

Does your carer take sugar?

Carers and human rights: the parallel struggles of disabled people and carers for equal treatment.

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Abstract:

This paper considers the struggle being waged by unpaid carers (sometimes referred to as ‘carergivers’) for recognition as ‘rights holders’. It locates the origins and describes the growth of the ‘carers movement’ and argues that it has many similarities with the Disabled People’s movement that came to prominence in the 1970’s. The paper: (1) identifies the distinct legal status that carers have in the majority of states in the world; (2) describes carers’ shared history of adverse treatment within most states; and (3) argues that carers’ social exclusion arises from a widespread hostility to ‘dependency’ – a hostility that is gendered and particularly evident in neoliberal political discourse.

The paper argues that there is a substantive human right ‘to care’ – one that fits most comfortably within the civil and political right to ‘privacy / private life’; that states have positive human rights obligations to carers; and that ‘being a carer’ should (and will) become a protected status for the purposes of non-discrimination legislation, on the same basis as other protected statuses (such as disability).

The paper concludes with a caveat: that the recognition of caring as a human right and of carers as ‘right holders’ (although inevitable and of great importance) will not in itself be sufficient – that this much we also learn from the Disabled People’s movement.

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35 years ago a BBC Radio programme came on air in the UK called 'Does he take sugar?'² The title was provocative, since the subject matter of the programme was disability. The title tilted at what it perceived (rightly no doubt) as the prevalent conceptualisation of a disabled person by its listeners: that of a compliant cripple seated in his wheelchair grateful for the services and sympathy bestowed upon him. A tragic unhearing victim, incapable of expressing independent opinions or knowing what he needed – an object of discussion, whose needs were primarily the responsibility of the social care authorities.

The programme was a symptomatic marker of the journey disabled people were travelling: towards a radical transformation of the way they understood themselves and the way non-disabled people understood disability. At the time of the programme a few legal milestones had been planted, of which the USA's Rehabilitation Act 1973 was a prominent, if modest example.

Today the popular conceptualisation of a disabled person would, I hazard, be quite different. The tragedy module still no doubt dominates – but the notion that disabled people are compliant, grateful and non-verbal would be discounted by the vast majority. To use the phrase 'a disabled person' is to conjure up the associated notion of discrimination legislation: of a group who are potentially prickly – who sue and who take direct action if you get on the wrong side of them. They are conceptualised by an increasingly large portion of the population as rights holders: people who win human rights cases and for whom it is no longer the social care authorities (or even public bodies) who have sole responsibility: all of us now have responsibilities – schools, cinemas, supermarkets, banks – even Ryanair.

In the mid-1970's few lawyers would have considered disabled people as candidates for non-discrimination legislative protection. Sex and race maybe (contested as of course these had been) but disability was such an elusive concept, and in any event it was viewed as a self evident handicap, unlike sex and race which were (by then) viewed as prejudicial inferiority constructs: lacking any material justification. Disabled people on the other hand, needed state supports and accordingly were better conceptualised in terms of positive obligations and as having the protection of the soft socio-economic rights rather than the hard negative civil and political rights.

With the widespread acknowledgment that disabled people are materially handicapped by social and physical barriers (the so-called 'social model' of disability) such an

² See B J Sweeney 'BBC Radio 4 and the experiential dimension of disability' in *Disability & Society* 20, No. 2, March 2005, pp. 185–199.

analysis is no longer tenable. In individual domestic legislative terms this new conceptualisation is manifest in the surge of provisions outlawing disability discrimination,³ which in turn led to regional and international action culminating in the UN Convention on the Rights of Persons with Disabilities (UNCRPD). In little over 30 years we have redefined 'handicap' and have come to regard it as normative to view disabled people as entitled to equal treatment: even if the prevalent conception of a disabled person is still a 'he in a wheelchair'.

Today when human rights lawyers consider the language of the key founding documents, for example the International Bill of Human Rights, the American Convention on Human Rights and the European Convention on Human Rights (ECHR), many express surprise at the absence of disability from the familiar litany of protected statuses: race, colour, sex⁴ – as if disability was a self evident category for protection: indeed it was not.

