act 2013 <b>L</b> - National Disability Insurance Scheme Act 2103 <b>L</b> DisabilityCare Australia Fund Act 2013 <b>L</b> - Fair Work Act 2009 <b>L</b> - The NSW Anti-Discrimination Act <b>I</b> - 2011 Productivity Commission’s Inquiry into a national disability care and support scheme.	<b>L</b> - Commonwealth Carer Recognition Act 2010 <b>L</b> - NSW Carer Recognition Act 2010 <b>L</b> - Fair Work Act 2009

HIGH Medium Term	<b>P/AO</b> - Disability Agreement NDA <b>P</b> - Stronger Together Two 2011-2016- Extended in 2013 by "Ready Together." Thus the NSW 10-year plan is extended until 2019, continuing the slated reforms and expansion of Stronger Together 2. <b>AO</b> - Commonwealth State and Territory's Disability Agreement (CSTDA) <b>L</b> - NSW – National Disability Insurance Scheme (NSW Enabling) Act 2013 <b>L</b> - NSW Disability Inclusion Act, 2014	<none>
MEDIUM Long Term	<b>I</b> - United Nations Convention on the Rights of Persons with Disabilities, ratified by Australia in 2008, <b>L</b> - Disability Discrimination Act 1992 (Commonwealth) <b>P/AO</b> - the Housing and Mental Health Agreement between the Department of Family and Community Services (ADHC) and NSW Health <b>P</b> -The National Disability Strategy (NDS) <b>L</b> - Home Care Service Act 1988: <b>L</b> - Guardianship Act 1987	<b>I</b> - April 2009, 'Who Cares...? Report on Inquiry into Better Support for Carers - 'the House of Representatives Standing Committee on Family, Community, Housing and Youth, Parliament of the Commonwealth of Australia - The Anti-Discrimination (Carers' Responsibilities) Act 2000.
MEDIUM Medium Term	<b>R</b> - National Disability Research and Development Agenda <b>R</b> - Productivity Commission: Report on Government Services	National Carer Strategy 2011
LOW	Numerous research and background reports by government, academic and others (sufficient funding for disability research to resource specialised disability research centres at universities <sup>15</sup>	<b>R</b> - Limited Australian Institute of Health and Welfare Reporting.

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<sup>15</sup> Due to the large number and low status of research reports, I will not analyse them. Below is a sample list that indicates the extent of the research on disability in comparison with the limited research on care. Disability research sample list:

R - Australian Institute of Health and Welfare: Disability publications -Disability Services National Minimum Data Set "data Cubes "with detailed information on disability services.for various AIHW reports

Tabulating and coding these documents helps to identify the comparative depth and breadth of the absence of carer texts. The table shows the distinct difference in the proliferation of high- and medium status disability policy (9 high and 6 medium status policies) when compared to the limited number of carer policies (3 high and 2 medium status policies). Disability policy has, in part, been necessitated by the historical identification of disabled people as a subgroup who require support in order to survive, whereas carers, as seen in Part 1, were first recognised as a subgroup in the 1980s, largely as a consequence of the shift in disability policy towards familialization of care.

High-status disability policy precedes carer policy by 26 years. One of the possible effects of this longer history is that it has given rise to a greater number of ensuing, higher status, disability-focused policies, legislation and funding arrangements than comparable carer policies. The policy analysis will show that the rights-based disability policy agenda contrasts with the absence of carers rights and reinforces why an approach that asserts the fair treatment of carers is defensible.

A number of high-status documents are legislation. When analysing legislation, it is important to recognise the hierarchy of clauses and sections, and appreciate the way they relate to each other. Within legislation, the schedules generally function as providing an explanation or descriptive statement; their power to actually enforce or oblige certain actions resides in the clauses of the legislation that refer to them.

As described previously in this chapter, an integrated WPR analysis is employed which only applies the most relevant of Bacchi's questions to the 'practical texts'. The next three chapters embark on a WPR analysis of each level (international, national and NSW State) of prevailing and immediately past policy, legislation and government commentary.

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R - Department of Health and Ageing: HACC MDS Statistical Bulletins

R - Disability Policy & Research Working Group: Small Area Estimates

R - Productivity Commission: Report on Government Services

## Chapter 3 – International Policy

This chapter applies an integrated WPR analysis to relevant international texts. In this case, these are three of the seven United Nations (UN) core international human rights treaties Australia is party to as stated by the Australian Government's Attorney General's Department:

- The International Covenant on Civil and Political Rights (ICCPR), ratified by Australia in 1980;
- Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), ratified by Australia in 1983; and
- Convention on the Rights of Persons with Disabilities (CRPD), ratified by Australia in 2008).

The 1948 U.N. Declaration of Human Rights is a fundamental charter of the UN organisation on which the conventions Australia is signatory to are built. According to the Australian Human Rights Commission: "A convention (sometimes called a covenant) is a binding treaty, coming into force upon ratification by a certain number of States" (AHRC 2013). Article 26 of the *Vienna Convention on the Law of Treaties* provides that: "Every treaty in force is binding upon the parties to it and must be performed by them in good faith" (AHRC 2013). Australia is therefore required to take all reasonable measures to achieve the stated features of these treaties. For example, Article 2 (2) of the International Covenant on Civil and Political Rights, 1966:

Requires Australia to take all necessary legislative and other measures to give effect to the rights in the Convention. The ICCPR is scheduled to the *Australian Human Rights Commission Act 1986* and the Australian Human Rights Commission is responsible for monitoring Australia's compliance with the ICCPR (AHRC 2013).

The majority of articles within UN treaties are written in a form which describes broad idealistic aims (using phrases such as 'freedom to' or 'protection from') or outlines the parameters of issues, not as a detailed prescription for action. UN treaties have general parameters and non-enforceable obligations. As such, the Australian Government's action in relation to these treaties depends on how it chooses to interpret and apply them. Each treaty specifies a regular review procedure, requesting monitoring reports at three- to four-year intervals.

None of the three relevant UN treaties mentions carers as a subject of concern or consideration. For example, the ICCPR addresses a range of general human rights, including the right of political and economic self-determination; the equal rights of men and women to enjoy all civil and political rights; freedom from slavery and servitude; and rights to liberty and security of person which is further specified to refer to no arbitrary arrest and detention. Thus, the ICCPR outlines a general frame of human rights in civic opportunities, public life, and under law. Similarly, CEDAW addresses three areas: civil rights and the legal status of women; aspects of equality within the family and the impacts of cultural norms on the equality of women.

Some of the assertions of human and civil rights in the ICCPR and CEDAW could be applied to ensure liberty for carers so they can access opportunities in the public sphere. Section 4.9 and the analysis of carer interviews in Chapter 4 shows carers feel burdened by care obligations and entrapped in the private sphere. As noted by Muir and Goldblatt (2011), carers have less participation in the public sphere than the community average, family carers are less involved in education, work, rest, leisure and participation in the community. These UN treaties and their subsequent clauses indicate they are intended to only apply to the public sphere, and do not apply to the restrictions binding carers to the private sphere. Article 9 of the ICCPR, for example, specifies that the only acceptable deprivation of liberty applies to people detained on a criminal charge of unlawful behaviour, whilst Article 1 of CEDAW defines discrimination against women as any “distinction exclusion or restriction ... which has the effect or purpose of comparing or nullifying the recognition and enjoyment or exercise by women ... of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.” This is interpreted in subsequent articles of the Convention to mean matters such as removal of legislative discrimination in the public sphere, thereby ensuring women can vote, participate in political forums and have equal access to education.

As mentioned, care obligations effectively tie carers to the private sphere. This is more fully explained in Chapter 7, in the discussion on feminist theorists, such as Okin, who maintain that legal rights in the public sphere cannot be fully realised, unless one addresses the obligations tying women in the private sphere, obligations which restrict them from practically enjoying their legal rights. The ICCPR’s and CEDAW’s Articles

would have relevance to some carers, were the treaty to be applied to their entrapment in the private sphere.

As Chapter 2 outlined, familialization of care results in “the entrapment of families in internationally heavy caring burdens” (Esping-Andersen 1999: 67). The effect of this silence is that carer entrapment in the private sphere is not problematised in UN treaties; this represents a critical silence in these treaties. This silence does not address the ongoing entrapment of carers, and the substantial restriction to their equal access to opportunities such as education, human rights and fundamental freedoms, including their liberty, freedom from servitude and ability to participate in economic and social opportunities.

The CRPD is particularly relevant to carers because of the carer–disability-services link and also because it ascribes a support role to carers. The longest of the relevant treaties, the CRPD, stands at 26 pages and 50 Articles. The CRPD specifies how the rights of people with disability apply in particular situations and problematises the achievement of those rights in several areas including accessibility, treatment under the law, education, health, employment, and participation in cultural and leisure activities.

This detailed specificity distinguishes the CRPD from other treaties. Unlike carers, not only are people with disabilities selected as a subgroup for specific attention under a treaty, but also their ideal treatment in a large range of situations is specifically problematised. This problematisation accords with dominant theories of disability, especially the social model which holds that disability is a product of the constructs in society which lead to the experience of impairment. The CRPD therefore advocates adjustments in all societal spheres, including the built environment, education, employment and familial care, to minimise the experience of impairment. The CRPD is effectively an international, detailed blueprint for the ideal treatment of people with disabilities in accordance with disability theory. It can be readily enacted in public policy, legislation and services; and significantly, it also facilitates the clear monitoring of achievements for specific situations against targeted goals.

When carers are referred to, they are referred to in their normative roles as ‘families and caregivers’; not as the subject of concern, but rather as part of the solution to the problem of disability by providing a typical familial environment for disabled people. For example, subclause (x) of the Preamble says:

(x) Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities. (emphasis added) (United Nations Commission 2009: 3)

Thus the protection of, and assistance to, families is to enable them to be the solution to support the full enjoyment of their disabled dependant. The silence on any enjoyment of family members is marked. A further example of carers being referred to as a solution for the problem of disability integration is seen in Article 18: "Children with disabilities, shall have the right ... as far as possible, to know and be cared for by their parents" (United Nations Commission 2009: 11).

Protection for disabled people within the family context is addressed in Article 16:

1. State Parties shall take all appropriate legislative, administrative ... measures to protect persons with disabilities, both within and outside the family, from all forms of exploitation, violence and abuse. (United Nations Commission 2009)

The focus of this Article is the protection of the person with disabilities from violence or exploitation, presumably at the hands of their carers. The CRPD isn't focused on carers, but this statement highlights the silence on carers in UN conventions on the possibility that carers may often be at risk of violence and exploitation at the hands of the person with disabilities in their care.

It is the reference to carers as a context rather than as subject in the CRPD that is relevant here. The absence of carers in other treaties is just that, a silence on carers. The mention of carers in the CRPD, however, is more concerning. Other treaties may mention a subgroup as equal-rights-bearing citizens and require government, and societies to protect and support such rights. The CRPD, however, focuses on people with disabilities as subjects and problematises their attainment of equal citizenship rights. The effects of this problematisation in the CRPD, is that disabled people are identified, as Bacchi says, as 'different' and needing 'special treatment' (Bacchi and Eveline 2010: 119). The proposed solution to this problematisation is to produce, as a presumed 'truth', that carers are obligated to support disabled people and are consequently institutionalised as a resource, not citizens with their own rights.

### 3.1 Australia's interpretation, implementation and monitoring of treaties.

UN Treaties do not address carer treatment or entitlement, thus their effect on carers depends on their interpretation and implementation by Australian institutions. This can occur through the interpretation that the ideals and language of treaties apply to carer treatment and enactment of specific carer legislation and policy, and monitoring of institutional compliance.

Whilst many nations have introduced human rights to their constitutional jurisprudence, Australia has not. Yeatman notes that this process, across nations is

unevenly developed -- it is currently actively resisted ... [in] ... Australia ... the essential point is that the status and rights of the person are positively existent only as they are specified and instituted by the state (Yeatman 2004: 404).

Although not fully incorporated in Australia's constitutional jurisprudence, elements of human rights treaties and human rights language are evident in legislation and policy in relation to some subgroups. CEDAW led to Australia enacting the *Sex Discrimination Act 1984*, which was later amended by the *Sex Discrimination Amendment Act 1995*; whilst the CRPD is referred to in both national and NSW state policy and legislation since 1986.

Australia has established legislation and specific administrative arrangements to educate and scrutinise compliance with UN treaties and related legislation. This includes an established formal complaints procedure and an investigation and review authority. The *Australian Human Rights Commission Act No. 125 1986*, as amended, establishes the Australian Human Rights Commission (AHRC). The AHRC describes itself as “an independent statutory organisation ... [responsible for] ... leading the promotion and protection of human rights in Australia” (AHRC 2013).

The AHRC also investigates and makes recommendations on matters brought before it in relation to the *Age Discrimination Act 2004*, the *Disability Discrimination Act 1992*, the *Racial Discrimination Act 1975*, and the *Sex Discrimination Act 1984*. Carers have no such legislated rights and are not protected by general human rights in the Australian Constitution. No carer-specific legislation is included for scrutiny by the AHRC. This means carer rights and treatment are not problematised for solving or monitoring.

Of its own volition, Australia has developed two initiatives. The first is Australia's Human Rights Framework, launched by the Attorney General in 2010, which addressed funding for education to promote human rights and reviewed various administrative systems. For example, it recommended the streamlining of federal anti-discrimination laws. The second initiative is the National Human Rights Action Plan 2013 (NHRAP) which draws from a Baseline Study, incorporating the findings of extensive institutional and community consultation (including 35,000 individual submissions). The NHRAP details Australia's specific human rights activities, responsible agencies, timing and funding commitments. In its introduction the report states:

The Australian Government has a vision for an Australia that is free, democratic, just and tolerant. An Australia in which all people are valued and included, and have an opportunity to make a decent life for themselves ... [The report] also articulates, in detail, how the Australian Government will implement the commitments we made in 2011 during Australia's Universal Periodic Review at the United Nations (Attorney General 2013: 4)

The 85-page plan briefly addresses human rights at a general level before addressing the rights of specific groups. The rights of the general populace are confined to broad protections from torture, assigning a priority to human rights education, and various reviews of administrative and technical practices which scrutinise compliance with human rights treaties and improve access to the justice system.

The bulk of the plan concerns specific actions for specified groups: aboriginals, women, children and young people, older people, gender-diverse people, homeless people, people with a disability, prisoners, and refugees. As carers are not identified as one of the groups for attention, they are also excluded from the commitments of the Australian Government and therefore excluded from that sweeping aspiration of being “valued and included and have an opportunity to make a decent life for themselves” (Attorney General 2013: 4).

This silence contributes to carers' lives and opportunities being largely ignored in Australian government policy. Ten carers interviewed felt it was a government's responsibility to provide support for both carers and dependants while four carers noted that many subgroups were treated unfairly, including carers who should get support:

Is it the government's job to make life fair? What's fair? Life's not fair, not for anyone. A whole range of things in people's lives are not fair. Look at fairness objectively; lots of sectors of society are not treated fairly. In an ideal world it would be fair to have a better way to support carers and the disabled as they get older (Catherine).

The section on people with disabilities in the NHRAP is 13 pages long and addresses the majority of key areas identified in the CRPD. Each key area lists associated actions, substantial funding commitments and responsible agencies. For example, nationally, \$11 million is assigned over four years to increase physical and technical accessibility; \$7.2 billion, over six years for disability care and support. Other measures include monitoring and mechanisms such as specific disability surveys and measures to improve employment in the Australian Public Service (such as introducing a Guaranteed Interview Scheme).

In contrast to the section on disability, the section on carers is three pages long. The Baseline Study which underlies the 2013 NHRAP reported that the consultation had included suggestions that the “rights of carers could be better protected” (Attorney General 2011: 130), but the remainder of the report does not refer to rights of carers. Both this report and the analysis of the CRPD demonstrate that the problem representation of carers is confined to better recognition of carers in their ongoing obligation to support disabled people, thereby mirroring the CRPD in its institutionalisation of carers as a support resource for disabled people.

This carer section notes that the 2009 Carer Inquiry, together with the National Carer Recognition Framework, represents the “Australian Government’s initiatives to increase the support and recognition provided to carers” (Attorney General 2013: 68). The problematisation of care is confined to adequate care support, recognition, employment protection, and carer payments, with funding limited to a discrete amount (\$1.6 million) to improve carer identity and recognition. Some carers interviewed said it was time to focus on carers, not just disabled people:

Governments spend so much time and energy they’re always about the child with a disability, they need to look at the life of the carer as opposed to the life of the person with disability (Anne);

The NHRAP will recognise and support carers but not problematise their entrapment, nor monitor or fund their rights or opportunities. This is in contrast to each of the other subgroups, most notably people with disabilities, who are framed to have rights,

services and policies focused around “consistent funding and support to help them realise their aspirations, and to participate in the social and economic life of the community” (Attorney General 2013: 54).

The comparison of carer funding with disability funding indicates that carer entrapment and lack of opportunities in the public sphere is unproblematised. It shows the institutionalised presumption that underlies the prevailing problematisation that carers will continue to care. The effect of this is continued carer entrapment. The carers of dependants experience entrapment as a result of the carer–disability link. New approaches to carer entrapment are needed to disrupt prevailing problematisations.

### **3.2 Australian Human Rights Commission research report 2013.**

#### **Investing in care: Recognising and valuing those who care.**

UN human rights instruments, including CEDAW, refer to the attainment of rights in relation to gender equality, and the challenges many women face in balancing work and care responsibilities; the Commission undertook a research report to address these international goals for women’s equality.

Two chapters of the AHRC report specifically discuss carers. Chapter 12 (running for half a page) discusses recognising and valuing carers and suggests marketing strategies to increase recognition and positive community attitudes, whilst Chapter 5 discusses carer legislation. An analysis of this report is in Appendix 1. In summary, the report merges carers with parents, which effectively dilutes the focus on carers and means their severe impacts and longer-term entrapment are subsumed and silenced. The report is published after the publication of the Carer Inquiry 2009 and references the Inquiry. Furthermore the Commission's report is endorsed by Elizabeth Brodrick, the Sex Discrimination Commissioner of the AHRC, who, on the 26<sup>th</sup> February 2013 (three weeks prior to the release of the report), noted in an article in *The Australian*: “carers have the lowest collective well-being of any group in Australian society and we need to and will start addressing this” (Broderick 2013). It is reasonable therefore to assume that both the AHRC and the Commissioner knew the severity of carer impact at the time of writing the report. However, this knowledge did not translate to an interpretation of well-being as including a problematisation of carer rights and opportunities but rather limited it to a problematisation of carer recognition and community attitudes.

In spite of the concern expressed for carers in the Carer Inquiry 2009, and by the Commissioner, the AHRC, in its only report focusing on carers, has missed an opportunity to argue for carer rights. The WPR analysis provides opportunities to identify new categories for attention. It shows that the discussion, which merges carers into a normative familial role, means the AHRC does not identify carers as a population category worthy of specific attention. The presumption of carer obligation can be disrupted by identifying carers as a category of concern, which provides opportunity to research alternative problematisations.

The AHRC report suggests that the existing legislation should be extended to contain enforceable obligations. The AHRC extension is limited to the creation of “legally enforceable obligations to request a carer assessment, modelled on UK legislation ... under the *Carer Recognition Act* (Cth)” (AHRC Australian Human Rights Commission 2013: 35). The UK legislation introduces a level of government obligation relative to carer capacity, so the presumption still prevails that carers provide care if they have the capacity to, and the problematisation is limited to how best to assess this carer capacity. This is a limited adjustment to prevailing problematisations. To disrupt these problematisations the AHRC could have recommended enforceable obligations such as carer rights, the same way as such rights are asserted for people with disabilities.

### **3.3 Monitoring**

Australia is a signatory to seven UN treaties, and therefore provides the UN with monitoring reports at specified intervals. Only two monitoring reports mention carers, whilst a report on women's discrimination notably omits carers. These are analysed below.

#### **3.3.1 Fifth and sixth reports under the International Covenant on Civil and Political Rights, 2006 and 2016.**

Bacchi's WPR approach asks what is not problematised and silenced. Applying this WPR question to a comparison of the 2006 and 2016 monitoring reports leads to the question ‘what has become more silent?’ A more detailed analysis is at Appendix 1. In summary, the 2006 report mentioned special care for dependants, to allow carers to work, whilst the 2016 report doesn't mention carers.

### **3.3.2 Australia's combined sixth and seventh report on the Convention on the Elimination of all Forms of Discrimination against Women July 2003–July 2008.**

The WPR analysis of this report is in Appendix 1. The analysis found that mirroring the treaty itself, Australia's report does not distinguish carers as a group requiring specific attention. The report identifies: indigenous, CALD (culturally and linguistically diverse) and disabled women as groups requiring particular intervention and support to ensure their full inclusion in all levels of employment, leadership roles, good health care, and education.

Since carers, the majority of whom are women, also experience exclusion from, or low achievement in, these areas, the fact that they are not identified for similar inclusion as other disadvantaged subgroups, represents a critical silence. This silence means that the Australian Government does not actively monitor the attainment of carers in these spheres, which in turn, means there is little incentive for policy to problematise the 'lack of carer societal representation and achievement' in, for example, leadership roles, employment and educational attainment. As carers are not identified or monitored for their levels of participation and achievement in the public sphere, their underrepresentation in valued public roles remains unproblematised; it also means that the UN Committee's recommended targets for attainment of valuable public and career appointments does not apply to carers. Both the treaty and consequent monitoring could be disrupted by identifying carers as a new category of concern.

### **3.3.3 Australia's initial report under the Convention on the Rights of Persons with Disabilities, 3 December 2010**

The status of this monitoring report derives from the agreement of the Australian Government to the CRPD and a commitment to its monitoring; this monitoring is the designated responsibility of two core federal departments namely the Attorney-General's Department and the Department of Families, Housing, Community Services and Indigenous Affairs. The Attorney-General Department's declaration that the rights recognised in the CRPD inform the purpose of the AHRC's statutory functions directs the AHRC to review, assess, promote and advise on policies and practices to attain the rights of people with disabilities. This means that both the treaty and its implementation inform government policy.

This monitoring report provides a sequential assessment of Australia's actions against the 33 active (non-administrative) articles of the CRPD. The 60-page monitoring report outlines examples of various tangible, legal and procedural arrangements undertaken by the Commonwealth and state governments. These descriptions are supplemented by several appendices, which document annual funding expenditure for various programmes and service types. For example, in documenting progress made against Article 29 (Participation in political and public life) the report notes that voting rights and accessibility measures are legislated and further, that the government provides funding for 12 national disability peak bodies “providing people with disabilities the opportunity to be actively involved in public affairs through representative organisations” (Commonwealth of Australia 2010: 51). *Article 19 -- Living independently and being included in the community* -- numerically details the change in housing situations for people with disabilities from the commencement of deinstitutionalisation in 1981.

Carers are referred to in *Article 23 -Respect for home and family*, which says that carers of people with disabilities are at “significant risk of isolation ... due to the intensity of their caring role” (Commonwealth of Australia 2010: 39). It describes two programs, which address this: a national respite program (worth \$8.6 million and servicing 5392 carers) and a carer peer support program. Thus, the carer problem is defined as carer isolation with this solution provided in the form of a respite program. More solutions to carer isolation could be justified. The attainment of carer freedom from entrapment and participation in the community is again unproblematised. Instead, the problem is represented as how to support carers to continue to be an resource for people with disabilities with some respite relief. The effect of this problematisation is that carers are obligated to live with, and support, dependants.

Such problematisation means that in its national practice the Australian Government is oriented towards the rights of people with disabilities and casts those carers who serve them as a resource who need occasional respite to continue to provide care. It is apparent that the problematisation is determined by the limit of the prevailing policy solution, namely respite. Applying relevant WPR questions, what could be disrupted? Prevailing problematisations could be disrupted to address carer isolation and carer entrapment. This would lead to alternative solutions such as an assertion of ideals in the same vein as the ideals asserted for people with disabilities. For example, by applying

the Attorney-General's statement on people with disabilities in the 2010 Australian Human Rights Framework to carers, carers should have "consistent funding and support to help them realise their aspirations and to participate in social and economic life of the community" (Attorney General 2013: 54). Such funding would include substantial increases in disability services, particularly for out-of-home accommodation for dependants, as this removes carer obligations to dependants and their entrapment in the private sphere.

### **3.4 Summary: Australia's international policy and care**

Ideal carer treatment is not addressed in UN treaties. The absence of a carer treaty or statement of carer rights means that carers are not recognised, internationally, as a group requiring particular attention. Within general civil rights and women's treaties, there are no sections addressing carers, or any use of the term 'carer' as an identified group requiring consideration. This treatment contrasts with a range of other groups who are identified for specific attention including children, indigenous Australians, immigrants and people with disabilities. Only the CRPD refers to carers, as part of the resource solution to the problem of integration of people with disability in the community.

In contrast to carers, disabled people are identified internationally as a group requiring specific attention and have idealised treatment prescribed for various spheres. Such treatment includes an assumption of integration of the disabled person with their family members. The terms of the CRPD align with disability theory. Chapter 6 details how disability theory developed and has been disseminated by disability research and advocacy. Its prescriptive style facilitates its direct adoption in policy and detailed monitoring against specified goals. Australian Commonwealth and NSW state policy specifically reference the CRPD as guiding their strategic principles.

Carers are briefly discussed in an AHRC research report and in the 2010 monitoring report on the CRPD which suggest increased respite to enable carers to combine work and care. The contrast between carer and disability treatment is marked in the AHRC's 2010 monitoring report on the CRPD. Here, the juxtaposition of the aspirational language applied to disabled people compared with the prosaic language applied to carers, is patent. The effects of such contrasting problematisations are to entrench a ranking of different entitlements for different groups. Thus, disabled people have

integrated lives with achievements in the “ social and economic life of the community” (Attorney General 2013: 54) whilst carers have a break from their ongoing use as a resource to support dependants.

Without explicit rights in UN treaties, carers must rely on the rights afforded to the general population. In Australia, however, there is no explicit statement of rights such as a Bill of Rights, only common-law rights that are not codified, but incidental, including such matters as fair employment. To apply Bacchi’s approach, it is not always what is said, so much as what remains silent, in this case the absence of carer rights in UN treaties and the absence of administrative systems to scrutinise compliance with such rights. This silence is accompanied by a problem representation that presumes ongoing carer obligation to being the familial environment and support for dependent people with disabilities.

Ironically, in monitoring Australia’s performance against the goals of the CRPD, the AHRC also effectively monitors the extent of carers presumed use as a resource. Thus, if X number of dependants have achieved integration with their families, X number of family carers are obligated, possibly entrapped. This WPR analysis confirms that international policy permits carer entrapment in the private sphere by problematising how best to keep family carers providing ongoing care to dependent people with disabilities. An assertion of specific rights and entitlements for carers, similar to those asserted for people with disabilities, is required to disrupt and replace the narrow problem representation of carers. The ensuing WPR analysis of Australian texts will demonstrate that the prevailing international problematisation of carers persists in Australian texts.

# **Chapter 4 – Commonwealth and NSW State disability policy and legislation**

This chapter applies Bacchi's WPR analysis to Commonwealth and NSW state disability policy and legislation. The majority of funding that directly affects carers in their caring responsibilities is administered to the states via a Commonwealth agreement known as the National Disability Agreement (NDA). The NDA provides an agreed framework between the Commonwealth Government and each of the state and territory governments for the administration and funding of disability services. Disability policies and services overlap a number of departmental portfolios including disability, education and health. Significantly, disability has typically been an identified key state responsibility, usually as the sole- or primary focus of a specific department. Carers are not specifically the subject of state/Commonwealth funding agreements nor are they the primary focus of any specific department. Carers are addressed incidentally in the portfolios of various departments. The practical assistance and relief of the workload of carers is primarily administered from the disability portfolio.

The NSW state disability portfolio operates as a substantial division, titled Ageing Disability and Home Care (ADHC), with its own budget, residing within the Department of Family and Community Services. This Department is one of NSW's four mega-agencies amalgamated to group similar portfolios. The disability division is responsible for the administration of all disability- and carer-related legislation and the creation of ensuing policy documents and direct service arrangements, including the administration of funding to non-government service providers.

The National Disability Insurance Scheme (NDIS) will change the federalist arrangement that funds the State disability portfolio by directly funding disabled people rather than funding state governments. As such, state government disability departments will be phased out. The staged commencement of the scheme has generated new policy arrangements.

This chapter will first analyse the commonwealth disability legislation before analysing NSW State disability legislation and NSW State disability policy, followed by an analysis of lower-status national strategy and research agendas.

## 4.1 Disability Services Act 1986 (Commonwealth)

The *Handicapped Persons Assistance Act 1974* focused on survival needs of people with disabilities. In 1986 it was replaced by the *Commonwealth Disability Services Act* (CDSA). The CDSA reoriented the focus of disability services to one premised on the deinstitutionalisation of care for disabled people, and their integration with the wider community, with a particular focus on lifestyle and employment.

The CDSA is a 71-page document that contains 36 active clauses (which it refers to as Sections). The CDSA provides instructions on the type and scope of services the Minister can fund and outlines how funds are to be administered. In this way, the Commonwealth Minister provides funding for disability services to the states and other defined eligible organisations.

Although the CDSA does not specifically reference disability theory as its guiding premise, its overarching approach embodies the principles and language of disability theories, namely: the social model of disability (SM), social role valorisation (SRV), and normalisation (N). As briefly outlined in Chapter 1, SM promotes the integration of all disabled people in all environments, and works towards overcoming or removing any impediments to their enjoyment of full citizenship. SRV and N envisage people with disabilities attaining an education, employment, and lifestyle in keeping with their chronologically same-aged peers. A more detailed explanation and analysis of these disability theories is provided in Chapter 6

Clause 3 of the Act outlines the objects of the Act, in terms of overarching principles which direct the funding of disability services and the organisations that administer them. The principles outlined in Clause 3 clearly espouse disability theory, as demonstrated in the excerpt below, which shows key phrases underlined with the relevant theory shown abbreviated in brackets:

### 3 Objects

(b) to assist persons with disability ... to work towards full participation [SM] as members of the community;

(c) of ... to integrate in the community ... to achieve positive outcomes, [SRV] such as increased independence, employment opportunities and integration [N & SM] in the community; and ... [that services] are provided in ways that promote in the community the positive self-image [SRV] of

people with disabilities and enhance their self-esteem [SRV]; (emphasis added)

The problem representation of the CDSA effectively elevates key disability theories as institutionalised truths and problematises how best to distribute funding to achieve these truths. The effects of this problematisation are that all funding is directed to address integration of people with disabilities. As Chapter 6 demonstrates, the DSA only includes carers as part of the general caring community. The repeated references to “community” in the objects of the CDSA construe carers as a presumed support for disabled people in an integrated community environment. The CDSA does not specifically consider carers, but the statement in Clause 3 (2) anticipates funding limitations and specifies that services should then be meted out based on equity and merit. In this way, the CDSA presumes that unpaid care by carers will supplement this limitation. As noted in Chapter 1, it is estimated that carers save the government \$60.3 billion annually (Deloitte Access Economics 2015). The absence of carers in the CDSA is critical because of the largesse of carer support and the impacts of this support on carers. The extent of this presumption, and the fact that carer treatment is unproblematised, indicates that carers are treated as a mute resource.

Clause 5 of the Act makes provision for the Minister to formulate legislative eligibility standards for employment services, advocacy and rehabilitation programs. Apart from the standards established by the Minister, Clause 9 defines ‘eligible services’ (such as employment and advocacy services) as services which further the objects listed in Clause 3 of the CDSA. This effectively furthers the advancement of the principles of disability theory in legislation and services. The principles of Clause 3 apply to all activities financed under the Act including, as specified in Clause 10, recurrent expenditure, land acquisition, construction, and equipment. Clause 12, which addresses research and development, is similarly bound to the principles of Clause 3. Clause 12 therefore ties all future research to the established 30-year-old principles of disability theory.

The definitions of the CDSA outlined in Clause 7 “Interpretation” are also prescriptive and limit services and structures to those that espouse the principles of disability theory; this is both a powerful and limiting control in that it defines what is eligible and what is excluded from funding. Thus, eligible accommodation support services are those that will “assist persons with disabilities to develop or maintain suitable residential

arrangements in the community.” The specification of ‘suitable’ in this clause means that accommodation for the disabled can only be provided in integrated community settings. Similarly, advocacy service is defined as a “service that seeks to support persons with disabilities to exercise their rights and freedoms ... [as] ... recognised or declared by the Disabilities Convention”, whilst employment services should facilitate access to paid employment. As explained in Chapter 6, intellectually disabled dependants have other criteria for accommodation and support than disability theories’ integration in the community. Their criteria include safety, adequate care, support and supervision, and community relations with other similarly disabled people. Thus, alternative congregate, not community-accommodation, models may suit them better and may be more affordable. The CDSA, in its adherence to disability theory does not permit these alternative models.

The effects of this problematisation are that the CDSA cannot fund services which advocate for alternative ideals or specialised disability accommodation and employment. For example, Stockton, a congregate accommodation centre in NSW is scheduled for closure under the CDSA. Its closure pits the views of parents against funded established disability advocates (O’Reilly 2014). Disability advocates are vehement that congregate care is not acceptable, whilst parents argue that the existing congregate care models achieve their dependants’ safety, access to established friendships and meaningful activities and facilities. The carers interviewed echoed the views of these parents. Most carers interviewed expressed frustration with the focus on integration, seeing this as irrelevant, unachievable and of no benefit. Some cited examples where agencies had insisted on placing their child in an integrated setting and this had resulted in embarrassment or failure. Carers often noted that their children were isolated and ignored by their peers. Most carers preferred to see a focus on tailored accommodation provided in a variety of models. All carers wanted the design of accommodation tailored to the needs of their disabled child. The service criteria they valued were safety, consistency and reliability of support and designs that facilitated friendships between disabled people. Some carers thought larger institutional settings should be maintained as an option:

They should keep large residential centres, should ask the existing residents what they want. There's too little accommodation and all of us deserve the opportunity to have a better life [Anne].

I disagree with integration; I want disabled people congregating together [Carol].

The CDSA expressly excludes funding to both research these parents and carers' alternative goals and refine new problematisations of these goals in policy.

Identifying the established institutionalised truth that the problem representation in national legislation adheres to disability theories, opens it up to disruption such as allowing funding for research and services premised on alternative concepts rather than established disability theories. This includes researching the views of carers on services and policy, and using the new fair care theory to explore whether alternative accommodation and support models that better suit the intellectually disabled and their carers. Such models are likely to include alternative congregate models that may be more efficient<sup>16</sup> and therefore reduce the obligation on carers to provide care.

## **4.2 National Disability Insurance Scheme: the Productivity Commission Inquiry and government's response.**

The Productivity Commission's Inquiry on the National Disability Long-Term Care and Support published its report in 2011. This report is considered to have a high-level and long-term status due to its endorsement by government. The Commission report recognised the chronically underfunded and inefficient disability service system and recommended reform to disability services and substantial increases in funding.

In reference to carers, the report states that carers' contribution to the support of disabled people was so significant that any government insurance scheme could only complement it rather than replace it; such support would allow informal carer arrangements to be delivered in a way that was "more equitable" and reduce the pressure on carers (The Productivity Commission 2011: 312-313).

Although assuming the continuation of carer support for disabled people, the Commission report entertained the notion that such support would not be assumed

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<sup>16</sup> Chapter 5 's review of the government's inquiry into care shows parliamentarians referring to government funded community care as expensive.

under obligation; this implies the Commission recognised the coercion of carers. This is seen in its discussion of the assessment process for disabled people entering the scheme which would include a component of the level of informal care that could be “reasonably and **willingly** provided by unpaid family carers” (The Productivity Commission 2011: 339) [emphasis added].

The Council of Australian Governments (COAG) is an intergovernmental forum involving Commonwealth, state, territory and local governments. Following the release of the Commission’s report in August 2011, COAG undertook the development of high-level principles to guide the consideration of the Commission’s recommendations, principally focusing on “foundation reforms, funding and governance. In “2012, COAG agreed to publicly release the principles for an NDIS and a progress report on the NDIS” (COAG 2013).

The substantial disability services reform agenda envisaged in the NDIS is only achievable with a commitment of considerable additional funding. In December 2012, the NDIS received landmark agreement when COAG signed an Intergovernmental Agreement for the NDIS Launch; this represented substantive funding by direct taxpayer levies. The NDIS was then negotiated via separate bilateral agreements with each state and territory government.

In December 2012 “COAG reaffirmed its ongoing commitment to an NDIS by signing an intergovernmental agreement for the NDIS Launch... [several states, including NSW]... signed bilateral agreements with the Commonwealth which confirm the operation funding details of the rollout of the NDIS” (COAG 2013b). A direct tax levy funds the NDIS. Thus, the NDIS and the in-principle ideas of the Commission’s report achieved bilateral government agreement. On the 21<sup>st</sup> March, 2013 new Commonwealth NDIS legislation was passed in Federal Parliament.

The NDIS represents a dramatic change in the delivery of disability services; tying disability funding to a direct national tax levy guarantees a substantial increase in disability funding. In terms of delivery, the Commonwealth Government changed the established federalist governance model, making the provision of NDIS funding conditional on the removal of state governments from the administration and delivery of disability services, and assigning national agencies the responsibility for funding disabled participants either directly or in association with nominated private agencies.

Such significant change led to the placement of a sunset provision which will effect the cessation of the CDSA in 2019 and the establishment of two new Commonwealth Acts: *Disability Care Australia Fund Act 2013*, and the *National Disability Insurance Scheme Act 2013*.

The NDIS has resulted in the NSW government also enacting legislative change which is analysed in sections 4.5, 4.6 and 4.7, below.

#### **4.3 Disability Care Australia Fund Act 2013 (Commonwealth).**

This Disability Care Australia Fund Act directs the administration of disability care funding; it serves a critical enabling function for the NDIS, creating alternative federal arrangements between the Commonwealth and state governments. Apart from establishing how money collected for the scheme will be held, distributed and accounted for, the Act does not elucidate any care- or disability policy.

#### **4.4 National Disability Insurance Scheme Act 2013 (Commonwealth).**

The scope of the National Disability Insurance Scheme Act (NDISA) reflects the COAG agreement of direct funding of disability services by the Commonwealth, bypassing state governments. As such, the NDISA details procedures for administering NDIS funding and is necessarily long, running to over 183 pages.

Following a typical legal format, the NDISA begins with Chapter 1 outlining its scope, aims and key definitions, with the remaining chapters describing the practical arrangements for distributing and administering funding. This includes the criteria and eligibility processes for becoming a “participant” of the Scheme, and the scope of services to be funded, according to an approved “Participant Plan”.

The NDISA establishes a funding Agency whose CEO is prescribed particular responsibilities and authority including assessing the eligibility of applicants to be participants, and distributing funding. The CEO and Agency will replace the Minister’s functions in the CDSA. This is significant as it means that in contrast to the preceding arrangement, a Commonwealth Minister will no longer be ascribed legislative responsibility for distribution of disability funding. The NDISA also establishes an agency board, to which the Agency is to report together within a separate Independent Advisory Council, and prescribes various administrative arrangements for organising funding for administration, appropriate supports and disability research.

The NDISA is more explicitly rights-based than its predecessor, the CDSA; it states its commitment to securing rights as outlined by UN Covenants. Broadly, the problematisation of the NDISA is how to fully effect the internationally specified rights for people with disabilities. The section titled “Part 2 Objects and Principles” (p3) clearly outlines the premise of the Act. As with its predecessor, the CDSA, the NDISA continues to espouse the attainment of disability theories’ integration in accordance with the social model of disability (SM). The NDISA specifically both presumes and emphasises the independence of people with disabilities. This is demonstrated in the extract below which shows key phrases underlined with the relevant theory abbreviated in brackets alongside:

(c) support the independence and social and economic participation [SM] of people with a disability; and...

(g) promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion [SM] in the community.

The above reference to inclusion and participation correlates with the SM’s ideals of integration via the removal of all disabling structures in society. Associated with this integration or ‘full inclusion’, the objects of the NDISA also emphasise choice:

(e) enable people with disabilities to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports.

These goals are then repeated in Section 4 -- General principles guiding actions under this Act, which mentions that choice for people with disability in three of its eleven subclauses, and again emphasises self-determination and independence, as shown in the key phrases underlined below:

(8) people with disability have the same rights as other members of Australian society to be able to determine their own best interest including the right to exercise choice and control or to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.

The reference to rights in UN covenants, and stating goals aiming to achieve choice and control for people with a disability, indicates a key problem representation in the NDISA is ‘how to enable the assertion of rights, choice and control for people with disabilities’. The reference to UN covenants shows this has come from an adherence to the goals of these covenants that are based on disability theory. The reliance on UN covenants, and their language of disability theories and rights, forms both a premise and, in relying on

an international agreement, a defence of this problematisation. The effects of this problematisation are significant because Australia does not have a Constitution or similar instrument that outlines citizens' rights. As noted in the introduction, Australia has a wage-based welfare system rather than a rights-based welfare system. This means that people with a disability, in comparison with carers and other subgroups, have legislation enacted, the NDISA, to affect their stated citizenship rights and to distribute funding to achieve ideals related to choice and control. Sheehan, a disability service provider, notes that this represents a paradigm shift from provider-designed services "to users exercising choice and control" (Sheehan 2014). Others also note this "new paradigm of disability support ... [wherein] ... people with disabilities are active bearers of rights rather than passive recipients of welfare" (Soldatic, Van Toorn et al. 2014). To disrupt this problem representation and assert the rights of carers, an alternative care theory and ideology must be promoted.

The NDISA defines funding recipients as participants after they are assessed by the Agency's CEO to be eligible. The CEO is then tasked with facilitating a 'participant plan' which should address all necessary supports including early intervention, personal care, activities. Clause 31 outlines the Principles that should apply in relation to plans. Such plans are to facilitate the choices and views of people with disabilities and:

(b) be directed by the participant

(g) be underpinned by the right of the participant to exercise control over his or her own life (Commonwealth of Australia 2013: 34 and 35 ).