A while ago I wrote to the BBC to suggest that they should broadcast a new programme: 'Does your carer take sugar?' – for it is at least arguable that carers (by which I mean people who provide care on an unpaid basis for a 'dependant person'⁵) find themselves in a position similar to that of disabled people 35 years ago. Today the prevalent conceptualisation of a carer is, I would suggest, of someone grateful for the services and sympathy⁶ bestowed upon her, and for whom the social care authorities have prime responsibility. Few human rights lawyers would conceptualise carers as rights holders: for being a 'carer' is an elusive concept and in any event it is not an innate characteristic (like sex, race and disability) and the handicaps experienced by carers are those they assume when they choose to take on their caring roles: carers' need for support is therefore better conceptualised in terms of positive obligations and as having the protection of the soft socio-economic rights rather than the hard negative civil and political rights. Carers, in a phrase, cannot legitimately be viewed as 'rights holders'.

In this paper I argue that carers should be seen as a category of persons entitled to protection from discrimination: that they should and will come to be viewed as self

³ Within 25 years of the Rehabilitation Act 1973, 38 states had introduced legislation outlawing disability discrimination – see , T Degener, 'Disability Discrimination Law: A Global Comparative Approach' in Lawson L & Gooding C (eds) *Disability Rights in Europe: From Theory to Practice* (Hart Publishing 2005).

⁴ See for example, Article 14 ECHR which specifies 'on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.'

⁵ Generally referred to as caregivers in the USA.

⁶ L Clements, 'Keynote Review: Carers – the sympathy and services stereotype' in *British Journal of Learning Disabilities* v.32 No. 1 920040 6.

evident 'rights holders'. By contrasting their two journeys I do not argue that they must follow the same route: all discriminations are unique and although there are profound similarities between the struggles waged by people subjected to discrimination on grounds of sex, race, disability, sexual orientation, age, religion and so on – each of these 'statuses' has its own inimitable core and distinct narrative. There is of course an obvious interconnection between the struggles of carers and disabled people for equal treatment, but this connectedness should not mask the challenging differences between their claims for recognition.

The Rights Moment

For a group experiencing oppression to unite and to express their disadvantage in the language of 'rights', depends upon the convergence of a number of socio-political, cultural and conceptual factors. This paper considers three: the development of an identity; a narrative; and a creed.

The group needs, in one way or another, to 'self-identify' as a category of persons oppressed by virtue of a particular uniting characteristic: as Shakespeare has observed⁷ (in the context of the development of the disabled person's movement) an identity that 'connects the social and the personal and involves the individual putting themselves in a collective context': a context that 'focuses on ... exclusion and injustice'. It is a process that needs a history: a narrative documenting the nature and the extent of the negative treatment they have experienced. Finally the group needs a convincing theoretical model that articulates and explains their adverse treatment in social and political terms. For disabled people, of course, this was the social model of disability.

Once these factors are in play, there is the potential for a radicalised campaign, challenging all aspects of the negative treatment experienced by the group: one that demands equal treatment in place of toleration or 'privileges'. It is the stage at which socio-political and economic forces converge creating a 'constitutional moment'⁸ - an imperative for legal change.

⁷ Tom Shakespeare, 'Disability, Identity and Difference' in Colin Barnes and Geof Mercer (eds) *Exploring the Divide* (The Disability Press, Leeds) pp. 94 – 113 at 100 and 101.

⁸ Robin West, 'The Right to Care', in EV Kittay and EK Feder (eds) *The Subject of Care: Feminist Perspectives on Dependency* (Roman and Littlefield 2002) p98.

Identification

As a simple matter of human rights and equality law, discrimination becomes unlawful when a person is treated unfavourably for a 'status' related reason – provided it is a recognised or 'protected' status.

The legal bestowal of 'status' is an explicit and highly symbolic act: evidence that society attaches such importance to a distinction that it demands explicit recognition. It is the stuff of power relationships and tribalism: of critical masses and crystallisations. It involves the assigning of a value to a difference: though in truth the process has generally the effect of devaluing – whether articulated in the language of paternalism (as it has been for women and disabled people) or the language of criminalisation (as with Gay or Aboriginal / First Nations Peoples).

Whilst the legal recognition of status is a necessary precursor to any rights movement – it is, in itself, insufficient. The group has to take possession of that status, redefine and own it. Although the process of reconceptualisation may often require a renaming (no longer nigger, cripple or queer) it will invariably be subversive and celebratory: of Ian Dury, Gay Pride and sisterhood – for the law and social change, like shackled prisoners, move together. The group must, in short, 'self-identify': its members must embrace sabotage and radicalise the status it has been assigned.

The section that follows considers these two issues. It commences with an overview of domestic laws that deal with carers as a specific group. It then considers the socio-economic and political factors that have produced the essential component for legal change – a critical mass of self identifying carers.

The legally entrenched status of carers

In much of the world, 'being a carer' is not only a designation that results from a process of self-ascription – it is also a legally created status. Whilst scholars differ as to the reasons for such provisions,⁹ laws obliging people to provide care, solely by virtue of a family relationship or marriage, are ubiquitous.