In structuring services to be directed by participants, the NDISA presumes the independence and full inclusion of all people with disability. This assumption underlies another key problem representation which can be distilled to: 'how to arrange well-administered, adequate and tailored support to fulfil the choices of the independent citizen with a disability'. To disrupt this problem representation one must question the presumption that all people with disabilities are independent and recognise dependency and the different goals of dependent people with disabilities.

If all people with disability are independent, they are therefore able to prepare, with the facilitation of the CEO of the Agency, their own participant plans and receive support in accordance with such plans. What is left unproblematic in this problem representation is the concept that a person with disability may be dependent and unable to exercise

choice and control; consequently, the treatment of carers, who act on behalf of such dependants, is also not problematised.

The NDISA defines a carer as essentially an unpaid person who provides personal care and support to a person with disability. Given the emphasis on independence for all people with disabilities, there are few references to carers and families and these few are loosely worded. The notion of needing care would imply some people with disabilities are dependent. In order to maintain the presumption of independence for all disabled people, carers are presented as a possible source of support only “where relevant” (Commonwealth of Australia 2013: 34).

The role of carers is not clear; there are few tangential references to carers, such as “respect the role of families and carers” (Commonwealth of Australia 2013: 6), ... [and]... (Clause 25 (iv)) strengthening the sustainability of informal support available to the person including through building the capacity of the person's carer” (Commonwealth of Australia 2013: 29).

Corresponding with the premise of disability theory, the NDISA presents all people with disabilities as independent and problematises the achievement of their independent lifestyles, with carers as a resource, part of the informal network of care. Thus in Clause 31(d), which refers to the preparation of ‘participants plans’, such plans should “where possible strengthen and build capacity of families and carers to support participants” (Commonwealth of Australia 2013: 34). Thus carers are a subject or resource, not an actor, in the plan. This is evidenced by the plan being facilitated by the CEO and directed by the participant, who would, where relevant, consider and incorporate support of the carer/family resource.

Four of the carers interviewed had received trial individual funding packages, and provide some insights on the administration of such packages. All were outraged at the proportion taken by the community agency for what was perceived as little or no service provision, as “just a money grab” [Sue]. Moreover, all were burdened by the administrative responsibility:

We have an individual funding package, our NGO [Non-Government Organisation-the administrator of the package] takes a big cut. They're very clunky to work with, very tedious administration and they do nothing - we wanted our vehicle modified for our son's transport they spent three months considering it, did nothing and took \$8000 [Joan].

I set up my son's respite house, I and my husband we do everything all the accounting, all the administration, then we get a bill for quarter of the package a quarter! For doing nothing but printing a bill [Cristina].

We were desperate so we got a family funding package, the package was administered via X-[church run community agency], immediately they took their 25% then I spent the next eight months sourcing my own services whilst the well-meaning 'teenage' case manager 'facilitated'. She did nothing, I spent more and more of my time having to photocopy bills, fill out forms, and placate the case manager who knew less than I did. To figure out and work within their funding rules. Some rules were at the whim of the local agency manager who said she would only endorse funding receipts for toys purchased from Kmart not Myers. It was a strain to administer hardly worth the \$30,000 [Sue].

These comments are particularly worthy of reflection given the shift in Australia towards individualised funding under the NDIS scheme. They demonstrate how individual funding for dependants places ongoing management and administrative responsibility on carers.

The effects of not recognising dependency and not problematising its effects are that dependants' and carers' needs are not directly addressed and carers' role in formulating and administering participants' plans is not recognised nor catered in policy.

In terms of carer obligation, the NDISA assigns parental responsibility, defining it as applying to people with disabilities who are children aged under the age of 18. In line with normalisation and the social model of disability, which presumes equal integration and roles as one's same-aged peers, the NDISA appears to assume that adults with a disability will function as typical adults in the community. This is not explicitly stated but is seen in the presumption underlying the application, function and administration of funding. For example in Clause 31(da) 'Principles relating to plans', there is a presumption that families and carers will support children, but if participants are adults, agreement by both participants and carers is required prior to funding carers to support adult participants:

If the participant and the participant's carers agree - strengthen and build the capacity of families and carers to support the participant in adult life (Commonwealth of Australia 2013 p 34).

Thus, carers have an obligation to children with disabilities, but requiring the agreement of carers implies that carers of adult people with disabilities are not necessarily obligated to care for them. Apart from a reference to the *Carer Recognition Act 2010* as a contextual document, carers are not otherwise mentioned. As the problem representation of the NDISA does not acknowledge the dependency of some people with disabilities it does not acknowledge the consequences of this dependency, which includes their inability to exercise choice and control and their reliance on carers to act on their behalf. In their review of the NDISA, Soldatic, Van Toorn, Dowse and Muir, note that the NDISA is likely to marginalise certain categories of people with disabilities, also noting that proving eligibility to the scheme may be beyond the ability of some

People with disabilities ... [who] ... are unlikely to have the sociocultural literacy to interpret and activate administrative rules for their own individual benefit ... Furthermore, while the NDIS and the UNCRPD align around the intention and commitment to increase individual rights, decision making, and control, this will only be realised if people ... have the support and capacity to advocate for, exercise, and realise these rights (Soldatic, Van Toorn et al. 2014: 9, 13).

Some intellectually disabled people who are dependent are unable to communicate, express or exercise their choices and lack the sociocultural literacy to independently access and navigate the scheme. As noted, carers have no legislative role in advocating or speaking for their dependants. The presumption of independence for people with disabilities doesn't acknowledge the dependency of some people with disabilities nor make explicit provision for carers to represent them.

In adopting a presumed truth that all disabled people are independent, the dependency of some disabled people and their reliance on carers constitutes an inconvenient truth. Such truths include that disability supports occur in and affect carers in the family home, and that carers, who negotiate services for dependants have valuable views on the efficacy of disability services. However, these truths are not reflected in disability legislation. Thus, there are no problematisations that include the 'need to tailor services and supports to reflect carers' views.'

Many carers interviewed stated it was important to listen to carers' views on disability services. Most carers noted their difficulty in using the disability service system, attributing this to lack of holistic and tailored service design. For example, one carer provided an example of the difficulty in accessing after-school care as there was no

complementary provision of transport from school to the after-school care service. All carers emphatically restated that far more service models should be available - especially accommodation- and other models of overnight care.

Carers also said that disability services should address the whole family including the siblings of dependent children who should be given choices and opportunities into their future. Most carers wanted services and government policy to widen the focus so disability services that were tailored to the whole family:

Focus on carers and siblings, there's too much focus on disabled [Cristina];

The government needs to speak to many carers, across the disabled range differences are high and that the government should have very different service criteria and models to meet the different needs and logistics of families [Luk]; and

The current disabled advocacy is not representing people with disabilities only pushing what they think [Anne].

Most carers interviewed thought that service design criteria should prioritise safety and security, noting that this could be met with more scrutiny incorporated into the structure and design of services, complemented by good key workers and service managers:

Disabled are vulnerable in group homes, the first one was bad, another boy there had to have his rectum reconstructed, it depends on staff as this one is better, and he has good key workers [Anne];

Want more kids more adults together and a safe and proper ratio between kids and adults, want true feedback [Fozia];

Safety, stop sexual abuse, more numbers equals more staff around, then I want cleanliness and hygiene [Luk].

Soldatic et al. (2014) mention the difficulty of dependants negotiating the NDIS. Carers interviewed said service design and access should recognise that carers have strong ties to their dependants and want to direct how services either entirely support dependants, or assist carers to support dependants. Significantly, carers' views on services referred to different criteria concerning safety and survival. In problematising the achievement of high-quality independent lifestyles for disabled people, disability legislation does not address the survival needs of dependants. As such, a presumed truth prevails that carers meet this basic need.

A further effect is that in presuming carers are a resource, the independent choices and lifestyle of carers are subsumed. Disability theory directs the problem representation of disability in international and national legislation and presumes the independence of all disabled people. An effective way to disrupt and replace this problem representation is by challenging the presumption of independence, acknowledging dependency and framing problematisations around meeting the basic needs of dependants and incorporating carers' views.

#### **4.5 The Disability Services Act 1993 (NSW).**

In order to explore the premise and evolution of disability policy, an analysis of the NSW Disability Services Act (DSA), now repealed, was undertaken. A WPR analysis is provided in Appendix 2. This shows that the DSA's problematisation is how to facilitate the release of disabled people from institutions and integrate them with the community. It then proposes as a solution, the creation a new framework of disability services to replace institutional care. In both its language, and the specification of administrative arrangements, the DSA is premised on disability theory. Thus its service framework and key principles problematise the achievement of independent equal social participation, integration and recognition.

The bilateral agreement between the Commonwealth and NSW state government on the NDIS represents a significant change to the provision of disability services in NSW. The NSW Government will no longer have a role in the provision of disability services, with such services being provided by the non-government sector. In recognition of these changes and the developments in the sector, particularly the signing of the CRPD, the NSW Government enacted new legislation. This legislation repealed the DSA1993 and established two new Acts: The Disability Inclusion Act 2014 (DIA 2014) and the National Disability Insurance Scheme (NSW Enabling) Act 2013 (NDIS NSW EA). Each is analysed below.

#### **4.6 NSW – National Disability Insurance Scheme (NSW Enabling) Act 2013.**

This Act enables the practical transition from existing state-owned and operated disability services to services administered in accordance with the Commonwealth's NDIS. It outlines the legal provisions and arrangements for the transfer of state-owned

and controlled assets, staff and services to other providers in accordance with the NSW – Commonwealth COAG agreement to allow the funding of such services when the state government's role in disability services ceases and the NDIS is fully operational by 1<sup>st</sup> July 2018.

Given its specific enabling function, the Act has limited policy discussion. Following the transition period, from July 2018, with the change to federalist arrangements for disability funding, there will be limited state government responsibility and oversight for disability.

#### **4.7 NSW – Disability Inclusion Act 2014.**

The NSW Disability Inclusion Act (DIA) repeals and replaces The Disability Services Act 1993. The DIA updates the previous Act and more firmly emphasises the rights and independence of people with disabilities, in accordance with the signing of the CRPD. The DIA can only direct funding for the limited period of transition to the NDIS that is until July 2018. Consequently, the vision of the DIA is to set general goals. To this end, the objects of the DIA contain phrases such as 'to acknowledge', 'to promote', 'to enable', as opposed to phrases like 'to ensure' or 'to guarantee'.

The DIA contains six parts and four schedules. Parts 4 to 6 include 32 clauses, which pertain to standards and arrangements for support and services, specifically the conditions that govern the distribution and review of financial assistance provided by state government to public or private entities during the transition period. These parts allow funding to be distributed directly to the individual, in accordance with their wishes and in accordance with the service standards which the Secretary may make governing the distribution of funding. The DIA frequently refers to persons with disability who fall in the "target group" as individuals:

Clause 26: "The secretary may provide financial assistance to or on behalf of an individual who is a person in the target group to obtain supports and services."

The individual's carer's views may be considered and their carer may receive funding on behalf of the individual.

Parts 1 to 3 of the DIA outline broad aims in regards to the treatment of people with disabilities (Part 1); an obligation for disability planning by all state departments (Part 2) and, the operation of the Disability Council of NSW (Part 3).

As with the 2013 Commonwealth NDISA, the stated aims and principles of the DIA make specific reference to the CRPD and outline emphatically rights-based principles for people with disabilities. Clause 3 Objects of the Act and Clause 4 General Principles of the DIA list the rights applicable in specific areas. The wording of these principles around integration (inclusion) and participation in valued social and economic roles, as underlined below, reflects the principles of the social model [SM] of disability and SRV, as shown in the excerpt below:

Clause 3:

(b) to promote the independence and social and economic inclusion [SM and SRV] of people with disability;

Clause 4:

“(2) people with disability have an **inherent right** to respect for their worth and dignity as individuals [SM]

(3) people with disability have the **right** to participate in [SM] and contribute [SRV] to social and economic life ...

Like the Commonwealth NDISA, the State DIA mentions independence for people; it also presents people with disability as individuals who exercise choice and control in respect of personal goals and the delivery of individual supports and services. However, the Commonwealth NDISA more emphatically emphasises and makes repeated references to independence and choice and control.

As with the Commonwealth NDISA, there are a few secondary references to carers. Again, the person with disability is at the centre of consideration; carers are those who form the context and enable the independent lives of individuals (who are defined as falling in the target group). Carers are people whose “crucial role ... as ... significant persons in the lives of people with disability ... is to be acknowledged and respected” Clause 4 (AIHW 2008). The NDIS “(5(5)(a)) recognises that a child with a disability has the right to full life in conditions that ... facilitate the child's active and full participation in family, cultural and social life” (PCO 2014).

The problem representation of the DIA can be summarised as ‘how best to service the person with disability to live a full life, integrated with their family and community’. The presumption of this representation is that care in the familial home forms an integrated environment for children with disabilities. The effect of such representation is an

asymmetry of rights between children with disabilities and non-rights-bearing carers who are, by legislation, obligated to provide care in the familial home. Disruption of this problem representation requires new ideals that address carer obligations and entrapment.

#### **4.8 NSW Policy: ‘Stronger Together 2’ extended by ‘Ready Together’.**

Stronger Together 2 is the second tranche in the NSW Government’s 10-year service plan for disability services. It correlates with the 2010 announcement by the NSW Government of an increase of \$2 billion in investment in disability services for the five years from 2011 to 2016, bringing the total spend over 10 years to \$6.3 billion. As this document outlines a framework for the expenditure of \$6.3 billion worth of funding, it is considered a high status- and medium-term document. ‘Stronger Together 2’ was extended beyond 2016 by ‘Ready Together’ to cover the period until the NDIS is operational in NSW.

Two analyses are relevant to this thesis, firstly to assess the way such substantial funding is oriented, by an examination of both overarching statements, and the goals specified for each issue and service type; and secondly, to broadly analyse the pattern of funding allocation against service type. These assessments will indicate the government’s priorities and underlying theoretical rationalisations.

In terms of overarching goals, the Minister’s introduction notes the goals of the next five years as:

*Stronger Together* will ensure that people with a disability are at the forefront of **decision-making and choices** ... through the expansion of **person-centred** approaches [emphasis added] (ADHC 2011: 6-7).

As remarked previously, the prevailing assumption places people with disabilities as the focus of the person-centred approach; where families as carers are mentioned, they are assumed to be the support system who require ‘more certainty’ about the support they will receive, presumably to enable them to keep caring. Thus the problem representation of the whole plan is oriented towards achieving choice and control for people with disabilities and better support to keep carers caring. There is an acute silence on measures of choice and control for carers as persons.

A WPR analysis of the plan is in Appendix 2. It shows that similar to the Commonwealth NDIS, the plan states its explicit compliance with the UNCRPD. The plan states that a key

theme was “that a person with disability must be at the centre of decision-making about their lives [sic], rather than having to fit into an existing suite of programs” (ADHC 2011: 14) . The problem representation of these person-centred goals is how to enable people with disabilities to build a good life. This represents an explicitly idealistic goal for people with disabilities. No similar idealistic framework is mentioned for carers.

Community consultation preceded the plan. Of note is the misinterpretation of community comments in the government's response which is evidence of an intentional silence around the adequate provision of government-supported accommodation. The community comment quoted in the plan requested the provision of “more accommodation options for people with disabilities. It should be planned with the family or carers to allow a smooth transition ... [however, the government's interpretation of this was] ... You said there needs to be more choice and certainty so that you can plan for the future”(ADHC 2011: 15). More choice in service type is not the same thing as more accommodation options. This is a government policy sophistry wherein the direct request for more accommodation options is dissipated into a vague requirement for more choice and certainty in support services to enable carers, as an assumed setting and provider for much of this accommodation, to plan ahead. Accommodation is necessary to relieve carers of the obligation to provide care in the family home. The intentional absence of a problem representation concerning adequate government accommodation explains the concomitant silence on carer choice and a presumption of ongoing carer obligation.

Carers interviewed were asked what they thought of the government's person-centred policy and the catch phrase of ‘living the good life’, promulgated as a goal in disability policy for people with disabilities (ADHC 2011). This question sparked a reflective, philosophical response from most carers along the theme of “what is a good life?” [Maria] and is it reasonable to assume that carers are entitled to it. Most reasoned that a good life is too much to ask for, but it was fair to expect a normal life.

What is living the good life? I'd like a full-time job, to eat a meal, in peace that's my good life. I went on holidays with more luggage and wheelchairs I came back more tired [Fozia];

A good life for me would be to get better connection with my daughter and husband, with less family pressure from disability [Anne];

What is the good life? What's fair? Life's not fair, not for anyone. All should have it; can anyone expect to live a perfect life? But a good life is to have

ambitions and hopes and dreams and to be able to follow them, but to do stuff I need a babysitter for Luke. Ideal would be enough care for Luke and support for carers [Barbara].

Some questioned whether the government should support a good life: "Whose responsibility is it to lead a good life? The governments? No, the government should support me to live a normal life" [Catherine]. These carers' views lead one to query whether problematising the attainment of 'the good life' is too aspirational for any subgroup. Perhaps it is more equitable if policy directed to all vulnerable groups, including carers and disabled, problematised the attainment of 'a normal life'. As one carer summarised in wishing that her disabled daughter and her family could all have the same lifestyle:

depends, if we can financially provide for her and us so she lives a good life and we're not struggling -- better if both of us are in the same lifestyle ... like to be able to maintain current lifestyle so we live within our means don't go to restaurants every week, buy groceries on special and save extra for our and her life - would be okay with holidays every year but too many extra dollars, [it would have] helped to have a cleaner but dollars don't allow it [Luk].

The proposed funding distribution by service category is summarised in Appendix 2. Of the seven service types funded under the plan, five provide partial support for dependent people with disabilities whilst they remain the responsibility of a carer in the carer's home. The attendant care service is defined as portable, flexible and individualised support for those who need personal help to live independently in the community. This service represents less than 1% of the total places and supports those who can self-manage the provision of support services, usually people with physical disabilities.

Out-of-home government-supported accommodation is the only service type that relieves the carer of obligations to care for their dependants. The analysis of the funding distribution in Appendix 2 shows that proportionally, less than 8%, or 7500 total places by 2016, are allocated to supported accommodation. Intermittent assistance for people with disabilities constitutes 92% of the total places (ADHC 2011). To compare with the baseline capacity in 2005/2006: 10.5% of total places were for supported accommodation, with approximately 89% of places allocated for discrete support, which is not equivalent to respite or accommodation. This represents a reduction in,

proportionally, approximately one third of the share of total accommodation places from 2006 to 2016.

The shift away from accommodation towards intermittent support demonstrates that, proportionally, the NSW Government is placing less emphasis on full support for dependants, which relieves carers of their caring responsibilities, with a concurrent increased emphasis on discrete support. Thus, the life-span problematisation of adult persons with disability is that they will be supported “to participate in and contribute to their communities” (ADHC 2011: 22). This obligates carers, as pivotal members of dependants’ ‘community’, to keep on caring for dependent adults in the ‘community’ of the family home. As such, the NSW government’s service delivery is shifting towards an increased emphasis on continued carer obligations rather than offering carers liberty and choice in whether to provide care to dependants.

#### **4.9 National Disability Strategy.**

The National Disability Strategy (NDS) was formally endorsed by COAG in 2011. The NDS represents a 10-year national policy framework to improve integration and coordination across government departments in regards to disability. The NDS promises to progress the principles of the CRPD, and lists long-term targets and broad strategic statements; it establishes six priority areas: accessible and inclusive communities, protection of rights under legislation, economic security in employment, support for independent living, learning, and health/well-being.

On the 3<sup>rd</sup> December 2012 the NSW Government launched “NDS NSW” an implementation plan which aligns with the NDS’s priority areas and complements the NSW Government’s disability service framework as outlined in *Stronger Together 2 2006–2016*. The NSW implementation plan “focuses on improving access to mainstream services so people with disability can enjoy equal rights and opportunities including access to education, entertainment, health, recreation, transport and housing” (ADHC 2013).

A ready way to see the silence on carer rights in comparison with the problematisation of achieving the rights of people with disabilities is to replace the term ‘people with disabilities’ with ‘carers’ in the above quotation. This makes it clear that a significant silence reigns on both carers as the subject of services, and as equal-rights bearing

citizens with “opportunities including access to education, entertainment, health, recreation, transport and housing”(ADHC 2013).

#### **4.10 The National Disability Research and Development Agenda.**

Although research would generally be considered low status, merely advising the early stages of draft government policy, The National Disability Research and Development Agenda is considered medium status, as it sets out nationally agreed and government-funded priority areas for disability research. In 2013 the agenda directed the allocation of \$10 million for disability research. As such, it indicates the likely interest and direction of future government policy.

The research agenda parallels the objects of both the Commonwealth and NSW State legislation and therefore embodies the principles of disability theories. The research agenda channels funding within specific channels which align with the principles of disability theory. It therefore promotes integration and typical, socially valuable roles for people with disabilities, including participation in community life, access to mainstream activities, social and economic inclusion and broader systemic change.

The level of funding attached to the disability research agenda establishes a firm base for the establishment of disability-oriented research structures and institutes. Thus, the National Disability Research Agenda supports continued research, advocacy and policy within the established channels of disability theory.

#### **4.11 Conclusion – disability policy**

Disability theories directs the problematisation of both Commonwealth and NSW state policy and legislation. Thus, these policies problematise the theories concepts of integration, normalisation and SRV for people with disabilities. The consequent policy solutions therefore aim to expedite the devolution of institutions and the return of all people with disabilities to live independently in the receiving community. In doing so, the Commonwealth and NSW Acts, like disability theories, also avoid recognising alternative problem representations, such as how to ensure the survival needs of dependants who cannot attain independence. In avoiding alternative problematisations of survival, disability theory and policies also avoid any problematisation of the consequent obligation and entrapment of carers who meet the survival needs of dependants.

The limited problematisation described above is entrenched as an institutional truth by three features identified by the WPR analysis of disability policy. Firstly, carers are identified in Commonwealth and NSW state legislation as providing a relational context and resource for the person with disability. Secondly, this legislation makes provision for disabled services to include access to advocacy support; and therefore provides an avenue for government funding of such advocacy. By comparison, such funded advocacy is not legislated for carers. Finally, this legislation makes allowance for further research and development but specifies that both the organisations and the design of the research are to be in accordance with the principles of each Act.

This last matter severely curtails any questioning of the principles underlying these Acts and the theories upon which they are predicated, namely the social model of disability, social role valorisation and normalisation. It also severely curtails the potential for funding of research by any organisation that does not specifically subscribe to these theories, and presumably even curtails the scope of works and the discovery of alternative care and disability theories to address the different needs of intellectually disabled people and their carers. This limitation severely restricts the development of new contrary discoveries and the development of any policy beyond the realms of disability theories established in the 1980s. This ensures that the 30-year-old constructs of disability theory will influence policy for a long time. As carers substantially support the integration of dependent disabled people, the restriction on disability research has implications for the resources made available to freely explore or permit carer research and theories.

The implementation of the NDIS in NSW was formalised in December 2012 via a joint agreement between the Commonwealth and NSW Government which ensured all eligible users would receive ‘person-centred supports’ by June 2019 (ADHC 2013). Summarising its approach to the NDIS, in 2013 the NSW Government stated:

Ultimately, the NDIS will provide people with disabilities with the reasonable and necessary support they need to live life their way, to achieve their goals, and participate in social and economic life. ... moving to more person-centred supports across the whole of NSW (ADHC 2013).

The phrases “independence”, ‘choice and control’, ‘full inclusion’ and ‘person-centred’ are repeated in key disability services documents. The person at the centre of policy and services is the person with disabilities. Although carers are profoundly impacted by

both the extent and design of disability services, the services are not to be oriented towards them, nor are they recognised as persons within such policy. Arksey and Glendenning comment on how, in UK policy, direct funding to disabled users doesn't provide full funding to carers nor indicate how carers' choices will be balanced with those of people with disabilities:

so far as the new policy initiative of individual budgets [direct payments to facilitate choice to the service user] ... it is not clear from any of the policy documents whether they will be available to carers in their own right, nor how the choices of carers and older people or those with disabilities will be negotiated and balanced (Arksey and Glendenning 2007: 166-167).

As noted, this asymmetry between specific, identified and interconnected subgroups creates a marked imbalance between them, for example, between the subgroup of persons with disability, who have person-centred goals which problematise the attainment of the ideals of disability theories, and the subgroup of unpaid, obligated carers, whose obligations and entrapment are not problematised and therefore not slated for ideal solutions. Such an imbalance amounts to an effective ranking of citizens.

The irony of this is profound. It means the problem representation in policy prioritises the needs of persons with disabilities and places carers in a curious contextual position wherein they are represented as both joint providers of disability care *and* impacted by a disability service system that is silent on their entitlements and choices.

The new NDIS legislation, at both Commonwealth and state levels, presumes the independence of all people with disabilities. Such legislation and policy provides no practical acknowledgement of dependency and the consequences of dependency, and consequently no clear role or specific authority for carers. Carers become the silent and unacknowledged resource to fill the gap in the disability system. In such a situation, carer obligation remains tacit and continues to be unproblematised in government policy and legislation. Following the application of Bacchi's WPR analysis, I have noted some of the effects of this problematisation and absence of alternative problematisations around dependants' survival needs and consequent carer entrapment. The following chapter further explores these issues in its analysis of relevant carer texts and carer interviews.

# **Chapter 5 – Australian Commonwealth and NSW State carer policy and legislation**

This chapter will employ the WPR approach to analyse relevant carer policy, legislation and government texts.

Australia has limited carer-specific policy and legislation. The 2009 Carer Inquiry is the first significant focus on the care situation in Australia. It generated specific legislative and policy outcomes. This includes the first carer-specific legislation in 2010 for both Commonwealth and NSW governments. The Inquiry also generated various high-to-medium status policies addressing its 50 recommendations.

## **5.1 The Carer Inquiry.**

The Carer Inquiry and report is considered high status and long term both for its significance as the first national review on carers and because it engendered the first national and NSW state, carer-specific legislation. The Carer Inquiry was conducted under the auspices of the House of Representatives Standing Committee on Family, Community, Housing and Youth. This committee included politically important committee members (including active senior members of Parliament such as Tony Abbott, the then shadow minister for family and community services and indigenous affairs).

The Carer Inquiry had relatively broad ranging terms of reference and was supported by reasonable financial resourcing, including a funded secretariat and the scope to review thousands of submissions and receive presentations from individuals and groups from across Australia. Its full influence, however, is yet to be borne out and will depend on how radically original its recommendations were, compared with existing trends in carer policy, and to what extent new approaches are taken up in policy in the ensuing decades. This analysis will apply Bacchi's WPR method to the Carer Inquiry report to see how carer treatment is problematised. As the Carer Inquiry formed the basis for ensuing national carer legislation and carer policy, it provides a unique opportunity to scrutinise both the premise and formulation of the problematisation of carers in government policy.

In its introductory comments, the Carer Inquiry Committee (hereafter referred to as the Committee) said it was “keen for the report to provide a platform for the voice of carers. The report makes extensive use of excerpts from submissions and transcripts, enabling carers to tell their own stories in their own words” (Australia 2009: 14). Written submissions to the Carer Inquiry were invited by advertisement in a national newspaper (The Australian) in May 2008. A total of 1305 submissions were received of which approximately 1200 were from carers. Additionally, 14 public hearings were held between July and December 2008; these hearings received evidence from approximately 250 representatives, of whom approximately half were carers. Carers and relevant groups provided direct insight into both the situation of carers and their views on various issues. This material is available in the final report of the Carer Inquiry which provides a selection of lengthy carer comments gleaned from both written submissions and presentations. Chapter 1 noted that the ‘imprint’ of carers’ voices is largely absent in government texts. The Carer Inquiry is one exception as it contains extensive comments from carers to the Carer Inquiry. This analysis will relay the stories of these carers along with those of carers interviewed.

The Carer Inquiry recognised that carers play a vital role in supporting the community care system; experience isolation from their peers and dislocation from mainstream employment; endure generally lower physical/ mental health and have less financial security. Its terms of reference listed four areas for focus:

1. the role and recognition of carers;
2. employment access for all carers;
3. practical measures to support carers; and
4. strategies to enable carers to access “the same range of opportunities and choices as the wider community” (Australia 2009: xv).

The terms of reference promised a broad scope of investigation. Carers are to be recognised, measures to support them in their caring role are to be examined, and critical issues like employment are to be highlighted; most significantly, carers are to have the same choices and opportunities offered to citizens.

The scope of the Carer Inquiry is particularly useful for this analysis as it allows me to explore the reasoning that underlies the problem representation of carer policy. This reasoning will emerge in the observation of the Committee's comments on the evidence

of carers and organisations to the Carer Inquiry. It should be apparent in the shift, if any, from this evidence, to the presentation, interpretation and problem representation of this evidence in the report and recommendations, and then in any shift in the government's response to recommendations and consequent ensconcing of particular problem representations in policy and legislation. The WPR analysis will note the shift away from some problematisations and the emphasis on others. The analysis will particularly examine whether the Carer Inquiry's fourth term of reference, ensuring carer choice and opportunity, is problematised in the Carer Inquiry and ensuing government policy and legislation.

The report of the Carer Inquiry is structured into eight sections, two pages of additional comments from the Deputy Chair and six appendices. The first two sections are essentially background sections that review the Australian policy context, summarise statistical data on care, and list the administrative portfolios and services that support carers. Of the remaining six sections, two address national carer recognition and impacts on the health and well-being of carers; the last four sections address the practical needs of carers in terms of employment, information, skills and financial assistance.

The sections on the practical needs of carers and their interface with policies and services are provided in sufficient detail to allow prescriptive policy and service recommendations. For example, the discussion on carer employment explores the financial and social benefits of employment and the interface between employment and the rules governing carer payments. The Carer Inquiry notes the disincentives for carer participation in employment, which arise from reductions of carer benefits related to negligible increases in wages. The details provided here are useful in understanding the way intersecting government policy affects or impedes carers. For example, unlike typical children, dependants require after-school care services to provide continual supervision and care well past the age of 12 years, to enable their carers to work a normal day. The report notes that typical disability day-programs and school days operate from 9 AM to 3 PM. It recommends that after-school care and adult day programs for disabled people match the typical working day of 7 AM until 6 PM, and suggests that employers introduce flexible practices to enable carers to support their dependants. The problematisation, focusing on extending childcare to enable carers to

work, is based on the presumption that carers will combine work with care of dependants, assuming that carers will continue to provide care.

The Carer Inquiry addresses the first three focus areas; the fourth key area of focus, carer choice and opportunity, is addressed in a mere one-and-a-half pages in a section on carer health and wellbeing, rather than a separate section. This discussion is limited, almost an aside:

8.46 evidence also raises the importance of support to assist carers to transition out of the caring role and to re-engage after long periods of social isolation. As one carer stated, she needed help with:

Rediscovering my own identity and support to regain mental and physical wellness again. I could well do with some life coaching, personal training (Australia 2009: 250-251).

The Carer Inquiry briefly discusses how to support and retrain carers to transition from the caring role – a transition, it conceives, that arises only from necessity (such as the dependant dying), not choice. In mentioning the need for carers to re-engage with the community, the Committee acknowledges that carers are isolated for “long periods” from the community and its opportunities.

Identifying the presentation of presumed carer obligation as a “fixed truth” makes it open to disruption in the WPR analysis. A disruption that invites other truths by asking: ‘could carer choice be exercised in other circumstances? Could carer choice arise from free will, not necessity?’

The brevity of the section on carer choice reinforces the limited problematisation of carer choices and opportunity, which are confined to improving carers’ financial situation and supporting carers to combine care and work. This limited problematisation does not fully address the scope of carer choice indicated in the Carer Inquiry’s fourth key area of focus, which refers to carers accessing the same range of “opportunities and choices available to the wider community”.

The Carer Inquiry report relayed carer evidence and views to illustrate a range of issues, including the scope of carer responsibilities, service shortfalls and employment constraints. A selection of remarks by carers is shown below. These are drawn from throughout the Carer Inquiry report. For ease of reference, the page number on which each remark appears in the Carer Inquiry report is noted.

Included in the section entitled 'The Role and Contribution of Carers', Carers said:

Endless, thankless, poor, a no-win situation, desperate, extremely depressing and very bleak (Australia 2009: 44);

terrifying, traumatic, overwhelming, confusing, stressful, isolating, lonely, undervalued, under resourced, not understood, unsupported, unheard, invisible, frustrating, depressing, emotionally draining, physically exhausting (Australia 2009: 44);

I have been called a hero! I never wanted to be one. I never want to be divorced mother to a child with disabilities ... the contribution I have made to society in monetary form can be calculated in very large figures (Australia 2009: 46);

there is an appalling level of awareness in our society of the impact of caring. The financial, social, medical impacts are often profound and result in poverty, social isolation and poor health for the carer (Australia 2009: 48).

In order to illustrate how the role of carers is undervalued, these carers' comments were included in the section titled 'Carer Recognition':

there can be little doubt that the role and contribution of family carers is undervalued, taken for granted, exploited and clearly sidelined by government and our society; by all those who should care (Australia 2009: 48);

we are the hidden army, as we have neither the time and energy nor the money to participate in society to any great extent, so we are unnoticed and easily ignored (Australia 2009: 49);

[The Carers Payment] can only be acknowledged as a pittance. It is means tested [so] ... the carer payment reduces to make sure they remain second class citizens (Australia 2009: 124).

An astute carer commented on the relative value of carer recognition in words versus government's provision of tangible services and fair payment or reward:

We have all heard the wonderful words spoken by many ... about the great contribution carers make in society and I am pleased that there is some recognition of my seemingly never-ending role. However, words do not put food on the table, or compensate carers for the loss of earnings they may have made ... carers of working age need to be paid a wage commensurate with the work they do (Australia 2009: 49).

In response to the sentiment expressed above, and echoed in several carer submissions, the Committee says that it is aware of the economic contribution of carers and notes

that carers frequently call for greater financial assistance and a range of services, particularly supported accommodation. Accommodation for dependent disabled people means carers are no longer obliged to live with, and support, dependants in the family home. As and as evidenced by both the carers' submissions to the Carer Inquiry and the carers interviewed (refer to Chapter 7), carers need policy to develop a problem representation that recognises their entrapment and provides them with the opportunity of relief of their care obligations, a problematisation that disrupts the presumption of ongoing care obligation and leads to policy solutions involving tangible services and accommodation for dependants.

The Committee remarks that even with provision of adequate supports, caring is inherently stressful. The report includes numerous comments from carers which express the physical, emotional and mental toll of caring:

Apart from the isolation and loneliness I was experiencing, like many carers I experienced anxiety and depression, trauma and grief as a direct result of the caring role ... they are a fundamental part of the lived experience for carers (Australia 2009: 236-237);

Unfortunately the role of carer is very damaging to my health and body (Australia 2009: 238);

Due to caring I have developed a stomach ulcer due to stress, fibromyalgia; muscle inflammation that prevents me from doing anything outside my caring role, a degenerative spinal condition and depression which all exacerbated because of caring (Australia 2009: 238).

The Carer Inquiry report includes surveys and statistics from discrete regionally based associations, and broader-based ABS and AIHW reports. An extract from the Australian Unity Well-Being Index Survey is quoted in the Carer Inquiry report and provides a synopsis of the impact of the caring role:

Carers have the lowest collective well-being of any population group yet discovered ... carers have an average stress rating that is classified as moderate depression ... carers more likely to experience chronic pain than is normal ... well-being decreases linearly as the number of hours spent caring increases (Australia 2009: 234).

Including this quotation in its report means the Committee is aware of the severe impact on carers. Most carers interviewed said the government should step in to support dependants:

Government should support families before it becomes a crisis [Barbara];

Yes, it's simple, disabled people can't support themselves the government should step in [Maria].

Within the Carer Inquiry report, the commentary provided by the Committee repeatedly acknowledges carers' views and expresses sympathy, understanding and concern:

the overwhelming evidence received by the Committee indicates that respite services and other essential supports are sustaining carers ... the evidence suggests that current respite services are unable to meet the need from carers ... access to those services that are available is often prioritised on the basis of the degree of urgency or severity of the caring and family situation. What alarmed the Committee however, is that this approach places carers and their families in the invidious situation of needing to present the worst possible picture of their circumstances (Australia 2009: 175).

Most carers interviewed resented the invidious position of needing to fight and justify their need for services. They said that even when services were available, they always needed to justify their eligibility for such services based on what seemed to be an arbitrary assessment: "my son was seen as being 'below the need' so I got no services. I'm angry about this, it's an arbitrary assessment, he's still hard work" [Maria].

There seem to be two grades of separation: from the raw carers' statements to the Carer Inquiry's commentary; and from the Carer Inquiry's commentary to its recommendations. Although carer submissions include references to exploitation, bleakness and describe extreme disadvantage and entrapment, the Committee is silent on the extremity of the carer situation; instead, the Committee expresses sympathy, avoiding any expression of alarm or language around carers' rights and choices. For example, some carer submissions expressed, in highly colourful language, feelings of despair and entrapment, possibly slavery.

The Carer Inquiry's commentary acknowledges both the length of the obligation and the range dependants supported by carers: "carers provide care for children and adults with a wide range of health and mental health conditions, disabilities and the frail aged. For some, the caring experience may span months and years, for others it spans decades" (Australia 2009: 43). In commenting on the difficulties of the role, the Committee said, "many have indicated that providing care, even for a loved one, is frequently demanding. The caring role is often a 24-hour a day, seven days a week responsibility ... [carer submissions to the Carer Inquiry demonstrate] ... the breadth

and intensity of the caring role” (Australia 2009: 44). However, the Carer Inquiry’s acknowledgement of carer obligation is markedly silent on recognising that many carers are exploited and entrapped. By avoiding the problematisation of carer entrapment, the Committee collaborates with those powers that entrench carers in obligations that spans decades.

The second separation concerns the difference between the Committee’s comments, and its recommendations. Whilst the Committee is sympathetic to the plight of carers, and included some references to tangible measures and services to address carer impact, and a discussion of what society, and government owes carers, it avoided a full and free discussion of carer exploitation and rights. As carer exploitation is not problematised, thus solutions, such as carer rights are not advanced in the Carer Inquiry’s recommendations. For example, the Carer Inquiry’s commentary includes an acknowledgement of the estimated cost savings to government, referring to both Access Economics and the AIHW’s estimates of between \$27 and \$30 billion for the 2005 year and a comment, under the section titled *Carer Recognition*:

Time and time again carers have specified that the best way to recognise carers and to demonstrate that their contribution is genuinely valued, through adequate provision of practical supports and services both for carers and care receivers. Specifically, carers frequently call for increased levels of income support ... greater access to community care services, ... and access to services for care receivers, including a range of supports and accommodation options (Australia 2009: 48-49).

Here, the Carer Inquiry report associates the cost savings to government by carers providing support to dependants, with the need for adequate recognition of this contribution in the form of practical measures to support carers and care receivers. Here, the Carer Inquiry also seemed close to problematising the need for substantial increases in disability services. The Carer Inquiry report then curiously shifts away from this acknowledgement of carer difficulty and the need for meaningful service changes, stating: “detailed consideration of issues associated with supports and services for carers is presented later in the report”(Australia 2009: 50), and then proceeds to list other, notably less-tangible options for ‘enhancing carer recognition’. These include increased community awareness, introducing national carer recognition legislation, and carer advocacy. Unfortunately, it is the less tangible options that form the core of the Carer Inquiry’s recommendations. The detailed consideration of carer supports and services is not addressed.

The phrasing of these comments shows that the Committee omitted the problematisation of government care of dependants. In doing so, it continues the trend remarked by carers who despise empty recognition in favour of tangible relief of carer entrapment. The effect of excluding such problem representation is the ongoing exploitation and entrapment of carers.

In summary, the Committee's commentary notes aspects of the carer situation but avoids problematising the extremity of this situation, and making tangible recommendations which reflect this extremity. The commentary shifts from raw carer's statements which, if one follows the argument logically, could have predicated a problematisation of the lack of choice and rights for carers, to an expression of sympathy and a discussion of improved services. The commentary then further shifts from improved services to problematisations around carer respect which engender less tangible policy solutions such as carer recognition.

Regardless of any bias in interpretation within the Carer Inquiry report, it is clear, even from the range of carer comments reported, that carers are certainly a group heavily impacted and entrapped. It is surprising then, in view of the ongoing entrapment and coercion of carers that the problematisation of securing carer rights, via guarantees of carer choice and opportunity, was absent. The reason for not addressing this area, although it was a specific term of reference of the Carer Inquiry, is not explicitly explained.

### **5.1.1 Availability of services for care receivers**

In its early background pages, the Carer Inquiry report refers to the carer-disability link:

2.60 Throughout the Inquiry, evidence emphasised that support for carers cannot be considered in isolation, as the support needs of carers and care receivers are intrinsically linked. In broad terms, carers are assisted by services which ... aim to indirectly support carers; and primarily aim to provide support to care receivers, but which also alleviate the caring responsibilities of carers (Australia 2009: 32).

However, only a brief four-page section of the Carer Inquiry's 259 page report is titled: *Availability of Services for Care Receivers*. This section prefaces its discussion with an oblique comment, that to venture into disability services is not within the purview of the Carer Inquiry. Thus "(6.109) an analysis of the services available for care receivers,

as distinct from carers, is outside the scope of this report.” (p190). This truncated reasoning is in spite of the Committee’s acknowledgement

that evidence suggests that services for care receivers are also extremely important for carers. As one carer commented in the closing remarks of her submission: ... the best way to support carers is to address all needs of the young and aged with a disability (Australia 2009: 190-191).

Therein follows a notation of how carers interact with the service system and how such services to both care receivers and carers could be better administered.

In explaining why the Carer Inquiry does not fully address services for dependants, the Carer Inquiry acknowledges that many of the freedoms and relief of care load reside with services for the care receiver and so, for a brief four pages, discusses care receiver services, particularly accommodation. Referring to twelve submissions from carers, the Committee finds:

6.116 The lack of appropriate, alternative accommodation and care options for care receivers is one of the most pressing concerns for carers. It leaves carers with little or no choice but to continue caring, often well past retirement age as explained below:

The one measure that must be put in place with urgency is a measure that will eventually see us relieved of a caring role. The best support the carer can have is to know that there is a finite tour of duty and that one day in the future we’ll no longer be required to care. This is because ... adults with a dependent disability ... will be taken care of by the community ... it seems to me to be totally inequitable that those parents who have the most difficult experience of parenthood are the same ones who may never have a retirement. Lifelong carers such as myself are desperate to see progress in the provision of supported accommodation, but we see only rhetoric, debate and promises [quoted from Ms E Shields submission to Inquiry No 35, also noted reference to three other carer and organisation submissions](Australia 2009: 193).

The Committee acknowledges the importance of accommodation, the lack of choice and carer entrapment and obligations to care well past retirement age:

6.119 in Hobart, Miss Sue Hodgson told the Committee that the current expectation that carers will care until they die or until they become incapacitated themselves, should be replaced with an expectation supported by policies and services that the people with disabilities will be able to live separately from their families when they reach adulthood [noted reference to transcript heard 9th of October 08]. The Committee can only concur (Australia 2009: 194).

Similarly, all carers interviewed expressed strong and immediate responses on the inadequacy and insufficient provision of disability services and accommodation.

All carers interviewed wanted more provision of accommodation. Four carers accessed regular ongoing accommodation; they said having their dependant cared for outside the family home was beneficial for both themselves and their dependant: “I get my life, my marriage ... back. It kept me sane; I was going down a hole” [Cristina].

Of the nine families who wanted out-of-home government-supported accommodation, all thought there should be ready provision of accommodation when requested.

I hate the crisis situation that waits for the parents to die; all should be assured of future accommodation [Carol];

Accommodation should be there when I want it [Maria].

In concluding this section, the Carer Inquiry report notes:

6.120 members were reminded again and again during the Inquiry that the needs of carers and of those they care for are inextricably bound. In a more practical sense, the levels of support for carers are directly affected by the levels of support for care receivers and vice versa. While the committee makes recommendations in this report to improve the lives of carers, the need to improve support of care receivers is just as pressing (Australia 2009: 190-194).

Unfortunately, this is one of the few subsections of the Carer Inquiry report that does not make any recommendations. It acknowledges that the provision of accommodation and services for dependants is important to achieve liberty for carers, but then continues the critical silence on this issue when it determines that this is outside the scope of the Carer Inquiry. No further explanation is proffered and the problem of carer entrapment remains unproblematised. The Committee’s reasoning for excluding such a key impact can be extrapolated from its comments on the possibilities of radical service reform and the feasibility of taxpayer provision of all disability support services:

The Committee appreciate that it is neither desirable nor economically feasible for all care to be provided by the taxpayer. Indeed many carers have indicated that they do not want to give up their caring role; rather they want to continue to provide care with adequate support (Australia 2009: 182).

Whilst presuming that it is unfeasible for the taxpayer to provide care, the Committee acknowledges inadequate support for carers:

This chapter has attempted to demonstrate the shortfall in services for carers from their perspective and in their own words. On this evidence, carers deserve better support from governments than they are currently receiving (Australia 2009: 182).

This commentary provides the clearest account of the Committee's underlying presumed truth that many carers do not want to give up the caring role. Whilst some carers may like to retain their caring role, submissions to the Carer Inquiry indicate it is unlikely that there are *many* carers who want to fully maintain the role, and what of those carers who want to relinquish the role? As evidenced by carer comments to the Carer Inquiry (including comment 6.119 noted above), and other organisations' submissions previously noted, a proportion of carers wants to relinquish their care obligations. Without any direct discussion of the validity of carer rights, choice or liberty, the Committee abruptly asserts that it is: "neither desirable nor *economically feasible* for all care to be provided by the taxpayer" (Australia 2009: 182) (emphasis added). Thus, the underlying rationale is to obligate carers to provide care and reinforce the absence of any problematisation of carer entrapment, engendering solutions around carer liberty as the Committee presumes there is simply insufficient tax revenue to solve such a problematisation.

The Committee then anticipates increasing deficits in disability services:

Moreover the shortfall in services is likely to grow as the population in need of assistance grows, and as government policies and the community continue to expect community living for care receivers (Australia 2009: 182).

In this way, it assumes that the government cannot provide the substitute care in the form of integrated community living expected by current disability policy.

The absence of problematisations around carer choice in the Carer Inquiry means consequent policy also avoids problematising carer entrapment as a public social issue. Instead, policy represents the problem as a personal tragedy, expressing sympathy (poor, self-sacrificing carers) and thereby assuming the presumed truth of the continuation of carer obligation. This limits the problem representation of care policy to sub-issues around mitigating carer impact. It is worthwhile to note the irony here; initial proponents of the social-model theory of disability strongly rejected the personal-tragedy view of people with disabilities, as this engendered a view of disabled people as sympathetic victims rather than citizens entitled to public support.

The strain of maintaining this approach, whilst appearing logical, is evident in the contradictory remarks of the Committee, as seen in the section of the Carer Inquiry quoted above. Carers clearly stated that they need removal of the care burden in order to exercise choice and liberty. The Committee concurs with the first part of the equation (that carer impact is linked to services for care receivers) but stops from reaching the logical conclusion: that relief from the carer entrapment and carer liberty is achieved if government assures services for care receivers, particularly accommodation.

If the Carer Inquiry discussed accommodation services for dependants, it would naturally lead into the benefits this would bring in terms of freedom and choice for carers. In not addressing accommodation, the Committee sidesteps the opportunity (and a looming government obligation) of providing choice to carers.

It is critical to review what is blatantly absent. There is no examination of one of the four key focus areas of the Carer Inquiry, concerning choice. This absence sustains the continued silence around carer liberty and rights. Rather than a fair portion, say one quarter of the final report, addressing carer choice, as noted previously a scant one-and-a-half pages of the report's 259 pages address carer choice. This discussion treats carer choice tangentially, only in reference to carers who must transition away from caring, not in terms of carer choice. Of the two short sections that tangentially address carer choice (placed 150 pages apart in the report), neither are entitled "carer choice and opportunity". Indeed the report contains no such section. In short, the Carer Inquiry report has chosen not to address carer choice but to present it in an alternative guise, a strained problematisation framed as "coping with necessary transition from the caring role". It is presented, not as a choice to transition from the role, but rather as applying to those cases where carers are no longer able to care, or the dependant has died (note the antithesis of choice is strongly featured here) and the carer must reluctantly transition from the role. The Carer Inquiry report's truncated, narrow discussion on carer choice indicates the extent of the strain to keep silent the care situation and not address of the views of carers.

In avoiding the problematisation of securing choice for carers, and the concurrent obligation of government to provide a range of support services for dependants, the Carer Inquiry makes what proves to consequently be a pivotal decision, to maintain the absence of any problematisation around carer entrapment; a stance that is echoed in ensuing policy and legislation.

Most sections of the Carer Inquiry report canvas an issue, and conclude with a list of recommendations. Totalling 50, these addressed: the recognition of carers' contribution; access to increased disability and care services; health supports; financial support to encourage carers to work; improvement and increase of the paid care-worker pool; and flexible carer employment practices.

It is particularly marked that the discussion on carer choice is one of the few key areas of focus that canvas an issue, and then fails to make specific recommendations. It appears the rationale of taxpayer funding limitations stopped the Committee from expressing alarm and horror at the situation of carers and recommending a substantial funding commitment from government to redress this situation by provision of adequate services, especially accommodation for dependants.

The Committee makes a twofold presumption: firstly, that taxpayer revenue cannot be increased. However, in 2013, the Commonwealth Government created a new tax levy under the National Disability Insurance Scheme that increases disability funding. And secondly, that the current form of "expected community living for care receivers" (Australia 2009: 182) is fixed and other economical or creative options cannot be developed. However submissions to the Carer Inquiry, noted previously, and carers interviewed, both requested adequate out-of-home accommodation and alternative criteria for this accommodation:

The design of accommodation should be run by families and have all the same age and intellect type. I've read reports of shocking abuse in integrated places. He isn't friends with normal kids. To have normal friends for Tom, it's not sustainable I'm happier if he fits in [Maria].

In discussing accommodation, carers interviewed noted they valued safety, kindness of staff and friendship with peers, not integrated community-living models:

Safety and security are very important, personal safety in relations with other disabled people and staff [Anna];

[There should be] more accommodation they should have safety first, no sexual abuse. More numbers equals more staff around, after this cleanliness and hygiene [Luk];

Based on the person there should be more models of accommodation, I want some models with same disabled peers living together, some living alone [Catherine].

Given its presumptions, the Committee's discussion of carer choice, one of the Carer Inquiry's terms of reference, was intentionally unproblematised. The Committee instead, assumes the strategy of helping carers to care by problematising "the unmet demand for carer support services" (Australia 2009: 182) and describing goals of better coordination, efficiency and innovative funding models.

How can the prevailing problematisation be disrupted? Before analysing discrete parts, it is relevant to look at the Carer Inquiry document as a whole. The document is structured into eight sections. Each addresses discrete care issues (employment, recognition, poverty) but this structure blocks any analysis of the care situation as a whole. The situation as a whole is different from the sum of its parts.

In viewing the care situation as a whole it is apparent that, on a simply functional level, what restricts carer health, finances and employment is the fact that carers are subject to an ongoing and direct obligation to care for someone whose dependency extends outside the bounds of ordinary care obligation. Equally apparent is that removal of this responsibility would facilitate carer access to employment, lifestyle opportunities and health and lifestyle improvements. Avoiding a holistic view of the care situation avoids the holistic solution: liberty from entrapment and a statement of carer choice. This means that given the imprimatur to examine carer choice, and with direct evidence of carer entrapment, the Committee chose to cast a firm silence on the extremity of the care situation and the solution. This is a critical silence.

If the Committee had examined carer choice, they would have to entertain an exploration of the two presumptions that limit this choice, namely the need for substantially increased taxpayer funding and more efficient forms of community living for dependants.

In 2013 the Commonwealth Government committed to substantially increasing funding for disability care. If the government were to look at efficiencies in living arrangements (outside the limits of disability theory and advocacy), incorporating both capital and operational innovations and the alternative views of carers, and if it sought to balance the needs and rights of dependants and carers, it's possible that the notion of carer liberty and rights could be problematised, addressed and attained.

Given the evidence provided by carers and government agencies of both carer impact and the importance of carer services, particularly accommodation, it seems that a

logical problematisation for the Carer Inquiry report would have included statements like: 'carer entrapment is a problem that should be addressed by providing adequate services for care receivers so that carers can exercise choice in both their caring responsibilities and their lifestyles'. Such problematisation would lead to recommended solutions involving the adequate and timely provision of a full range of care services, from respite and support through to accommodation outside the family home. The absence of a recommendation in this vein represents a critical silence on fair carer treatment.

As this policy analysis is examining the government's treatment of carers in Australia, it is relevant to examine two submissions to the Carer Inquiry by peak government-funded organisations, the Australian Institute of Health and Welfare (AIHW), and the Australian Human Rights Commission (AHRC). These two statutory organisations are enacted under government legislation, speak directly to government on key welfare and human rights issues, and operate therefore as quasi-independent, government-funded and affiliated institutions. AIHW is charged with researching critical issues to inform future government policy; the AHRC's role is to assess and report on human rights in Australia. Therefore both institutions provide an insight to the development of government thought on the treatment of carers.

### **5.1.2 Australian Institute of Health and Welfare submission to the Carer Inquiry**

The AIHW is a national independent statutory authority established under an Act of Parliament in 1987. Its opening webpage states:

Our aim is to improve the health and wellbeing of Australians through better health and welfare information and statistics ... Governments and the community use our reports and data in discussing, debating, and making policy decisions on health, housing and community services matters (AIHW 2013).

Thus, the AIHW is a key research source for government. The cover letter of the AIHW's submission notes that it will address only two of the four key areas of the Carer Inquiry, namely the role and recognition of carers, and practical measures to support carers. It therefore does not address the employment of carers, or strategies to enable carers to exercise choice. Given its expertise in data assessment and research, the AIHW submission numerically describes the various groups of carers and their role and contribution in supporting dependants, referring to its own imputed calculation of the

economic value of unpaid care for the disabled at \$27.4 billion in 2005/2006. The submission highlights a looming crisis in the provision of care, related to a projected carer shortage wherein the number of people able, and with a predisposition, to provide unpaid care is predicted to decrease in proportion to the number of people requiring care.

The AIHW submission lists the impacts on carers as reduced participation in the workforce (with consequent financial insecurity and poverty), social isolation, stress, negative familial relationships, and reduced physical and emotional well-being.

Although this submission does not attempt to address issues regarding choice for carers, it does note the extent to which carers are not happy with their caring role and wanted assurance of adequate out-of-home accommodation:

two thirds of primary carers in 2003 were not satisfied with their role and almost one third attributed frequent worry and feelings of depression to being a carer... a key concern of older carers of adult children was about who will provide care when they no longer can. Many wish to see alternative arrangements made for the future of the care recipient (AIHW 2008: 12-14).

In listing the practical measures to better support carers, the AIHW notes that services that support care recipients also directly assist carers; particularly highlighting that comprehensive, socially inclusive respite is especially beneficial for long-term carers as it enables them to reduce their isolation from society.

### **5.1.3 Australian Human Rights Commission submission to the Carer Inquiry**

At the time it made its submission, in July 2008, AHRC was known as the Human Rights and Equal Opportunity Commission (HREOC 2008). For the sake of clarity, it is referred to as the AHRC. The AHRC's 16-page submission addresses each of the four terms of reference of the Carer Inquiry. However, its ability to address each of them with equal clarity and depth appears to be hampered by the scope of its existing research and discussion papers. Relevant papers issued by the AHRC are listed in the introduction to their submission; many of these revolve around carer family and work balance, discrimination in the workplace, and disability discrimination. Thus, of the 16-page submission, the first half focuses on a specific problematisation of how carers can combine work and care. Only two paragraphs refer to the Carer Inquiry's fourth 'key area of focus-, carer choice and opportunity', stating that it recognises that carers

should be assisted to have opportunities and choices “including strategies to increase the capacity for carers to make choices within the caring roles, transitioning into and out of caring, and effectively plan for the future and to improving access to supports and services for people who are receiving care” (emphasis added), (HREOC 2008: 4-5). The submission then shifts into an approximately two-page discussion on the rights and needs of care receivers, particularly those with a disability.

The AHRC submission mentions carer choice and then veers into a discussion of how a reduction in carer responsibilities, by the provision of sensitive services for disabled people, should be predicated on ensuring greater opportunity for people with disability to participate in the community. In a later section, on services for people receiving care, one line mentions that carer recognition and support is required, but only on the proviso that is provided: “not to the exclusion of addressing the needs and rights of those receiving care”(HREOC 2008: 7). In other words, the needs and rights of care receivers take precedence over any carer recognition and support. The concluding recommendations state that carer-support services should be delivered in such a way that furthers the important rights and dignity of those with a disability or mental illness. Clearly, carers are not discussed outside of the fixed problem representation pertaining to how they can best meet the needs of their disabled dependant.

This single submission provides a valuable juxtaposition of the state of carer rights as compared with the rights of dependants. People with disabilities are slated as having rights, choices and dignity. In its submission, the AHRC draws on much of its own research and discussion papers, together with international UN disability rights agreements, disability policy and legislation. In short, an established rights framework based on disability theories’ conceptual understanding and problematisation of attaining the equal rights, integration and opportunities for people with disabilities.

In comparison, carers are considered to require recognition and support in the form of strategies that would improve their lives within their caring role. Where carer choice is mentioned, the AHRC does not refer to any support documents, legislation or care theories that endorse carer rights. This indicates that there is limited or adequate care theory or documentation around carer rights and liberty. The broadly stated and expressed rights of people with disabilities contrast sharply with the truncated view of carer rights. In fact, throughout the submission, there is no specific mention of carer rights but rather carer support and two brief notes on carer choice.

The Carer Inquiry, as well as pivotal submissions to the Carer Inquiry from AIHW and AHRC, recognise carer impact to varying extents. However all three seem to struggle with an intellectual and theoretical conflict in asserting carer rights as a key problematisation, as if in doing so they would be in some conflict with the institutionalised truth which presumes carer obligation and underlies the problematisation of ensuring disability care in the integrated setting of the family home. Instead of rights for carers as citizens, the Carer Inquiry and key submissions promote an ideal of a society that supports relational care. All three note the link between provision of services for the disabled and concurrent reduction in carer obligation. Some, like AHRC, see this as achieving greater independence for the disabled, but ironically do not seek to grant the equivalent independence to the carer. Thus, impacts on carers are noted but carer entrapment is not problematised.

The AIHW clearly quantifies the contribution of carers to society, both in terms of the human cost and economic contribution. The AHRC and the Carer Inquiry, whilst both being aware of the potential of the Carer Inquiry to address carer choice and opportunities, as nominated as its fourth key area of focus, do not explore this beyond an official statement that they are a good idea. The AHRC more firmly notes the link between disability services and care but expresses greater concern at disabled persons' rights being asserted than any exploration of carers' rights. This is incongruent in a submission to a Carer Inquiry about carers by the only Australian agency formally charged with promoting and facilitating human rights for all, not just people with a disability, particularly when there are numerous other forums in which disability rights have, and will continue to be, asserted and explored. The absence of any problematisation around attaining carer rights in the AHRC submission is critical.

Apart from the sharp contrast between carer- and disability rights, is the underlying assumption that one group, carers, have a role – 'to serve' – whilst another group, people with disabilities, have rights. The continued problematisation of disability rights indicates a presumption that there is a hierarchy of rights, rather than equal rights for all.

#### **5.1.4 Government response to the Carer Inquiry**

In 2009 the Commonwealth Government issued its response to the Carer Inquiry. The response addressed each of the 50 recommendations of the Carer Inquiry. Carer

recognition formed the central focus in the government's response: "The Commonwealth government will introduce Commonwealth carer recognition legislation in 2010. Following this, we will lead the development of a national carer recognition framework" (Commonwealth of Australia 2009: 1).

Carer legislation and other legislation, which makes special arrangements for carers, is analysed below. It will show that the government's problematisation of care is limited to carer recognition. Following this, the National Carer Strategy, a medium-term, medium status document, is analysed.

## **5.2 Analysis of carer legislation**

Prior to analysing the content of the *Commonwealth Carers Recognition Act 2010* and the NSW Carers Recognition Act 2010, it is worthwhile to examine their titles, which, apart from their jurisdictions, are identical. In looking at these titles in terms of what is there and what is absent, there is a specific piece of legislation addressing carer recognition but these titles do not refer to rights or services. If carer legislation had mirrored disability legislation, it could easily have been titled: the "Carer Rights Act" or the "Carer Services Act", or the "Carer Inclusion Act". From their opening titles, it appears that the problem representation of carers is confined to recognition and does not extend to addressing carer entrapment or guaranteeing carers' choice and opportunity.

Both the Commonwealth and NSW Carers Recognition Acts list the majority of principles on carer treatment in a Schedule. As with other legislation, the clauses of these Acts determine the status and implementation of these in-principle statements.

## **5.3 Commonwealth Carers Recognition Act 2010.**

The Commonwealth Carers Recognition Act (CCRA) is a brief 4-page document consisting of 12 clauses and a Schedule. This schedule is entitled 'The Statement for Australia's Carers' (SAC) and contains 10 principle statements regarding the rights, choices and opportunities of carers, and their recognition and entitlements, including an entitlement to external opportunities and timely responsive support. As the SAC is a schedule of the CCRA. The status of the principles it outlines is dependent on the clauses that refer to them.

The clauses of the CCRA define the meaning of the term 'carer' as an individual who provides unpaid personal care and support for a person with a disability, medical

conditions, mental illness, or who is frail. The CCRA describes the obligations incurred by the Act on public service agencies, public service care agencies and associated providers. All public service agencies must “Clause 7(1) ... have an awareness and understanding of the SAC ... [and in terms of employing carers] ... human resources policies ... are to be developed having due regard to the Statement for Australia's Carers”(Commonwealth of Australia 2010). Clause 8 outlines additional considerations which apply to service providers including that their practices reflect the principles of the SAC, that they consult carers in the development of care support, and that they include a section, within their annual report, that addresses their compliance with these obligations. Essentially, the CCRA limits the problematisation of carers to awareness and recognition.

The CCRA is silent on any enforcement of the principles of the SAC and so does not enforce carers’ rights or prescribe an ideal level of service or treatment of carers in various spheres. Significantly, Clause 10 expressly excludes any rights or legally enforceable obligations arising as a result of the CCRA; it expressly does not take precedence over other laws or regulations which govern public sector agencies:

10 Act does not create legally enforceable obligations.

This Act does not create rights and duties that are legally enforceable in judicial or other proceedings.

A failure to comply with this Act does not affect the validity of any decision, and is not ground for the review or challenge of any decision  
(Commonwealth of Australia 2010).

#### **5.4 NSW Carers (Recognition) Act 2010.**

The scope of the title is reflected in its content; the Carers (Recognition) Act 2010 (CRA) is a limited, 4-page document containing 15 clauses, and one schedule, Schedule 1, which outlines the NSW Carers Charter. The clauses of the CRA essentially define carers as the unpaid persons providing ongoing support to dependants and state that public sector agencies must have regards to the NSW Carers Charter. The CRA also makes

provision for the establishment of a Carers Advisory Council to advise the Minister.<sup>17</sup> Agencies are required to publicly report on their compliance with the CRA.

The CRA expressly states that it excludes any legal rights arising for carers:

Clause 9 Legal rights not affected

nothing in this Act gives rise to, or can be taken into account in, any civil course of action, and without limiting the generality of the foregoing, nothing in this Act:

operates to create in any person in the legal rights not in existence before the enactment of this Act, or affect the validity, or provides grounds for review, of any judicial or administrative act or omission (PCO 2010).

Schedule 1 of the CRA contains the NSW Carers Charter and represents the CRA's in-principle approach to carers. It lists 13 matters, identifies subgroups of carers that require particular attention (such as young carers, and remote and rural-based carers) and encourages recognition of the particular contribution of carers, as well as prescribing, in general terms, the preferred approach and treatment of carers.

In both the CCRA and the CRA, their limiting clauses, Clauses 10 and 9 respectively, explicitly exclude any additional civil or legal rights arising for carers. This exclusion takes precedence over the guarantee of such choices and rights listed in Schedule 1. Thus, when Schedule 1 of both Acts provides that: "(i) Carers should have the same rights, choices and opportunities as other Australians", substantive Clauses 10 and 9's exclusion of additional rights effectively renders Schedule 1's reference to carers' rights as a pleasant idea, not a legally enforceable entitlement. As noted in the WPR analysis of the Carer Inquiry, the underlying reasoning for the exclusion of carer rights is that the Committee stated it was unfeasible for the taxpayer to fund all supports for dependants. Thus ensuing carer legislation excluded any problematisation of carer entrapment and the attainment of carer rights and choices.

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<sup>17</sup> This Act enables the establishment of an advisory council to provide a carer's perspective and advice on matters as requested. State government staff support the Council. This compares with the longer-established Disability Advisory Council which is funded to provide its own secretariat, and may therefore operate independent of government and can critique the actions of government.

Further, whereas Schedule 1 mentions the value of carers' roles, that carers' views on service design should be sought and carers' health should be considered, Clause 7 of the CRA only obligates public sector agencies to have "an awareness and understanding of the NSW Carers Charter" (PCO 2010). Clause 8 of the CCRA only requires that carers be consulted and 'practicable measures', reflecting the principles of the SAC in Schedule 1, be developed. In summary, this requires agencies to do nothing more tangible than recognise, and have an awareness of, carer issues and take account of carers' views of service provision.

There are two analytical strands worth pursuing. The first is, to ask what is the problem representation and therefore the theoretical premise of the CCRA and CRA? Schedule 1 of the CRA lists the stated approach to carers, noting firstly: "(a) the valuable social and economic contribution that carers make to the community and the persons for whom they care should be recognised and supported" (PCO 2010). The remaining points in Schedule 1 refer to considerations of carers' health, their views and an awareness of carers' roles and difficulties. Whilst not explicitly stated, it appears that both the CCRA and the CRA are premised on recognition of the value of carers to dependants, and by association, therefore, to society. As carers are prescribed this obligation, the problem is represented as 'how best to mitigate the worst impacts or effects of carers' obligation with a view to maintaining this obligation and to allow carers some influence in how they would like to be supported'.

The second strand worth pursuing is to ask what is absent in the problem representation of the Commonwealth and NSW carer legislations, as highlighted in discussions about their titles, and borne out in the explicit absence of carer choice and carer rights. Carer entrapment is unproblematised and therefore solutions to attain fair treatment of carers are not derived. Thus, both the CCRA and the CRA do not detail solutions which prescribe the fair treatment of carers in various settings. This contrasts with the explicit, legislated problematisation of disabled people's rights choice and opportunity and ensuing detailed solutions demonstrated in the analysis of disability texts.

## **5.5 Legislation to improve carers' workforce participation.**

There are two portions of legislation aimed at increasing carer participation in employment: The Commonwealth Government's *Fair Work Act 2009* and the *NSW Anti-Discrimination Act 1977 No 48*.

Section 65 of the Commonwealth Fair Work Act includes provisions for carers of children under 18 who have a disability, to request flexible working arrangements, and have a reasonable expectation that employers will accommodate the request or detail why the request is denied. It also makes provision for carers' leave (Commonwealth of Australia 2009).

The NSW Anti-Discrimination Act defines a carer in the most general sense as anyone who has 'responsibilities as a carer' if they are a guardian to an immediate family member or another who is in need of care and support. The Act makes it discriminatory to mistreat or hinder the attainment of such carers on the basis of their 'caring responsibilities'[Cl 49V (4)]. Thus, rather than addressing the core issue of carer entrapment, the Commonwealth and NSW governments problematise sub-issues around carer employment.

## **5.6 National Carer Strategy.**

The 2011 National Carer Strategy (NCS) forms part of the Australian Government's National Carer Recognition Framework. It is a medium-term strategic document which gives effect to "The Statement for Australia's Carers" as described in Schedule 1 of the Commonwealth Carer Recognition Act. The NCS describes the Commonwealth Government's overall approach to carers as: "the one thing all carers and the people they care for have in common is being in a care relationship ... it is these care relationships, and the health and well-being of each person in the relationship that needs to be supported and sustained" (Commonwealth of Australia 2011: 9,10). Thus, the stated problematisation for carers is how to support ongoing carer-dependant relationships.

The NCS outlines six areas of focus which presume ongoing carer-dependant relationships: carer recognition, information, economic security, services, and supports linked with employment and health.

## 5.7 The Problem Representation of carers

The WPR analysis shows how an existing representation of the problem can be interrogated, disrupted, and replaced. This analysis shows that much of the problem representation of prevailing care- and disability policy and legislation is premised on disability theory, and generally accords with the emphasis on carer-dependant relationships encouraged in the ethic-of-care theory. Conversely it shows that there is an acute absence of problematisations addressing carer entrapment.

Whilst relevant care- and disability texts have been analysed using Bacchi's WPR approach, in order to gain a contextually complete and full picture of the policy treatment of carers, it is necessary to apply the problem representation analysis to the framework and interactions of these texts as a whole.

As identified by carers in the 2009 Carer Inquiry, and reiterated by the Committee, the lives of carers are inextricably bound to the dependant in their care; this is the carer-disability link referred to in this thesis. In many ways carer recognition and treatment is a reflective consequence, a kind of residual echo shaped by disability policy. Put simply, the role (and scope thereof) which carers perform for dependants is in direct inverse relationship to the role performed by government; strong government policy which supports dependants, directly reduces the carer load. An important strand of the WPR analysis will therefore be to identify key ways disability policy and carer policy relate.

Australia has no statement of rights or liberty in its constitution. Accordingly, any claim of carer rights or choice depends on their assertion in other policy vehicles. In Australia, rights and choice have not been declared for carers. At an international level, carers are not recognised as a subgroup warranting specific attention, and are not the subject of a treaty. Australia's commitment to UN treaties, associated monitoring reports, and organisations (such as the Australian Human Rights Commission) represent the explicit rights-based initiatives within Australia. The absence of carers as an identified rights-bearing subgroup, represents a critical silence which is mirrored in the silence around carers' rights in legislation and policy.

Compared with carer policy, disability policy has had a longer history. Historically, people with disabilities have been identified as a group needing support to survive. In Australia, the policy treatment of people with disabilities was reoriented in the 1980s, from simply survival, to an assertion that people with disabilities should thrive as equal

and integrated citizens. This reorientation has occurred internationally, nationally, and at state levels, and is based on three theories of disability, namely the social model of disability, normalisation and social role valorisation. These prominent disability theories promulgate the integration of all people with disabilities, in roles equivalent to their peers; they presume the co-option of carers to support this integration. Disability theories' longer history, prescriptive theoretical underpinning, and advocacy have directly resulted in problematisations focused on how to achieve the tenets of disability theory. Chapter 4 shows that the language of disability policy and legislation echo disability theory. There are a greater number of higher status rights-based disability policies and funding arrangements than comparable carer policies which haven't an established needs-oriented service history, or prescriptive rights-based theoretical foundation.

Nationally, the CRPD and the Commonwealth Disability Services Act together with the NSW Disability Services Act assume the devolution of institutions housing and supporting people with disabilities, and the return of the disabled to the community. Until the 1980s, families were told that their disabled children were too burdensome to support at home and that they should be supported in state institutions whilst families went on to pursue their normal lives. The shift in disability policy in the 1980s meant there was an emphasis on maintaining on-going relationships between families and their dependent disabled children. Thus, these families became carers with a responsibility to provide unpaid support to their disabled dependants.

Disability policy and legislation, particularly the CDIA and DIA, assert as a presumed truth the independence of all people with disabilities and thereby silence and deny alternative truths concerning the dependence of some people with disabilities. It is unclear how this is to be practically enacted in situations where familial care obligations extend beyond the normative frame, which occurs when parents are obliged to care for their adult disabled children. As statistical data and submissions to the Carer Inquiry show, many carers have a lifelong obligation to care for dependants.

The report of the 2009 Carer Inquiry has been analysed. The Carer Inquiry found that carers were a group highly impacted by their care obligations. The evidence from carers cited in the Carer Inquiry report detail a number of negative impacts (including lack of status and recognition, poor physical and mental health, poverty and uncertain finances, difficulty in accessing information, dealing with the challenges of inadequate or

inappropriate supports and services, and difficulties attaining and maintaining employment). Many carers expressed severe impacts linked with exploitation and entrapment. As described in Chapters 1 and 5, the carers interviewed echoed these sentiments. Whilst the Carer Inquiry report expressed sympathy and concern for carers, there was a significant absence of outrage and associated problematisation of the entrapment of carers and the concurrent absence of solutions in policy to address this entrapment.

Upon receipt of the Carer Inquiry's report and recommendations, the government responded positively to the majority of recommendations, but did not go beyond them in its framing of care legislation and policy. Both Commonwealth and NSW state carer legislation explicitly excludes carers' rights arising. Thus, carer rights are not simply absent but specifically prohibited in the problematisation of carers in this legislation. The Carer Inquiry sets the future direction of carer treatment in Australia, possibly for decades. The exclusion of carer rights in such a broad-ranging and high status discussion is therefore of concern. It contrasts markedly with the righteous indignation, outrage, and advocacy that accompanied the CRPD and the 1983 Richmond Report on disability services. Here there was a distinct recognition, not only of the disabled person's situation, but also a judgement that the situation was inhumane and that disabled people should be guaranteed the rights and freedom and opportunities of other citizens. The rights of disabled people as citizens was thereafter formalised in legislation and policy.

The absence of discussion of carer rights in the Carer Inquiry, and the explicit prohibition of rights in carer legislation, decisively indicates the government's stance towards carers as one in which their rights and liberties and equal citizenship are not to be countenanced. This, therefore, establishes the policy framework, as one in which carer problematisations do not include strategies towards achieving rights and liberty for carers. Instead, policy expresses positive ideals framed around the integration of people with disabilities (reflecting the ideals of the social model of disability and normalisation theories) and the maintenance of (usually long-term) familial care relations. Thus, in the face of evidence of substantial negative impact on carers, the Carer Inquiry and care policy and legislation are based on the consistent presumed truth that carers must continue in ongoing carer-dependant relations of obligation. This limits the overarching problem representation of carers to 'how to sustain carers in

their ongoing carer–dependant relations so they can provide ongoing, unpaid care to dependants in the integrated setting of the family home.’

This overarching problem representation is further detailed in more discrete problem representations that are reflected in both disability- and carer policy<sup>18</sup> and thus carer poverty is problematised as: ‘carers have difficulty accessing and maintaining employment whilst balancing care obligations.’ Based on this problematisation, the policy solution is to encourage carers to combine work and care or to provide supplementary, discrete payments and recognition. It is important to note the large silence around alternative ‘truths’ such as carers wishing to relinquish their care obligations in order to pursue work opportunities, or recognising that carers are actually already working long hours in the unpaid role of caring for dependants and problematising adequate financial payment. As quoted in the Carer Inquiry, some carers feel the government is only paying them a ‘pittance’ for the care work they do.

In response to agency and carer submissions documenting carer isolation and societal abandonment, another discrete problem representation is ‘how best to recognise carers and provide them with a break so they could be invigorated in their ongoing obligation to dependants.’ Consequent policy solutions include activities such as ‘Carers’ Week’, information on discrete supports, techniques for increasing carer resilience, respite solutions and bonus payments. Here it is important to note the significant silence and mis-recognition of carers’ feelings of unfair burden and entrapment.

In short, the kinds of problem representations derived are those that can be solved by the fulfilment of specific and discrete recommendations. The Committee effectively dissipated the raw voices of carers into a series of particular discrete problematisations within the overarching problem representation of maintaining carers in ongoing relationships that support dependants.

What is the likely reasoning for government to adhere to this overarching problematisation? In the Carer Inquiry, carers have voiced their feelings of entrapment and burden; the Carer Inquiry has expressed sympathy. Unfortunately, the Carer

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<sup>18</sup> Policy such as the Commonwealth and NSW, Carer Recognition Acts 2010, Commonwealth Fair Work Act 2009, the NSW Disability Services policy -- Stronger Together 2 and Ready Together.

Inquiry avoids representing the problem as the lack of carer liberty, rights and choice, a problem that can be solved by adequate services, particularly accommodation for dependants. Instead, the Committee simply claims that disability services lie outside the scope of the Carer Inquiry. In making this claim, the Carer Inquiry report contradicts both its own terms of reference, which include addressing carer choice, and its earlier claims that carers' lives are inextricably bound to dependants and therefore affected by disability policy and services. Early sections of the Carer Inquiry report stated that accommodation and respite-service deficits would be addressed later in the report; they were not addressed later in the report.

The 2009 Carer Inquiry was an opportunity for government to recognise carer entrapment as problematic. As the Carer Inquiry demonstrated, carers of dependants are isolated and unable to actively pursue their rights as equal citizens. The same views were echoed in the carer interviews. Carers' responsibilities to dependants restrict them from gaining and holding employment, accumulating security in the form of income and retirement savings, and freely pursuing lifestyle opportunities including socialising, holidays, sport, and education – essentially to enjoy the liberty and opportunities of other citizens.

The Committee, including its Chair, have determinedly dismissed alternative problematisations of carer choice and opportunity. The underlying reasoning is based on neoliberal thinking around the projected cost to government of providing the level of service, in the form of integrated community living, required by disability theory and policy. The Carer Inquiry clearly states that it considers it unfeasible for the taxpayer to provide all care in the integrated model of community living. Its report included quotes from AIHW reports which show carers saving the government \$27.4 billion through free care labour. The Carer Inquiry report did not canvass any alternative non-integrated, possibly more feasible, accommodation and service models that could be generated following alternative care and disability research and theories.

Both the carers interviewed and carers' evidence to the Carer Inquiry show carers want alternative models of support that are tailored to them and their dependants and do not specifically value disability theories' integration. The carers interviewed were directly asked about design criteria, and said new models of accommodation and other services are vital and they valued other features in these models such as safety, consistency of care, scrutiny, and settings that fostered friendships between similarly disabled people.

Integrated living has been interpreted by disability theory and advocacy to specifically mean individual small-group homes, housing no more than two to four disabled people. Re-designed services and accommodation which reflect the needs and views of carers and dependents, for example larger group care or cluster-model housing, which foster group friendships, may be more efficient. These more efficient accommodation models coupled with the government's 2013 approval of new taxpayer levies to fund disability support (under the National Disability Insurance Scheme), can make it feasible for a large proportion of care to be provided by the taxpayer.

A good summation of the Committee's underlying reasoning is provided in the summary remarks by the Carer Inquiry's chairperson Ms Annette Ellis MP who, recognising the extreme duress under which carers suffer, says:

Over the years, the shift from institutional care to care in the community has greatly increased reliance on informal care provided by family and friends. In the absence of adequate support, carers are already in crisis. Emerging demographic and social trends are predicted to result in larger numbers of people requiring care and smaller numbers of people able and willing to provide it. (Australia 2009: X)

Rather than acknowledging the evidence of carers to the Carer Inquiry, who discuss their poor health, isolation and entrapment, quoted previously, Ms Ellis "strains" to continue the overarching problematisation of maintaining ongoing carer relational obligation:

the Committee understands that with adequate levels of appropriate support in place, most carers wish to continue to provide care for as long as they feel able to do so. It is therefore in the best interests of all concerned – carers, care receivers, governments and society – to share the responsibility of providing care more evenly. If realised, this will allow carers and their families to participate more fully in society through engagement with education, employment and social activities (Australia 2009: X).

Here, Ms Ellis acknowledges that the government's policy of deinstitutionalisation of people with disabilities, and an absence of government-resourced support meant unpaid, usually family, carers are obligated to care. Unfortunately, whilst Ms Ellis acknowledged that carers are in crisis, she did not express outrage at the entrapment of carers. Instead, Ms Ellis limits the discussion and the resultant problematisation to an absence of adequate government support, proposing as a solution appropriate supports so government can 'share the care'.

Submissions to the Carer Inquiry demonstrated that carers are a distinct subgroup under extreme duress due to their caring role; the Carer Inquiry recommendations narrowed to address discrete problematisations around carer recognition, increased support, and employment assistance. These recommendations were ensconced in ensuing policy and legislation. The funnelling and consequent fragmentation of the whole carer picture into particular issue-compartments, subject to particular interpretation, limits the free and full measure of the carer situation in its entirety and subject to open interpretation.

The problematisation of carers in policy, legislation and the Carer Inquiry is related to the historical and theoretical developments in care and disability theory and advocacy. When the CRPD and the 1983 Richmond Report were released, the government adopted a problem representation which viewed people with disabilities as entrapped in institutions, and sought their integration, adopting key disability theories as its underlying policy rationale. The government could have chosen to avoid the problem representation that recognised the entrapment of disabled people in the same way as it has denied the problem representation of carer entrapment. It seems, in part, that the clear and prescriptive nature of disability theory and advocacy has allowed them to be readily adopted in policy. Thus, the language and principles of disability theories' emphasis on independence and integration in typical and valued roles has been shown to direct government policy and legislation at the international, national and state levels.

The prevailing presumed truth, overarching problem representation and policy solutions in the Carer Inquiry and carer legislation echo those of prevailing disability policy and legislation and result in the long-term entrapment of carers. To disrupt this problem representation requires a more holistic view of dependency and the carer situation, which acknowledges that carers are in an extreme situation in which they are exploited and entrapped.

Carers should also have their rights to equal citizenship and inclusion asserted, in the same way that they are asserted for disabled people. From this analysis however, a broader picture emerges wherein there seems to be a lack of developed care theory and language, or acceptable way to talk about carer rights, independent of their care relations and obligations to dependants. Instead of the assertion of rights, choice and opportunity for carers, carer policy problematises the maintenance of carer-dependant

relationships. The ideal of maintaining carer-dependant relationships broadly mirrors the ideals of dominant carer theories, particularly the ethic-of-care theory and some aspects of Kittay's dependency critique (Kittay 1999) which both seek to maintain ongoing carer-dependant relationships. Carer theory, by reinforcing the importance of carer-dependant relationships, does not directly disrupt or challenge the prevailing problematisation.

The silence on carer rights and the concurrent emphasis on carer-dependant relationships are compounded by the institutionalisation of carers as a service resource, in disability rights treaties, legislation and policies, for the disabled.<sup>19</sup> The underlying assumption being that one subgroup, persons with disabilities, are equal-rights-bearing citizens and, by contrast, carers are a presumed care resource.

Carer and disability policy and legislation dovetail; disability policy argues for the equal citizenship rights of disabled people to be integrated into society, and assigns a role for carers to support this integration whilst carer policy and legislation complements this by reaffirming the ongoing relationship of carers and dependants, and seeks to continue this relationship. Most government policy, as seen in Chapter 4's policy analysis, is premised on this view. It is noteworthy that two of the carers interviewed held this view. It is pertinent that these two carers attributed their belief to either their specific Chinese cultural and, or, for one carer, Muslim religious beliefs. The significance of this insight would need to be confirmed by more extensive research but the potential implications are that the government's policy premise only applies to a limited number of carers with specific cultural and religious beliefs, beliefs which are held by only a small proportion of the Australian population. whilst the majority of the carers interviewed expressed familial connection, they also expressed a view of care as a life-long entrapment.