In the England and Wales a liable family rule was formalised in the Poor Relief Act 1601 and persisted (though reformulated in the Poor Law Act 1930, s14) until repealed by the National Assistance Act 1948, s1. The Poor Law was exported to the colonies where it

⁹ It has, for example, been suggested that there are philosophical – rather than simple community cost avoidance reasons for such obligations see for example MC Stuijbergen and JJM Van Delden, 'Filial obligations to elderly parents: a duty of care?' in *Medicine, Health Care and Philosophy* (2011) 14,63.

has proved to be more tenacious. In the USA, for example, it appears that 30 states¹⁰ still retain filial responsibility statutes.¹¹ Such laws are also present in most Canadian states¹² (albeit endangered¹³) in India¹⁴ and Singapore.¹⁵

In Europe, duties on family members to provide care (or financial support in lieu of care) are found in the Constitutions of Greece and Ireland¹⁶ and in the Civil Codes of many states – for example, Belgium,¹⁷ France,¹⁸ Germany,¹⁹ Italy²⁰ and Spain.²¹ The Civil Codes of many South American Constitutions contain a similar obligation (the duty on family members to provide ‘alimentos’) for example in Argentina,²² Peru²³ and Brazil.²⁴

¹⁰ Alaska, Arkansas, California, Connecticut, Delaware, Georgia, Idaho, Indiana, Iowa, Kentucky, Louisiana, Maryland, Massachusetts, Mississippi, Montana, Nevada, New Hampshire, New Jersey, North Carolina, North Dakota, Ohio, Oregon, Pennsylvania, Rhode Island, South Dakota, Tennessee, Utah, Vermont, Virginia, and West Virginia

¹¹ See generally K Wise, ‘Caring for our parents in an aging world: sharing public and private responsibility for the elderly’ in *New York University Journal of Legislation and Public Policy* (2001-2002) 5: 563; S Moskowitz, ‘Filial Responsibility Statutes: Legal and Policy Considerations’ in (2000-2001) 9 *Journal of Law and Policy* 709-736 see pp 714-717; and CHV Houtven and EC Norton, ‘Informal care and health care use of older adults’ in *Journal of Health Economics* (2004) 23, 1159-1180.

¹² See for example, British Columbia’s *Family Relations Act* 1996 s90 and *Newson v Newson*, 99 BCLR 2d 197 (1994, BCSC); Saskatchewan’s Parents’ Maintenance Act 1978, s2; Manitoba’s Parents’ Maintenance 1996, s1; and Ontario’s Family Law Act 1990, s32.

¹³ See for example, British Columbia Law Institute, ‘Report on the Parental Support Obligation in Section 90 of the Family Relations Act’ Report No. 48 (BCLI 2007) and Ministry of Attorney General (British Columbia) ‘White Paper on Family Relations Act Reform Proposals for a new Family Law Act’ (2010) at www.ag.gov.bc.ca/legislation/pdf/Family-Law-White-Paper.pdf accessed 15 May 2013.

¹⁴ India’s Code of Criminal Procedure 1973, s125 and the Maintenance and Welfare of Parents and Senior Citizens Act 2007.

¹⁵ The Maintenance of Parents Act 1995 s 167B; and see for example, G, H, Y Ting and J Woo ‘Elder care: is legislation of family responsibility the solution?’ *Asian J Gerontol Geriatr* 2009; 4: 72–5.

¹⁶ In Greece as Article 21 (and the Civil Code) – see G Kagialaris, T Mastroyiannakis and J Triantafillou, ‘The role of informal care in long-term care National Report Greece’ (Interlinks 2010) at http://interlinks.euro.centre.org/sites/default/files/WP5_EL_FAMCARE_final_04.pdf accessed 15 May 2013; in Ireland as Article 41(2) - see Alan Brady, ‘The Constitution, Gender and Reform: Improving the Position of Women in the Irish Constitution: Working Paper’ (National Women’s Council of Ireland 2012); and J O’Connor, and H Ruddle, ‘Caring for the Elderly Part II. The Caring Process: a study of carers in the home. Dublin’ National Council for the Aged. Report No. 19 (1988).

¹⁷ Articles 205 - 207.

¹⁸ Articles 205 and 206

¹⁹ Bürgerliches Gesetzbuch (para 1601 Civil Code) entitles close relatives to financial support against each other in times of need although this can be financial, as opposed to the actual provision of social care – see Meyer, M (2004) *National Background Report for Germany EUROFAMCARE Hamburg* para 2.1.4; see also R Means, S Richards & R Smith *Community Care: Policy and Practice (Public Policy & Politics)* 4th edn (Palgrave Macmillan 2008) p220.