The emerging discussion of carers' rights and choice disrupts disability theory and policy, which assumes ongoing relationship between carers and dependent disabled

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<sup>19</sup> UN treaties directly attribute rights for disabled children to be cared for by their families. For example, Article 18 of the CRPD ascribes families this obligation, whilst national legislation assumes families will care for their disabled child until they are 18 years old.

people and the practical provision of care support by carers. There appear to be gaps in the discussion of how to treat carers fairly whilst still recognising their relationships with dependants. To explore the premise of government policy and legislation and point to alternative theoretical rationales, problematisations and solutions, the following chapters will explore disability- and carer theory and examine how they address the problem of carer entrapment and choice, with a view to framing just solutions.

## **PART 2 –DISABILITY AND CARER THEORIES**

This Part will review and analyse existing disability- and care theory and derive a new fair care theory.

### **Chapter 6 – Disability Theory**

Studies of care and disability have been conducted as distinct and separate fields. The emergence of disability studies that began in the 1950s, as an examination by non-disabled people of the treatment of disabled people, was, from the 1970s onwards, primarily led and directed by disabled people driven by a self-activist, rights-movement model. In contrast, carer theory and discussion appears to have arisen in research and academic circles, without self-activist rights-oriented advocacy. The nature and impact of care have been explored. There has been some attempt to research the impact of caring in terms of carer health, workforce participation and income.

Given the historic and continuing powerful, independent identity and voice of disability studies and advocacy, I will review this field separately from the discussion on carer issues. I must however state my proviso: that I consider that for many, though not all, people with disabilities, disability and carer issues are intimately bound and can benefit from combined studies. Such studies should be nuanced to reflect not only the difference of the carer–disabled experience but indeed the differences within each of these populations, particularly the substantive difference of the severely intellectually disabled person from the physically disabled person. A collective voice should reflect areas and priorities of broad agreement, with detailed enquiries and recommendations applying to discrete subgroups. This hope applies to the whole field of carer–disability studies. It is beyond the bounds of this thesis to attempt it; instead I will critique both fields from the point of view of their relevance and impact to carers of the dependants.

This analysis will show two features of disability theory and advocacy that significantly affect carers. Firstly, it will show that the emphasis on deinstitutionalisation and integration focuses on the structural positioning of people with disabilities in society. This results in most dependent disabled people being supported by carers in the family home. Secondly, it will show that the dependency of some disabled people is overlooked. This means that both their needs are not accurately addressed in policy and

services and that the effect of their dependency on carers is ignored. This is particularly the case for many intellectually disabled people who are not distinguished from physically disabled people in disability theory.

This chapter will document how most disability theory focuses on disability rights and entitlements as relevant to the needs of the physically disabled, thereby obscuring the different needs and dependencies of intellectually disabled people and consequently the effect of such dependencies on their carers. Highlighting the prescribed role for carers in disability theory provides a deeper understanding of the presumed truths and problematisations directing disability policy and legislation, as seen in Part 1. This evaluation permits a scrutiny of whether this theoretical policy premise is fair, and shows that alternative approaches may better suit dependent disabled people than their integration in the community, as promoted by disability policy and legislation. As mentioned, such integration often obligates carers. Understanding the basis of disability theory will indicate its limits and provide room for alternative approaches, such as alternative carer theories and alternative policy solutions.

Before beginning the discussion of disability theory, it is worth remembering the rapid gains which attest to the political power of disability theory and advocacy, as summarised by disability researcher David Gerber:

So powerful is the voice of disabled people becoming, and so powerful are the intellectual and ideological forces that seek to give that voice centrality in shaping discussion of disability, that it may soon become difficult to recall that a short time ago people with disabilities were little more than the objects of study. Their voice had less legitimacy and less authority than that of medical ... and welfare bureaucracy professionals who studied and worked with them. (Gerber 1990: 4).

## **6.1 Rejection of institutional care**

Until the 1960s, the majority of people with disabilities in the Western world either lived apart from society, in isolated conditions alone, or unseen within the family home, or supported in institutions which housed large numbers of disabled people.

Arising from dissatisfaction with the isolated treatment of disabled people, in the 1970s two new key approaches emerged. From Britain emerged the social model of disability (UPIAS 1976 in Oliver 1986), and from the United States came the principles of normalisation and social role valorisation (Wolfensberger 1972). With its smaller

population and research base Australia has drawn selectively from both traditions. In Australia, the social model was touted as a form of political theory and a central theme for a collective disabled-led advocacy movement, which declared that society must make its structural constructs and physical environment more enabling for people with disabilities. The principles of normalisation and social role valorisation informed the treatment of disabled people (especially intellectually disabled people) by society, an application led mainly by non-disabled professionals. Both approaches advance the practice of integration, whereby disabled people are integrated with their non-disabled, age-related peers. Each of these approaches is described below.

## **6.2 Britain and the social model of disability**

In the 1960s in Britain, awareness around disability issues grew. The physically disabled began to organise themselves in response to an increasing dissatisfaction with the institutional structures created for disabled people. Several pro-disabled advocacy groups emerged and from this milieu one group described a new approach to disability which would form the basis of a disability theory – the social model of disability.

The origin of the social model of disability arose substantially from the actions of a group of physically disabled people “The Union of the Physically Impaired Against Segregation” (UPIAS) who in 1976 published a manifesto titled ‘Fundamental Principles of Disability’ which asserted that:

In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (UPIAS 1976 in Oliver 1996: 14). This statement formed the primary principle which was later identified and conceptualised as the “social model of disability”. The social model distinguishes disability from impairment. Thus impairment constitutes the individual loss or untypical function of the body, whilst disability refers to the attitude society attaches to the impairment and its consequent disabling treatment of the impaired (Chappell, Goodley et al. 2001). Following this UPIAS publication, disabled academics within the new discipline of Disability Studies began to expand and conceptualise the basic precepts outlined in the UPIAS document, to further elaborate and develop the social model of

disability as locating the “problem” of disability with the of inability society to provide appropriate services and environments. Thus, a person in a wheelchair is ‘disabled’ from accessing a building because the building only provides stair access.

One of the founding academics of disability studies, Michael Oliver, who is physically disabled, details the emergence of this new model as honestly and simply arising from the actions of disabled people who acted, at times, in contradiction to those experts or professionals who did not truly represent them. This view of disability protest and advocacy around the social model of disability is echoed by other key academics, notably Barnes, Mercer, Shakespeare and Morris (Shakespeare 1993, Mercer 1997, Colin Barnes 1999, Morris 2001). These authors describe the emergence, growth and legitimacy of distinct disability studies, listing authors and journals and specialist ‘disability courses’ across the Western world.

The development of the social model of disability has not just had a liberating effect on individual disabled people but has also had significant consequences for the kind of research which is carried out about our experience (Morris 2001: 4). The social model identifies disability as a social oppression of the impaired by society. Thus people are disabled by their societal treatment not their impairment. Until the development of the social model disability was viewed as a personal tragedy. Thus disabled people were unable to fully participate in society due to their individual impairments. From this viewpoint, the onus is borne by the disabled person individually. Under the social model the onus is placed on society to adjust structures such that the impaired person is not disabled. As described by Oliver: “I have referred to this different view as the ‘individual’ and ‘social’ models but they might perhaps more emotively be called ‘personal tragedy theory’ and ‘social oppression theory’ ” (Oliver 1986: 6).

Oliver and other disabled advocates and academics have rejected the dominant and prevailing individual tragedy framework of disability held by non-disabled researchers and the medical profession. These “medical approaches” seek to identify the extent of impairment with a view to classifying an individual’s capabilities and needs. From the individual tragedy perspective, having impairment is what causes the experience of

disability; an experience which is then individually 'treated' by other professionals. Oliver argues against this approach, likening personal tragedy theory to deficit theory which is commonly applied in other situations (such as deviancy used to explain criminal behaviour).

Like all other victim-blaming theories ... personal tragedy theory has served to individualise problems of disability and hence to leave social and economic structures untouched. ... let us hope that personal tragedy theory, the last in the line will soon disappear also, to be replaced by a much more adequate social (oppression) theory of disability (Oliver 1986:16).

In wholly rejecting traditional sociological and medical approaches to disability, advocates of the social model also rejected any identification and measure of impairment and the very different experience and impact differing impairments engender. In this way, the different experience of being intellectually disabled as opposed to being physically disabled has been subsumed.

In founding the field of disability studies, disabled academics themselves mirrored the advocacy movement their ideas sprung from. Their personal struggle in the world of academia reflected the intellectual struggle of their emerging ideas against the prevailing views. Disability advocacy reflected the experience common to most disenfranchised groups, wherein the struggle for respect and recognition is transformed via political jostling into a process of self-validation and group identity in which one's rights to be heard are legitimised (Honneth 1995). The efforts of disability academics and advocates to have their views validated in both the intellectual circles of disability studies and political world of advocacy created a strong independent identity as "persons with disability". The independent empowered disabled person's identity is prescribed by social model theorists who fiercely protect this hard-won validation. In rejecting the individual tragedy view, the social model, as expanded by disabled academics in disability studies and disabled people in political advocacy, seeks to empower the disabled person as fully entitled independent citizens seeking the structural reform of society.

Framing disability issues as matters of citizenship is potentially a powerful strategy for the disability movement. It challenges old images and stereotypical beliefs about disability, ... [assisting us in] ] ... advocating for reforms in the world we want (Prince 2004: 463). The social model rejects notions of dependency which are linked to society helping the

unempowered, unemancipated non-self-determining disabled individual. Thus Oliver notes: "personal tragedy theory seems endemic to the helper/helped relationship as it is presently constituted" (Oliver 1986: 15). The denial of help and care means the effects of dependency on carers is difficult to acknowledge in the purist interpretation of the social model.

The limitations of the social model of disability have been noted by many of its proponents, namely Barnes, Mercer and Shakespeare, Oliver and Morris (Oliver 1986, Colin Barnes 1999, Morris 2001) Much of this criticism emphasises the need for a comprehensive social theory on disability which would incorporate the nuances of their disabled experience. Oliver acknowledges these limitations.

Firstly we must not assume that models in general and the social model in particular can do everything; that it can explain disability in totality. It is not a social theory of disability. (Oliver 1996, p.41).

In the UK, the social model of disability was the ideological catalyst for further development of disability theory, research and prescriptions for implementation. It also marked a definite shift in the thrust of the disability movement from victim to expert, activist, entitled person with disabilities (Morris 1993, Oliver 1996, Barnes 1999). Disability advocacy and the expansion in disability research and academic writing have had a significant impact on disabled people.

The exclusion of disabled people from the mainstream of economic and social life has been the subject of mounting political protest and mobilization. ...[increasingly]... policy makers and politicians... have introduced some form of legislative framework (Colin Barnes 1999, p1).

### **6.3 The United States – normalisation and social role valorisation**

The principle of normalisation emerged in the United States in the mid-1960s. In the early 1970s this concept was expanded through the influential publications of Nirje (Nirje 1976) and Wolfensberger (1972). Wolfensberger's writings and speeches on the matter established him as the primary founder of normalisation in the United States, where his work provided a blueprint for an alternative approach to institutionalisation of disabled people. As remarked by Sherrill:

the best known of these pioneer thinkers in North America was Wolf  
Wolfensberger ... whose speeches and writings captured the imagination ...

in the societal battle for deinstitutionalisation and the return of persons with mental retardation to their neighbourhoods... both the Association of Retarded Citizens and the American Association on Mental Retardation adopted the goal of normalisation (Sherrill, 2003).

Whilst it has implications for the physically disabled, in the United States and Australia the principle of normalisation were primarily applied to people with intellectual disabilities.

Klotz observes that normalisation promulgated by Nirje and Wolfensberger “supports the rights of people with intellectual disabilities to a normal life and lifestyle has subsequently become legally enshrined and implemented throughout the social services for intellectual disabled people in the USA, Europe and Australia” (Klotz 2004: 96).

Wolfensberger defines the normalisation principle as the

utilisation of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible (Wolfensberger 1972: 28).

The principle of normalisation relies on the disabled person achieving non-deviant or normative behaviour and being enabled to fully exercise appropriate societal roles including the right to self-determination, choice and participation in typical roles integrated in society. Wolfensberger promulgated this specific meaning of normalisation in a stringently controlled training wherein his “disciples” were grounded in the real meaning of normalisation.<sup>20</sup>

Later, Wolfensberger (1983) reformulated and expanded the principle of normalisation, in the theory of social role valorisation (SRV) wherein the

most explicit and highest goal of normalisation must be the creation, support and defence of valued social roles for people who are at risk of social devaluation (Wolfensberger 1983: 234).

Wolfensberger argued that it was inadequate to simply state the value of disabled people without also addressing the situation into which they are placed. He emphasised

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<sup>20</sup> This training program was referred to as PASSING (Program Analysis of Service System Implementing Normalisation Goals) see (Altschul 1992)

that the assessment of the person's role extended beyond their occupation to their entire self, their societal image, competence, and sphere of activity (Discussed in Harry and Rueda 1999).

According to Crotty, Wolfensberger promoted the placement of the disabled person in valued roles and the adjustment of that person to the requirements of the role “by enhancing their personal competence” (Crotty 2002: 9). Thus the dominant values and framework of society at any given time determine what constitutes a valued life external to any intrinsic value within the disabled person, particularly where this intrinsic value does not accord with society's values at that time.

An Australian academic with a particular interest in intellectual disability, Trevor R Parmenter, states that the popular acceptance of the normalisation principle was related to community disgust at the treatment of people with an intellectual disability or psychiatric illness in state institutions. This propelled society to adopt policies which “saw the deinstitutionalisation of thousands of people back into the community and a moratorium on the acceptance of people with disabilities into segregated living environments” (Parmenter 1999: 324). From the 1980s, SRV was of great significance in the formulation of education, and community care and service principles for people with intellectual disabilities (Dowse 2001: 133).

In Australia, the translation of SRV has led to governments and service providers structuring disability education, employment and support services to mirror those of same-aged peers and within the same integrated settings. As seen in the policy analysis in Chapters 4 and 5, Australian disability policy and legislation is based on disability theories, in particular the social model of disability, normalisation and SRV. Thus, it problematises how best to achieve disabled people's choices, participation, integration, social and physical access and valued status in the community (Crotty 2002). Following theories of normalisation and SRV, an intellectually disabled 19-year-old, who is unable to reason, write or read, is entitled to automatic admission to the socially valued roles of attending university and integration with their same-aged peers in all associated lifestyle and academic opportunities.

## **6.4 Disability theories and intellectually disabled people**

The integration of people with disability is seen as the primary means for effecting the implementation of the social model of disability and the principles of normalisation and

SRV. Within Australia, each theory differed on the details of how this was to be achieved and who should be the primary agents to achieve such changes. Social-model theorists and activists see the practice of integration as the logical outworking for the entitled (disabled) citizen who by their own initiative moves freely within an enabling and supportive society. Meanwhile, perhaps by default, disabled people who could not advocate or communicate themselves (such as intellectually disabled people) were acted upon by the proponents of normalisation and SRV, who would proceed to place them in appropriately integrated situations and improve them (via therapies and education) so their capabilities could meet the requirements of these new and valued roles.

Both theories agree that separation of disabled people from society is punitive and that the person with disability should be integrated with non-disabled people in all peer-related roles, structures, and physical environments. As noted by Australian academics Cummins and Lau in 2003:

The institutions with their exclusive enclaves of social interaction are the antithesis of what became, and is now seen, as desirable. Contemporary service policy is steadfast in its commitment to accommodating people with disabilities in the general community and facilitating their integration with nondisabled people (Cummins and Lau 2003: 145).

It is important to recognise that the social model of disability, the principle of normalisation, SRV and the practice of integration do not explore the implications of different impairments and circumstances amongst those with a disability:

Criticisms of inclusion and representation within the (disability) movement have come from those on its margins; disabled women, black disabled people, those from ethnic minorities ... . Activists from these groups have argued for a more flexible approach that recognises difference and acknowledges multiple and simultaneous oppressions and identities (Dowse 2001: 133).

Intellectual disability is an important category of difference that needs to be recognised. As mentioned previously, the social model and its resultant laws and policies are substantially aimed at the structural reform of society. As Meekosha notes in a review of the 2002 British publication: "Disability Studies Today" by Barnes, Oliver and Barton:

The founding fathers of British disability studies ... have been the most sustained proponents of a materialist vision of disability studies ... A

structural approach concentrates on the disabling process, given form as 'the social model' (Meekosha 2004: 729).

She then goes on to cite other authors who suggest that the social model is simplistic and she proposes a deepening of the materialist theorisation of disability that could include an appreciation of difference and impairment including variable feelings of pain, hope and joy. She notes that social-model protagonists rigorously reject the medical and individual pathology models, probably because they fear that acknowledging the individual experience of the body would attract the focus of social policy "at the cost of the hard-won societal commitment to overcoming discrimination" (Meekosha 2004: 730). Meekosha suggests that rather than detract from the social model, the sociology of impairment can *add* a dimension to it.

Later theorists critiquing the social model, while acknowledging its political strengths, seek to "highlight some of the theoretical limits and question its feasibility to inform social theories and policies" (Terzi 2004: 145). They point to feminist and post-modernist theorists within disability studies who have identified other dimensions to disability, which have been stifled by the strictly materialist (or structural) framework. Thus, "the concept of difference comes to be included in disabled people's agenda, with reference not only to general cultural settings, but also to the specific culture of difference connected to gender, ethnicity, sexuality and type of impairment. ... Evidently, it is argued, (for example) deaf people experience a very different form of exclusion ... [rather than the] ... traditional barriers identified by the social model ... accessing built environments, for instance" (Terzi 2004: 146).

It should be noted that, even in debates about the necessary role of impairment in disability theory, it is referred to as a primarily bodily experience; the explicit difference of intellectual disability, a fundamental disparity, is rarely addressed (Dowse 2001). Thus, intellectually disabled people are seldom directly considered. The impact of this exclusion, asserts Chappell, reproduces the marginalisation of intellectually disabled people:

Writers committed to the social model have applied it with great enthusiasm to physical and sensory impairment, but they have neglected people with learning difficulties.... the present authors would argue that 'learning difficulty' has been tagged on only as an afterthought within much of the literature generated by the social mode (Chappell, Goodley et al. 2001: 46)

Marion Corker asserts that this exclusion is intentionally suppressive: "It highlights the tendency of mainstream disability theory and politics to address differences within self-imposed limitations of censorship, silencing, subordination and negative evaluation, which has resulted in the policing of disabled people's experience" (Corker 1999: 629). Thus, one is first marginalised by being disabled and further marginalised by having one's experience of intellectual impairment ignored by disability theorists.

As Dowse notes, the need for acknowledgement of "not only biological, but psychological and cognitive difference ... can allow an appreciation of difference in all its forms and lend weight to a more inclusive collective identity which can in turn inform a new theory and politics of disability" (Dowse 2001: 138).

The social model's non-identification of different impairments makes it difficult to tailor resources to different needs:

The rejection of normality as the guiding concept, if applied consistently, leads to some untenable conclusions, both theoretically and practically, in fact, if we can deny normality in terms of average human functioning, how would we evaluate impairment and disability? ... There are impairment affects that lead some people to a more significant and continued use of personal assistance or mobility aids than others. (Terzi 2004: 155).

I echo Terzi's comments; the denial of individual impairment and the yardstick of normalcy within the social model are artificial. It makes it awkward to frankly examine, or measure, difference from normal human functioning; this, in turn, makes it difficult to not only frame a fair disability policy, but also to justify increased resource allocation for greater deficits from the norm and to accurately tailor services.

The social model's rejection of measures of deficit from normal functioning means there are "not only theoretical and political limitations, but also a mismatch between the theoretical basis of the social model and some of its practical, political aims" (Terzi 2004: 155). As seen in the policy analysis in Chapters 3 and 5, much policy implements disability theory and so also does not problematise the deficit of intellectual disability. As such the practical survival needs of dependants are not problematised. Therefore, the impacts of this deficit on both dependants and their carers is not identified, measured and addressed. This absence serves to deny, neutralise and minimise both the extreme experience of being severely intellectually disabled and the load that is borne by those carers who are obliged to make up this deficit.

If the difference and specific impairment of intellectual disability is not openly researched, recognised and incorporated at a theoretical level, policy cannot accurately respond to the disadvantage this difference represents. In short, in both theory and its implementation in policy, one must first accurately recognise the difference of intellectual disability in order to acknowledge and respond to the specific disadvantage it represents to both dependants and the carers upon whom they depend.

The shift in attitude, from specialist disability arrangements for housing, education and services, to one where the supports for the disabled mirror, and are situated in, the community, is known as the concept of integration. Normalisation and SRV informed the interpretation of integration for intellectually disabled people. As noted by Australian academics, Cummins and Lau, citing Wolfensberger (1972, 1983, 1995, 2000) "the issue of community integration has been seen as a critical aspect of successful service provision ever since the issue of normalisation and social role valorisation (SRV) started to impact on service delivery for people with intellectual disability" (Cummins and Lau 2003: 145).

Normalisation and SRV, however, do not differentiate between different types of intellectual disability. For example, the term intellectual disability encompasses those with a genetically based disorder, an acquired brain injury, a biological deterioration or a mental illness. Within these categories there are further substantial distinctions related to the extent of affectation. Some people with intellectual disability are unable to speak and need assistance to eat or go to the toilet; others are loud, active and violent, while some may have mild intellectual disabilities and be semi- independent.

Intellectually disabled people have varied capabilities; regardless of the intervention and therapies they receive, many will never achieve basic self-maintenance skills, let alone social or employable skills. Clearly, if intellectually disabled people do not thrive and improve with the application of normalisation/SRV (applied in the form of early intervention and ongoing skill-based therapies) to lead independent lives, someone, in nearly all cases, their family carer, must continue to support them. For example, some intellectual disabilities are genetically based and cause an ongoing deterioration of skills, which cannot be addressed by education or intervention. For instance, individuals with Rett or Angelman syndromes may undergo rigorous early intervention and education within the precepts of normalisation but because of their genetic disability will nevertheless experience a marked decline in skills. One of the carers interviewed

described their daughter who had, from the age of three, progressively lost speech, the ability to walk, and a reduction in hand and spinal function, requiring full bodily support and nappies. He expects to be the carer of his dependent daughter for the term of his natural life.

Normalisation and SRV instructs the education and training of intellectually disabled people, with a goal of enabling them to acquire and maintain a typical occupation in society and a typical and valued lifestyle. Thus, the prevailing peer curriculum and measures of success are applied in schools that educate intellectually disabled people. Where the capabilities of intellectually disabled people prevent them from obtaining a peer educational standard, core curriculum areas are adjusted, but the primary principle, one may say illusion; of enacting a “normal curriculum” is maintained. For example, an “Individual Education Plan” is formulated each year for each child at a Sydney School for the intellectually disabled. This plan is formulated in consultation with teachers, parents and therapy specialists and attempts to ‘fit’ each child’s achievements to the ‘Key Learning Areas’<sup>21</sup> of their same- aged peers.

Implementation of the principle of normalisation continues to assume the fundamental belief that all disabled people have the same potential as others in society to make choices, develop skills, and ultimately occupy valued societal roles. This is a false-positive position as

a technical problem lies in the assumption that people with low social skills can actually increase their skills to a level that substantially benefit their sense of social connectedness with non-disabled people. ... The evidence that this can be achieved for people with severe cognitive disability is slim. As is well understood, cognitive disability is the limiting factor to general social integration (Cummins and Lau 2003: 153).

The principles of normalisation and SRV operate on the premise of negative inherent value in intellectually disabled people and of endless potential to achieve external value and integration within culturally normal society, essentially emphasising the negative value placed on intellectual disability and isolating people with intellectual disability

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<sup>21</sup> ‘Key Learning Areas’ is a phrase used to describe core outcome categories for typical students in the New South Wales public education curriculum.

from collective identity, support and relationship or friendship with each other and promoting association with more valued groups (Dowse 2001, Cummins and Lau 2003, Barnes 2007). I contend that this requires one to assume little distinction among, and sameness across, the intellectually disabled population. This premise is beyond patronising, it is dehumanising; every human is unique and different; it is appropriate to recognise and value this difference in intellectually disabled people. It is equally important to recognise the implications of this on their carers.

There has been some research on the progress and improvement in the lives of intellectually disabled people following the implementation of the social model and normalisation. This research shows that by both quantitative and qualitative measures (including longitudinal case studies), there have been limited improvements in the integration of intellectually disabled people (Reinders 1997, O'Brien, Thesing et al. 2001, Terzi 2004). For example, a longitudinal study in New Zealand examined the lives of a group of intellectually disabled people who were removed from an institution to a small house community setting. They found that living in the same housing style, a suburban home, there was a sense in which people were in the community but not necessarily part of it. Evidence showed that "people had acquired new social and self-help skills, but these did not extend to the development of new social roles such as those of friends, neighbour, worker, relative, club member" (O'Brien, Thesing et al. 2001: 78).

Carers interviewed for the thesis were specifically asked whether they valued the current service focus on integration of their disabled child with typical same-aged peers. All carers expressed either derision, or dismissed the concept of integration as irrelevant in their view. Some noted that, in their experience, it had been hurtful for their child, and humiliating for themselves. "Even when she's got an hour of planned integration, she doesn't respond to the other normal teenagers, I feel embarrassed for the visiting kids and Izzy is soon ignored. We often turn back and the other normal kids have left her alone" [Sue].

All carers spoke strongly about desiring their dependent child to have other disabled people who were similar to them as a friendship group, describing such friends as 'real' or 'genuine'. Some carers stated that the focus on integration had meant that their children did not receive the right services or that the money wasted on the integration could be spent on the greater provision of services. Many carers said that rather than

being focused on integration, government services should instead focus on tailoring services that would facilitate a community of similarly disabled people:

Integration with peers is unreal, that 'circle of friends' advocated is simply not available, this idea of voluntary friend help, no it should be genuine friends with the same interests [Carol];

Integration is bad and got my son in trouble -- he was abused [Anne];

With the differences between disabled people, especially difficult behaviours, disabled people need institutional settings. It is appalling that people are trapped in their homes. Such severe behaviours should be in institutions otherwise its isolation of carers [Carol];

I want activities that give disabled people the same type companions [Carol];

Not integration but mixing with other disabled kids in the local area [Fozia];

I want her in smaller settings with other disabled kids her age not 'normals'. I've tried integration, for example brought two other siblings friends over, no one talks to Ming [Luk]; and

Integration is only good in small doses to remind people that Izzy exists, to make the world more compassionate. Even in her integrated program with the nearby normal high school the kids ignored her or talked to the teachers or me. I can understand this as Izzy doesn't talk or respond much. It was hard for the normal teenagers to do much more than stand around her. And these were the kind ones who'd volunteered for the joint school's integration program [Sue].

Work undertaken by Robert Cummins and Anna Lau in 2003 concurs with the views of carers interviewed. Both lead to the conclusion that integration should not remain the primary goal in the design of disability services, particularly for intellectually disabled people. It is worth particular exploration, both for its critique of disability research and its sourcing of critical material primarily from an Australian database. The paper titled "Community Integration or Community Exposure? A Review and Discussion in Relation to People with an Intellectual Disability" questions the meaning and benefits of integration in reference to intellectually disabled people, and outlines the potential harm, to both carers and intellectually disabled people, of imposed integration. This paper reviews the relevant studies/articles maintained in The Australian Centre on Quality of Life collection, supplemented by other articles.

Cummins and Lau echo other critics discussed previously (Chappell 1994, Dowse 2001), who question what constitutes valuable social integration for intellectually disabled

people. Cummins and Lau question whether the physical exposure of moving through the community is integration. Thus, even when intellectually disabled people are physically located in the general community, they are often not socially part of this community. They point out that because of the presumption that physical exposure equates to valuable social integration, many studies simply measure community exposure with the underlying assumption that more exposure equals better integration (and presumably a better quality of life).<sup>22</sup> Significantly, these indexes and techniques for measuring community impact simply numbered the instances of physical exposure. They observed that during trips to the community the typical proportion of time each person spent in contact with a member of the public was approximately two percent.

Cummins and Lau observe:

It seems amazing to note that none of the studies cited for the paper measured the extent to which people desire community integration ... the vast majority of existing measures, and all of the formal scales, are concerned exclusively with objective integration. This fact creates a heavily biased literature which misrepresents community exposure as integration because it fails to address the realm of personal experience (Cummins and Lau 2003: 152).

Their reviews of several articles indicated that people with an intellectual disability have small social networks and remain generally isolated from non-disabled people. Their assessment of various studies echoes the findings by O'Brien et al. (2001) that even when they reside in the local community and are exposed to the typical community, people with an intellectual disability have extremely small social networks (primarily with staff, family members or other disabled people), have less contact than non-disabled people normally have with their neighbours, and remain generally isolated. In short, intellectually disabled people may be physically located in the community though not, socially, a part of their community. If community exposure or

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<sup>22</sup> Cummins and Lau outline the range of instruments used to measure community integration or 'community exposure'. These instruments include the Community Integration Questionnaire; The Guernsey Community Participation and Leisure Assessment (which comprises a checklist of 35 types of community contact); the Index of Community Involvement (recording frequency of involvement in leisure and community-based activity in the proceeding 4 weeks); the Assimilation, Integration, Marginalisation, Segregation Interview (where 10 types of community activity are rated by carers).

physical proximity with the community does not engender social relationships for intellectually disabled people, then what are the benefits of this strategy?

Cummins and Lau systematically reviewed and dismantled a number of studies whose findings reinforce the benefits of integration. They categorise these benefits from three standpoints:

1. Benefits from a service provider/government perspective;
2. Measures of objective benefit; and
3. Subjective personal relationships which benefit the intellectually disabled individual.

Appendix 3 further discusses these standpoints. Cummins and Lau note that integration achieves limited benefit in the first two standpoints and fails in the third: “everybody regards the domain of relationships at the top of their list, and the domain of community at the bottom” (Cummins and Lau 2003: 148). They conclude that the third standpoint is, ultimately, the only justifiable policy and service goal.

Finally, Cummins and Lau explore the negative side of integration. Within the general community, people with disabilities report encountering prejudice, stigma and discrimination; these responses undermine their self-esteem and, rather than creating community, create a sense of alienation, loneliness and social isolation. These impacts may commence in preschool and continue through school, work and living environments wherein students, teachers, fellow employees may choose not to engage, relate or even tolerate the presence of difference. In short, throughout their life a person with an intellectual disability may never have one genuine friend. “In conclusion, the literature suggests that physical integration may be damaging for some people ... The belief that general community integration based on physical presence is necessarily beneficial to the individual, is false” (Cummins and Lau 2003: 151).

Cummins and Lau’s review of studies examining the less ideologically controlled environment of the family notes that of the generally 50 percent disabled adolescents who had a friend outside of staff or family members, their friend was invariably another adolescent with an intellectual disability. This research suggests that it is relevant to value relationships between people with an intellectual disability and reject the notion that it is superior for intellectually disabled people to have relationships with non-disabled people. Other researchers have also noted the assumed greater value of

“integrated” friendships, that is, friendships between disabled people and non-disabled people Chappell points to the “clear assumption in much of the literature that friendships between disabled and non-disabled people are of greater value than those relationships between disabled people” (Chappell 1994: 1). Reinterpreting the application of normalisation and SRV, Cummins and Lau note that the “social roles advocated so passionately by Wolfensberger could be achieved far more easily within the community of people with similar levels of ability than within the general community” (Cummins and Lau 2003: 153).

As noted earlier, for many people with an intellectual disability, integration with the community effectively means a lifetime residing with their birth family. The Cummins and Lau paper refers to a review of 17 studies which measured stress levels amongst caregivers and produced alarming results: “the uncomfortable truth that seems to emerge from this analysis is that the physical integration of severely disabled people within the family home is generally damaging to the life quality of other family members” (Cummins and Lau 2003: 149). The issue of the impact on carers of supporting a person with intellectual disability has been noted, and will be appraised in Chapters 7 and 8, in discussing the additional impacts on carer lifestyle that emerged in the responses of the carers interviewed. It is relevant to flag here, because this severe carer and family impact is a direct result of disability theory insisting on the physical integration of all persons with disabilities.

In conclusion, sweeping measures for integration are proposed for all people with disabilities, and do not recognise the implications arising from different impairments, particularly the differences arising from people with physical and intellectual disabilities and from different levels of intellectual impairment. The existing research that supports integration relies on superficial measures, which equates physical presence in the general community to genuine community integration.

Many of the benefits attributed to physical integration are more logically explained by other causal factors. Analysis of this research highlights the difficulty of achieving meaningful integration (in the form of stable intimate relationships) and going beyond the appearance of normalcy, as in the facade of a physically integrated life, to the deeper understanding of normalisation and social role valorisation (Wolfensberger 1972, Wolfensberger 2000). The deeper understanding of normalisation incorporates ideas of being a valued and embedded member of the community in both practical (lifestyle)

and relational sense. Indeed research which questions the value of integration, questions the whole value of the premise of integration (between disabled people and non-disabled) to intellectually disabled people and the community. Significantly, it highlights the lengths and contortions undertaken by researchers to comply with the apparently fundamental belief that integration is always good and always confers benefits on both the intellectually disabled participants and the receiving community. In particular, the Cummins and Lau paper (2003) which dissected the data underlying many of these studies shows a disturbing conformity in most disability research, to support integration in spite of findings that show it is not beneficial to intellectually disabled people.

## **6.5 Translating disability theory into policy**

In the UK, disability advocacy resulted in the social model and the conceptual reconfiguring of disability in society and government policy (Oliver 1996, Chappell, Goodley et al. 2001). This activism continues in the 21st century: “The movement in Britain comprises a network of grassroots organisations, issue-specific lobby groups, direct action coalitions and their allies, controlled and run by disabled people” (Dowse 2001: 123).

As demonstrated, disability advocacy, research and theory creates a collective identity which both informs and develops ongoing academic endeavours in disability studies and theories as well as pursuing socio-political aims in public policy and therefore influencing social and service structures (Oliver 1996, Chappell, Goodley et al. 2001, Dowse 2001, Prince 2004).

Intellectually disabled people, especially those who are dependants, are not active in disability advocacy or research. Disability advocacy necessarily reflects some degree of self-interest; the advocacy movement provides a channel within which the (primarily) physically disabled project their views into either the direct improvements for themselves or the group.

This raises serious questions about how disability studies embraces the perspectives of representative organisations of all disabled people in developing enabling theories and practices. Too often, people with learning difficulties are only partially included in major theoretical development in disability studies; their activism is not given the same weight as that of the physically impaired comrades (Goodley 2004, p.49).

Other critics note a duality in the application of disabled experience, with physical disability advocacy informing the broad socio-political enactment of the social model whilst those with intellectual disability advocacy are confined to the details of specific support services. There are contradictory explanations for this. Some claim that physically disabled people automatically identify the problems of people with intellectual disability as relating to their impairments (Chappell, Goodley et al. 2001). Others, such as Oliver, assert that the fault belongs with the intellectually disabled advocacy group themselves, because their focus is erroneously confined to the details of service provision excluding them from being a true disability movement and achieving broader socio-political objectives (Oliver 1996).

In terms of advocacy, a concern remains as to how well dominant mainstream disability advocacy and studies incorporate the different experience, restriction of impairment and perspectives of those with an intellectual disability. Australia mirrors Britain's advocacy structure with grassroots organisations representing specific subgroups of disabled people. Thus Australia has specific grassroots interest groups operating at federal and state level including: the Council for Intellectual Disability; People with Disabilities; the Deaf Society of NSW; the NSW Association of Children with Disabilities. Many of these groups receive some government funding. Some receive funding for specific support services for their target constituency.

In NSW, the official legislated, government-sanctioned and funded advocacy organisation with direct responsibility to advise and inform the NSW Government is the NSW Disability Advisory Council. This body, and in particular its key position holders (the Chair of the Council and the Director of the Secretariat), have direct access to key ministers and bureaucrats. As a past member of the NSW Disability Advisory Council, I observed key government officials attend Council meetings and much direct discussion between the Chair or Director and key government officials.

Historically, disability theory and advocacy are led mainly by the physically disabled, and has directly influenced theory, legislation, policy and practice. As noted previously, the principle of normalisation, predicated on integration, primarily instructs the treatment of intellectually disabled people at the hands of professionals: "this principle served to accord professionals a central role in interpreting disabled people's socially valued roles and activity thereby investing them with a legitimacy and power to advocate for people with learning difficulties. The terrain open to legitimate

intervention and action by ... [intellectually disabled groups] ... has been limited by the dogma of normalisation" (Dowse 2001: 134).

Disability advocacy promotes self-representation primarily by people with physical disabilities. Moderately and severely intellectually disabled people are excluded, by their limited speech and ability to meaningfully discuss issues. Their carers are also excluded as this contravenes the requirements of self-representation. In this way, the physically disabled, grounded in the philosophies of self-determination in policy and advocacy, co-opt the views of intellectually disabled people and can claim a greater legitimacy to do so regardless of the vast difference in their experience of disability or their lack of intimacy with people with intellectual disability. As argued, intellectually disabled people do not benefit from integration; acknowledgement of this allows other theoretical ideals to direct policy for intellectually disabled people.

In applying disability theory, it is difficult to see how someone with a severe intellectual disability could be expected to fully participate in, and enjoy, university training or a professional career. This substantive difference is tacitly acknowledged in NSW in the provision of day services for the intellectually impaired. Day services consist of controlled and monitored centres offering support and a range of stimulating activities including play, music, and movement programs rather than employment in the community. By not expressly addressing this difference, disability theory, research, advocacy and ensuing policy and service practice do not accurately meet the needs and choices of intellectually disabled people.

A tangible example of how (physical) disability theory, advocacy and policy caters primarily to the physically disabled, and ignores the different needs of the intellectually disabled, is seen in its success in adjusting the physical environment to make it more accessible for the physically disabled. This adjustment has included the redesign of many public spaces to facilitate wheelchair access, provision of access ramps such that the wheelchair-bound are able to readily access buildings, wheelchair accessible taxis and importantly, the provision of disabled toilets. In NSW developers are required by law to ensure public buildings provide a proportion of wheelchair accessible toilets. That is, a toilet built to exacting design specifications such as nil stair entry and specially designed taller toilets, with specific doorframe and internal circulation widths and fitted support rail to cater to the physically disabled. Thus, the physically disabled are less

disabled by the physical environment and they can more freely move throughout society.

Intellectually disabled people are frequently incontinent and require nappies or incontinence pads 24 hours a day; they therefore require the provision of appropriate facilities to change these pads; this usually consists of an appropriate clean, weight-bearing platform at a typical adult's waist height. This would allow them the same freedom as the wheelchair disabled to circulate more than a toileting trip away from home. Surprisingly, not a single highly regulated toilet for the disabled requires the provision of an appropriate nappy/pad-changing facility. This 'oversight' places marked restrictions on the free movement of intellectually disabled people and their carers.

For example, Steve, one carer interviewed, has a severely intellectually disabled teenage daughter who requires nappies 24 hours a day. He said when she was younger he could change her soiled nappies in the boot of the car, and when older, in the back seat of the car. Now as a teenager, he described changing her, in desperation, sometimes shamefacedly, behind public bushes, which is an undignified practice. He said he and the whole family have had to return home in order to change her soiled nappy. This curtails the whole family's activities. This example clearly and tangibly demonstrates that disability advocacy, whilst fine-tuning the societal environment to the needs of the physically disabled, does not address some of the most basic needs of intellectually disabled people and by extension, their carer.

Klotz's critique of intellectual disability research notes that the majority of studies focus on only the experiences of people with mild intellectual disability "extrapolating from these experiences conclusions about the nature of intellectual disability in general, while the experiences and life worlds of those whose impairments are severe, profound, and often multiple are often ignored" (Klotz 2004: 93). Klotz advocates recognition of the ontological reality of intellectual disability and the difference this makes to one's experience.

Given that intellectually disabled people have different needs, there is also a need to break from prevailing disability theory and advocacy which advocates an independent identity and rejection of dependency. For the dependent intellectually disabled there is an alternative identity in which dependence is central (Edwards 1997, Ells 2001); "self identity for people with disability features interconnections with and inter-dependency

upon, body, others" (Ells 2001: 599). The absence of the body in sociological discussions is an artifice as "our lives are in fact profoundly bodily based ... and its care provide[s] an existential foundation for day to day existence" (Twigg 2000: vii). As noted by Julia Twigg, the structuralist approach emphasised within the disability movement since the 1980s censors all mention of the body or the impairment of disabled people, seeing this as potentially demeaning and therefore largely excluding the subjective experience of disabled people. The denial of the body's essential need for personal care is an effective denial of the often lifelong dependency of intellectually disabled people.

There is a clear argument for recognising and valuing the different identity and needs of intellectually disabled people, one which recognises their dependency. There is a need for a new policy- and service approach to intellectually disabled people; one which recognises their whole and varied identity, including their dependency. Currently the fundamentally different requirements of intellectual disability are not clearly acknowledged in Australian policy and legislation. As noted in a 2006 Australian conference on Intellectual disability:

The shift from a differentiated approach of the past, where separate policy was enacted for people with intellectual disability (to) one generic version of disability and inclusion ... Potentially this disguises some of the unique needs of people with intellectual disability or the very different ways in which their needs have to be met (Bigby, Fyffe et al. 2006).

From the theoretical, policy and services perspective, the disability movement co-opts and represents intellectually disabled people, thereby ensuring that their different and particular needs are not too closely analysed. This ensures that the assumptions and criteria that suit those with physical disabilities direct the policy agenda, service structure and budget.

## **6.6 Disability theory and care**

The social model of disability and its proponents, primarily people with physical disabilities, have an historical and ongoing "hands-on" influence in Western policy, legislation and consequent service structures of disability support. This is to the exclusion of intellectually disabled people and their carers. If dependency is recognised it allows a frank recognition of the Cummins and Lau's "uncomfortable truth" about the severe impact of this dependency on carers, an uncomfortable truth which was

apparent in the carer interviews. As highlighted in Part 1's analysis of policy and legislation demonstrated the intentional diminishing of this truth meant it was not adequately problematised. Recognising dependency, recognising the "uncomfortable truth", can impel alternative underlying theories, and result in alternative problematisations which direct different policy solutions.