²⁰ Article 433 see also B Da Roit, BLe Bihan and A Österle, ‘Long-term Care Policies in Italy, Austria and France: Variations in Cash-for-Care Schemes’ (2007) 41 *Social Policy & Administration* 653–671.

²¹ Article 143 - see A Jauregi (2004) *National Background Report for Spain EUROFAMCARE Hamburg* para 2.1.3

²² Civil Code Articles 367, 372 and 376 (bis).

²³ Articles 472 and 474.

²⁴ Articles 1694 and 1696.

The obligation is found as far afield as in the Civil Code of Taiwan²⁵ and in the customary laws of some African states.²⁶ In such customary laws (as indeed in the Irish Constitution) the gendered nature of the obligation is explicit: it is the duty of wives / women.

Even in those states where such obligations do not exist, or where the obligation is not in practice enforced, the evidence suggests that the dominant social attitudes exert strong moral pressure on family carers to fulfil this role. The assumption being that the family has primary responsibility for care giving: indeed, not so much family, as women whose duty it is to look after sick and frail elderly parents and in-laws.²⁷

In Australia, where no filial responsibility laws exist²⁸ it is said that there is an 'expectation that families will take the primary role in looking after the elderly members'²⁹ and in the Netherlands although there is no formal legal duty to provide care, the assessment of need under the state's Long Term Care Insurance Scheme includes an amount of 'customary' care family members are expected to provide for each other free of charge.³⁰

In much of Asia, it is said that the 'Confucian ideal of filial piety is ubiquitous'³¹ and to be highly gendered:³² in Japan for example these values create the assumption that 'middle-aged women' will provide the home nursing required by infirm elderly relations.³³

²⁵ Article 1114 of the 1929 Civil Code.

²⁶ Ghana's customary laws, for example, make it the duty of the wife and children to support their husband and father – see *Quartey v. Martey & Another* [1959] GLR 377 per J Ollenu (as he then was) and E Dankwa, 'Property Rights of Widows in their Deceased Husband's Estate' in [1982-85] 16 University of Ghana Law Journal 1, 2.

²⁷ For the UK context - see Means, Richards & Smith – footnote 19 above p 218.

²⁸ M Collingridge and S Miller, 'Filial responsibility and the Care of the Aged' in Journal of Applied Philosophy Vol. 14, No. 2 (1997) 119-128 and P A Gunn, 'The development of laws relating to filial support in Australia' in J Eekelaar and D Pearl (eds), *An aging World* (Clarendon Press 1989).

²⁹ S Sutherland *The Royal Commission on Long Term Care With Respect to Old Age: Long Term Care - Rights and Responsibilities* Cm 4192-I (Stationery Office, (1999) p.201.

³⁰ C Glendinning and N Moran *Reforming Long-term Care: Recent Lessons from Other Countries*, Social Policy Research Unit, June 2009 Working Paper No. DHP 2318 para 3.2.2. and see also A Struijs, *Informal care: the contribution of family carers and volunteers to long-term care* (Council for Public Health and Health Care, the Netherlands, 2006) p 66.

³¹ Jon Hendricks and Hyunsook Yoon, 'The Sweep of Asian Aging: Changing Mores, Changing Policies' in H Yoon and J Hendricks (eds) *Handbook of Asian Aging* (Baywood Publishing 2005) pp5-6.

³² H Zhan R Montgomery *Gender and Elder Care in China* Gender and Society, Vol. 17, No. 2, (2003), pp. 209-229

³³ GT Ng, 'Learning from Japanese Experience in Aged Care Policy' in 'Asian Social Work and Policy Review' (2007) 1, 36-51, 39; and see also JW Traphagan, 'Power, family and filial responsibility related to elder care in rural Japan' 'Care Management Journals' (2006) 7 205-212; N Ogawa and RD Retherford, 'Shifting Costs of Caring for the Elderly Back to Families in Japan: Will It Work?' in 'Population and Development Review' (1997) 23, 59-94, 70 and N Yamamoto and MI Wallhagen, 'The continuation of family caregiving in Japan' in 'Journal of Health and Social Behavior' (1997) 38, 164-176.