Disability theory and its advocacy of integration is often couched in terms of de-institutionalisation and the return to the community of the disabled person; in reality however, particularly for intellectually disabled people, "return to the community" actually means returning to their birth family and becoming the responsibility of a specific carer. The denial of bodily needs in disability theory, as seen in Part 1, translates to an absence of any problematisation on the bodily survival needs, and dependants' acute dependency related to these needs.

Being dependent and unable to practically care for themselves or manage their affairs, intellectually disabled people do not mirror their same-aged peers' lifecycles and develop to live independently. Effectively, they rely on their carer for support which can span 40 or 60 years, perhaps even a lifetime. However, carers are not directly identified in disability theory, discussion or implementation. They are rather, euphemistically, lumped in as part of the generic "community setting" into which the disabled person is placed. According to Julia Twigg, the frustration of disabled people at being controlled by professionals prompted them to achieve autonomy through the recasting of community care to the more impersonal role of personal assistant, where the worker exactly follows the instruction of the disabled person, requiring no special explanations or gratitude. This dynamic leads to the "denial of the personhood of the worker who is required to efface him or herself totally" (Twigg 2000: 193).

This attitude of entitlement without relational gratitude extends to the unpaid carer. Thus disability activists, in order to maintain their appearance of autonomy, require carers to be faceless, treated as irrelevant to the purist position of placing only the disabled person's view at the centre of discussion. This attitude is discussed by Kroger who notes that key disability researcher Jenny Morris and other disability researchers object to the inclusion of the role of carers where recognition of care cannot lead to empowerment. "Disability studies, based on the social model of disability, have to a large extent abandoned the concepts of care, family care-giving, informal and formal care" (Kroger 2008: 1).

The insistence on independence as part of the disabled identity makes it an anathema to acknowledge the dependency relationship between carers and intellectually disabled people. In order to maintain this generality, carers themselves must remain a non-specific and faceless setting. Carers are loosely glossed over as part of the community of integration and therefore satisfactorily a part of the “community care” for disabled people. This generality to speak frankly is a lie. As seen in Part 1, in prevailing policy and legislation carers are often the ‘hands’ presumed to be available to achieve the skill improvement envisaged in normalisation and SRV. Professional therapists act only in an occasional advisory capacity ranging from 1 to 15 sessions per year. Carers are also assumed long-term providers of daily care when intellectually disabled people do not achieve independence.

I interviewed a mother of a severely intellectually disabled girl. When her child is incontinent, when she soils herself and spreads the faeces throughout her bedroom, the community do not appear on her doorstep to “care” (clean up the mess). It is left to her mother, as her carer, to perform this unsavoury task in the midst of her ordinary life. It is both an insult to the care provided, and a lie, to ignore the specificity of the responsibility of specific carers to specific dependent people with disabilities – a responsibility, as discussed in the ensuing sections on care, which is ensconced in law. In short, if her mother did not clean up the mess *she* would be held liable for neglect under NSW state law, *not* the general community.

As noted previously, in the initial thrust for integration, carers were simply part of the generic setting for the disabled person. This is perhaps understandable if one appreciates the roots of the social model of disability in the emerging disability movement. In the initial stages of disability advocacy, the independent identity and collective voice of disabled people was actually a demonstration of the citizenship to which they aspired. As outlined previously, the philosophical underpinning of the disability movement relies on rights, not help. Disabled people are citizens entitled to service, not help. The independent disabled identity was perhaps required in order to effect change. Necessarily perhaps, the message must be both clear and simple.

What is less understandable or justifiable is that one may expect that, once change is initiated and the integration of disabled people under way, there would be some feedback on the impacts of such practices on all of those affected (including carers and intellectually disabled people). There appears to be an intentional blindness to these

impacts within the disability field. This is surprising given the widely available government research on the situation, which shows alarming impacts on carers; impacts that morally urge the investigation and adjustment of disability theory and policy.

## **6.7 Conclusion**

The social model of disability has been a powerful political force. It has initiated broad-based structural changes of concern to many disabled people. In particular, it has focused on the civil rights and entitlement of people with disabilities, to live integrated lives within the general community. It was the catalyst for positive changes for some people with disabilities, providing improved living environments, economic independence, education, employment, communication and physical access (Colin Barnes 1999, Morris 2001, Oliver 2001, Terzi 2004). These improvements are not, however, relevant, evident or consistent across the whole disabled population. Intellectually disabled people did not instigate or contribute to the UPIAS (Union of the Physically Impaired Against Segregation) movement which generated the social model. Nor are they specifically distinguished in the further development or implementation of the model. The dependent intellectually disabled do not benefit substantially from these changes and may even be negatively affected by them.

The effective marginalisation of intellectually disabled people has been noted by a number of researchers (Chappell 1992, Chappell 1994, Reinders 1997, Chappell, Goodley et al. 2001, Goodley 2001, Clegg and Lansdall-Welfare 2003, Cummins and Lau 2003, Goodley 2004, Terzi 2004). Normalisation provided a guideline for the positive treatment by professionals of the (primarily) intellectually disabled person within the community. Intellectually disabled people did not choose normalisation and SRV. It is not clear whether intellectually disabled people agree with the values guiding normalisation and SRV and care to be 'improved' and placed in what professionals, following prevailing dominant cultural norms, regard as socially valuable roles.

Disability theory and advocacy promoting the social model, the principle of normalisation and SRV, ignore differences within the intellectually disabled population and the receptivity of the receiving community and thus do not measure whether the integration touted is achieved. Some models are also premised on the superior value of the relationships between disabled people and non-disabled people and the limited or

nil value of disabled people in relationship with each other. This marginalises the impairment of the dependent intellectually disabled, devalues their choices and preferences in choosing to relate with other similarly disabled people and ignores their specific needs. This does not allow for an appreciation of the experience of intellectual disability and consequent modification of the social model of disability and normalisation.

There are likely to be other criteria that are more important to intellectually disabled people than the current application of integration within the bounds of disability theory. The implementation of disability theory aims to achieve the appearance of a normal life but does not guarantee basic bodily survival, tangible lifestyle improvements or reduced isolation for intellectually disabled people.

The progress and development of disability theory has appeared to proceed with little regard to carers and intellectually disabled people. Criticisms of the social model by theorists who support the general thrust of the model, such as Morris (Morris 2001) only go so far as to acknowledge her particular experience of difference as a female and mother with a physical disability. Ignoring the difference and dependence of intellectually disabled people effectively excludes carers who support them.

In summary, some researchers have identified that disability theory research and advocacy marginalises intellectually disabled people. I have demonstrated that the theoretical disability framework is flawed in three ways. Firstly, in promulgating integration and normalisation, it ignores the differences within the disabled population and particularly the unique needs and choices of the dependent intellectually disabled. Secondly, it ignores that intellectually disabled people are dependants requiring support, which is often provided by carers at substantial personal cost. Thirdly, many people with intellectual disabilities are unable to represent themselves and advocate for their own needs, or promulgate their opinions, and rely on others to sensitively perform this role. As Part 1 demonstrates, disability theory directs government policy and legislation, and the impacts of these flaws are therefore translated to the lived experience of dependants and carers.

# Chapter 7– Carer Theory and Discussion

This chapter critiques carer theory, seeking an approach that guarantees fair treatment of carers that is in a sufficiently clear and robust framework to direct government policy, similar to the way disability theory directs policy. This Chapter will first briefly analyse those “social care” theorists whose work is used or particularly relevant to the development of care theories. It will then analyse early feminist views of care, followed by an analysis of the three iterations of an ethic of care. Only discussions relevant to the treatment of carers will be analysed, not the full range of discussion on care and women's roles.

In her review of UK policy in relation to care, Marion Barnes observed the absence of an appropriate approach to care in theory and policy, in comparison with the policy gains ensuing from disability theory:

The development of socially just policies and practices ... is something the disability movement has had considerable success in. Their articulation of the social model of disability has influenced practices, policies and services in a way that emphasises the citizenship of disabled people. ...We need something similar which can address ... how caring values can inform the decisions about policies which shape the circumstances in which people live their lives (Barnes 2006: 158).

The WPR analysis in chapters 3, 4 and 5 reinforce Barnes’s observation. It identified that disability theory prescribed the problematisation of disability in policy and legislation, to attain integration, opportunity and value for disabled people; by comparison, it highlighted the critical silence on carer treatment and absence of solutions which guarantee fair treatment of carers.

Carer theory originated in early feminist critique of women’s place in the private sphere of the family. This discussion formed an understanding of care (referring to ‘general’ care, as distinct from the subset of care of dependants) as one of the responsibilities tying women to the private sphere. By the 1970s, some feminists extrapolated this view, stating that care constituted a burden on women. In the 1980s, a branch of the feminist movement derived a contrasting theoretical view, known as the ethic of care. The ethic of care sought recognition and celebration of the contribution of women’s care, claiming that this constituted an essential female paradigm which should inform policy and

direct societal structures in the same way as the predominant male paradigm directs these structures.

The ethic-of-care concept largely cemented the view that care, as a relationship or function should be prioritised, rather than focusing on the entitlements of carers as individuals. Whilst some feminist literature has been critical of care theory, these critiques have failed to resolve carer obligations to dependants and the consequent entrapment of carers under such obligations.

This chapter demonstrates that whilst care theorists address care values, none specifically focuses on fair treatment of carers and concludes that a universal carer theory, focusing on the fair treatment of carers, has not been framed.

## **7.1 Social Responsibility – Goodin and Nussbaum**

Robert Goodin's book, *Protecting the Vulnerable: a reanalysis of our social responsibilities*, describes a vulnerability model which involves a hierarchy of obligations relative to the extent of vulnerability. In Goodin's model the obligation of one party to care for another arises from the vulnerability of one party to the actions of another, with the one in a position to meet the needs having a moral obligation to do so (Goodin 1985). Goodin's approach includes measures of need or "vulnerability" and also measures of the ability of the one obligated. Goodin argues that such responsibilities may have the same strength between people within familial relationships as those outside familial relationships.

What I shall be arguing is that there is nothing special about those responsibilities. There are many others with precisely the same basis ... as those responsibilities ... we are not justified in our present practice of serving one set of claimants systematically to the exclusion of others (Goodin 1985a: 782).

Goodin emphasizes obligations to a larger group rather than the "special" obligations such as those of carers to dependants. His approach frames social obligations to the vulnerable which is apposite to fair societal responsibilities.

Goodin describes how this responsibility extends from those in immediate relation to us – family, friends, and colleagues – to others in our society, where such help is delivered by the welfare state, and then to rich countries being in a position to help poor countries:

The starving people of the world certainly are vulnerable to the actions and choices of those of us in rich nations, taken collectively. Hence we collectively have heavy responsibilities in respect of them (Goodin 1985a: 781).

In further development, Goodin states that the circumstances of justice must be premised on a basis of fair distribution of wealth (Goodin 2001).

Martha Nussbaum, in *Frontiers of justice: disability, nationality, species membership* argues against most justice theories' conception of society as reciprocal arrangements between equal citizens. Nussbaum replaces the concept of reciprocal arrangements with a conception that all, including those with extreme disabilities, are citizens entitled to societal support to live full, independent lives (Nussbaum 2006). Nussbaum premises her alternative conception with the claim that society is comprised of "sympathetic citizens", people who intuitively value equal dignity and respect for all, including the disabled, and would therefore support them adequately, without any expectation of reciprocity. Nussbaum alleges that such societal support would be in the form of government funded disability services which are designed to enable people with disabilities to live full, independent lives.

Although much of Nussbaum's argument parallels the assertion of disability theory to support for equal citizenship, she arrives at her concept from the perspective of citizens' responsibility to disabled people rather than from the social model of disability. Like disability theorists, Nussbaum does not discuss care relationships or carers.

## **7.2 Feminists' view – care as a burden.**

Feminist researchers in the 1970s identified the incongruity between being granted rights to goods and opportunities, and having the practical freedom to access them. They recognised that whilst early feminists and activists had successfully gained formal entitlements such as equality under law, voting, property rights and education, women's access to enjoying the benefits of the public sphere were constrained by women's obligations to care (variously referring to this care as oppressive, burdensome, or exploitative) in the private sphere. This discussion was on general care, not specifically focusing on carers of dependants.

Feminist philosophers noted that this incongruity was echoed in prevailing liberal theories which, they claimed, were also beset by internal contradictions, effectively

limiting women to the private sphere by not explicitly addressing the entitlements of women as citizens in the private sphere (Rossi 1970, Brennan and Pateman 1979, Evans 1983, Rossi 1983, Davis 1984, Evans 1984, Coole 1986). As summarised by Brennan and Pateman:

In a formal sense the battle is more or less over. In the last quarter of the 20th century, the principle of individual equality and freedom... is now being institutionalized in the liberal democracies ... this ,, has served to highlight the contradiction between women seen formally as free and equal individuals, and women as wives and mothers within the family ... the new feminist movement of the last decade has been particularly concerned with the private world of the family (Brennan and Pateman 1979: 198).

Studies documenting the development of feminism and the women's rights movement observe the range of participants and the diversity of their views (Rossi 1982, Evans 1983).

As summarised by Williams, feminist writing from the 1970s

sought to reveal the sexual division of labour between men and women, the exploitation of woman's unpaid labour as carers and the role of the state in maintaining this ... Central [to the critique of community care policies] was the concept of care as (oppressed) labour and the political demand for the recognition and reward of carers (2001: 475).

Feminists' interpretation of care obligations varied. Some viewed care obligation as preventing the vocational achievements and social life of women (Tovey 1974, Evans 1984), whilst others, like Bubeck, had a more damning view, which interpreted women's obligation to care as an intentional societal mechanism intended to exploitatively channel women into caregiving duties and extract unpaid care from them. These feminists challenged society's allocation of care, arguing that care is a social, not a private, responsibility (Bubeck 1995a).

The 1970s feminist view of care-as-burden was a response to the restriction, or entrapment, of most women to the private sphere, curtailing their enjoyment as equal citizens in the public sphere. This feminist view did not constitute a theory on care which could guarantee the equal citizenship of all women, in all circumstances, including women supporting long-term dependants. The 1970s feminist view has translated to improvements in the situation for some women who provided 'general' care within the home.

By the late 20<sup>th</sup> and early 21<sup>st</sup> century, public policy endorsed increased practical and institutional support for women aimed at relieving them from the care burden and participate in the public sphere. These women-oriented shifts in policies, services and payments included generally improved pay rates, legislatively assured employee rights, such as guaranteed paid maternity leave, and systemic supports such as subsidised or government-provided childcare. Generally, a greater choice became available for many women to find a balance between their ties to care in the private sphere and their opportunities in the public sphere. These initiatives have lessened the restrictive nature of care in the private sphere. Although women's citizenship may not be practically, fully realised, it appears to have improved. This improvement has contributed to the shift away from theoretically viewing general family care as a burden. Some feminist scholars had engaged in the complexity of politics involved in women's citizenship. Orloff (2009) notes that whilst gender equality has been institutionalized there are continuing dilemmas of care and domestic work which affect women's citizenship. Effective citizenship is reliant on policies around employment, social support and benefit and parenthood. Other feminist scholars such as Jane Lewis and Susannah Gillian (2005) remark that the shift from male-worker to adult worker-citizen, which includes women as worker-citizen, results in a tendency for policy to "swing between the promotion of women participation in the labour market and the support of women as carers" (p96). They note that such programs allow carers, primarily women, to add work to care. They recommend the role of Amartya Sen's Capability Approach to inform the practical tailoring of institutional support to the individual situations of women in order to practically facilitate women's negotiation of care and inclusion as adult workers-citizens. Similarly, Susan Okin, contends that whilst women have formal and legislative entitlements to engage in the public sphere, ongoing practical limitations to this engagement require more institutional support to relieve women of their obligations in the private sphere so they can practically avail themselves of opportunities in and engagement with the public sphere (Rossi 2001, Okin 2005).

From the 1980s, the term 'carer' became more narrowly applied to those providing care to dependants. Thus, from a general view that all women were oppressed and entrapped by the burden of care, came a narrower understanding of care and carers, whereby "the concept of care came to mean the support provided at home to those who were dependent as a result of illness, disability or frailty" (Fine 2007: 81).

Policy and practical improvements to general care are not realised by carers of dependants. The research on carer impact and work participation indicates that carers do not have access to the same government-supported choices available to their same-aged peers (Daly and Lewis 2000, Arksey and Glendinning 2008). The carers interviewed expressed feelings of entrapment, isolation and lost opportunities, when asked to reflect on their lives. All but two of the eleven carers interviewed talked about a sense of being apart from the rest of society, on a different path to friends, family and peers, a sense of otherness, of “living in a time bubble” [Maria].

You feel excluded from others your age and other family members, my son's physical needs mean I can't go to lots of places. Just to wake up in the morning when he is in respite, to get up, just get myself ready is luxury. When I'm sick I just have to keep on doing it, Mark's toileting, it wears you out, adds to the stress I try not to get resentful especially when down [Joan].

When asked about the choices they would have made had they not been carers, a number of carers spoke passionately about losses that affected their life-course, some becoming teary:

Stretches over a lifespan even if supported care I'd still be a carer still her advocate still overseeing emotional side and administrative side, the in between person resolving things [Catherine]; and

Impacts are different at different times in life; lately socially as others get older I can do less with other mums. Now as my other boys go out by themselves, we're at the beginning of the empty nest time but with disabled child harder to keep up friendships ... like I have to be still alert to him, like watching a toddler [Barbara].

There was a sense of longing and regret for the “what-ifs”, with all carers noting the difference between their life and the life they had envisioned for themselves and their families. A common thread for all carers was a sense of being trapped in the private sphere and unable to explore and thrive in the public sphere:

can't get away, can't have a normal day and be part of a normal community ... no one else takes that responsibility. I have a sense of mental entrapment. Even when travelling the needs of Karen takeover, supersede the needs of other siblings, I long for freedom, for a normal day and to be part of a normal community [Catherine];

There are lots of things I've missed out on,. First, you need to have time for yourself, to go out socially and not feel guilty that my son is okay. To go out and do what you want to do and they can go out and do what they want to do too. I could have travelled more, had more freedoms taken up more

sports activities. This would have involved more fitness played tennis and had more friends, I could have studied more and met new people [Anne];

When my family went overseas I stayed back here with Luke. Socially, travel, I've missed out enormously. Missed out on community can't go to meetings so absent from school and church community, affects everyone [Barbara]; and

I want the same things as everyone else: security, stability, exploring my interests. I would have been out at work full time and travelled a lot more [Carol].

As evidenced above, carers typically continue to provide care to dependants far longer than their peers as such, models that address care as a burden and care as entrapment in the private sphere, are applicable to them.

### **7.3 The ethic of care.**

Seen from the perspective of broad feminist trends, if the 1970s represented feminists requesting release from the burden of care in the private sphere, then in the 1980s, some feminists presented a uniquely feminine care paradigm, the ethic of care. This recognition was accompanied by an emerging identification and disparagement of liberal values and structures, as being male driven and oriented. As noted by Williams:

By the 1980s, the paradigm, of care as oppressed labour, shifted as feminism moved against the notion of women simply as victims and into the celebration of women's difference and a woman-centred culture (Williams 2001: 475).

The ethic of care is presented by many of its proponents as a comprehensive moral theory. Since its emergence, the ethic of care has had several iterations. Initially presented as an alternative to prevailing theories of justice, later iterations sought to broaden its scope, attempting to combine care and justice. Each phase of an ethic of care is outlined here, along with prevailing critiques, with a view to analysing whether any constitute a framework for the fair treatment of carers.

#### **7.3.1 1980s – Carol Gilligan and Nell Noddings**

The initial phase of the ethic of care emerged from an appreciation of a woman-centred culture. Carol Gilligan, an American psychologist, was one of the key initiators of the approach. Gilligan named the prevailing moral approach an 'ethic of justice', identifying

it as a male approach, and described the ethic of care as a new female moral paradigm or ethic of care:

Because women's sense of integrity appears to be entwined with an ethic of care (Gilligan 1982: 171). The [moral] dilemma itself is the same for both sexes, a conflict between integrity and care ... different perspectives are reflected in two different moral ideologies, since separation is justified by an ethic of rights while attachment is supported by an ethic of care (Gilligan 1982: 164-165).

Gilligan's ethic of care highlighted the value of a woman's feelings of responsibility and connection in caring relationships; she argued for greater recognition of care in the public sphere. Whilst Gilligan highlights a distinct female morality, she does not propose this as a superior approach to the male-based ethic of justice. She is at pains to present it as an important, new and different voice to complement that of justice, although she does not specify how or which of the two moral views would be applicable in what circumstances:

As we have listened for centuries to the voices of men and their theories of development, ... so we have come more recently to notice ... the silence of women ... Yet in the different voice of women lies the truth of an ethic of care, a tie between relationship and responsibility ... While an ethic of justice proceeds from the premise of equality – that everyone should be treated the same – an ethic of care rests on the premise of nonviolence (Gilligan 1982: 173-174).

Gilligan's work goes on to further elucidate the differences between the two moral orientations and the significance of a moral viewpoint articulated by women (Gilligan 1987). Gilligan's later discussions acknowledge that the difference in the moral approaches is not distinctly gender bound. These later works continue to emphasise that connections and relationships with others are fundamental to society (Gilligan 1995).

Gilligan's approach resonated with the 1980s' feminist view and received public and popular acclaim. As one academic noted, Gilligan's book received considerable attention and enthusiastic reviews in such disparate places as: *The New York Times Book Review*, *Contemporary Psychology* and *Vogue* (Black 1985: 549). Although some academics voiced reservations about the reliability of her research techniques, many welcomed Gilligan's wholly new presentation of a different, female value which validated the female experience and emphasised caring and responsibility towards others (Lifton 1982, Germain 1983, Black 1985, Kerber 1993).

Following Gilligan, Nell Noddings stridently argued that the ethic of care was superior to that of justice which was limited by abstract principles and rules. Her approach centred on an understanding of human connections as arising from particular loving relations. She outlines a moral behaviour, which she terms natural caring, as underlying the ethic of care, noting how this concept is intrinsic to all humans, but is more developed amongst women (Noddings 1984).

Criticisms of the Gilligan and Noddings versions of the ethic of care include that it “risks entrenching those familiar gender stereotypes which some feminists have blamed for the continuing oppression of women” (Diprose 1994: 11-12). Other criticisms (Brabeck 1993, Greeno and Maccoby 1993, Walker 1993) include that the ethic of care presumes that all women value caring, an assumption that isn’t proven, or supported by carers interviewed or carers’ evidence to the Carer Inquiry. Others note that these early versions of the ethic of care go too far, or in some cases not far enough, in attributing blame to the primarily male authority (Hankivsky 2004), whilst others express concern at the exaggerated emphasis on relationships to the detriment or exclusion of other values, such as self-fulfilment and creativity (Slote 2010). Other critiques note the lack of conceptual clarity of the ethic of care, arguing that it needs a structural framework that can be readily implemented in policy (Prakash 1984, Edwards 2009).

The most prevalent criticism concerns the separation of justice and care ethics; for example, Friedman asserts the role of justice to minimise the potential for violence or harm within relationships:

Gilligan’s interpretation of justice is far too limited ... [it doesn’t] acknowledge the potential for violence and harm in human interrelationships ... The complex reality of social life encompasses the human potential for helping, caring for, and nurturing others as well as the potential for harming, exploiting, and oppressing others. Thus, Gilligan is wrong to think that justice’s perspective completely neglects “the reality of relationships” (Friedman 1993: 267).

Many criticisms claim that the ethic of care requires justice’s rationalism to form a judgement about *how to care*. They argue that not all care is good care; some care can be harmful, or less than ideal. As explained by Allmark: “in order for an action or mental state to be morally defensible more is needed than that the mental state or action stems from care” (Allmark 1995: 23 cited in Edwards 2009: 232). To illustrate this concern, consider the case of a disabled 20-year-old who occasionally hits himself. To control the

self-harming behaviour, his mother straps her son's arms to his wheelchair for long periods. Over time, the son's arms stiffen and lose mobility, and he eventually loses the ability to hold a spoon and feed himself. In this example, whilst the carer's motivation may stem from care, her actions are harming her son in the long term. As this example illustrates, there needs to be an element of justice to judge what constitutes good care.

Justice is also seen as informing our ability to judge *who* to care for; the ethic of care permitted its actors to exercise their particular interests in determining who to care for. Some supporters noted that this very particularity is essential to the provision of informed and sensitive care (Blum 1993). In her fine-grained moral justification for particularity, Friedman asserts that a "responsiveness to the other person in their wholeness and their particularity is of singular importance. This idea ... points towards the notion of moral commitment which takes *particular persons* as its primary focus. A form of moral commitment which contrasts with this is one which involves a focus on general and abstract rules, values, or principles" (Friedman 1993).

Critics of early versions of the ethic of care object to an emphasis on particularity, asserting that whilst one may prefer to offer care on the basis of those with whom we have a personal connection with, this approach lacks an obligation for all people to treat others in a fair and impartial manner. Thus, justice should not only be applied *within* particular relationships, but also in determining *who* one must care for. According to Edwards, the inability to guarantee impartiality cemented the view that the ethic of care should clearly incorporate a role for justice in order to present a viable approach:

Impartialism is not an optional extra in approaches to ethics, but is plausibly regarded as an essential element of them ... even those very sympathetic to this first wave of care based ethics came to recognise this, and abandoned the view that an ethics of care is of a fundamentally different kind than an ethics of justice (Edwards 2009: 233).

Friedman and later care theorists, notably Kittay, advocate an approach which acknowledges the value of particularity as well as the value of justice. A critical point for this thesis is that the emphasis on on-going carer-dependant relationships in the first version of the ethic of care cannot guarantee the fair treatment of carers and needs to more explicitly incorporate justice.

### **7.3.2 1990s–2000s Broadening the ethic of care: Joan Tronto, Diemut Bubeck, Grace Clement, Michael Slote, Selma Sevenhuijsen**

In the 1990s carer theorists continued to struggle to frame a workable theory combining care and justice. Later iterations of an ethic of care sought to remove some of its gender assertions, adopt some aspects of justice, and create a full moral theory of care. As noted by Tronto in her critique of the 1980s version of the ethic of care:

Unless feminists assume responsibility for situating the ethic of care in the context of the rights/community discussions, the end result might be that caring can be used to justify positions that feminists would find unacceptable. ... feminists should no longer celebrate an ethic of care as a factor of gender difference ... they must now begin the arduous task of constructing a full theory of care (Tronto 1993: 251).

Joan Tronto's 1993 work, *Moral Boundaries*, shifted the debate about care ethics and removed the gendered association of care with women, transforming care from a focus on particular relations to a public, political morality which recognised that: "Care is both a practice and a disposition" (Tronto 1993: 104).

Tronto views care as a central element of societal function. From this perspective, society's 'boundary' on what constitutes the moral, political, public and private spheres is challenged. Tronto describes care as a: "species activity that includes everything we do to maintain, continue and repair our world so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web" (Tronto 1993: 103).

Tronto proposes four phases of care within her practice of care, together with four essential elements of care. The four phases of care are: caring about; taking care of; caregiving; and care receiving. The elements of care are attentiveness to the needs of others; an automatic responsibility to provide care to the other; competence in the provision of care; and responsiveness of the care receiver to the caregiver. Tronto argues that these four elements should be integrated into each of her four phases of care. Tronto's schema of care could best be summarised as an account of caring attitudes, which she prescribes as essential to moral citizenship.

In broadening the scope of care to a public notion of care for all and explicitly incorporating a role for justice, Tronto avoids the general criticisms that her version of an ethic of care is partial and excludes justice.

Tronto's outline of the practices and elements constituting good care has been expressed in other, similar ways in other contexts. As described by Edwards in his attempt to apply care ethics to nursing, Tronto's schema is indistinguishable from other approaches, such as the norms that apply to nurses, exhorting them to be responsible for their patients, care for their patients and care competently (2009: 237).

Furthermore, Tronto's approach depends on a liberal society inhabited by caring citizens. "She argues, in effect, that our existing liberal democracy will be more caring if people only cared more. Her proposal for translating care into political theory thus remain highly abstract, utopian, and ultimately incomplete" (Engster 2004: 118).

In many ways, Tronto's scheme is so general that it is universally applicable to all, whilst conversely obligating none. Tronto's scheme does little in the way of exploring specific care relationships and their obligations. Her later writing continues the theme that the problem of care is solved by "return[ing] to a political understanding of the interrelationship of care and justice, of needs and rights" (White and Tronto 2004: 449). Rather than being a theory of care with a framework for policy implementation, Tronto's practice of care describes an ideal citizen's attitude to care. As Tronto's scheme is so general, I suggest that it does not actually constitute a *concrete theory* but rather constitutes a *concept* of care.

Sevenhuijsen's earlier discussions echo Gilligan's schema. She advocates for the public recognition of those matters pertaining to women in the private sphere (Meehan and Sevenhuijsen 1991). Sevenhuijsen's later work continues in Tronto's vein, advocating a universalist paradigm for the ethics of care, in which care is seen as a social process engendering elements of justice within an overarching concept of public citizenship (Sevenhuijsen 1998). The public citizenship advocated by Sevenhuijsen carefully attempts to address the synthesis of the ethic of care with the ethic of justice wherein the radically counterposed concepts within both ethics are reconstructed within the practices of a democratic citizenship, proffering a concept of care-based values in viewing concepts of justice and vice versa. Although viewing care as central, Sevenhuijsen runs close to advocating an almost sympathetic, or 'caring justice', without stipulating how such caring attitudes are to be implemented.

In 1995 Diemut Bubeck drew upon Marxist categories and class analysis in her investigation of the subordination of women in the caring role. Bubeck states that the entrenched association of care with women provides a basis for women's exploitation. Bubeck argues that justice should be introduced with the carer ethic to guide the distribution of the care load. She claims that care is over personalised, a form of particularity in relationship which permits the exploitation of caregivers. She posits a solution whereby the sentimentalised reputation of unpaid family care as being superior should give way to good public caregiving institutions, which would in some cases be superior to private care and resolve the 'exploitation dilemma'. In this way Bubeck negates the centrality of particular relationships and proffers a practical solution to the exploitation of carers in the form of policy intervention and the provision of public care (Bubeck 1995a). Bubeck does not, nor does she intend to, frame a care theory. She presents a well-reasoned discussion which advocates the practical distribution of the work of care.

Grace Clement meticulously examines the viewpoint of various theorists, pointing out what justice- and care ethics, in three opposite contrasts have to offer: abstract – concrete, separate – connection, equality – maintaining relationships (Clement 1996). She explains that both justice- and care ethics contribute something of value and therefore both ethics need to be clearly distinguished and applied in the public and private spheres. Although Clement adequately explains why both the recognition and integration of justice- and care ethics is justified, she does not elucidate how her integrated vision would be constructed.

Michael Slote attempts to incorporate justice with care ethics by introducing the concept of a 'fully developed' or morally sound empathy into an ethic of care (Slote 2007). Slote advocates expanding one's empathy towards others to incorporate the ideals of justice such as respect, autonomy, social justice. Slote's morally sound empathy admits space for justice, beginning to address criticisms concerning the partiality, and consequent injustice of care ethics. Although idealistically admirable, how Slote's fully developed empathy is to be assured in all citizens is unclear. Without this assurance adequate care to those in need is not guaranteed.

Tronto recommends a concept of care for all without specifying a framework to direct policy - Bubeck's solution begins to formulate a path of addressing potential exploitation arising from ethic of care by endorsing a complementary ethic of justice.

Further development of this incorporation is required to develop a universal care theory. Clement simply does not go far enough in outlining a framework for justice and care. These further attempts to integrate ethics and care each contributed new aspects to the debate, but did not constitute a definitive theory integrating care and justice.

### **7.3.3 1990s–2000s: Virginia Held, Marion Barnes and Eva Kittay**

In the 1990s–2000s ethic-of-care theorists continued to try to combine justice and care ethics. These approaches are exemplified in three iterations: Virginia Held's approach which sought to mesh care and justice by incorporating, and subordinating, justice; Marion Barnes's approach which sought to introduce justice and an ethic of care into society's social practice within the context of the nuances of care relationships, and Eva Kittay who argues that a just approach to care is achieved via societal support of specific carer-dependant relationships. These three approaches are representative of key developments in care theory. Each is analysed below.

The American philosopher Virginia Held has been grappling with integrating care and justice since the early 1990s. In *Feminist Morality: Transforming Culture, Society, and Politics*, (1993) she explored the theoretical paradigms drawn from an idealised vision of attentive mothering, to develop an idea of a post-patriarchal family, and advocated the application of this model of care to social connections outside the family. In this way, Held sought to reduce the injustices associated with inadequate care both within and outside the family. Her subsequent work explores what a care-based moral approach could offer globally but struggles with integrating care and justice.

In 1995, Held summarised the impasse facing feminists in trying to reconcile the different bases of care and justice:

Feminist discussion has ... made clear that neither [justice nor care] can be dispensed with: both are highly important for morality ... How does the framework that structures justice, equality, rights, and liberty mesh with the network that delineates care, relatedness, and trust? (Held 1995: 128).

In distilling this critical question, Held goes on to tease out questions related to striving to mesh justice and care: as the ethic of care recognises unchosen relationships, how does this relate to justice's premise of persons as individuals? Where care is long term, what limits domination of the carer and humiliation for the care receiver? If care and justice, exist separately, how does one determine which applies to different situations?

Where the values of justice and care conflict, how is this reconciled and does either have priority?

From these initial deliberations, Held indicates her inclination towards favouring care as the more dominant framework into which justice should be incorporated: "I now think – somewhat tentatively – that care is the wider moral framework into which justice should be fitted. Care seems to me the most basic moral value" (Held 1995: 131). However, she does not outline this framework and does not consistently advocate care as having a higher priority to justice: "One possibility I've considered in the past is that justice deals with moral minimums, for moral requirements beneath which we should not sink. ... In contrast, care deals with what is above and beyond the floor of duty" (Held 1995: 131). Clearly, if justice is the floor upon which care rests, it means justice has a more foundational value upon which the ideals of care can be vested; this contradicts with Held's earlier comments that justice should nest within the framework of care. In her later book *The Ethics of Care: Personal, Political, and Global*, (2006) Held goes on to describe the key features of an ethic of care continuing to argue for its superiority as an overarching moral framework to the morality of justice espoused in Kantian and utilitarian ethics.

Held promotes a complex description of care, as an activity and practice which imbues a range of attentive and responsive characteristics and values that stem from the care relationship. Held also asserts that care is a feminist ethic that can be applied universally and therefore serve as an ethical theory. However, whilst advocating equality for women, she simultaneously, and somewhat contradictorily, regards as a moral affront the effect this would have on care relationships, and seems unable to resolve this conflict:

If women, in their justifiable quest for equality, pursue justice at the expense of care, morality will suffer. ... [if carers] ... become more and more like the free and equal, rational and unencumbered individuals of theories of justice it will leave no one to ... cultivate the ties of caring (Held 2006: 64).

Other carer theorists and feminists (Tronto, Calhoun) have criticised Held's "unfair critique". Calhoun shrewdly points out Held's internal contradiction in that her

rejection of liberal moral theory on the grounds that it necessarily depends on the mistaken conception of persons causes trouble for her own view that justice considerations can be raised within the broader framework of care.

If liberal moral theory intrinsically rests on a mistake, then it is unclear how any defence of justice considerations would be possible (Calhoun 2008: 186).

Tronto highlights Held's internal contradictions, lack of clarity, and overstated claims about the achievements of the ethics of care supplanting the need for human rights.

Toronto finds

Held's optimism about the eventual decline in the concern for human rights not entirely convincing. ... Held seems to suggest that ... the two realms [that of care and justice] may present two ways to look at the same problem, ... at other times, Held asserts that care is more fundamental (Tronto 2008: 214).

Furthermore, whilst Held is critical of the abstract, universal nature of justice theories, she does not propose a definitive alternative framework; she refers to an ethic of care's different conception of persons and consequent values as somehow comprising a framework to inform "how government should foster caring connections between persons" (Held 2006: 119).

It is difficult to see how a general and vaguely defined concept of persons, which one might stretch to defining key values, could then be extrapolated to constitute a logical universal framework, capable of directing government policy.

Held's broad-brush, utopian vision, of national and international governments imbued with ethically caring values, whilst it may be attractive, does not go much beyond an appealing idea. Without a clear framework, it is difficult to see how Held's ethic of care could be enacted in policy.

Held's work is rightly criticised for presenting a superficial comparative assessment of other theories; making claims which are not fully substantiated or explained; exhibiting internal inconsistencies; and lacking a clear, holistic and robust framework. In spite of this critique, Held's work makes a notable contribution. She both frames and courageously grapples with the critical question facing ethic-of-care theorists, namely how to mesh and incorporate the core features of the ethic of care with theories of justice, in order to inform and direct the public policy setting. In her review of Held's 2006 book, Tronto, states:

What those fuller elements of moral life will look like when described in detail is the task still ahead of us ... Held's book helps clarify the contours for the broad direction for future feminist moral theory. (Tronto 2008: 215).

Held paves the way for an interrogation of how care can be incorporated with justice within a politically applicable framework. Held succeeds in further fleshing out the core values of the ethic of care and her struggle to assert the priority of care attests to the difficulty of deriving a fair and just care theory.

Marion Barnes's ethic of care is recast as a gender-neutral-, central-social care practice on a public platform, as opposed to a private sphere activity. In her definitive book, *Caring and Social Justice* (2006), Barnes claims her social-care practice, with the correct societal recognition and support, can embody social justice.

Barnes starts, like Tronto, with a broader notion of social justice than that which relies solely on individual rights, noting that the inclusion of principles of "attentiveness, reciprocity, responsibility, competence and responsiveness [are] defined as constituting an ethic of care" (Barnes 2006: ix). Barnes deplores the artificial distinctions between care and rights, and representations of carers and dependants as separate, competing individuals. She claims this view does not reflect the interrelatedness of caring relations or the contribution of care to all in society:

Social policy ... is in danger of reinforcing the view of society as comprising isolated individuals. .... We need an approach to social justice capable of incorporating care as well as rights ... based on an understanding of the universality of human inter-relatedness (Barnes 2006: 151).

The core of Barnes's argument is an understanding of care as "an inclusive concept and practice of social justice" (Barnes 2006:144). According to Barnes, good social practice would not relieve carers of the burden of care but would support carers within the caring relationship. In this way there would be an: "explicit recognition of caring as a practice which takes place *through* relationships, rather than arising *from* relationship ... [policy would emphasise] supporting care-givers and care-receivers jointly to engage in social, political, cultural or leisure pursuits" (Barnes 2006: 176).

Barnes's analysis of UK policy finds that there is recognition of the large number of carers and the considerable saving to the taxpayer they represent. The recognition of the societal dimension of caring has led to policy casting care as a duty of citizenship where the carer is recognised as "doing work for society and for community. From the perspective of the state, family carers make an essential contribution to meeting the welfare needs of the population. One consequence of this is that caring has been expressed as a responsibility or even an obligation in welfare discourse" (Barnes 2006:

17). Barnes argues that contrary to UK policy, care receivers and carers should be counted in measures of public social citizenship.

Barnes's criticism of UK policy and society seems to stem from the public identification of care as burdensome labour, imposed on carers, to which the state provides limited relief. Barnes's solution, distilled from its idealistic language, is to recognise the relationship underpinning the practice of care, and provide adequate, tailored support for both carers and dependants within this relationship.

Barnes's book draws from her interviews with twelve carers. These interviews allowed Barnes to "drill down to" the specific and subjective experience of carers and their dependants. Barnes claimed the characteristics revealed in these interviews, particularly their subjectivity and complexity, provided evidence that particular relationships demonstrate the qualities of good care practice, a practice that only requires adequate, tailored public support, to be fair:

A feminist ethic of care offers a different way of understanding the relation between obligation, responsibility and care ... A relational ontology recognises that individuals can only exist because they are members of networks of care and responsibility ... The nature of the support they received ... from state agencies could make a significant difference to the effectiveness of that balancing act (Barnes 2006: 149).

The extent of justice incorporated into Barnes's care ethic is that carers would not be exploited provided society recognised and supported care in an integrated network of care relationships.

Whilst Barnes highlights the dangers in UK policy of carers being depicted as a dutiful resource, her whole approach assumes a continuity of the carer relationship supported by public policy. In this way, Barnes claims both carers and dependants are able to maintain their relationships without duress and hardship.

Barnes refutes abstract claims, and consequently the majority of citizenship/rights-based principles outlined in the ethics of justice, including principles of choice and autonomy, for either carers or dependants:

Finally distinction between rights and care, and those which separate care providers from care recipients, do not reflect the fluid identities and experiences of those involved in caring relationships ... we need an approach to social justice capable of incorporating care as well as rights . (Barnes 2006: 151).

Barnes's approach appeals to both sentiment and policy and reinforces care of dependants as a carer's responsibility. Barnes only indicates her dislike of rights-based justice and its consequential effect of viewing all as "isolated individuals" (Barnes 2006) without explaining further how her version of an ethic of care can incorporate "care as well as rights" and thereby guarantee justice for carers.

## **7.4 Kittay's Dependency Critique and Justice**

In a similar vein to other ethic-of-care theorists, notably Barnes, Eva Feder Kittay argues for societal support of carer-dependant relationships. She is foremost in attempting to derive a sound political theory that combines care and justice.