In the USA, where few of the filial responsibility statutes are actively enforced³⁴ federal policy requires that social care plans detail the ‘expected participation of informal carers’ to ensure a ‘reasonable division between informal and formal support systems’.³⁵ In similar fashion, in Germany it is suggested that the ‘internalization’ of the traditional family caring role / responsibility continues to be an important factor for individual caregivers.³⁶ So too in Ireland where, although the Constitutional obligation is not litigated, there exists a ‘strong moral obligation’ on families to provide care.³⁷ The position is said to be the same in Spain and Greece where (regardless of the legal situation) women have internalised their role as carers – often with materially adverse impacts on their physical and mental health.³⁸

Compensatory provisions

A significant literature exists that critically examines various examples of positive state action to address the needs of carers,³⁹ particularly where these take the form of direct financial payments.⁴⁰ In addition to such arrangements, a wide variety of other ‘carer compensation’ provisions exist in the domestic laws and policies of many states. These may, for example, provide for indirect benefits (eg through the tax or pension assessment systems) or mandate flexible employment rights.

‘Carer Recognition’ statutes exist in Australia⁴¹ and the UK,⁴² and specific measures to support carers have been acknowledged as a political priority in the majority of

³⁴ M Pakula, ‘A Federal Filial Responsibility Statute: A Uniform Tool to Help Combat the Wave of Indigent Elderly’ 39 Fam. L.Q. 859 (2005-2006)), 858 – 877, 862; and see also Shannon Frank Edystone, ‘Filial Responsibility: Can the Legal Duty to Support Our Parents Be Effectively Enforced’ in (2002) 36 FAM. L. Q. 501.

³⁵ Means, Richards & Smith – footnote 19 above pp218-219, citing US Department of Health and Human Services, ‘Application Guidelines for Long-Term Care Systems’ Washington DC Office of the Assistant Secretary for Planning and Education (1980).

³⁶ Means, Richards & Smith – footnote 19 above p220 and see also Runde et al, ‘Die Einführung des Pflegeversicherungsgesetzes und seine Wirkungen auf den Bereich der häuslichen Pflege’ in Band II. Arbeitsstelle für Rehabilitations- und Präventionsforschung. Veröffentlichungsreihe der Universität Hamburg (1999).

³⁷ C Glendinning, *Support for Carers of Older People – Some International and National Comparisons* (Audit Commission 2003) p10.

³⁸ Means, Richards & Smith – footnote 19 above p221.

³⁹ See for example OECD *Help wanted? Providing and Paying for Long-Term Care*: Chapter 4 (OECD, 2011) and C Glendinning (footnote 37).

⁴⁰ See for example, J Keefe and B Rajnovich, ‘To pay or not to pay: examining underlying principles in the debate on financial support for family caregivers’ in (2007) 26 Suppl. Canadian Journal on Aging 77–89; S Kunkel, R Applebaun and I Nelson, ‘For love and money: Paying family caregivers’ in *Generations* 2003-2004 Winter; 27 (4) 74-80; and C Ungerson, ‘Whose empowerment and independence? A cross-national perspective on ‘cash for care’ schemes’ in *Aging & Society*, (2004) 24, 189–212.

⁴¹ In Australia the South Australia Carers Recognition Act 2005; the New South Wales Carers (Recognition) Act 2010; the Northern Territory Carers Recognition Act 2006; the Queensland Carers Recognition Act 2008; the Western Australia Carers Recognition Act 2004 - with proposals for a Federal Carer Recognition Bill 2010 – and see also ‘Who

European states⁴³ with many providing for formal (but generally modest) ‘carer’ payments or ‘respite’ care arrangements – Finland,⁴⁴ France,⁴⁵ Hungary,⁴⁶ Spain⁴⁷ and the UK⁴⁸ for example. In Canada a Compassionate Care Benefit scheme for working carers⁴⁹ has been developed as part of the Labour Code. In the USA the National Family Caregiver Support Program⁵⁰ provides for grants⁵¹ to states to fund a range of supports designed to sustain the care provided by informal caregivers⁵² and specific provisions exist for the caregivers of veterans.⁵³ Official carer specific measures are not solely a Western manifestation: they can be found in (for example) Taiwan,⁵⁴ South Africa⁵⁵ and India⁵⁶ - and are being proposed in Columbia.⁵⁷

Cares? Report on the inquiry into better support for carers House of Representatives Standing Committee on Family, Community, Housing and Youth’ (The Parliament of the Commonwealth of Australia 2009).

⁴² In the UK the Carers (Recognition & Services) Act 1995 and see generally L. Clements, *Carers and their Rights – the law relating to carers* London’ 5th edn (Carers UK 2012).

⁴³ C Glendinning, F Tjadens, H Arksey, M Morée, N Moran, and H Nies *Care Provision within Families and its Socio-Economic Impact on Care Providers: Report for the European Commission DG EMPL: Negotiated Procedure VT/2007/114*. Social Policy Research Unit, University of York May 2009 Working Paper No. EU 2342 para 1.2.3.

⁴⁴ The Finland Family Carer Act (312/1992) 1.7.1992.

⁴⁵ Payments for ‘des aidants familiaux’ under Loi n° 2005-102 du 11 février 2005 pour l’égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées.

⁴⁶ The Social Welfare Act 1993 – and see also K Czibere and R Gal *Long-Term Care in Hungary* Enepri Research Report No. 79 (2010) at <http://aei.pitt.edu/14612/1/Hungary.pdf> accessed 15 May 2013 and Z Szeman, *Eurofamcare: National background report for Hungary* (Institute of Sociology of the Hungarian Academy of Sciences 2004).

⁴⁷ Law 39/2006, 14 December 2006 de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia (on the Promotion of Personal Autonomy and Care for dependent people) at http://noticias.juridicas.com/base_datos/Admin/l39-2006.html accessed 15 May 2013.

⁴⁸ See for example the Regulatory Reform (Carer’s Allowance) Order 2002 SI 1457 and Carers & Disabled Children Act 2000 s2.

⁴⁹ Canada Labour Code 1985 s204 and see J Keefe and B Rajnovich, ‘To pay or not to pay: examining underlying principles in the debate on financial support for family caregivers’ in *Canadian Journal on Aging* (2007) 26 Suppl 77–89.

⁵⁰ Federal Older Americans Act of 1965, s371 (as amended); see also, for example the Family and Medical Leave Act of 1993 that provides for up to 12 weeks of unpaid leave for qualifying carers (and the qualification requirements are not-inconsiderable) and the Affordable Care Act 2010 in relation to which see generally Karen Czapanskiy, ‘Disabled Kids and Their Moms: Caregivers and Horizontal Equity’ in *Georgetown Journal on Poverty Law & Policy* 19 (1) 2012 pp 43 - 73.

⁵¹ Over \$150,000,000 in 2011.

⁵² E Giovannetti and J Wolff, ‘Cross-Survey Differences in National Estimates of Numbers of Caregivers of Disabled Older Adults’ in *The Milbank Quarterly* Vol. 88, No. 3, September 2010: 310-349.

⁵³ Caregivers and Veterans Omnibus Health Service Act 2010.

⁵⁴ The People with Disabilities Rights Protection Act 1980 Article 51 (as amended) provides for (amongst other things) ‘supports to the caregivers’ and services ‘to promote the capability of family caregivers’.

⁵⁵ The Care Dependency Grant Social Assistance Act No. 13 2004 s7(a) – see K Malherbe, ‘The social security rights of caregivers of persons with disabilities’ in Ilze Grobbelaar-du Plessis and Tobias van Reenen (eds) *Aspects of disability law in Africa* (University of Pretoria 2011) 181-195.

⁵⁶ Department of Social Welfare Kerala, The Aswasa Kiranam Scheme (2010) see http://www.socialsecuritymission.gov.in/index.php?option=com_content&view=article&id=58&Itemid=62 accessed 15 May 2013.

⁵⁷ A draft law has been proposed to provide for formal recognition of Caregivers – see proposals of Senator Yolanda Pinto ‘Law Proposal No. 33 of 2009’ at

Self identification as carers

The acquisition of a social identity is a distinct process for every marginalized group – albeit that there are general and reoccurring themes. In terms of the struggle for human rights, such self categorisation is invariably bound up with the idea of oppression and of ‘imposition’: of a collective identification with unjust subjugation.⁵⁸ Shakespeare refers to the particular conceptual difficulties that disabled people had in this respect (compared to ‘women, blacks, or gays’), in that the oppression they experience is ‘couched in terms of paternalistic support and charity’.⁵⁹ Clearly this observation is particularly apt in relation to many carers. Many carers consider caring to be an inherently private, family and charitable activity: it is very commonly reported that many people providing care in such situations ‘do not identify themselves as carers’.⁶⁰

Identification based on ‘being a carer’ has the additional complexity for those who perceive that their caring role has robbed them of their (former) status – that like the acquisition of an impairment – it has resulted in a lost sense of self identity.