Although Kittay discusses care relationships as central, she rarely uses the phrase 'ethic of care', (she occasionally refers to dependency relationships as being more suited to a model of an ethic of care than an ethic of justice) and distinguishes her analysis as specifically referring to carers of dependent people (dependants). I have included her in the discussion on ethic-of-care theorists as her argument accords with many of their precepts. Kittay's discussion is particularly relevant to my question as she specifically focuses on naturally arising carer-dependant relationships, exploring in detail both the intricacies and societal implications of this relationship.

Like other ethic-of-care theorists, Kittay tries to incorporate justice with care values. Kittay focuses on John Rawls's theory of justice, highlighting how it excludes care relationships, and finally suggests that care relationships should be given a high priority in any theory, which should also incorporate justice. In undertaking such thorough analysis of Rawls's theory, Kittay seems to at least give fair appreciation of the intricacies and strengths of Rawls's concepts and his framework for the just treatment of citizens. Mirroring other care theorists, Kittay asserts the primacy of care, concluding that "principles of right and traditional notions of justice depend upon a prior and more fundamental principle and practice of care" (Kittay 1999: 108).

Finally, Kittay proposes a future direction for a new equality, based on connections and care relationships, not on individually held rights and powers, that she terms a connection-based equality. Kittay's thoroughness means she has gone further than other care theorists in truly attempting to mesh care and justice. Because of its rigorousness, depth and relevance to carers, her work is more thoroughly explored and analysed in Chapter 8.

The prevailing ethic-of-care theorists considered above, Gilligan, Noddings, Tronto, Held, Barnes and Kittay; promote the value of ongoing carer-dependant relationships. However, the carers interviewed did not enjoy such relationships. In response to the question 'would you choose to be a carer?' they responded:

Choose to be a carer? No with a capital N; loss of control of own life ... caring lasts a life span even with supported care, I'd still be a carer, still his advocate still overseeing emotional and administrative side plus being the in between person resolving things (Maria);

When I'm home with Izzy in the house, I just feel trapped, in a prison, another universe, not a normal person sometimes I have to escape to the front lawn to feel air and breathe (Sue);

(As a carer I] feel excluded from others your age and other family members can't go to lots of places (Barbara);

Mark has changed my path, not easy, very hard at the beginning. You must first have time to yourself to go out socially and not worry and not feel guilty that Mark is okay. Make sure you can go out and do what you want to do and disabled child can go out and do what they want to do and maybe I'd like to be out at work in an office in the city, sought a higher career and also studied and mixed a lot more and met different people. It's changed my life (Joan); and

Next thing has been able to enjoy my life without wondering what will happen next, as I used to, and get to be part of my daughter's life, and rediscover my husband (Anne reflecting on how life changed when her teenage dependant son moved from the family home to government funded accommodation).

Most carers interviewed considered their relationship with their dependant-disabled child as burdensome and thought they should have a choice in how to care; a sentiment echoed in the broader group of carers who made submissions to the Carers Inquiry. The burden and entrapment of care relationships must be addressed in any fair care theory. So, have ethic-of-care theorists addressed these issues to derive a fair care theory? Their success in this endeavour is discussed below.

## **7.5 Has a universal fair care theory been derived?**

Most of care theorists promote the primacy of care or government support for care relationships, whilst later theorists struggled to combine justice and care. Gilligan's original version of the ethic of care view has been critiqued and, in many ways, superseded by subsequent iterations. However, the motivations and constructs

embedded in Gilligan's approach provide a clear insight into what care theorists considered as lacking in prevailing theories of justice, and what they sought to advance.

As noted previously, the ethic of care has its origins in a branch of the feminist movement which sought to distinguish the 'female' ethic of care from the 'male' ethic of justice. In this interpretation, both justice and care are severely boxed and artificially gendered. Initially, this appears to represent a dated feminist view; the dichotomy between an ethic of care and the principle of justice could be seen as superseded, and therefore of little consequence. However, its effect appears to have had longer-term consequences.

The ensuing discourse on an ethic of care has struggled to add the values and considerations of justice as another value-set to the other values encompassed by an ethic of care. In other words, rather than commencing with a blank slate about what priorities of justice and care should figure, theorists have attempted to insert some of the values of justice, within ideals which are grounded in the ethic of care. Thus we have *some* of the values of justice (by no means all of its safeguards or values), incorporated within an ethic of care. This combination is presented without a framework and therefore cannot clearly inform situations where the values of justice and care conflict.

It seems the impetus to insist on care as always occupying the higher moral ground has continued throughout the iterations of the ethic of care. Significantly, this approach presents care values and care relationships as an alternative, usually superior, moral approach than that contained in the principles of justice. Attempts to incorporate justice and care, struggle to always maintain care relations as a higher priority to justice. Only two of the eleven carers interviewed agreed that it is morally better to prioritise care in the context of ongoing family care relationships, and these said this was because of their Muslim, religious or Chinese, cultural beliefs. Thus, in response to the question: do you think carers should have the right to decide whether to provide care? The other nine carers expressed sentiments like:

Yes! (Cristina); and

Every carer should have a right as to how and when they choose to care for their child; it's their right (Catherine).

The requirement for the ethic of care to have either an equal, or superior, priority to the ethic of justice is understandable if one looks at its origins, as representative of female

values. It would not be acceptable for an ethic of care to rank such gender-linked values as having a lesser priority than other moral values, particularly those identified, originally, as male values. The obligation to assert an equal or superior priority to care relations over other values, notably justice, has constrained the construct of a robust theory of care. A care theory which nominates those circumstances, where a higher priority of justice applies and so guarantees choice for carers (Bubeck 1995a, Edwards 2009).

Whilst later versions of the ethic of care refer to justice, they are vague as to how justice should be incorporated, and therefore do little to provide the kind of universal guarantee of fairness, which is central to justice-based theories. Without an explicit explanation of how justice and an ethic of care operate, one is left with a pleasant idea on the values of care and relationship, and hopes that justice values will somehow intervene to mitigate against any potential unfairness. This does not constitute a universal fair care theory.

Various care theorists have criticised established philosophical frameworks, particularly those relating to the ethics of justice, and, as in the case of Kittay and Bubeck, suggested how specific approaches or features of justice could be altered to better prioritise care. Held and Tronto, idealistically stated that care and justice together should operate without specifying a framework. Whilst some theorists, such as Kittay, have said that they have not attempted to proffer a comprehensive care theory, others have claimed that one is offered, but later indicated that further work is required.

A useful comparison to carer theory is the framework that applied to disabled people prior to the advent of the social model of disability. Previously, people with disabilities were viewed as being disabled by their individual impairment, and government policy focused on helping them cope and survive with their impairments (a victim-blaming view according to disability theorists and advocates). Now, under the social model of disability, society is asked to address global structures which result in the experience of impairment, and therefore impede people with disabilities from attaining full citizenship.

Society's response to carers is to address the individual impact of the care situation. Thus, research and policy focuses on alleviating the impact of the care load, and supporting carers to keep on caring; it has not examined the lifestyle of carers. This

policy response could be seen as a bizarre version of the aforementioned victim-blaming once-transferred; wherein the effect of the impairment is borne, not by the dependent person, but transferred to their carer, who then becomes a victim by dint of obligation. In this way, carers have the misfortune to be individually impaired by their obligation to care and are 'helped' to cope with their individual caring obligation, or impairment, by society. In this way, care of the most needy is addressed, whilst other citizens (including disabled people) are free to pursue their chosen life activities. For a liberal society, this double standard in relation to care is not fair.

Instead of examining lifestyle, carer choice and carer views, a sizeable portion of the research on care has focused on the public and formal world of service provision:

Much of the work on community care has focused on the views of higher status actors like policymakers, care managers, social work professionals. ... Research has also been biased ... The more service dominated an area is, the more we know about it ... in research terms... we know least about those services that are ... obscured in the private world of home (Twigg 2000: 3).

This is particularly ironic, given the policy imperative that many disabled people be cared for within the family home.

## **7.6 Disability theory, carer theory and the fair treatment of carers**

Carer identity and treatment is inextricably linked to the treatment of dependants. The theoretical and political approach to care effectively lies at the intersection of care and disability fields. For example, when disability theory recommended deinstitutionalisation and the integration of all people with disabilities in valued roles with their same-aged peers, care theory placed value on continuing care relationships and government policy instigated the closure of institutions, returning dependants to their birth families. Carers were then assumed to undertake the responsibility for providing ongoing unpaid care and support within the 'integrated' setting of the family home with only limited government support. As noted by Arksey and Glendinning (Arksey and Glendinning 2007), prevailing UK policy is based on the social model of disability with its prescriptive citizenship-based focus. Chapter 4 shows that Australian policy is also based on disability theory. Given the absence of a similar citizenship-based carer theory, and the dominance of disability theories in directing policy, the treatment of carers in disability theory is relevant.

As seen in Chapter 6, under the social model of disability, care is reduced to a commodified activity, undertaken to mitigate the experience of impairment by disabled people. This view is furthered by two factors, namely the emergence of the formal, paid service system, and disability activists who, to demonstrate their independence (as opposed to being presented as burdensome dependents in the context of a care relationship), must reduce care to a series of enabling tasks carried out by faceless care providers.

As Kroger observed:

many disability researchers have rejected the concept of care, claiming that the notion carries an understanding of disabled people as passive and dependent recipients. ... [it does not] ... promote empowerment and independent life. Disability studies, based on the social model of disability, have to a large extent abandoned the concepts of care, caring, family caregiving, informal and formal care (Kroger 2008: 1).

Both Jenny Morris and Colin Barnes rely on the commodification of care to directly oppose any notion of dependency amongst the disabled (Morris 2001, Barnes 2002).

Thus, Morris, states:

Feminist analysis in this field thus resulted in disabled and older women being excluded from the category of 'women', and classed as 'dependants', whose existence was a threat to nondisabled women's economic opportunities. ... We need to [have] ... a clear understanding about what rights disabled people have to receive practical assistance in their homes. (Morris 2001: 7-8).

Morris draws the above quotation from an article which is entitled "*Impairment and disability: constructing an ethics of care that promotes human rights*". Morris actively argues against carer recognition and rights, stating that for an ethic of care to fully respect the rights of the disabled, any notion of dependency must be removed and care must be described as purely practical assistance.

This is a narrow and specific view, which acknowledges the work or labour aspects of care and studiously ignores discussion of the intimacy of much of the "body work" involved in personal care of the disabled and the relational context in which much of it takes place. Perhaps the commodification of care work can be partially justified for some people with disabilities. However, this view ignores the reality of "what is" for many dependent disabled. For these disabled people, many aspects of their being casts

them as dependent people who rely on others, usually an obligated and specific carer, for their care.

Kroger argues that the separation of the carer and disability research fields is illogical and detrimental as the two research strengths are often complementary, have much to offer each other, and would benefit both their respective constituencies. As disability discussion excludes consideration of carers' views, how does it encompass the different needs of dependent disabled people, given that most dependants rely on carers for both support and representation?

Apart from the commodification of care, Chapter 6 demonstrated disability theory's denial of the different needs of intellectually disabled people from mainstream physically disabled people. This denial meant that alternative, more efficient service structures that suit intellectually disabled people are not countenanced, which in turn means the cost of supporting intellectually disabled people is prohibitive and practically reduces choices for carers to relinquish their role as an integrated support setting.

In terms of care theory, both the care-as-burden- and the ethic-of-care approaches identify carers via their relation with dependants, albeit from opposing viewpoints. This consequently influences the recognition and treatment of carers in society. The ethic-of-care approach assumes carers wish to continue to support dependants, within the context of a supportive society, whilst the care-as-burden approach casts all care relationships as burdensome, and seeks their termination. Neither approach views the carer as a citizen, entitled to citizens' choices – choices which would include an option on how to interpret their relationship with dependants.

The care-as-burden approach appeared to have greater currency at the time when it was assumed that women, as primary carers, wanted the same position in the public sphere as men. This certainty around women's aspirations has softened as the recognition of what has been identified as particularly women's characteristics and strengths has grown in the ethic-of-care branch of feminist discussion. This, together with some legislative and practical support, increasingly allowed women to access the opportunities of the public sphere. With these shifts, the care-as-burden approach has been largely discarded by care theorists, although elements of this approach are still echoed in research on the negative impact experienced by carers and policies focusing on how government services can reduce the impact of this burden.

As the WPR analysis in Chapters 3, 4 and 5 shows, government policy and services are directly led by disability theory which is written in a prescriptive and universal manner. This is evidenced in the analysis provided by Arksey and Glendenning, which found that UK government policy was primarily led by the social model of disability with a concurrent absence of focus on the lifestyle choices of carers:

Written from the social model of disability perspective... proposing that people with disabilities should be supported to realize their full potential ...whilst the current policy proposals emphasis of choice for users of welfare services, they have far less to say about choice in relation to informal carers. Indeed, informal carers – who provide by far the greatest volume of social care and support, are relatively invisible comparison to disabled, ill or elderly people. (Arksey and Glendenning 2007: 166-7).

Most carers interviewed viewed their obligation to care as a burden which entrapped them in the private sphere. These sentiments echo earlier feminist views of care as a burden and restriction from the lifestyle and opportunities of the public sphere. These earlier feminist discussions have not been developed into a theory addressing the fair treatment of carers, whilst the concept of the burden of care has been largely lost in ethic of care discussions.

The ethic-of-care concept is not framed to enable direct implementation in the policy arena. Sheila Neysmith remarked on the way the "ethic of care had been conducted in highly theoretical terms ... quite separate from, or even relevant to, the real-life politics involved in the restructuring of care work" (Neysmith 2000: 7).

In their critique of care research, Dow and McDonald suggest that in order to address positive social change and social justice issues, care research should be informed by critical theories which offer a deeper structural analysis; researchers "must further develop their own critical research orientations and methodology, informed by explicit theoretical perspectives. This research knowledge should be used to promote social justice and social change" (Dow and McDonald 2003 : 207).

I follow Neysmith and Dow and McDonald and propose that existing care discussion does not address fair treatment of carers and lacks an explicitly prescribed focus and framework to direct policy. Ethic-of-care theorists have struggled to mesh justice and care values within a clear framework. Without achieving this, the ethic of care does not

constitute a theory that can instruct policy on the fair treatment of carers. As Chapters 3, 4 and 5's policy analysis show, the critical silence on carer treatment and the absence of any problematisation on carer entrapment has allowed the problematisations of disability theory, which ignores carer treatment, to prevail in policy and legislation. This has permitted carers to be commodified to a resource, an assumed support for dependants, not persons with entitlements in their own right.

As noted in Chapter 1, the carer interviews set out to address the dearth in research on carer lifestyle. In these interviews most carers expressed regret and longing at missing out on a career, and all the benefits of advancing in a career, including financial losses and being out and a part of the wider world. All carers expressed regret at their lost opportunities to develop their sense of self-including their identity, self-development and self-satisfaction:

I 'd have liked to work full-time and contribute to society being active and continuing to work in my [x-high status]<sup>23</sup> profession. I'd have a career path and a sense of personal achievement and I'd be more involved in the community not just the politics of disability, but politics and much fitter [Catherine];

I would've had a different career path, worked longer hours, done further studies to pursue my career [Cristina];

I'm the only one of my uni-friends who had to work part-time; I'm grades behind all of them, all the rest are managers and directors. I would've had a different career path, at Uni I blitzed it, I'm frustrated, I work way below my ability (Sue); and

I would have gone out to work and sought a higher career and also studied would have had more money be more socially happy I would mix with many more people and make many more friends [Maria].

Most carers noted that their lives had different financial outcomes because of their restriction to the private sphere, particularly financial outcomes:

dollar wise, without caring, we would be better off, it's a huge disadvantage, I've only worked part-time my husband left job in x-industry to work from home so he

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<sup>23</sup> The identification of professions has been removed from all carer quotes to protect privacy.

could help with Mark we've both had a lot of time off work. We're nearing retirement and can't afford to retire [Joan].

I had to say no when my office offered to put me through an MBA. Big career loss. I had to or our family would've imploded with the stress of caring for Sarah (Steve).

Some remarked on their lifestyle and financial losses in apparently practised wry and mocking terms: "It's lucky that I can't go on holidays because I wouldn't have the money to anyway" [Luk].

All carers interviewed expressed a deep sense of regret about losses that they experienced for many years, over their adult life-course. Only two of the eleven carers interviewed felt these losses were justified. As noted previously, these two based their views on their religious and/or cultural beliefs. Two, who had been carers for over 20 years, said they had missed many "normal" experiences all their lives and it seemed that now this loss would continue into their retirement: "there's no retirement for us, I'd have liked to have travelled, we're doing more caring now as Mark deteriorates" [Joan].

The injustice of the existing framework is borne in the lives of carers. All carers interviewed commented on the ongoing acute lifestyle losses, recounting the various opportunities and experiences they had missed, the acute perception of difference from their peers and being unable to participate in the public sphere. These comments signified that most carers felt entrapped by their care obligations in the private sphere. Any care theory should incorporate justice to address carer entrapment and isolation from opportunities in the public sphere.

Ethic-of-care theorists argue that care should be acknowledged in public policy and resources, and support for care relationships should be ensconced in our service system. These general notions of care do not begin to comprise a theory capable of addressing just and fair carer treatment. As shown in Chapter 6, disability activists would not be satisfied with such a general helpful/charitable model of support. Various ethic-of-care theory iterations have been developed and critiqued by other researchers. It is curious then, that in identifying the flaws of other approaches, and highlighting what is needed, these theorists have not identified carers as entrapped and presented a

robust alternative care theory to address this injustice in a clearly outlined framework.<sup>24</sup>

Care and the caring relationship are often discussed in the widest terms encompassing many care situations. A universal care theory has not yet been derived, in spite of substantial research on the nature and impact of care, and attempts to derive a theory of care which incorporates the ethics of justice. The discussion by Eva Kittay (1999) on the dependency critique, provides a way of exploring the values of an ethic of care which can be applied to the specific situation of carers of dependants and be extended to encompass other care situations. Whilst Kittay has not presented herself as the proponent of the ethic of care, nonetheless the dependency critique promotes the centrality of the carer–dependant relationship and provides an insight as to how such a version of the ethic of care, focused on this relationship, could begin to incorporate justice.

Kittay's holistic analysis of carer–dependant relationships distinguishes her as a key proponent of a care-prioritised approach. As noted, several care theorists have attempted to mesh or resolve the values of justice and care. However Kittay has most thoroughly attempted to derive a logical premise to incorporate both care and justice. Kittay's seminal 1999 book *Love's Labor*, begins to outline the parameters of a theory of dependency-based equality. As noted by Tronto, in her review of this book "as Kittay has admitted, her project is not complete; the [Kittay's dependency] critique is more developed than the constructive alternative. Nevertheless, this book points to a much bolder philosophical project" (Tronto 2002: 1192).

Carer discussion, from the analysis of international socio-economic trends, to policy, legislation, research and theory, focuses on the activity of care, mitigating the impact of care, and valuing the relationship of care. It does not focus on the fair and just treatment of carers. Care theory has failed to incorporate justice with an ethic of care.

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<sup>24</sup> It is marked that even later iterations of an ethic of care, which claimed to have melded care and justice, are criticised for their lack of framework, being based around ill-defined values, and vaguely worded (Bubeck 1995, Tronto 2008, Edwards 2009).

What is required is just such a 'bold philosophical project' (Tronto 2002: 1192), a new fair care theory that recognises care relationships, incorporates justice's ideals of autonomy, choice and rights and can inform both research and policy. This is attempted in the following chapter.

# Chapter 8 – Deriving a fair care theory for public policy.

## 8.1. Introduction

This chapter attempts the “bold philosophical project” referred to by Tronto in Chapter 7, and will derive a new fair care theory that combines care and justice. I note that the policy analysis of the Carer Inquiry in Chapter 5 and the carer interviews demonstrate that the obligation to care can extend for several decades, even a lifetime, and entraps carers, limiting their liberty and opportunity. The policy analysis in Chapters 3, 4 and 5, finds that government policy problematises how to ensure ongoing familial care and presumes family carers will provide care to dependent family members in their homes, rather than funding institutional care to address the unjust entrapment of carers. Following Thomas Nagel’s premise that justice is practically realised by institutions administered within nation states (Nagel 2005), this suggests that justice is not practically realised for carers.

To derive a new fair care theory, which can be practically administered by government, this chapter analyses what constitutes the fair treatment of carers by exploring the underpinning philosophical approaches relating to care and the just treatment of citizens. It compares John Rawls’s liberal approach with the ethic-of-care approach, specified by Eva Kittay.

Kittay’s approach advocates government support for carers to provide care as part of an ongoing relationship. Rawls’s theory of justice<sup>25</sup> constructs a framework for the ideal and fair treatment of citizens. Rawls’s theory holds that citizens should first be guaranteed their fair share of liberty and opportunity, prior to their obligations to

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<sup>25</sup> I use the outline of Rawls’s principles and the elucidation of some aspects of his theory from *Justice as fairness : a restatement* (Rawls 2003) whilst Rawls’s key concepts are drawn from *Political Liberalism*, (New York: Columbia University Press, 2005).

others. This chapter compares both approaches and argues that Rawls's theory forms the ideal framework for a new fair care theory that addresses carer entrapment.

The political response to known carer impact is expedient. Rather than address carer entrapment by providing alternatives to family care, governments emphasise the carer-dependant relationship, seeking to facilitate its continuation. The policy analysis notes the presumption of on-going familial care; this presumption is consistent across Western societies. Neysmith reviews care policy in Europe, North America and Canada and observes that the policy response to known carer impact is not impartial and analytical. Instead, Neysmith notes, policy adopts normative familial and moral values:

Today, when people talk about long-term care they are referring to care provided within a person's home. Across countries, financial pressures driving the restructuring of long-term care have resulted in institutionally-based care being minimally available, while homecare has expanded ... raising questions about the ethical underpinnings of home-care policies (Evans, Baines et al. 1998: 234-235).

Changes in institutional frameworks have resulted in increased familial care obligations. Such obligations conveniently reduce the socio-economic responsibilities of government and sidestep the issue of what constitutes a fair approach to carers. Effectively, the carer's life operates as a parody of a familial paradigm, where the primacy of sustained relational obligations takes precedence over individual liberty.

Public policy emphasises familial obligations on carers to support dependants, and does not allow carers to choose whether to undertake this obligation. The critical issue is that particular carers are obliged to undertake the responsibility for the care of particular dependants (to whom they are related) and are unable to remove this obligation. I argue that, notwithstanding the level of government support, unless carers choose to care, such an immutable obligation amounts to carer coercion.<sup>26</sup> The injustice of carer coercion warrants a new, holistic and grounded approach: a new fair care theory.

As shown in Chapter 7, care theorists stress the importance of carer activity, address care of dependants, or remark on the severity of carer impact, but none discusses the

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<sup>26</sup> I am following Kittay's use of 'coercive' to mean an obligation to serve another, in which the extreme form of coercion is the condition of the slave.

fair treatment of carers. I have focused on Kittay's critique because, as noted in Chapter 7, of all the care critiques, it is the most developed in attempting to incorporate justice and it most closely reflects the premise of government policy in Western democracies which emphasises ongoing care provided by family carers. Thus, in examining whether Kittay is right, I also examine whether the premise of government policy is fair. Rawls's work and his theory of justice are selected because it addresses the just treatment of citizens and because it represents, as Kittay maintains "one of the most powerful and cogent theories of a liberal, democratic egalitarianism" (Kittay 1999: 75).

Kittay argues that Rawls's theory excludes dependency concerns and should be reoriented to centralise relationships. Kittay proposes a number of positive features around care relationships, but in prioritizing carers' ties and obligations to dependants, she permits carer coercion. Rawls's theory of justice prioritises liberty and opportunity prior to obligations to others and thus prevents coercion. I argue that the injustice of carer coercion provides a moral warrant to use Rawls's theory, as it offers a legitimate basis on which to form a new approach to carers. I then show that with limited and careful alterations, Rawls's framework can be used to derive a new fair care theory. Some of the concepts and features of Kittay's critique, particularly her model of positive carer-dependant relationships, can be incorporated within the framework of a Rawlsian-based fair care theory. This new fair care theory can inform fair care policy and institutional arrangements to secure the just treatment of carers.

Kittay's critique proposes to alter Rawls's concepts and theory. Therefore, to explore Kittay's critique I must first outline Rawls's key concepts.

## **8.2. Rawls's theory of justice and the primacy of liberty.**

Rawls's theory centres on two principles of justice which should be understood in the context of Rawls's explanation of key features and preconditions. Rawls's principles are framed to direct the basic structure of society as constituted by its major social institutions (Follesdal 2011). These principles, originally outlined in 1971 (Rawls 1971), were revised in 2001 as follows:

- (a) Each person has the same infeasible claim to a fully adequate scheme of equal basic liberties, which scheme is compatible with the same scheme of liberties for all; and

(b) Social and economic inequalities are to satisfy two conditions: first, they are to be attached to positions and offices open to all under conditions of fair equality of opportunity; and second, they are to be to the greatest benefit of the least advantaged members of society (The difference principle) (Rawls 2003: 42).

Rawls ascribed a strict lexical order to his principles. He stresses that the first principle (a) must be entirely fulfilled and never compromised in the achievement of the second principle (b). Further, in the second principle, fair equality of opportunity has priority over the difference principle.

In order to appreciate the potential of Rawls's scheme to liberate entrapped carers, it is important to recognise that Rawls begins with a conception of persons as free and equal citizens and to understand his conception of equal basic liberties. In 2001 Rawls further elaborated on the scope of what constitutes the equal basic liberties as encompassing multiple positive liberties,<sup>27</sup> specifying those liberties which citizens have the freedom to exercise. These liberties include the rights and liberties covered by the rule of law (Rawls 2003: 45) and encompass: freedom of thought and liberty of conscience, political liberties (for example the right to vote), as well as the rights and liberties specified by the liberty and integrity (physical and psychological) of the person. Rawls states that his broader concept of basic liberties enables citizens, collectively and individually, to exercise powers to pursue their conception of the good, such that this conception is manifest in just institutions, in policies and in their own lives. Thus, Rawls has a conception of liberty that goes beyond political liberty, and can contribute significantly to the discussion on what constitutes the fair treatment of entrapped carers. Hereafter I will employ Rawls's broad conception of liberty.

Rawls emphasises the pre-eminence of the first principle, in guaranteeing equal basic liberties. If his theory were adopted it would direct the basic structure, and form the underlying premise achieved via a constitution or similar "constituent power ... (which) is to be suitably institutionalized in the form of a regime" (Rawls 2003: 146). By giving

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<sup>27</sup> Rawls notes in *A theory of justice*, 1971, that this broad conception of liberties may be obscured by "the use of the singular term 'basic liberty' in a statement of the principle in *Theory*" (Rawls 2003: 44). It is possible that a misunderstanding of Rawls's broad conception of liberties has limited an appreciation of the potential of Rawls's theory to care.

the first principle priority, the fundamental character of the basic rights and liberties and the fundamental interests they protect are assured.

The priority afforded to the first principle means that the second principle then operates within the framework of institutions which fulfill the requirements of the first principle. Rawls is at pains to emphasise that the basic rights and liberties addressed by the first principle should not be compromised to attain increased social and economic advantages to society as a whole (2003: 47). In this way Rawls provides an alternative approach to the then prevailing utilitarian theory which justified the sacrifice or 'utility' of treating some individuals or sub-groups as a resource if this benefited society as a whole.

Within the second principle, Rawls requires that background institutions should secure fair equality of opportunity. Within this framework, the difference principle governs the distribution of resources, according greatest benefit to the least advantaged. The difference principle is a construct which motivates, via social and economic rewards, those with greater natural advantages and abilities to pursue those occupations fitted to their abilities, particularly where this pursuit results in cumulative benefit to (primarily) the least advantaged members of society.

Rawls's principles of justice enable a fair political framework which gives citizens a "confidence in their future, and a sense of being treated fairly in view of the public principles which are seen as effectively regulating economic and social inequalities" (Rawls 2003: 57). Within this fair political and institutional framework, Rawls then introduces the concept of 'the good'. Rawls defines his notion of primary goods as "things citizens need as free and equal persons, and claims to these goods are counted as appropriate claims" (Rawls 2005: 180). The primary goods form both a public understanding of the kinds of claims that citizens can make, as well as an explanation of how these claims would be supported. Rawls's five categories of primary goods can be summarised as:

The basic rights and liberties

Freedom of movement, free choice of occupation and diverse opportunities

Powers and prerogatives of offices and positions of authority and responsibility

Income and wealth

The social basis of self-respect (Rawls 2003: 58-59).

Rawls envisaged that the primary goods constitute both an entitlement and a limit on what it is reasonable for citizens to claim from public institutions. Particular specification or addition of goods could be outlined, as required: "Rather, a more specific index defines for more concrete cases what are to count as citizens' needs, allowing as necessary for the variations" (Rawls 2005: 188). Rawls's anticipated variations of his primary goods to cater to specific cases permits an extension to allow them to apply explicitly to care, provided such an extension can be justified within Rawls's core conceptions.

### **8.3. Kittay's dependency critique, centralising care relationships.**

In her seminal 1999 work *Love's Labour: Essays on Women, Equality and Dependency* (Kittay 1999), Kittay says she first began by attempting to formulate a new theory of equality that embraces dependency, and she discovered that "there was too much work to be done in simply clearing the ground. So this book is but a propaedeutic to some future theory of equality" (Kittay 1999: xii).

Kittay begins with a conception of society as comprising persons in relationship. She refers to relationships between carers and dependants as "dependency relationships". Kittay argues that dependency relationships form the foundation of an alternative theory, which prioritises a connection-based equality sustained by government support. The core of Kittay's societal restructuring is based on a model that she describes as 'doulia'. The model consists of a series of nested relationships, with the relationship between carers and dependants receiving societal support via a sensitive network of encircling relationships. Kittay's connection-based equality relies on the ongoing continuation of care relationships. For Kittay, dependants are those with severe disability or long-term illness and carers are those who are relationally tied to care for them.

Kittay says society has a responsibility to care: "we think it reasonable and right humans care for those in a weakened or impaired condition. Thus it is reasonable to expect that a well ordered society is one that attends to the needs of dependants" (Kittay 1999: 104).

Kittay's insights on the carer-dependant relationship are both extensive and profound she notes: On the nature of care - care work is of a unique, non-fungible nature, necessitating an obligation to always act in the other's best interests. Long-term

dependants require sustained periods of care, and will rarely reciprocate this care. Thus, carer-dependant relationships are uniquely asymmetrical and out of the “natural order” (Kittay 1999: 165). The extreme needs of dependants in all aspects of life results in a dependant’s needs having a higher priority claim than the needs of the carer, claims which are of an “overbearing nature” (Kittay 1999: 52). On the carer’s internal conflict – that carers must remain sensitive to dependant’s claims, even when their own needs conflict with that of their dependants: “The interest of the dependency worker remains attached to that of the charge, even as it exists in tension with that of the charge” (Kittay 1999: 41). Further, carer obligations are usually not voluntarily assumed and are hidden as “the atomistic character of contemporary society makes dependency work especially invisible” (Kittay 1999: 40).

Apart from the expected direct effects of care labour and emotional obligation, Kittay also identifies two socio-structural impacts. Firstly, she identifies that carers experience a derived dependency as their care obligations amount to systemic exploitation:

Dependency ... has a crucial bearing on the ordering of social institutions ... the occlusion of dependency ... make[s] our obligations to those in need of care part of the system of exploitation, one which diminishes the moral worth of the caregiver as well as the person cared for. A society in which such a system of exploitation is the norm cannot be said to be a society in which equality, as both a moral and social value, thrives (Kittay 1999: 28).

Secondly, Kittay recognises that care obligations place carers in an unequal position compared with independent free citizens. Carers’ obligations to dependants hinder them from availing themselves of society’s goods, particularly work opportunities, because the energy required for entrance and performance in the public competitive arena is instead “channelled into the preservation and promotion of another ... [making it less] ... possible for the dependency worker to enter as an equal” (Kittay 1999: 46-48), which makes carers economically dependent on a paternalistic state.

Kittay features Rawls’s theory because it provides “a comprehensive systematic social and political theory ... [which addresses the] ... welfare of women and others that have been excluded from the political domain” (Kittay 1999: 77). However, Kittay seeks to alter Rawls’s theory because, “for all of its comprehensiveness and power ...[it]... fails to attend to the fact of human dependency and the consequences of this dependency on social organization” (Kittay 1999: 76).

Kittay systematically builds the case that liberal political theory, as exemplified by Rawls, has ignored the importance of care and dependency. Kittay's key criticism is that Rawls regards persons as free, and ignores dependency, relegating it to the private sphere where it is not seen or considered a public concern. Kittay argues that Rawls, in neglecting dependency, ignores carer-dependant relationships and carers. Kittay proposes that the derived dependencies of carers and their consequent exploitation are best addressed by caring for both parties who comprise the carer-dependant relational unit.

She claims the recognition of persons in relationship would form the "basis of a *connection-based* equality rather than an *individual-based* equality" (Kittay 1999: 28). Kittay goes on to argue that Rawls's elemental concepts should be altered to include dependency concerns, as these areas constitute the "most fundamental presuppositions for the conception of equality and justice evoked in Rawls's scheme" (Kittay 1999: 83). Kittay's key conceptual alterations include a conception of society as comprising persons in relationship and including dependency in the circumstances of justice and in conceptions of the good. Kittay proposes that her concept of *doulia* replaces the reciprocal arrangements employed in Rawls's theory. This goes further than other theorists who apply Rawls to the private sphere.<sup>28</sup>

Kittay justifies this societal reordering on the grounds of moral fairness, noting that activity in the public sphere is "dependent on women's care of the inevitable human dependency" (Kittay 1999: 184) observing that:

The claim on third parties to support and help sustain the dependency relationship ... is realised in the public obligation to recognise caregiving within the arrangements of social cooperation through the principle of *doulia* ... Its basis is the undertaking of care, and responsibility for care, and the dependency to which the caregiver then becomes vulnerable (Kittay 1999: 140).

Kittay re-titles Rawls's concept of 'primary goods' as 'social goods' and argues that the 'goods' of dependency and care-relationship should be included to truly enable carers to

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<sup>28</sup> For descriptions of how others apply Rawls to the private sphere see Neufeld (2009) and Okin (2005).

realise the entitlements of full citizenship. She then discusses the benefits and logic of including care as a social good, discussing how this might translate into demands in policy. Finally, Kittay proposes an amendment to Rawls's first principle of justice to include dependency relations, and adds an additional principle:

The principle of social responsibility for care would read something like: to each according to his or her need for care, and from each according to his or her capacity for care, and such support from social institutions is to make available resources and opportunities to those providing care, so that all will be adequately attended in relations that are sustaining (Kittay 1999: 113) .

In order to address dependency relationships, Kittay proposes substantial changes to Rawls's theory at all levels. At a conceptual level, she suggests areas in which Rawls's elemental concepts and consequent theory are flawed, arguing that Rawls's theory should be structured to a connection-based equality. At a functional level, Kittay outlines a new principle of care that centralises carer-dependant relationships and her *doulia* model of societal support. These changes represent a substantial reorientation of Rawls's theory and undermine Rawls's core concepts.

#### **8.4. An analysis of Kittay's argument.**

Kittay's structural placement of dependency, specifically carer-dependant relationships, at the centre of society, jostles uncomfortably alongside Rawls's principles. Rawls ranks citizens' liberty and opportunity higher than the care of the least advantaged. Both approaches are problematic in terms of forming a fair care theory. This section will analyse Kittay's approach followed by an analysis of Rawls's approach. As noted previously, Kittay states that she is not presenting a comprehensive new theory. This allows Kittay to make the claim that her 'care elements' and alternative principle should be employed to reorient Rawls's theory, without stipulating how it should be reoriented. It is therefore worthwhile to assess whether Kittay's proposal is sound and robust enough to form the framework of a new fair care theory.

Kittay consistently refers to the provision of care within a relational context. She presents the *doulia* model as representing her prioritizing of carer-dependant relationships, both ideologically and institutionally:

A political theory must attend to the well-being of dependants *and* caregivers, and also to the *relation* of caregiver and dependant ... A

principle of care<sup>29</sup>, then, must hold that: In order to grow, flourish, and survive residual illness, disability and frailty, each individual requires a caring relationship with significant others who hold that individual's well-being as the primary responsibility and a primary good (1999: 108).

Kittay's principle of care raises the question of who constitutes the parties to such a relationship. When Kittay refers to caregivers, she is talking about "significant others" who provide care in a relational context. Within Western society, the majority of long-term dependant relationships involve the familial, usually parental, carers of dependent offspring. Such care and responsibility can apply for decades, extending to the length of the dependant's or carer's life. Kittay's model assumes long-term relational obligations that are rarely voluntarily assumed. The relationship between family carers and dependants closely resembles the *doulia* model.

In instances where carers perceive the relationship and its concurrent obligations and impacts, as so limiting that they want to reduce responsibility or sever the relationship does the *doulia* model allow this? This raises issues of coercion on carers to continue in non-fungible relationships with dependants. If carers are unable to exercise choice in whether to continue in relations of care, this means carers who prefer to relinquish care are coerced.

According to Kittay's principle of care, the care relationship must operate within the capacity of the carer and provide relations that are *sustaining*. Kittay argues that the *doulia* model ensures that public institutions should provide sufficient support to make it sustaining. It is valuable to explore what Kittay means by 'sustaining'. Presumably, she means that such relations should not just enable survival but be mutually positive. However, Kittay does not address the non-voluntary nature of the relationship, which may mean the relationship is *unsustaining* for carers.

In prioritizing care relationships and outlining an additional principle of social responsibility, Kittay notes that she sees "no natural way of converting [her] principle to

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<sup>29</sup> Kittay substitutes the phrase the 'principle of doulia', with 'principle of care'. In her later discussions, she refers to the need for a principle of justice which is "a principle of doulia for a caring that is justly compensated, and a justice that is caring" (Kittay 2001p. 573).

either of Rawls's two principles of justice" (Kittay 1999: 113). Kittay argues against Rawls's prioritizing of equal basic liberty. She claims that a higher priority holds for carer-dependant relationships and ascribes her social care principle the highest priority. In doing so, she does not explain how Rawls's liberty is to be exercised or prioritised.

Kittay's conceptions and prioritizations disturb the core conception and lexical ordering of Rawls's principles wherein Principle 1, guaranteeing liberty, must be fulfilled before Principle 2, which includes consideration of the least advantaged. Kittay positions the practice of care as prior to principles of right, to achieve a connection-based equality rather than a rights-based equality. Such a proposal potentially entraps carers and effectively negates Rawls's first principle of equal liberty for citizens. Kittay acknowledges the relevance of Rawls's first principle in protecting equal liberties for all citizens, including carers, but dismisses it as being of little relevance to achieving egalitarian outcomes for *dependency*:

The first principle, the principle of equal liberties, is irrelevant to our concerns, although dependency concerns introduce a worry that those who do dependency work will not be guaranteed their fair value of political liberties (Kittay 1999: 110).

Kittay mentions carer capacity and sustaining but does not mention carer choice. Some carers may have the capacity to provide care but not be willing to care. Kittay expresses concern that carers could potentially be coerced to remain in relationships with dependants, but does not address this issue. The potentially coercive nature of the *doulia* relationship raises significant concerns with Kittay's approach achieving fair treatment for carers and is discussed in the next section.

Kittay herself recognises the injustice of carer entrapment and the limiting of carer choice, which she refers to as coercion in which the "extreme of coercion is the experience of the slave" (Kittay 1999: 71). She notes that such coercion is morally unwarranted, as all, including carers, are entitled to consideration. However, simply stating that coercion and entrapment is unwarranted is no guarantee of carers' freedom from such coercion. Kittay's argument that dependency relations should be central to, and supported by, society fails to address the entrapment of carers in relationships. Is the cage of relational obligations less coercive and entrapping for being gilded by

societal support? The following section discusses Kittay and the problem of carer coercion.

## **8.5 Kittay and the problem of coercion.**

In distinguishing her model from Goodin's vulnerability model and Thompson's voluntaristic model, Kittay argues that coercion in her carer-dependant centred connection-based equality is avoided. This reasoning is critical because, if Kittay's argument is sound and universally applicable, then it presents a genuine argument for a relationship-based theory.

Robert Goodin's work, *Protecting the Vulnerable* (Goodin 1985), contextualises the notion of care, not as a relationship between specific carers and dependants, but as a range of special and general obligations. He describes a vulnerability model in which obligations arise from the vulnerability of one party to the actions of another, with the one in a position to meet the other's needs having a moral obligation to do so. Kittay refers to such obligations as "vulnerability-responsive obligations". According to Goodin, a "pragmatic ought" stays attached to the vulnerabilities, no matter how they arise, until they are discharged or redefined. Goodin's argument supports the notion that those who are better placed have an obligation to support the vulnerable. Such support can be provided either directly or indirectly (via taxation), and does not narrow care obligations to particular carers. Rather, Goodin's model distributes the responsibility more widely to all people whose actions could assist the vulnerable.

Kittay claims that Goodin's 'pragmatic ought' can oblige citizens in unjust allocation of responsibilities and can result in coercive obligations:

If Goodin insists on the pragmatic ought, so that an unjust allocation of responsibilities nevertheless obliges us, then he must agree that it can do so even in the face of coercive conditions (Kittay 1999: 59).

Kittay argues that Goodin's 'pragmatic ought' is too coercive and claims that because her responsibilities are limited to how they arose, her responsibilities avoid the coercive conditions of Goodin's 'pragmatic ought':

In arguing against Goodin's pragmatic ought, we needed to evoke a conception of justice - a justice that pertains to how 'the existing allocation of responsibilities itself' came to be (Kittay 1999: 63).