Many accounts that document the radicalization of disabled people in the 20th Century locate its origins in the USA, with Vietnam veterans returning to experience the handicaps imposed on them by environments constructed by and for non-disabled people. Vietnam created a tipping point, by generating large numbers of young, educated and physically impaired people who experienced adverse treatment for the first time in their lives and for whom the activism of the civil rights movement acted as a catalyst in the development of their group coherence.

http://servoaspr.imprenta.gov.co:7778/gacetap/gaceta.mostrar_documento?p_tipo=11&p_numero=33&p_consec=23985 accessed 15 May 2013.

⁵⁸ The social identification of carers and the extent to which they can, as a group, be viewed as a new social movement lies outside the central purpose of this paper: in this respect, however see Tom Shakespeare, ‘Disabled people’s self-organisation: a new social movement?’ in *Disability, Handicap and Society*, (1993) 8, 3, pp. 249-264 and in particular his critique as to the extent to which ‘post-materialism’ is a core feature of such movements: see also Alberto Melucci, ‘Challenging Codes: Collective Action in the Information Age’ (Press Syndicate 1996) and John Turner, ‘A Self-Categorization Theory’ in John Turner (ed) *Rediscovering the Social Group, A Self-Categorization Theory* (Blackwell 1987) pp 18–41.

⁵⁹ Shakespeare (ibid) at 256, and see also Christine Kelly, ‘Wrestling with Group Identity: Disability Activism and Direct Funding’ in *Disability Studies Quarterly* (2010) Vol 30, No 3/4.

⁶⁰ OECD *Help wanted?* (footnote 39 above) p135; see also (for example) G Ng, *Study Report of Singapore Family Caregiving Survey*, Working Paper No. 2006-01, (National University of Singapore 2006) p 17; M Bittman et al *Identifying Isolated Carers: Contacting Carers with Unmet Needs for Information and Support* (Social Policy Research Centre, (University of New South Wales 2004); and R V J Montgomery & J M Rowe, ‘Respite’ in C.B Cox (ed.) *Dementia and social work practice: Research and intervention* New York: (Springer 2007) pp. 339–364 – whose ‘caregiver identity theory’ describes the change that takes place when a carer moves from identifying as a (say) daughter to identifying as a caregiver.

The exponential growth in disabled people's organisations in the decades following Vietnam is being mirrored by the remarkable growth in carers' organisations, alliances, networks and support groups that has occurred in the last two decades. As with disabled people's groups these come in all varieties – local, user specific (eg by the nature of impairment, ethnicity, age, or sex) international⁶¹ and so forth. The recent proliferation of organisations of self-identifying carers' results from the spectrum of socio-legal factors addressed in this paper – particularly from the impetus created by their recognition in domestic legislation and other formal policies. These measures are, however, merely a response to wider social forces. A number of commentators argue that for carers, the significant motive force (the 'Vietnam' issue) is the impact of neoliberalism⁶² – and its disparagement of dependency.⁶³ It is however the coincidence of this political phenomenon with a dramatic growth in the numbers of the 'old old' (and to a lesser extent of childhood disability⁶⁴) that has created the carers' tipping point'. In many western states, the increased numbers of disabled and frail elderly people has been accompanied by community living programmes. Whilst a debate exists as to whether the closure of large institutions can be attributed to human rights awareness or state 'cost cutting'⁶⁵ the effect has been to increase the demand for 'community care'.

These two factors – demographic change⁶⁶ and the welfare residualism that comes with neoliberalism – have resulted in a substantial increase in unpaid caring⁶⁷ which in many developed nations, is nearing the limits of what families can provide.⁶⁸

However, at the same time in most OECD countries, there has been an even more remarkable increase in female employment rates.⁶⁹ In the USA for example, women's

⁶¹ For example, The International Alliance of Carers Organizations and the European network organization EUROCARERS.

⁶² This paper uses neoliberal in its political sense: a system that adheres to civil and political rights and values, but believes that these cannot be used to limit the 'free market' – 'a natural organic entity that must be left, untrammelled, to flourish and so liberate individual entrepreneurial capacities and thereby create great wealth' – see David Harvey, *A Brief History of Neoliberalism* (OUP, 2006).

⁶³ N Busby, *A Right to Care?* (OUP 2011), pp 5, 42 and generally see Martha Albertson Fineman, *The Autonomy Myth: A Theory of Dependency* (The New Press, 2004).

⁶⁴ As greater numbers of low birth-weight babies have survived – see for example, S Broach, L Clements and J Read, *Disabled children' A legal handbook* (Legal Action 2010).

⁶⁵ L Clements, 'Disability, dignity and the cri de coeur' in *European Human Rights Law Review* (2011) 675 at 680.