Kittay notes that the voluntaristic model is proffered as an answer to coercive obligation. She discusses Judith Jarvis Thomson's (Thomson 1971) reasoning to explore this model. Thomson's case of the dependent violinist is drawn as an analogy of the rights of women to voluntarily choose abortion. In Thomson's analogy, a famous violinist has fatal kidney disease, and Thompson asks you to imagine that you have been kidnapped and, without your consent, the violinist's circulatory system is attached to yours in order to sustain his life. Thomson's argument is that you can refuse the obligation to sustain the violinist's life. That it is not unjust to refuse an obligation to another, in spite of their complete dependence, if the obligation is not undertaken voluntarily. Kittay admits the appeal of voluntarism but dismisses its universal application: "a previous relationship between ... two persons can alter [the intuitive appeal]" (Kittay 1999: 61).

Kittay surmises that Goodin's obligations may be coercive, whilst the voluntaristic model does not adequately recognise right-obligations:

Contrary to Goodin, then, our intuition about whose needs we have obligations to respond to, partly depends on how or why we find ourselves in the position to meet the needs. Contrary to the voluntarist, however, voluntarily undertaken obligations are not the only source of obligations in relationships (Kittay 1999: 61).

Kittay suggests that one should put aside the premise of contract theory's reciprocal arrangements comprised of individuals, equally situated, who voluntarily assume an association. Instead, she states that one should first begin with persons connected in relations of dependency, as "there is a sufficiently large class of such responsibilities and obligations. These non-coerced yet not voluntarily chosen associations fill our lives ... therefore whether or not the relationship is voluntary fails to play a vital role in establishing moral obligations" Kittay (1999: 62, 73). Thus, Kittay argues, dependency relations rank before other associations.

Kittay's solution to coercive obligation, without admitting a moral warrant to voluntarism, is to recognise a social order that begins with relationships of dependency:

The prescription against coercion and domination inheres in a moral vision that begins with relationships no less than one that begins with individuals. We can have a vulnerability model without giving a moral warrant to coercive allocation of responsibilities ... without Goodin's pragmatic ought (Kittay 1999: 73).

Kittay asserts that her obligations are moral, as, unlike Goodin's 'pragmatic ought' obligations, they arose from a prior relationship. Kittay's later work continues to feature the *doulia* model, further describing it as social network of responsibility of care, which forms an "Infinite spiral of relationships ... call[ing] for a collective, social responsibility for care, but one that doesn't dilute relationships between dependant and caregiver" (Kittay 2001: 536).

Kittay's solution has its appeal in terms of the value placed on relationships and the presentation of an alternative connection-based society. However, the question remains as to whether Kittay has adequately dealt with the coercion problem she criticised in Goodin's 'pragmatic ought'.

I contend that both Goodin and Kittay seek to limit coercion, just in different ways. Goodin limits coercion by the degree of obligation; whilst Kittay limits coercion by the way the obligation arose. It seems that whilst each of these approaches limits coercion, they do not guarantee its absence. Kittay has discussed Goodin's coercion problem, but what of her own? What is needed is an analogy of dependency that begins with relationship. Following in the vein of Thomson's violinist, I offer one here:

A cycling athlete and world-renowned motivational speaker and her 12-year-old child are both rendered unconscious following a plane crash. The athlete, though unconscious, will recover fully, but the child is critically injured and severely brain-damaged. To sustain the child's life, whilst both are unconscious, surgeons connect the athlete's body to the child's as a long-term life support system. The otherwise healthy parent is now permanently linked to the child and unable to continue her former athletic- and speaking career. Both are supported within caring institutional structures.

Presumably, under Kittay's reasoning, the prior non-voluntary relationship between parent and child presents a valid moral warrant, which obligates the parent to remain connected to the dependent child. Kittay's later comments show she continues to prioritise the maintenance of relational ties over choice; she refers to the "severing of valued connections ... [as a] ... moral harm understood to be less a matter of violation of rights and more the consequences of failures of responsibility and responsiveness" (Kittay 2011: 53). However much sympathy one feels towards both child and parent, and regardless of the acute dependence of the child, the parent is still coerced. However

fundamental the ties of relationship are, how can it be argued that the parent is not coerced?

If Kittay provided some place for carers to exercise choice she would have protected this essential liberty, which would have directly addressed the problem of unjust coercion. By not explicitly referring to the right to choose, and undermining rather than endorsing Rawls's priority of liberty, Kittay permits coercion, justifying this on the basis that care obligations arise from relational ties. As the analogy of the cycling athlete shows, Kittay's reasoning does not address carer coercion.

I contend that Kittay's mitigation of entrapment by society's recognition and support of dependency relationships does not adequately address the coercion of carers. However vulnerable and valid the dependant's claims are, however much society provides support, unless the care relationship is chosen, carers are still coerced. Kittay's model does not permit carers the choice to relinquish some, or all, obligations to dependants. Relinquishment of dependency claims may sever the relationship. If the relationship is severed, Kittay's model does not allow for care relations outside a prior relationship – such as support by intermittent agency workers, which mirrors care activity rather than the relationship-based care of *doulia*. As Kittay makes no space for such care activity, it is unclear how this care activity sits in relation to her *doulia* model.

Kittay's solution to coercion, by limiting our obligations to certain relational ties, and then supporting these care relationships via her *doulia* model, still has a problem of coercion. Carers need a guarantee of liberty – liberty in the broad sense described by Rawls. The problem of coercion undermines Kittay's potential connections-based model.

Kittay's inability to explicitly resolve the critical internal conflict between priority of relationship, and the priority of liberty afforded to individuals within relationship, makes it difficult to directly employ her critique to guarantee fair treatment of carers. Liberty for carers should first be guaranteed in a Rawlsian framework, which assures full liberty for citizens, under his first principle. Then, following the lexical ordering of Rawls's principles, it would seem that a just society should guarantee support of the vulnerable. Whilst the *doulia* model is not so universally applicable as to allow its prioritization and application to all care situations (as Kittay envisaged), I believe it can be employed only in those cases where carers have freely chosen to be in relations with

dependants. Hereafter I shall apply the term ‘modified *doulia* model’ to refer to the reduced circumstances to which Kittay’s *doulia* model may apply.

Thus, Kittay’s modified *doulia* care model can be incorporated within the framework of Rawls’s second principle which applies only *after* Rawls’s first principle, guaranteeing liberty, is fulfilled.

## **8.6 Applying Rawls’s liberty to care.**

Whilst Kittay’s connection-based model is coercive, it still remains to explain how Rawls’s schema can apply to carers and dependants. Criticisms of Rawls’s schema range from fundamental disagreements with its underlying conception, to questioning how its principles can be applied to carers and dependants. The following account will demonstrate that Rawls’s underlying conception, of free persons in reciprocal arrangements, need not be strained to accommodate care, but employs realistic socio-political reasoning which can actually contribute to a more robust premise for incorporating care. This argument is followed by a discussion of other critiques of Rawls, prior to highlighting the elements of Rawls’s framework which can address carer coercion and form the basis of a logical and grounded fair care theory.

Kittay, Nussbaum and ethic-of-care theorists hold that reciprocal contract arrangements, which form the premise of Rawls’s theory, exclude carers and dependants who are unable to reciprocate. Nussbaum dismisses Rawls’s reciprocal arrangements in favour of her assertion that society is comprised of “sympathetic citizens”, people who intuitively value equal dignity and respect for all, and would therefore support disabled people, via government-funded services, without any expectation of reciprocity. However, Nussbaum’s assumption of society comprising sympathetic citizens does not account for society’s *unsympathetic* citizens. Rather than assuming Nussbaum’s sympathetic citizen, I build the case that Rawls’s conception of citizens as participating in reciprocal, primarily self-interested arrangements can be employed as a motivation for ensuring societal care for the disabled. Rather than relying on fluctuating sympathy, this approach co-opts both the sympathetic citizen and her less altruistic brethren in support of disabled people. In any case, as Nussbaum does not explore whether carer–dependant relationships or carers as individuals take precedence, nor how to guarantee fair treatment of carers, I shall only draw on a few of her comments.

I argue that it is not necessary to rework the premise and core conception of Rawls's theory to incorporate either people with disabilities or their carers. I argue that liberal society is reasonably perceived by Rawls, as a society comprised of "reciprocal citizens". These citizens engage in reciprocal contract arrangements whereby they earn pay or resources. I recognise that care theorists variously assert the a priori treatment and support of care relationships or disabled people, but in doing so they do not adequately explain how this support will be justified to those citizens who earn the resources to sustain such support. In this way, care theorists obscure what Rawls is at pains to construct, that those in need (Rawls uses the term "least advantaged") need the resources and special consideration of Rawls's "reciprocal citizens" to survive. Support of the least advantaged must be justifiable to those citizens such that they agree to resource such support. Rawls's framework embeds a logical reasoning for support of the least advantaged; it only remains to explain how this reasoning can be applied to extreme cases of dependency, such as disability.

I argue that the reasoning for supporting the resourcing of dependants by Rawls's "reciprocal citizens" can be derived from the concepts underlying Rawls's contract theory framework. Rawls's theory is derived from citizens who agree to a contract whilst operating under his 'veil of ignorance'. This construct means Rawls's citizens do not know whether they will be reciprocal citizens or dependants who are unable to reciprocate. As such, these citizens are motivated to insure themselves against a calculated risk that either they, or their associates, may be not only, as Rawls envisages, less talented or disadvantaged, but also subject to long-term illness or dependency. Such citizens would want to be assured that there would be adequate societal care available. This motivation can logically underpin "collective dependant insurance". Such "collective dependant insurance" is justifiable to such citizens because the extreme support required by dependants represents a small risk and limited cost to address. In this way, mitigating even the extreme risk of long-term dependency can fall within the credible motivations underpinning Rawls's reciprocal principle. Such self-serving motivation can be tempered by Nussbaum's conception of "sympathetic citizens", which incorporates people who exhibit sympathy and concern for others as an abiding motivation for funding care of dependants.

In this way, carers are given both equal political citizenship and guaranteed the practical means to realise it. The guarantee of ongoing funding for dependants is based

on “reciprocal citizens” motivated by the need for “collective dependant insurance” who could then centrally pool such funds via taxation, levies or similar mechanisms.

Apart from criticizing Rawls’s underlying conception of citizens in reciprocal arrangements, Kittay and other theorists also state that Rawls’s principles do not address extreme needs such as disability, carers and carer-dependant relationships.

Rawls intended that his theory evolve to apply to specific circumstances, albeit as a variation from the norm:

Thus the problem of the special health care and how to treat the mentally defective are set ... if we can work out a viable theory of justice for the normal range, we can attempt to handle these other cases later ... modified to include important but unusual considerations such as special medical requirements (Rawls 1971: 80).

However, his comment that ‘extreme cases’ such as disability could be considered later, means that such cases are not within his existing consideration. An explicit extension to Rawls’s theory is required to address the support needs of people with disabilities. Theoretical liberty must be practically obtainable to those who undertake care. Practical liberty of the carer requires full government support of the dependant, via either compensation to the carer or the direct institutional support of dependants. Both Goodin and Nussbaum agree that society has an obligation to support the vulnerable and disabled. The task then is to show how to extend Rawls’s theory to encompass such societal support.

Daniels proposes an extension to Rawls’s primary goods to include the health needs of all citizens. Daniels’s definition of health is the absence of diseases and deviation from ‘normal functioning’ and as such, encompasses deviations such as disability. Daniels claims that this would be a logical extension to Rawls’s primary goods as Rawlsian:

Contractors have a fundamental interest in preserving the opportunity to revise their conceptions of the good through time. They will both have pressing interest in maintaining normal functioning by establishing institutions, such as health care systems, that do just that (Daniels 2003: 270, 258).

Daniels’s proposal falls more within the tenor of Rawls’s theory than Kittay’s. Daniels’s extension both defends and maintains the coherence and adequacy of Rawls’s schema. However, Daniels’s extension needs more justification beyond the fact that it is logical and within Rawls’s anticipated range of alterations to enable application of his theory to

specific circumstances. After all, the circumstance of disability was present in Rawls's time, and Rawls himself did not simply extend his primary goods in order to address it.

Further, whilst Rawls's theory anticipates that society will provide for those who experience a temporary need of care, Rawls specifies that such provision should only be extended to those in temporary need. It seems such extension to the primary goods would need greater justification for Rawls's citizen to endorse such a high resource commitment towards supporting dependants whose needs are long term, not temporary.

The motivation of reciprocal citizens to endorse a "collective dependant insurance" discussed previously allows Daniels's extension to fall within the tenor of Rawls's original conception, by making support for disabled people more justifiable to Rawls's reciprocal citizens.

Thomas Nagel's explanation of Rawls's difference principle provides further justification for Daniels's extension to Rawls's primary goods. Nagel explains that Rawls's difference principle is based on the premise that a just society must try to mitigate suffering which is caused by differences between people, when such differences are not their fault. Nagel is not referring to disability but his explanation of the vagaries of difference can easily apply to disabled people:

A society that does not reduce such differentials is not just, and that applies whether the differences in question are racial, sexual ... or disparities in the fortunes of birth, such as being born ... with or without unusual natural abilities. It is this last point, the unfairness of society's systematically rewarding or penalizing people on the basis of their draw in the natural genetic lottery, that underpin the difference principle (Nagel 2003: 70).

The above argument justifies extending Rawls's primary goods to address disability and dependency. This argument is constructed from Rawls's own concepts and principles, specifically the "collective dependant insurance", derived from Rawls's construct of original citizens, and Nagel's explanation of the scope of Rawls's difference principle.

As most care relationships are located in the private sphere in a family context, it is relevant to examine how Rawls treats this sphere. As noted by Nussbaum:

The most difficult problem Rawls's theory faces in connection with women's equality is how to treat the institution of the family ... the family is among the most significant arenas in which people pursue their own conceptions of the good (Nussbaum 2003: 499).

Okin and Neufeld have demonstrated how Rawls can be extended to explicitly ensure liberty and opportunities for women in the private sphere. Okin defends Rawls's principles, reasoning via a clear critique, that Rawls's principles can achieve equality in the private sphere without undermining his essential assumptions (Okin 1989). In *Justice as Fairness*, Rawls responds to Okin's comment, declaring that the family is part of the basic structure and therefore the principles of justice apply to the family. In terms of securing justice for women in the internal life of families, he notes that whilst the principles do not

apply directly to its internal life they do impose essential constraints on the family as an institution and guarantee the basic rights and liberties and fair opportunities of all its members. This they do, as I have said, by specifying the basic claims of equal citizens who are members of families. The family as part of the basic structure cannot violate these freedoms. Since wives are equally citizens with their husbands, they have all the same basic rights and liberties and fair opportunities as their husbands (Rawls 2003: 164).

Rawls's assertion, that his principles apply to the family and ensure justice for all its members, does not adequately address women's relationships with those they care for. For Kittay this means Rawls does not recognise carer-dependant relationships. For Okin and other feminists, it means Rawls does not address women's obligations in the home, which practically restrict women's freedom to access opportunities in the public sphere and attain Okin's 'meaningful equality'. It would have been useful, for this discussion, if Rawls addressed Kittay's criticisms in the way he directly addressed Okin's.

In her later 2005 discussion, Okin demonstrates how Rawls's "pre-eminent liberal theory of justice can meet the challenge of fully including women as equals" (Okin 2005: 234). Okin systematically analyses: the feminist critique of the *Theory of Justice* (1971), Rawls's comments in *Political Liberalism* (1993) and his last published works in *Justice as Fairness* (2003). She notes that his limited responses in *Political Liberalism* to feminists' criticism, and his changes in theory in *Political Liberalism* both generated greater feminist criticism, which was only addressed in his last publication, *Justice as Fairness*. However, Okin notes a thread in Rawls's argument, which she claims may allow Rawls's principles to achieve meaningful equality for women, beyond legal equality. She refers to socio-structural intervention to relieve women from care obligations, which restricts their ability to practically access the opportunities of legal equality:

No matter how thorough the achievement of women's formal legal equality, as long as the social structures ... [ensure that] ... women in fact continue to bear disproportionate responsibility for domestic work, raising children, and caring for the sick and the elderly, and as long as this work continues to be privatized, undervalued, and unpaid or underpaid, the anti-caste principle continues to be violated and women remained systematically disadvantaged (Okin 2005: 244).

Here Okin extends Rawls's reference in *Political Liberalism* to the need for structural intervention to achieve black emancipation, and his general requirement that changing situations require commensurate changes in existing institutions to address the oppression of women. Neufeld argues for the legitimacy of government institutions and policies to partially regulate gender equality within the family. His account encompasses "most of the policies proposed by Okin for promoting gender equality in society, without abandoning the core features of political liberalism" (Neufeld 2009: 49). He cites the provision of publicly funded welfare as a demonstration of policy assumptions about women and family organization, noting that such policies "*directly* govern the organization of the family, ... despite the fact that women are not legally required to marry and form families" (Neufeld 2009: 46).

Rawls's clear statements in his last book appear to support this assertion, referring to Okin's comment that the family and social institutions are subject to the principles of justice:

I should like to think that Okin is right. If we say the gender system includes whatever social arrangements adversely affect the equal basic liberties and opportunities of women, as well as those of their children as future citizens, then surely that system is subject to critique by the principles of justice (Rawls 2003: 167-168).

Following this reasoning, Rawls's principles can be applied to the social arrangements of carers of dependants in the private sphere of the family. Further, the funding amassed by 'collective dependant insurance' makes Okin's "meaningful equality" attainable for carers as it guarantees sufficient resources for institutional support of dependants, thereby ensuring that the coercion and entrapment of carers can be practically addressed.

I have outlined Rawls's theory of justice and shown how it can be used to justify support for dependants and applied to carers and the family sphere. It now remains to explore what Rawls's theory and concepts have to offer in terms of assuring the fair treatment

of carers, to find a place for Kittay's modified *doulia* model (which would only apply where carers have chosen to remain in relationship) and to demonstrate how Rawls's framework can form the basis of a fair care theory.

Rawls's schema is grounded in a profound respect of a person's dignity. In her later work, Nussbaum (Nussbaum 2011: 18)<sup>30</sup> notes that central to Rawls's (and her own) work is:

The idea of the respect, respect for persons is not a subjective emotional state, such as a feeling of admiration. It is a way of regarding and treating persons ... treating humanity as an end and never as a mere means. Respect is thus closely linked to the idea of dignity, to the idea that humanity has worth and not merely a price. Equal respect would then be respect that appropriately acknowledges the equal dignity and worth that persons have as ends (Nussbaum 2011: 18).

Rawls's emphasis on respect for persons is a response to the prevailing utilitarian theory, which justifies the sacrifice or 'utility' of treating some people as a resource if this benefits society as a whole. Rawls believed this approach would unjustly permit the sacrifice of some people's liberty if this raised the level of overall wellbeing, believing that this is particularly heinous where more is demanded from the worst-off in society for the sake of the better-off: "Indeed, asking that of the least advantaged would seem to be an extreme demand" (Rawls 2003: 127).

Rawls was particularly critical of the limited guarantees of fairness that the utilitarian approach provided to those so used: "the utility principle put more weight on what is a considerably weaker disposition, that of sympathy, or better, our capacity for identification with the interests and concerns of others" (Rawls 2003: 127). Rawls's prioritizing of the first principle of liberty and opportunity guarantees a person's liberty. His second principle, which assures support for the worst-off, cannot be achieved by compromising the liberty guaranteed in the first principle. Titelbaum explains that the strict lexical order of Rawls's principles limits coercive obligations to

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<sup>30</sup> Here Nussbaum shows that Rawls's profound respect for individuals inspires his commitment to protect citizen's choices. See also her later comments, in which she discusses how respect for citizens is shown by "creating and protecting spaces in which they can be accorded their own views." p. 36. Where one's "own views" includes one's own choices within the scheme of one's conception of a full life.

support the worst-off where “such actions ... would infringe on basic liberties” (Titelbaum 2008)<sup>31</sup>. Rawls argued that there is first the need to have a theory of fair shares as a limit to the way in which people can be legitimately used for the benefit of others.

In describing the primary goods and framing his principles, Rawls refers to basic rights. Nagel interprets this to mean that “Rawls’s account of the individual rights central to liberalism is not instrumental ... [there] are principles of right and that the right is prior to the good ... [this gives each person] ... a kind of inviolability ... that cannot, in Rawls’s view, be explained by its tendency to promote the general welfare” (Nagel 2003: 65). Thus, good ends must not be sought at the expense of justice. If applied to care, the good result of support for dependants must not be achieved if it violates the just entitlement of carers.

According to Rawls, the higher priority he accords to basic rights means people who are denied these rights are described as coerced, and that the maintenance of such rights indicates the minimum standard of what he describes as merely decent (Rawls 2001). As noted by Nagel, governments and societies which “afford only human rights are simply decent; they are not ideal or just from the point of view of many comprehensive doctrines” (Nagel 2003, p. 47)<sup>32</sup>.

In summary, public policy obligates carers to provide long-term care for dependants, which limits carers’ liberty. Kittay and other ethic-of-care theorists, although advocating societal help for carer-dependant relationships, risk coercively obligating carers to provide long-term care to dependants. This chapter considers what might be the ideal and fair placement of carers as citizens of a well-ordered society. Rawls’s principles are particularly applicable because his framework sets out to first guarantee liberty for all

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<sup>31</sup> Here, Titelbaum discusses an ethos which motivates a citizen to maximise the condition of the worst off, but only where this does not conflict with the citizens’ pursuit of their own plans of life, including their individual commitments and aspirations as protected by their rights to the basic liberties and fair equality of opportunity.

<sup>32</sup> Nagel’s discussion critically frames the attainment of basic liberties, not as an idealised notion but as a minimum requirement for any decent society. This is a challenge to policy, which usually presents the application of such a minimum requirement as unobtainable for carers, who are presented as having prior obligations to dependants.

citizens. His principles seek to 'place' the citizen justly in society, precisely what I am attempting to do in respect of carers. The lexical framework and directive nature of his principles means they can be readily translated to public policy in any liberal democracy with a stable institutional structure. As Rawls states:

We are concerned with principles that take seriously the idea of citizens as free and equal, and so with principles suited to shape political and social institutions so that they may effectively realise this idea (Rawls 2003: 79).

If Rawls's principles are applied to carers, via a new fair care theory, they will provide a framework to direct the premise of care policy and assure carers the entitlements of free and equal citizenship.

### **8.7 Rawls's principles: Deriving a fair care theory of justice.**

The thoroughness of Rawls's theory and the elegance of his principles mean they can provide a comprehensive framework for the fair treatment of citizens in liberal policy. The previous section shows how Rawls's principles can be logically extended to apply to care, carers and dependants. This extension is justified because, as Nagel argues, the assurance of basic liberties for all is the minimum requirement for any decent society. Thus, it seems that such a minimum requirement should apply to carers and ensure adequate care for dependants. I have demonstrated that Kittay's prioritizing of carer-dependant relationships, over considerations of a person's liberty, can result in coercion of carers. Rawls's theory of justice guarantees all citizens freedom from coercion by prioritizing a person's liberty, above care of the least advantaged. However, some of Kittay's concepts, particularly the recognition of carer-dependant relationships and aspects of her *doulia* model, should have a place within a Rawlsian-framed care theory within the context of Rawls's care of the least advantaged.

It now remains to frame a Rawlsian-based fair care theory which guarantees liberty and incorporates care and dependency. Like Okin and Daniels, I believe care and dependency concerns are comprehensively addressed by incorporating the specific circumstances of care within the lexical framework specified by Rawls. To ensure freedom from coercion, Rawls's first principle which asserts the priority<sup>33</sup> of liberty and

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<sup>33</sup> Following Nagel's clear appreciation of Rawls's assignment of priority, in which what is just and correct is given priority over what is good, see Nagel (2003.)

opportunity should be explicitly asserted for carers, followed by extension of Rawls's second principle to include support for disabled people and dependency relationships.

Such an extension, following Rawls's framework, does not propose any additional principles (as suggested by Kittay). Instead, care is guaranteed by extending the primary goods to address the 'ill-health' of disability (as outlined by Daniels) and justified by the robust reasoning for 'collective dependant insurance' and Nagel's explanation of Rawls's difference principle, discussed earlier. If the dependent person is assured societal support, then the practical obligation on carers to provide care is reduced. In this way, coercive relational ties are not just mitigated but removed. Carers can freely choose whether to remain in relation with dependants and to what extent and manner they wish to relate. Carers can then fully realise Rawls's schema of liberty and opportunity and exercise Okin's "meaningful equality" in that they can practically access the entitlements of equal citizens and enjoy the opportunities of the public sphere.

Dependency relationships, particularly a modified version of Kittay's *doulia* model, can be incorporated in a fair care theory; Kittay's model must be modified in order to uphold Rawls's first priority of liberty. Thus, Kittay's *doulia* model only applies to those carers who choose to directly care for the least advantaged by continuing in carer-dependant relationships. In such cases, an assurance of support for the modified *doulia* relationship is provided by the application of Rawls's second principle, as extended. In this way, Kittay's modified *doulia* model functions as a kind of extended reciprocity, and is justified to Rawls's citizens within the terms of the previously described arrangement of 'collective dependant insurance'. Such an arrangement also echoes Kittay's concept of extended reciprocity; "the dependant cannot reciprocate the care or concern the dependency worker devotes to her ... The obligation to redress the 'cost' that duties of dependency work exact from the dependency worker must fall on those outside the relationship itself" (Kittay 1999: 106).

Kittay's modified *doulia* model is best incorporated within Rawls's second principle (b) (recognising disadvantage). As the *doulia* model is not universal to all care situations, it

can be included as one expression of a care model, which addresses the needs of the least advantaged in the context of a relationship. Support for dependants could also be provided by institutions or a combination of institutional and carer support. This framework, which assures liberty and opportunity for carers, together with guaranteed societal support of dependants, permits 'space' for the exercise of positive freedoms, including positive and freely chosen carer-dependant relationships.

Thus, this new 'fair care theory' is based on a Rawlsian framework, confirms Rawls's core conceptions and applies and maintains the lexical ordering of Rawls's two principles. Thus, the first principle of liberty and an inherent conception of citizens as free and equal must be entirely fulfilled, without compromise, before the second principle of equal opportunity and structures that benefits the least advantaged. Following Rawls, I set an expanded list of primary goods within such a framework.

## **8.8 A new fair care theory:**

**Principle 1** - follows Rawls's first principle asserting that all persons are entitled to the equal basic liberties:

That carers are at liberty to choose how they are recognised by society and have access to the same liberties, powers and opportunities as others in society. This would involve carers choosing what priorities of the social goods and freedoms they want and what relationships they wish to foster.

Carers may choose to remain in, or to relinquish, the care relationship and attendant obligations. If the carer chooses to remain in relationship, they may choose what caring activities they undertake and to what extent. This includes, but is not limited to, which of the caring activities they wish to perform, to what extent they wish to undertake these activities, how they wish to situate their caring responsibilities within their lifestyle, and some say over what range of services and mode of delivery they consider would best suit themselves and the dependent person in their care.

Carers are entitled to equal opportunities to access the social and economic positions outlined in Rawls's primary goods, and that such equality is supported by alterations to institutional and societal structures that make such entitlements practically

attainable.<sup>34</sup> Such institutional support would include a choice of various forms of care: either care for the dependant, which releases the carer to take up work/social opportunities, and/or to support the carer in their support of the dependant, following Kittay's modified doulia model.

**Principle 2** - follows Rawls's second principle of equal opportunity and motivations for citizens to ensure benefit to the least advantaged in society:

That the disadvantaged, specifically dependants, be adequately supported by society such that they may enjoy and have access to the liberties, opportunities and primary goods as befit their needs and abilities. That this support be considered primarily a responsibility of society. That such support be delivered either sensitively to the individual, or in support of the carer-dependant relational unit,<sup>35</sup> as appropriate.<sup>36</sup>

That in the spirit of Rawls, further specification of the primary goods to more "concrete cases" (Rawls 2005: 188), the primary goods be naturally extended along their trajectory to include the responsive care of those experiencing ill-health.<sup>37</sup>

The fair care theory could be summarised as 'Carers are citizens first who are entitled to the basic liberties and opportunities of citizens. They are entitled to choose whether to care, how to care, and how much to care and to have an influence on the disability and carer services provided to them and their dependants. In addition, to practically attain carer liberty, society is responsible for providing adequate support to the dependent person in a manner that suits the dependent person '.

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<sup>34</sup> In the spirit of Susan Okin's meaningful re-organisation of societal structures to secure actual, beyond merely legislative, equality of opportunity.

<sup>35</sup> It is this point that Kittay's modified doulia model sits -- thus carer-dependant relationships are supported via a series of nested relationships embedded in, and resourced by society.

<sup>36</sup> 'As appropriate' refers to situations where carers choose to support dependants and the extent to which they want to support dependants, and where the government scrutinises the adequacy of the support.

<sup>37</sup> 'Ill health' in the manner described by Daniels which means variations from full health and functioning.

In summary, Kittay's critique was selected as, of all care theories, it most closely resembles public policy. This analysis of her theory therefore also tests whether current policy trends could potentially ensure fair treatment of carers, if modified with Kittay's *doulia*-style support. As the analogy of the cyclist and dependent child shows, Kittay's approach, and government policy, permits carer coercion. Carers need a guarantee of liberty from coercion and of opportunity prior to their obligations to others.

Rawls's theory provides such a framework via the strict lexical order of his principles, which guarantees liberty prior to obligation to the 'least advantaged'. Furthermore, Rawls's elemental concepts are arranged to provide a cohesive internal logic. Rawls's "conceptions of justice should have a 'practical role' in a well ordered society as they provide a basis for 'public justification' among persons" (Freeman 2003: 29) and are directly applicable in the structures of society including its legislation, public policy and institutional priorities. I have built the case, relying on Nagel, Okin and Daniels's discussion, that Rawls's theoretical framework can be employed to derive a fair care theory that is grounded in Rawls's principles and extended and modified to incorporate the concerns of care and carer-dependant relationships. This theory represents the specification of Rawls's principles to the concrete situation of carers and dependants in a way that ensures their positive liberties and fair opportunities, whilst incorporating key features of Kittay's dependency critique, together with Okin's, Nagel's and Daniels's approaches to care in the private sphere.

## **8.9. How does the fair care theory resonate with carers?**

The interview responses around carer choice and obligations provide an insight to how well the fair care theory resonates with carers.

### **8.9.1 Do carers agree with Principle 1 – that carers are entitled to liberty and choice?**

All but two carers strongly endorsed carers' right to chose, asserting that this right applied to all carers. When asked whether carers should have the right to decide whether to provide care, these carers were unequivocally affirmative:

Of course, because this life is too hard, has too much crap [Steve];

Yes, absolutely, everyone should have a choice [Maria];

Yes, definitely, this is the crux of the matter especially in day to day care - should have a choice [Catherine];

I had a choice when I was first in hospital, but I wanted to have him at home, but I had a choice! Yeah, I think you should have the right. But when you think you know you're beyond it, you should have the right then [Joan];

Yes! We're all people, no one deserves to be stuck in this life, caring is too difficult. For me, I barely know who I am, or what I've become. I need to know that there is an out [Sue].

In terms of the premise of the new fair care theory, carers were torn in their discussion on choice between strongly supporting a theoretical right to choice for all carers and what they would themselves chose, with some carers expressing strong ties to their dependent child<sup>38</sup>.

Seven of the eleven carers wanted the government to be responsible for their dependant's care whilst having the option to influence the nature of this support and continuing to relate to, whilst not being obligated towards, or responsible for, their dependent child:

Yes, definitely, should be a choice for many. I'm still very involved with what Karen is doing and have meaningful input on what should happen to her but I want others involved in looking after her too. Regular people she likes and trusts. The parents can decide whether to care or not care but [not only this choice] too extreme or nothing, should also be [offered] graduated choice [of] how much to care [Catherine].

Carers varied in the way they saw their ties to their dependant. Four of these seven carers wanted minimal or no relationship beyond an assurance that their dependent child was safe, whilst the other three carers, wanted no obligation but the ability to direct their dependant's care service.

Of the other four carers who wanted to retain responsibility for their dependant, two saw this as their own personal choice to continue to care for their dependant. These two carers envisaged a continuing relational obligation in the medium term, continuing for

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<sup>38</sup> As noted in Chapter 1, the word 'child' is used to refer to the relationship between the parent-carer and the child-dependant. The age of the dependants ranged from 9 to 37years.

“10, say 15 years?” [Carol]. It appeared that these carers valued the right to choice, emphasising that care should be a choice, so, as a choice, they should also have a choice to reduce or have no care when they wanted to. These carers expressed a strong relational obligation to their dependant, but conversely couldn't envisage such obligations continuing in the long term and wanted assurance that they would have a choice in the future to “not be a carer” [Barbara].

The remaining two carers said their cultural and religious beliefs meant they viewed care not as a choice but as a relational obligation stating that as “part of my Chinese culture” or “Muslim conviction of rewards in heaven”, carers should have a lifelong obligation to care and to remain responsible for their dependent children. “It’s not the government's responsibility, it's ours” [Fozia]. These carers expressed a strong belief in their obligation to be responsible for their dependent child throughout their lives and to pass this responsibility onto their normal children:

Everyone has different backgrounds, different financial backgrounds, different family dynamics ... [pause] my upbringing, in our culture it's your responsibility to be responsible for your children and parents, no handouts from the government [Luk, referring to her Chinese culture].

As the interview continued particularly in its discussion on disability accommodation and the design of disability support, a few carers revisited the issue of choice stating that if they could be assured their dependant was safe, they might then feel they could relinquish their relational obligation and freely live their own lives.

All carers noted some familial relational ties with their dependent children. In discussing carer choice, most carers interviewed echoed the dilemma of asserting their own liberty at the expense of their ties with their dependants. However all carers, apart from two with particular cultural/religious beliefs, emphatically stated that carers have a right to choose whether to care and a desire for reasonable opportunity in their lives. Their responses were therefore in accord with Principle 1 of the fair care theory.

### **8.9.2 Do carers agree with Principle 2, that society is responsible for supporting dependants?**

In terms of financial responsibility, carers were asked open-ended questions about whether it was carers or government's responsibility to financially support the care of disabled people. Most said that the government was, on balance, responsible for funding all or most services:

Yes, the government and taxpayer are responsible [Carol]

The government is responsible, or society is responsible, including me as I pay taxes, yes the government is responsible to give carers and disabled people a chance to be the best possible. Carers don't have the resources to give their disabled children a good life [Anne].

Although a few (three of the eleven) questioned the premise of government versus individual/ family-carer responsibility:

Carers are responsible for the base expenses and government for all other expenses over normal expenses [Barbara].

It is our responsibility based on my Islam religion [Fozia].

### **8.9.3 Should carers influence service design?**

This provision is included in Principle 1 of the fair care theory. All carers interviewed were adamant “yes absolutely” [Catherine] “definitely “ [Luk] that carers are vital to designing disability and carer services to suit their dependant and themselves/their families:

Yes, it's a pointless waste not to ask carers as it means we're left with a system that doesn't work” [Carol].

Must ask carers, we're the only ones who live it, so we're the only ones who can design the right disability services [Maria].

Most noted that this was because only they as parents and carers understood the needs of their dependent child, themselves and their families.

## **8.10 The fair care theory, carers' views and public policy.**

Current policy trends emphasise obligations on familial carers to provide care to dependants for long periods. Such obligations amount to carer coercion, burden and restricted access to the goods and opportunities of citizenship and warrant urgent moral attention. These restrictions were apparent in both the analysis of evidence to the Carer Inquiry and carer interviews discussed in Chapter 5.

All eleven carers interviewed expressed concern for their dependent child. Apart from the two carers who referred to religious or cultural beliefs, the other nine carers wanted a reduction in their care obligations and more government support. Four of these carers wanted an assured choice to relinquish their care obligations in the future.

The remaining five carers noted that whilst they would always *care about* their dependant that they wanted no relational obligations to support their dependant. These five carers noted the emotional strain of trying to assert their own sense of self or simply survive, against the overwhelming needs and demands of their dependent child. To resolve this conflict these carers felt they must relinquish their care obligations for their own mental or physical survival. These carers said they felt they had to do this but would have been happier knowing that their dependant was safe and well cared for. Three of these five carers believed their dependant ought, as adults of 18, 33 and 35 years, to live separately reasoning that this constituted a better life, not just for themselves, but also for their dependant.

The five carers who wanted no care obligations had dependants who ranged in age, one in their early teens, two in their late teens and two in their 30s. All of these five carers had children with severe intellectual disabilities and/or behavioural issues. It is tempting to deduce that carers who have been caring for a long time (16 to 30 plus years), or those whose children have severe intellectual disabilities or exhibit difficult behaviours, were more likely to reduce relational ties. However, the sample is too small to draw such conclusions. Suffice to say, most established carers want choice in how much to care and some carers want choice not to continue in relational obligations with their dependant.

Does the new fair care theory resonate with the carers interviewed? The fair care theory resonated with all carers interviewed apart from those with specific cultural or religious beliefs. Ultimately, all but those with strong religious/cultural beliefs think carers have a right to relinquish relational obligations. Whilst this belief was expressed strongly it was arrived at with much soul-searching and fraught with internal conflict. This conflict was apparent when, as mentioned previously, carers struggled to define and refine their beliefs around carer choice. All carers expressed concern for the well-being of their dependants. All carers said their lives, health and emotional well being were deeply affected by their care obligations, echoing Kittay's observation on "the overbearing nature of the other's needs" (1999: 52) to which the carer must remain sensitive even when it conflicts with their own needs.

Carers felt deep concern for their dependant which was often in conflict with their own needs. As discussed, in spite of this conflict, the majority of carers decided that carer choice took precedence over obligations to care for dependants. Most carers were more

comfortable about enjoying their liberty if they could be assured of adequate care for their dependants. Principle two of the fair care theory, by guaranteeing adequate care of dependents, addresses carers' concern for dependants, allowing carers freely, and without guilt, to make choices to relinquish all or some care obligations.

The feeling of entrapment, together with carers' stated belief in the primacy of carer choice indicates support for the new fair care theory's first principle of guaranteeing liberty of the person. Carers responses also indicate that the goods of integration and "living the good life", touted for people with disabilities, are also relevant to carers. Principle 1, in securing carers a right to the same powers and opportunities of others in society, assures them of the 'reasonable life' many carers referred to as discussed in Chapter 5.

Some carers want choice and greater provision of tailored services to support them in their relationship with the dependent to the extent to which they wanted to remain in the relationship. The fair care theory also addresses these carers. Principle 1 of the fair care theory makes provision for carer choice as the primary right, including a choice to remain in relationship. Principle 2 provides support for dependents, either outside or as part of a chosen carer-dependant relationship. This assures carers their dependants will be supported by services that are tailored to their dependants, services that reflected their views on service design. Principle 2 of the fair care theory addresses the needs of those carers who choose to remain in relational obligations with dependents to the extent that they wish to remain; This Principle, in providing adequate government support for this relationship incorporates Kittay's modified doulia model as one model of care delivery.

The fair carer theory resonates with most of the carers interviewed. Moving forward, as the fair care theory is built on the framework and concepts of Rawls's theory of justice, it is directly applicable in the legislative and policy constructs of any liberal society. If adopted in policy, the fair care theory can assure adequate care of dependants, and fair treatment of carers.

This chapter derives a new fair care theory and demonstrates that it accords with the views of most carers interviewed. Following the pattern of disability theory, the fair care theory can be implemented via disrupting both the broad problematisations and associated premise underlying care policy.

Implementing the fair care theory means recasting care policy to reflect the principles of the fair care theory. Thus, following Principle 1 of the fair care theory, policy would guarantee carers' entitlement to liberty. Thus the broad problematisation, identified in Chapter 5, of increasing carer resilience, premised on ongoing carer obligation, would be replaced by a core problematisation in policy of: 'how to ensure liberty for carers'. Other problematisations would follow such as ensuring carer choice and opportunity via adequate out of home care for dependants. The prevailing problematisations on addressing carer work restrictions, premised on the difficulty of carers combining work and care obligations, would be replaced by problematisations around carers, attaining equal access to high status positions and opportunities in the public sphere. The policy solutions for such problematisations would then translate to solutions similar to those for other marginalised groups, including job targets and guaranteed interview schemes.

Following Principle 2 of the fair care theory, new underlying presumptions would include that society is responsible for care of dependants, and problematisations are then framed around how best to achieve full societal support and accommodation for dependants and, where carers choose, support for the (modified doulia) carer-dependant relationship.

## Chapter 9 – Conclusion

This thesis sets out to explore whether carers are treated fairly in theory and policy and questions what constitutes the fair treatment of carers. It arose from my involvement on government advisory and community boards where I observed a sharp contrast between disability theory and policy asserting entitlements for disabled people and a silence on carer entitlements in carer theory and policy.

To answer this question I employed three different analytical methods that addressed the question and could extend and complement each other. Bacchi's WPR approach was used to analyse government texts. The WPR approach found most government texts advocated person-centred ideal treatment for people with disabilities, which were premised on disability theory. The clarity on the ideal treatment for disabled people contrasts with a relative silence on carers' views, ideal treatment and theoretical premise. To explore this silence I undertook qualitative interviews with eleven carers to ascertain their views, and critiqued disability and carer theories. Deducing that carers felt entrapped and prevailing theories did not address the fair treatment of carers, I examined key theories and derived a new fair care theory. The new fair care theory builds on the reasoned argument and endeavour of ethic-of-care theorists, particularly Kittay, and rests on the thorough reasoning and logic of Rawls's theory of justice.

The use of combined methods has yielded a clear view of carer treatment in policy, from identifying its silences and its problematisations, to explaining its underlying theoretical premise, justifying the derivation of a new "fair care" theoretical solution and documenting carers' views on policy and the new fair care theory.

The combined analysis shows that government policy and legislation together with disability and carer theory all converge to effectively entrap carers in long-term relationships of service to dependent people with disabilities. The problematisation of carers in policy and legislation does not focus on the ideal treatment of carers, thus carer treatment is a result of the incidental treatment of carers prescribed in disability theory and tacitly permitted by carer theory. In disability theory, carers are an assumed resource and form the normative familial environment of people with disabilities. The ethic-of-care theory envisages ongoing carer-dependant relationships, which are supported by society.

The WPR policy analysis identified the problematisation of carers as ‘how best to improve the identity and resilience of carers to ensure that they keep on providing unpaid support in the family home for people with disabilities.’

## **9.1 Significance of this thesis**

This thesis is significant because it provides a practical solution for governments to achieve fair carer treatment in policy both within Australia, which had 2.7 million carers in 2015, and internationally. As Neysmith, Esping-Anderson and Daly remark, throughout the Western world there is an increasing emphasis on familial obligation. Whilst my thesis examines policy and legislation affecting Australian carers, it is noteworthy that Australian policy is based on United Nations treaties and internationally established disability theory; as such its findings are applicable wherever these theories and treaties direct policy and where familialization of care is emphasised.

The views of the eleven carers interviewed are woven through the thesis and provide an insight on how the policy and theoretical analysis resonated with these carers. Notwithstanding the limitations of the sample (described in Chapter 3), these interviews show that carers view existing policy as entrapping. The views of the carers interviewed closely aligned with the views of carers to the 2008 Carer Inquiry. This was particularly evident in the sentiments expressed by most carers seeking to be the direct focus of government policies, wanting choice in their lives and increased services tailored to themselves and their dependants. These common sentiments lend weight to the idea that whilst my sample is limited, its broad findings and direction are consistent with the larger carer cohort who made submissions to the Carer Inquiry.

As discussed previously, the Arksey and Glendenning study found a shortage of research on carer choice. This, together with the entrapment expressed by carers interviewed, indicates a critical need to address carer choice in research and policy. The carer interviews conducted for this thesis help address this shortage by asking carers their views on their lifestyle, goals, choices and their views on services and the government's responsibility for dependants.

The WPR analysis uncovers the premise of government, including a steadfast avoidance of issues around carer choice and lifestyle associated with resultant costs to government. This is evident in a number of texts analysed, where government and

legislators set out to address carer choice and entitlements and then veer towards alternative problematisations around increased carer resilience so carers can continue in long-term relations that obligate them to support dependants.

The insights into carers' lives gained in this thesis, particularly from the carer interviews and the evidence of carers to the Carer Inquiry, and the extreme impacts on carers described in media reporting demonstrate that, regardless of the cost to the taxpayer, choice, liberty and entitlements for carers are morally justified.

Significantly, the new fair care theory resolves the theoretical conflict between the good of ongoing relationships with the just protection of individual choice. The fair care theory provides a new framework that can be employed in policy and legislation to address the fair treatment of carers.

## **9.2 Key findings**

This section will first coalesce the findings gained throughout the thesis and then discuss the overarching links that emerged. I applied Bacchi's WPR method to relevant carer and disability texts and identified their 'presumed truths', prevailing problem representations and underlying theoretical rationales. It allowed these truths to be interrogated, disrupted and replaced. This analysis indicated carers were absent or presented as a resource at different levels of government.

At the international level, United Nations treaties are premised on disability theory and use the language of individual rights and choice, emphasising the independence of people with disabilities. Whilst carers are not identified as a subgroup for attention in these treatises, they are a presumed support resource and the family home a presumed setting, for dependent disabled people.

The WPR analysis of The Australian Human Rights Commission (AHRC) report on care and submissions to the Carer Inquiry indicates that the absence of carer treatment is premised on an absence of research and agreed concepts around carer theories and treatment that could support or inform Australia's leading government-funded rights agency to assert carer rights.

Australian Commonwealth and NSW State texts identify carers. Commonwealth and NSW State legislation and policy of the 1980s and 1990s aligned with disability theory and emphasised integration with the community. Because the spectre of out-of-home

institutional care has receded, newer legislation both incorporates disability theory and directly reflects the language of international treaties. Thus, integration and valued societal roles prescribed in disability theory are assumed and new policy and legislation presumes all disabled people are independent and problematise's their attainment of equal rights and opportunities.

International, Commonwealth and NSW State policy and legislation presume independence and autonomy of all disabled people, and so ignore the dependency of some disabled people and the impact of this dependency on carers.

### **9.2.1 Comparing carer and disability policy and texts**

At the outset, the policy analysis observed a greater number and longer history of disability texts compared with carer texts. The treatment of disabled people contrasts with the treatment of carers across all levels of government. The most significant difference is that disability policy and texts are written with a clear and consistent mandate, to assert and implement disability theory, which prescribes specific treatment for people with disabilities. In contrast, carer policy and texts do not exist across all levels and where they do exist, they lack a consistent and clear theoretical direction and therefore fall into the space allotted by disability theory and permitted by the ethic of care theory. The WPR analysis exposed the consistent "presumed truth" that carers are a resource and the family home constitutes the integrated environment for some people with disabilities. The thesis demonstrates that the Australian Government is silent on carer's rights and choices. In Australian policy, the problem representation of care is how to ensure carers continue in caring relationships with dependants, with some support. Although there is not a direct reference to any care theory, these sentiments echo both the ethic-of-care theory and Kittay's dependency critique, both of which advocate for societal support for the ongoing maintenance of care relationships. It should be noted that care theories do so on the guarantee of a reasonable level of support for such relationships, whilst government policy does not guarantee this level of support. The WPR analysis shows that both Commonwealth and state carer legislation, whilst mentioning carer rights in their schedules, firmly negate any guarantee of such rights arising.

The comments of the Committee evidence the tension of holding this position when the tone, desperation and entrapment expressed by carers' submissions to the Carer Inquiry point towards alternative positions around carer choice and opportunity.

As established, liberty for carers is inextricably bound to provision of adequate services, especially government-supported accommodation for dependants. Increasing services for the disabled may result in the practical lessening of the carer load, but, without an orientation towards carer rights and liberty, funding for disability services is not focusing on the concurrent goals of both carer and disability rights but rather only disability rights.

The discrepancy in treatment for specific, identified and interconnected subgroups creates a marked imbalance between each subgroup. Persons with disability have an idealistic fair treatment prescribed in policy in contrast with carers who are presumed to be obligated, unpaid support people and have no idealistic fair treatment stipulated in policy. Such an imbalance amounts to an effective ranking of citizens.

### **9.2.2 Care and disability theories and carer views.**

Chapter 1 described the difficulty carers had articulating their views on carer choice and lifestyle, noting the marked pattern of their replies which included stumbling, truncated answers. Whilst this pattern was evidence of a number of factors, it also shows that most carers interviewed were torn between their relational ties to their dependant and their own, individual entitlement to choice and lives apart from this relationship. Most carers reprised their responses towards the end of the interview, where they asked to go back and strongly reiterated, clarified or emphasised definitive answers.

The struggle of carers interviewed parallels a similar struggle, at a theoretical level, with ethic-of-care theorists who grappled to include justice for carers whilst maintaining the primacy of carer relationships. This struggle amounted to many care theorists beginning to outline ideal theories combining care and justice and pulling away from structuring an actual theory. These carer theorists, including Kittay, exhibit the desire to maintain relational ties, akin with Kittay's concept of *doulia*, but are unable to resolve the conflict of affording priority to care relations whilst guaranteeing citizen's liberty as described in theories of justice. The struggle to incorporate justice whilst maintaining long-term carer-dependant relationships is particularly developed in

Kittay's dependency critique. As shown in Chapter 8, particularly in the discussion on coercion, Kittay's argument for maintaining carer-dependant relationships permits coercion and does not guarantee justice or fair treatment of carers. This is because there is no way to give priority to both carer-dependant relationships and carer liberty,

Chapter 8 explored theories around the ethic of care especially Kittay's dependency critique alongside Rawls's framework in the theory of justice. To guarantee carers' freedom from coercion, as argued in the discussion in Chapter 8, any care theory must give priority to liberty, over care for others. This chapter demonstrated both the need for the primacy of liberty as extolled in Rawls's theory, following Rawls's broad understanding of liberty as discussed in Chapter 8 (that includes choice, attainment of goals and self-actualisation). This discussion demonstrated how Rawls's theory could be justifiably applied to the treatment of carers. This discussion argues that Rawls's theory of justice provided a framework which resolved this conflict by justifying the priority of liberty over care for the 'least advantaged' (Rawls 2003).

The fair care theory derived from this discussion prescribes how to assert the primacy of liberty for carers, thereby addressing carer coercion, while still recognising carer-dependant relationships and a place for carers to speak for themselves and their dependants on the design of disability services.

In answering questions on their rights to choice, the pattern of carers' responses evidenced an acute personal struggle with the conflict of maintaining relational ties and asserting their choice and liberty. In spite of this, the carers interviewed managed, by the end of an hour and a half's interview, to decide between the 'goods' of rights and liberty and on-going care relationships. All but two of these carers effectively affirmed the priority of justice over maintaining carer-dependant relationships in their assertion that carers should have rights to choice and lifestyle opportunities. In asserting the priority of carer choice, most carers added the proviso that there would be assurances dependants had adequate government care. Thus, the new fair care theory resonates with most carers as, in Principle 1; it first prioritises carer liberty and opportunity, and, in Principle 2, secondly, guarantees adequate care for dependants and carer input on support services.

### **9.3 The intersection of policy and theory.**

In reference to disability policy, Chapter 3 shows that prevailing disability policy is based on key disability theories, which primarily serve the more independent physically disabled; consequently, services oriented towards the dependent disabled and carers, requires a reinterpretation of disability theories to address the intellectually disabled.

Recalling the critique of disability theory, detailed in Chapter 6, a critical omission in disability theory is that it ignores the unique needs of dependent intellectually disabled people. It particularly ignores their inability to attain meaningful normal functioning in the typical social roles of their same-aged peers. Their long-term dependency must be addressed with adequate support to enable their survival and quality of life.

Acknowledging the dependency of some people with disabilities disrupts the assumption that all disabled people are independent rights-bearing individuals. This permits a broader understanding of dependency and the effects of this on both dependants and their carers. Such disruption admits space for new policy to address dependants' needs, especially the need for long-term support and accommodation.

This thesis shows that carer theory does not focus on the fair treatment of carers. As noted in Chapter 7, both the ethic-of-care theory and Kittay's dependency critique do not sanction carer rights and choice but rather emphasise societal support for the continuation of relationships between carers and their dependants. As demonstrated in Chapters 7 and 8 neither the ethic-of-care theory nor Kittay's dependency critique address the problem of carer coercion and entrapment. The WPR analysis of Australian policy in texts identifies the absence and, in the case of carer legislation, the explicit denial of carers rights. The premise and justification for this government sophistry includes (perhaps unconsciously, certainly conveniently) some of the principles and sentiments espoused in the ethic-of-care theory and Kittay's dependency critique, both of which hold that familial relationships between carers and dependants is valued by carers and society.

Chapters 2 and 6 show that in Western democracies, governments have endorsed a normative approach, whereby the familialization of care is assumed (Esping-Andersen 1999) in the shift to deinstitutionalisation, and integration of dependent people in the community.

The application of normative expectations is stretched beyond credibility for carers of dependants. Described in Chapters 1 and 6, the extremity of this situation is illustrated in circumstances occurring in Western democracies, where family care can consist of 60-year-old “parents” obligated to care for their 35-year-old “children”. This recalls Neysmith’s observation on the negative impact of this obligation:

The research that underpins discussions ... documents the high price that women pay .... The expectation that it is women's responsibility to provide care is unjust, ... and the well-being of persons in need of care is entrenched as a familial rather than a social responsibility (Evans, Baines et al. 1998: 233-234).

Familialization is the key assumption that frames the problematisation of care in public policy. Research and policy echo disability and care theories by presuming familial care of dependants. Thus, the policy problematisation focuses on those supports targeted to ensure carers can continue to provide care. Consequently government policy gives limited attention to developing feminist ideals and more attention to the details of social work practice to assist women in familial caring roles (Quam and Austin 1984).

This thesis demonstrates that the new fair care theory can disrupt and replace the underlying normative frame of ongoing familial care.

## **9.4 Future Directions.**

The WPR analysis affirms the silence and strained avoidance of carer choice and equal opportunity and the consistent presumption of ongoing carer–dependant relationships. I have demonstrated that the fair carer theory can disrupt prevailing policy in two areas. The first is by reorienting policy to accord with the new fair care theory, thereby guaranteeing carer liberty, choice and opportunity; the second by redesigning disability policy constructs to reflect the difference of dependency and addressing the support needs of dependants.

This thesis demonstrates that the fair care theory resonates with carers and can justifiably disrupt the prevailing problem representation to obtain fair carer treatment. Following Okin's argument (Okin 2005) that policy goals should be practically obtainable, one must ask whether implementing the fair care theory is feasible in the Australian policy context. To practically obtain fair care theory’s liberty for carers, including carers’ choice not to provide care for dependants in the family home, requires adequate support for dependants, especially out-of-home accommodation.

Three factors will enable the implementation of the fair care theory. Firstly, disruption of prevailing disability theory, research and policy to permit broader research on dependants and carers, and admit other views, including those of carers and dependants, which results in alternative disability service goals than integration in community settings. Such alternative views can facilitate new, more feasible, service and accommodation models.

Secondly, support by government and society is necessary. The 2009 Carer Inquiry is evidence of increasing focus on carers in Australia. The enactment of specific legislation for carers in 2010 indicates that Australia is ready to directly address the needs of carers as an identified group. Although the Carer Inquiry and the carer legislation it gave rise to, explicitly prohibit new rights arising for carers, the Carer Inquiry mentions carer choice, whilst the in-principle ideals listed in Schedule 1 of both the Commonwealth and NSW Carer Recognition Acts say that carers should have the same rights, choices and opportunities as other Australians.

The underlying reasoning for prohibiting of carers rights is explained in the Carer Inquiry report, which said that it was financially unfeasible for the taxpayer to fund full support of dependants, in the form of community living. As the WPR analysis shows, this reasoning affected the ensuing policy and legislation. The new taxpayer levy for the National Disability Insurance Scheme represents a substantial funding opportunity that may make taxpayer-funded support of dependants feasible. Particularly if this new funding is directed to the new service and accommodation models derived by alternative research and carers views as discussed above.

Finally, implementation of the fair care theory is both socially and morally crucial socially crucial, because carers are increasingly reluctant to care. This was noted by researchers, the Carer Inquiry, (Esping-Andersen 1999, Australia 2009) and carers interviewed who emphasised that they deserved to have a life, choice in their future, that no one should assume they will keep “on and on doing it” [Catherine] “I’m not going to be a slave, the backstop, the good old carer. I have a life too” [Sue].

Morally, media reporting of carers’ lives, particularly the snapshot of the Sydney family of four whose murder-suicide in Sydney in October 2016 is a sobering reminder of the extreme desperation experienced by some carers that must warrant urgent moral attention and an assurance of carer liberty and choice.

Thus, employing the fair care theory in policy means different design criteria, which suit dependants, and will inform the development of additional and new service and accommodation models that are more efficient. This, coupled with new funding under the NDIS scheme and the moral imperative to guarantee carer liberty, can make taxpayer-funded care of dependants feasible and means the fair care theory can be implemented.

Apart from a reorientation in policy to reflect the fair care theory, the vehicle for facilitating its implementation is by amendments to carer-specific legislation. As noted, both national and NSW state carer legislation include schedules addressing carer choice and equal opportunity. These Acts should be adjusted to include the principles and language of the fair care theory, remove clauses that prohibit carers' rights and thereby guarantee liberty and choice for carers and care of dependants. To complement the new Disability Inclusion Act 2015, amending carer legislation should also signify that the focus of carer treatment is not recognition but *inclusion*, and thus future amendments should retitle carer legislation to "Carer Inclusion Act".

Prevailing government policy and legislation together with disability and carer theory all converge to effectively entrap carers in long-term obligations to dependent people, a situation which is both socially and morally urgent. The new fair care theory can be practically implemented in policy both within Australia, and internationally to guarantee fair carer treatment.

## **Appendix 1 Carer interview questions: Carer choice in lifestyle and services**

The interviews were conducted in a semi-structured format using the questions below.. The nature of this sort of interview meant that I asked supplementary questions, used prompts ( as shown in italics) to explore issues raised by participants, or pursued themes as they emerged through the interview.

**Introduction:** This is a discussion about you. Thank you for agreeing to participate.

I'd like to explore your thoughts and wishes about your lifestyle, your thoughts about your caring role, and your ideas on what's important in the carer/disability service system.

Please let me know if you need more time, if you need me to explain the questions better, or if you want to return to some questions later in the interview. If at any time, you would like me to pause or stop the interview -- please let me know.

I'd like to start by asking some background questions about yourself and your family situation.

### **Background questions**

1. How old **are** you?
2. Record gender=
3. Are you currently studying?
  - a. If yes, what are you studying and how much of your course is complete?
  - b. If no, what is the highest level of education or training you have done?
4. Do you work outside the home?
5. Were you born overseas?
6. How would you describe your cultural background?
7. Describe your family situation.
8. In regards to your child/other with a disability -- how would you describe the disability?
9. In any typical week how many hours would you spend caring for your child/other with a disability.
10. Do you regard yourself as the primary or main carer?

### **Carer Lifestyle**

Government and service providers, like Family Advocacy, talk about 'person centred' and 'living the good life' when they are talking about people with disabilities. Do you think these goals should also apply to carers/parents? ... What would 'living the good life' mean to you?

I'd now like to explore some of your lifestyle choices. The following questions are about the impact caring might have had on your life and on the choices you've made.

1. If you did not have the extra responsibility of caring for your son/daughter- what would you have done differently?

*PROMPTS:*

1. *Do you think have been materially better off?*
    - a. *In what way*
  2. *Different job, career-path?*
  3. *Home environment*
  4. *Different relationships and social life*
  5. *Involvement in the community?*
  6. *Level of health and fitness?*
  7. *Would your emotional health/well-being be different?*
  8. *Would you have pursued other leisure or travel opportunities?*
  9. *Are there any other interests you would have pursued?*
  10. *Are there any other lifestyle choices you would have made?*
2. Out of the differences, you have described; what are the ones that you feel most keenly?
3. You have a named... X... Y...Z... choices/ areas as important to you. In thinking about these choices, would you have liked to have your caring responsibility reduced so you could pursue them?

### **Fair Treatment for Carers**

We were just speaking about what you would like in your life and the impact of caring on your life.

4. Government policy for people with disability assumes that carers like you will keep caring as long as possible, rather than relying fully on professional services. Do you think this is fair?
5. Do you think yourself and other carers should have the same freedom and opportunities to 'live a good life' as other people do?
6. Sometimes the obligation to care can hinder you pursuing work and other opportunities/interests. Do you think carers should have the right to decide whether to provide care?
7. And to what extent they provide care?
8. Do you think is a government's responsibility or carers' responsibility to financially support the care of their disabled daughters/sons?
9. On balance, would you choose to be a carer? (*Why/why not*)

10. How much longer do you see yourself being a carer to your son/daughter?  
(Ideally /realistically)

11. Do you think carers' opinions are valid and helpful in designing carer and disability services?

### **Views of the Service System**

I'd now like to explore what you think are the key requirements for services to you and your son/ daughter.

12. Do you and your son/daughter receive support and services? (Prompt: What types of services)

### **Accommodation -- provision and design criteria**

Let's talk about accommodation services. The government is planning to close down larger residential centres and provide small group homes or individual accommodation - it plans to provide enough accommodation for around 6% of all disabled people over 18 years old.

13. What do you think about this?

14. What would you prefer and why?

15. What do you value in the design of accommodation services? -prompt towards operational criteria

16. In terms of other carer and disability services, what services do you wish you had more of? (sic)

17. In the design and goals for these services, what do you think are the most important features?

*Only use these prompts if further exploration needed:*

*So that I can "tease out" your thoughts on service criteria I'd like you to think about common needs and criteria, I'd like you to tell me which of these needs you think are the most important?-*

*Which do you think are the next most important? Why?*

18. How well do you think services are meeting these needs?

19. Do you think any of these, or any other, needs are of critical concern?

20. Do you feel assured that the government will meet the most important needs in the future?

21. What would you like to tell government/service providers about the design of the carer/disability service system?

**Concluding questions**

So far, we have talked about your lifestyle, caring roles and goals/criteria for the service system.

22. Is there anything else is like to say about these issues?

23. Is there anything else you want to say?

Thank you for taking the time to participate in this interview.

24. If I do not understand some of the information you have provided, can I contact you again via phone or e-mail to clarify details?

After today, if you find other ideas spring to your mind that you would like to discuss with me, please contact me. My e-mail address is on your copy of the consent letter.

## **Appendix 2 WPR analysis of relevant practical texts**

### **A2.1 Fifth and sixth reports under the International Covenant on Civil and Political Rights, 2006 and 2016.**

The 2006 report contains two sections, sections M and R, which have an oblique reference to carers (Attorney General 2006).

Section M is titled “right to liberty and security of person”. However, this section applies to liberty in the public sphere, via political rights and mainly deals with treatment in immigration, detention and prison. Again, the concept of liberty from coercion in the private sphere is unproblematised.

Section R of the 2006 report had an oblique relevance to carers and dependants. It outlined mother and child physical protection, and parenting support. Generally, this section refers to the need for governments to support families to balance work and family commitments by provision of direct child support, maternity payments, and rights to maternity leave and family/carer leave. Government supported childcare is intended to enable parents to work. The particular needs of carers for specialist childcare are discussed, with a recognition that additional funding is required to provide specialist support for dependants up until the age of 18 (childcare for typical children ends at age 12). In comparison, the 2016 report (Attorney General 2016) does not refer to carers. The report focuses on treatment of Indigenous people and women, women with disabilities, counter-terrorism and treatment of asylum seekers. This change reflects an increasing silence on carers.

### **A2.2 Australia's combined sixth and seventh report on the implementation of the Convention on the Elimination of all Forms of Discrimination against Women July 2003 – July 2008.**

This monitoring report (Attorney General 2008) is a 104-page document that addresses each of the treaties 16 Articles. Carers are not identified as a disadvantaged group who are entitled to equal treatment in key societal areas. Instead, carers are mentioned as firmly ensconced in a normative familial care situation, along with parents of typical children. Thus the reports assessment against Article 11: Employment, reads: “the Australian government respects the choices of Australian parents about their decisions

to work or stay at home to care for family members” (48) and goes on to refer to helping parents and carers by recommending workforce flexibility, increased childcare and achieving a balance between paid work and care responsibilities.

In the assessment against Article 13: Economic and Social Participation, a brief single page addresses the care of children, people with disabilities and the elderly, and outlines the government's provision of specific carer services and financial support schemes such as Carer Payments.

Article 16, which addresses violence in the private sphere of the family is again silent on carers as entrapped and possibly subject to physical and emotional violence and abuse. Instead, domestic violence (particularly on indigenous women) and the violence and abuse of women with disabilities in formal supported accommodation are monitored.

In July 2010, a United Nations (UN) committee provided a report on its review of Australia's sixth and seventh combined CEDAW monitoring report. The UN committee expressed an overarching dismay that Australia had not adopted a Human Rights Act. It favourably remarked on several improvements, under legislation, to women's workforce entitlements and conditions, expressing some uneasiness that despite Australia's initiatives, there was an:

under-representation of certain vulnerable groups of women, including indigenous women, women with disabilities, ... there has been slow progress ensuring their equal participation in leadership and decision-making positions, in public and political life as well as the equal access to education, employment and health (United Nations Commission 2010 Comment 26)

The UN committee recommends Australia adopts a more aggressive policy of temporary targets with a particular focus on indigenous women and women with disabilities. The UN review committee did not include carers as one of the 'certain vulnerable groups', nor identify them as requiring interventionist policies to facilitate their equal access to valuable social roles in the public sphere. As carers are not identified or monitored for their levels of participation and achievement in the public sphere, their underrepresentation in valued public roles is absent.

### **A2.3 The NSW Disability Services Act 1993 (DSA) -repealed.**

The DSA begins by stating its objects and listing pertinent definitions. It then outlines a further 24 clauses and two schedules: Schedule 1 which contains the key principles and

administration of disability services; and Schedule 2 which, in anticipation of the closure of institutions for the disabled, addresses the treatment of the finances of disabled residents.

The DSA is an Act which is predicated on the human rights of persons with disability In NSW. The introduction to the principles in Schedule 1 states: “persons with disabilities have the same basic human rights as other members of Australian society. They also have the right to ensure that their specific needs are met” (PCO 1993: 17). On the premise of such rights, Schedule 1 then goes on to specify the nine circumstances in which these rights are to be realised. The DSA’s key principles of equal citizenship, age-appropriate treatment, and integration form the basis for many of the principles and objects which are to apply to the majority of key settings.

In practice this means people with disabilities would reside with their families and attend ordinary or typical educational facilities and later, exercising choice, live independently, be gainfully employed and occupy a valued social identity, comparable to their same-aged peers, as opposed to a devalued, deviant identity.

Like the CDSA, the DSA does not specifically reference disability theory; however its overarching approach also espouses the principles and language of disability theory.

An example of the social model (SM) social role valorisation (SRV) and normalisation (N) is seen in the following excerpt drawn from the aims of the DSA. For ease of reference, key common phrases are underlined:

To ensure the provision of services necessary to enable persons with disability. To achieve the maximum potential [SRV and N] as members of the community (PCO 1993).

The effect of this problematisation is to ignore the particular dependencies of people with disabilities and the impact of this dependency on carers. For example, following disability theories, the DSA presents as a key problem the achievement of integration, independence and equal employment for all people with disabilities:

to ensure the provision of services that:

further, the integration [SM, N] of persons with disabilities in the community...

enable persons with disabilities to achieve positive outcomes, such as increased independence, employment opportunities [SRV] and integration in the community, and

are provided in ways that promote in the community of positive image of persons with disabilities and enhance their self-esteem [SRV]... (PCO 1993: 2)

A severely intellectually disabled person will not achieve this assumed independence. The effect of this problematisation is to ignore the impact on carers under the mistaken presumption that valued social roles of independent living and employment are achievable for dependants. Similarly, the principles contained in Schedule 1 mirror the social model theory of disability:

a) ... positive outcomes for persons with disabilities, such as increased independence, employment opportunities and integration into the community ...

g) to promote the participation of persons with disabilities in the life of the local community through maximum physical and social integration in the community,

[and, reflecting the ideals of social role valorisation and normalisation:]

b) ... that the conditions of everyday life of persons with disabilities are the same as, or as close as possible to, norms and patterns which are valued in the general community...

j) to provide opportunities for persons with disabilities to reach goals and enjoy lifestyles which are valued by the community generally and are appropriate to their chronological age[also SRV &N] (PCO 1993: 18).

The problematisation of the DSA can be summarised as: 'how best to achieve the precepts of disability theories'. As with other legislation, the status and enforceability of the DSA's objects (aims) and the principles contained in Schedule 1 are dependent on the clauses of the DSA.

The first of the DSA's active clauses – Part 2, Division I, Clause 6 states: "it is the duty of the Minister in providing and funding designated services ... either directly to those persons or indirectly to other persons or bodies, to ensure that the services are provided and funded in conformity with the objects of this Act and the principles and application of principles set out in Schedule 1". A further clause (Clause 8) assigns the Minister the responsibility of facilitating the provision of appropriate services, again either directly or via funding to other organisations.

Division 2, Clauses 10 through 20 outline the mechanisms whereby the Minister is able to approve financial assistance to persons with disabilities, or persons/organisations providing care or support to persons with disabilities. Eligible service organisations are defined as those which conform to the principles of Schedule 1. There is also a reference to the ability of the Minister to provide financial assistance to the Minister for Health, for people with psychiatric disability. Clause 20 provides a mechanism to review financial assistance to ensure compliance with the principles of Schedule 1.

Clause 24 of Part 3 binds the Crown as far as legislative power of Parliament permits and holds that it does not allow for the Crown to be held liable for prosecution. Clause 25 states that it does not give rise to, or hold to account 'any civil cause of action'.

Schedule 1 of the DSA uses the principles and language espoused in disability theories, particularly the social model of disability, social role valorisation and normalisation. Thus, in binding the Minister by the provisions of Schedule 1, the DSA restricts ministerial funding to only those services or organisations that achieve the principles of disability theory.

The implications for carers here is both implicit and direct. It is implicit in the silence around the Minister's obligations to provide a certain level or extent of service, and explicit in prohibiting any civil liabilities arising, particularly in relation to the adequate provision of government-provided services. This means that the Minister is only responsible for the distribution of such funding as is made available by government, in the manner prescribed in Schedule 1. There is an acute silence on what happens when such funding is inadequate. The effect of this silence within the problem representation of the DSA is borne out in the lives of carers who are obligated to fill the deficit in government-funded support.

#### **A2.4 NSW Policy: 'Stronger Together 2' extended by 'Ready Together'.**

The funding distribution between various service types is based on actuarial modelling which factors in specific inputs to yield the best distribution scenario against a stated outcome. Significantly, the key impetus in this modelling is to avoid a crisis-driven service approach and take account of specific demographic shifts to provide a best-fit level of service within a projected budget. The specific demographic inputs were the

increases in the number of people with disabilities, the reduced capacity of ageing carers, and the anticipated benefits of early intervention and prevention. Note the term 'capacity' in relation to carers rather than recognising carer choice in whether to provide no, partial or full care support.

This orientation continues with the in-principle commitment of the new plan which says that it will build on the DSA's objects (which are based on disability theory) and refresh and enhance them in compliance with the UN's CRPD.

The overview of consultation presents a quote from participants followed by the NSW Government's summary response. Key issues were cited as: planning across the lifespan, efficient use of increased funding, community integration, employment, information, and choice and certainty. There is a marked difference between community submissions and government's interpretation of them. The community comment quoted in the plan says: "Provide more accommodation options for people with disabilities. It should be planned in advance with the family or carers to allow a smooth transition ... [The government's interpretation of this is:] "You said there needs to be more choice and certainty so that you can plan for the future" (ADHC 2011: 15). More choice in service type is not the same thing as more accommodation options. This is a government policy sophistry wherein the direct request for more accommodation options is dissipated into a vague requirement for more choice and certainty in support services, to enable carers, as an assumed setting and co-partner for much of this service delivery, to plan ahead.

Following this, the plan describes four broad strategic goals followed by details of the fiscal funding distribution via specific service types. The four service goals are described as person-centred approaches for people with disabilities to direct service resources; a life span approach; a commitment to large residential institution closures by 2017/18; and the creation of a service system that works efficiently.

The proposed funding distribution by service category is described below; I have derived this 'proportional service' table from the data provided in the service summary Table described on page 19 of the Plan which shows the number of places allocated to each of the seven service types at 5- and 10-year intervals.

The distribution of places does not directly translate to the distribution of funding; places in some service types cost more than others. Nor does a place correlate with a

single person; a person with disabilities may simultaneously utilise places in several service types. An analysis of projected places by broad service type is useful in indicating the broad pattern of services planned by the government; it helps to answer the core question of what services government prioritises. The projected provision over 5- and 10-year intervals allows an analysis of the comparative service split between various service types and any significant shift in the NSW Government's service orientation. This shift in patterns indicates the government's problematisation development or consolidation.

Proportional Services Table:	% Allocation of places at baseline – 2005/06	% Places in 10 years 2006 till 2016 as % of all places provided in this 10-year period.	% Places in total as a % of all places provided by 2016	Total number of places by 2016.
Community support ¥	41.9	49.2	46.6	51 200
Respite	11.9	8.9	10.3	11 300
Family support ¥	10.5	21.9	17.3	190 000
Post school programmes	9.4	8.9	9.1	10 000
Day programs	15	5.5	9.3	10 200
Attendant care	0.7	<1	<1	930
Supported accommodation ¥	10.5	4.3	6.8	7 500

Total number				109 930
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The proportional service table shows the percentage allocation of places at both the baseline capacity (2005/06) and the projected capacity as at 2016. The service delivery types marked ¥ are not defined in the glossary. Unfortunately, this applies to the two critical service types that directly affect carers: community support and supported accommodation. Community support is critical because it constitutes almost half of the total places provided by 2016. A search of the Department website refers to community support as providing links to a range of discrete services such as information, skill development, therapy, and general support; effectively a form of case management. Such discrete supports could be available for dependants who remain the responsibility of the carer and the family home. The supported accommodation is also referred to in the Department's website as the provision of a variety of build models (e.g. group homes, villages, cluster models, apartments) in which people with disabilities live and are supported.

The life-span goal states that adult persons with disability will be supported 'to participate in and contribute to their communities' (ADHC 2011: 22); it is unclear what proportion of these adults are presumed to continue to be supported by carers 'in the community'. However, it is reasonable to assume that the majority of such adults will be supported by carers given the limited total number of new accommodation places (a portion of which will be absorbed by deinstitutionalisation).

## Appendix 3 – Cummins and Lau’s benefits of integration

Cummins and Lau list the benefits of integration from three key standpoints. They argue that the first two benefits are irrelevant, of limited benefit or achievable via other means, noting that only the third, which benefits the disabled person, could reasonably justify enforced integration with the general community.

**1. Benefits from a service provider/government perspective** – in line with current professional thinking, incorporating the theories of normalisation, which state that integration is beneficial; that integration increases resources by increasing public visibility; that community exposure changes public attitudes; and finally, that integration necessarily confers tangible benefits to intellectually disabled people.

**2. Measures of objective benefit** – this refers to measures of improved performance of the individual, in terms of reductions in verbally or physically hostile behaviour, or general developmental skills including life skills. These are the typical improvements envisaged in the principles of normalisation and SRV. For the two key life stages – preschool-school and adult working life, it was observed that generally many studies made exaggerated claims of potential benefits. For example, in the school and preschool environment, whilst there were small advantages in increased social behaviour, there were no changes in verbally or physically hostile behaviour or general developmental skill improvement. The relational and positive personal network gains promised as result of school integration are not evidenced in the empirical literature. Whilst some studies observed moderate degrees of contact between disabled and non-disabled students, when the observational data was standardised it was discovered that most non-disabled students did not initiate any interaction with their disabled peers. For example, Cummins and Lau, in reviewing one study<sup>39</sup> found that over half the disabled

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<sup>39</sup> A report by Cutts and Sigafoos (2001) “Social Competence and Peer Interactions of Students with Intellectual Disability in an Inclusive High School”. In the Journal of Intellectual and Developmental Disability 26, p127-143. This report included naturalistic observations of 9 children aged 14 to 18 with mild- to moderate levels of intellectual disability integrated within a Brisbane high school; Cummins analysis notes that the outliers of the disabled group distorted average values and examined the studies in terms of initiator/recipients of social interaction and the interaction observed for each individual student.

group had very little recorded contact with their non-disabled peers; they concluded that:

just as it cannot be assumed that all children with a disability will make better developmental and scholastic progress in an integrated environment, so it cannot be assumed that all intellectually disabled children will be embraced by their nondisabled peers (Cummins and Lau 2003: 150).

In terms of disabled adults in their home and work environments, a similar predisposition to selectively interpret results, to show the benefits of integration, prevails: “the benefits of integrated living are emphasised while the areas of non-benefit or even disadvantage, are de-emphasised.” (Cummins and Lau 2003: 147). Thus studies that compare cluster housing with individual community (group) homes invariably show that the group home occupants enjoy a significantly better quality of life. When examining the data behind the claims of one such study<sup>40</sup> it was found that the analysis was severely flawed. The quality of life improvements reported in the study referred to a larger circle of relationships; on further examination, it was found that this larger circle was effectively a reference to the higher staff-to-resident ratio found in group homes. Studies which compare integrated- to segregated employment situations show that integrated employment shows positive effects on quality of life of intellectually disabled people. When the data behind another study was further analysed and subjected to statistical correction techniques the only significant change was the increase in weekly income<sup>41</sup>.

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<sup>40</sup> Review of a study by Emerson et al. (2000). Published as: “The Quality and Costs of Community-Based Residential Support and Residential Campuses for People with Severe and Complex Disability” in: *Journal of Intellectual Developmental Disability* 25, pp 263 to 279. This study concluded that people living in community homes when compared with cluster homes, “enjoyed a significantly greater quality of life” (p 263). Cummins notes however this indicates more complex results; for example there was no difference between the two environments in terms of person-centred planning, assessment, teaching or the frequency of residents/staff interaction; furthermore, in the community home there was more disengaged activity, no differences in family community network size (after staff had been accounted for) or any difference in engaged activity. The definitive conclusion of the study is therefore very surprising.

<sup>41</sup> Review of a study by Inge et al. (1988) whose findings were reported in an article : “ Quality of Life for Individuals Who Are Labelled Mentally Retarded: Evaluating Competitive Employment Versus Sheltered Workshop Employment” in *Education Training and Mental Retardation* -- 23, pp 97 to 104 – a study which compared 20 people, who moved from segregated- to competitive employment, to a control group who remained in the segregated employment setting – the authors claim the study provided an ‘ all encouraging picture of the positive effects of competitive employment on the quality of life of persons with mental retardation’ (p 97) – Cummins claims their analysis is severely flawed due to the miss-application of statistical tools which when corrected found no significant main effects.

Cummins and Lau claim that much of the literature on integrated employment is flawed because it is premised on an incorrect causal relationship - it assumes that the intellectually disabled persons well-being and social competence is caused by their physical integration, however an alternative explanation would be that those disabled with higher social skills are more likely to obtain integrated employment, remain employed, and report benefits of their employed situation. Thus it is the higher-functioning intellectually disabled person's individual skills and attributes (higher social skills) which enabled their sustained employment, integration, social competence and well-being. Cummins concludes: "thus, it should come as no surprise to find that when people with poor social skills are placed into a workplace environment, they do not integrate well with other employees" (Cummins and Lau 2003: 150).

**3. Subjective benefit to intellectually disabled people individual** – Cummins's "Comprehensive Quality of Life Scale" (CQLS) (Cummins 1996) measures quality of life as perceived by the individual. In application, the CQLS consistently demonstrates that individuals regard intimate, stable, personal relationships as integral to their quality of life. A study conducted by Disability Services Victoria in 2000 involved 444 personal interviews and 14 focus groups. In terms of the aspirations of people with a disability, they found that having an intimate friend ranked above community integration. Eight studies reviewed by Cummins found negligible or modest improvements in subjective personal benefit as a result of community integration, compared with cluster housing, institutional living, or living with one's birth family. The CQLS is utilised for study with the general population and people with intellectual disability. The scale asks people to rank 7 domains in terms of their importance and satisfaction, "and the rank order is highly predictable. Practically everybody regards the domain of relationships at the top of their list, and the domain of community at the bottom" (Cummins and Lau 2003: 148). If sustained personal relationships are valued by most people, including those with intellectual disabilities, then sustaining these relationships is, ultimately, the only justifiable policy and service goal.

## Appendix 4 – Further Notes on Virginia Held Ethic of Care

Held describes how the ethic of care has much to offer in global relations between states and nations, in addressing global inequality. She claims that this enlightened view would contrast with the current situation where, typically, morality is absent, or only the morality of justice is applied. Held believes the adherence to individual rights, equality and universal law (within and amongst citizens of a nation), without responsibilities towards other nations, permits a view of rival and competing nation states who individually pursue their own national interests:

The ethics of care, in contrast, understands the importance of cultivating relations of trust, listening to the concerns of others, fostering international co-operation, and valuing interdependence (Held 2004: 149).

Held's dismissal of the ethic of justice in liberal moral theory, as contemporarily exemplified by John Rawls, is based on an arbitrarily narrow and superficial assessment. Held casts liberal theory as defining all persons (mistakenly) as isolated individuals, independent and non-relational, bound within an artificially abstract universal moral theory in which we agree

to imagine each other as liberal individuals and to adopt liberal policy to maximise individual benefits. ... The ethics of care offers a view of ... human relations on which satisfactory societies can be built. It provides new theory with which to develop new practices and can perhaps offer greater potential for moral progress (Held 2006: 28)

Held outlines ideas around how the alternative moral theory of care can influence nation states to view their global responsibilities differently. In proffering this account, Held paints an idealised view of "a globalization of caring relations [which] would help to enable people of different states and cultures to live in peace, to respect each other's rights, to care together for the environment, and to improve their lives so that all their children might have hopeful futures" (Held 2004: 153). Held presents ideals and concepts, but despite her claims otherwise, she has not outlined a new theory.

## Appendix 5 - Copy of Final Ethics Approval



### Faculty of Arts

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18 June 2010

A/Prof Marion Maddox  
Director  
Centre for Research on Social Inclusion  
Macquarie University

**Reference: 5201000516**

Dear Associate Professor Maddox

### Final Approval

#### **Re: The family carer - choices on lifestyle, caring roles and priorities for service**

Thank you for your recent correspondence. Your response has addressed the issues raised by the Human Research Ethics Committee and you may now commence your research. This approval is subject to the below mentioned condition:

1. Please forward to the Committee a copy of the approval from each of the companies where the interviews have taken place.

The following personnel are authorised to conduct this research:

Associate Professor Marion Maddox – Chief Investigator/Supervisor

Ms Michelle Dellagiacoma- Co Investigator

Please note the following standard requirements of approval:

1. The approval of this project is **conditional** upon your continuing compliance with the *National Statement on Ethical Conduct in Human Research (2007)*.
2. Approval will be for a period of five (5) years subject to the provision of annual reports. **Your first progress report is due on 18/06/2011.**

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

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

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

3. If the project has run for more than five (5) years you cannot renew approval for the project. You will need to complete and submit a Final Report and submit a new application for the project. (The five year limit on renewal of approvals allows the Committee to fully re-review

-2-

research in an environment where legislation, guidelines and requirements are continually changing, for example, new child protection and privacy laws).

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

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

5. Please notify the Committee immediately in the event of any adverse effects on participants or of any unforeseen events that affect the continued ethical acceptability of the project.
6. At all times you are responsible for the ethical conduct of your research in accordance with the guidelines established by the University. This information is available at the following websites:

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

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

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

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

Yours sincerely



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Dr Karolyn White  
Director of Research Ethics  
Chair, Ethics Review Committee (Human Research)

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