⁶⁶ Even if the 'dependency ratio' (the percentage of the population that is under 18 combined with the percentage that is over 65) is not itself changing dramatically – see N Folbre and J Nelson, 'For Love or Money' in *The Journal of Economic Perspectives*, Vol. 14, No. 4 (Autumn, 2000), pp. 123-140 at 124.

⁶⁷ D Patsios, *Trends in the receipt of formal and informal care by older people* (ESRC 2008) RES-000-22-2261.

⁶⁸ See for example the Sutherland Report, *With Respect to Old Age: A Report by the Royal Commission on Long Term Care* (HMSO 1999) research Volume 1 Part 1 Chapter 6 p162; and L. Pickard, *Informal care for older people provided by their adult children: projections of supply and demand to 2041 in England* Report to the Strategy Unit (Department of Health 2008).

participation in the labour force has increased dramatically — for women age 55 and older the increase has been 50% in the past 15 years.⁷⁰ During this period average household incomes have not increased⁷¹ - indeed they would have declined but for 'women joining the workforce alongside their husbands'.⁷² For many women, much of the additional income from their employment is absorbed in paying for care costs – a process categorized as de-familialization – where a cost advantage (generally small) accrues by commodifying the care needs of both children and adult dependants.⁷³

Many of today's carers, like the Vietnam veterans, are young and well educated, and aware that their adverse treatment derives from socio-legal environments constructed by and for people who do not have caring responsibilities: environments predicted on the ability to work and 'inherently hostile' to care-givers.⁷⁴ Unlike the Vietnam veterans however, this group is predominantly female. It is an understanding of this question that produces the 'creed' – the necessary theoretical model that carers require in order to become a 'rights movement' – and which is discussed below.

A narrative of oppression; a new historical account;

There is considerable national and international evidence that carers in general experience adverse social, economic, health and political consequences as a result of their caring role.

An impressive longitudinal well-being study of Australians found that female carers had the lowest collective wellbeing of any group it had considered⁷⁵ and that Australian

⁶⁹ F Jaumotte, *Female Labour Force Participation OECD Economics Department Working Papers No. 376* ECO/WKP(2003)30 (OECD 2003) and see also (for example) Maria Gutiérrez-Domènech and Brian Bell, *Female labour force participation in the United Kingdom: evolving characteristics or changing behaviour? Working Paper no. 221* (Bank of England 2004); and A Stewart, S Niccolai, and C Hoskyns, 'Disability Discrimination by Association: A Case of the Double Yes?' *Social & Legal Studies*, 2011, 20(2); and Siv Gustafsson and Roger Jacobsson, 'Trends in Female Labor Force Participation' in Sweden *Journal of Labor Economics* Vol. 3, No. 1(1985), pp.S 256-274.

⁷⁰ MetLife, *Caregiving Costs to Working Caregivers* MetLife Mature Market Institute, National Alliance for Caregiving, and Center for Long Term Care Research and Policy, New York Medical College (2011). This dramatic increase in female employment is mirrored in the UK.

⁷¹ *ibid*

⁷² J Stiglitz, *The Price of Inequality* (Allen Lane 2012) p14.

⁷³ N Busby (footnote 63 above) p.7 citing G. Esping-Andersen, D. Gaillie, A. Hemerijck. and J. Myles, *Why We Need a New Welfare State* (OUP 2002).

⁷⁴ N Busby *ibid* p18 and citing Susan Moller Okin, *Justice, Gender and the Family* (Basic Books, 1989) and C. Pateman *The Sexual Contract* (Polity Press, 1988).

⁷⁵ R Cummins et al, *the Wellbeing of Australians – Carer Health and Wellbeing* (Deakin University 2007) – female carers fairing even worse than the average – at www.deakin.edu.au/research/acqol/auwbi/survey-reports/survey-017-1-report.pdf accessed 15 May 2013. See also JM Teno *Caregiver Well Being* Brown University at www.chcr.brown.edu/pcoc/familyburden.htm (accessed 15 May 2013) for a review of caregiver well-being measurement instruments.

carers as a whole had an average rating that classified them as suffering 'moderate depression'. Adverse impacts of this nature have been identified by a number of studies from Singapore⁷⁶ to Greece:⁷⁷ from Brazil⁷⁸ to Italy⁷⁹ and Norway.⁸⁰ A 2011 study found that carers exhibit a higher prevalence of mental health problems across OECD countries than non-carers, with the rate increasing with the amount of caring. 'High intensive' caring in general increased the prevalence of mental health problems by 20%, but in Australia, the United States and Korea this became '70% or 80% higher'.⁸¹ UK evidence suggests that carers are a third more likely to be in poor health than non-carers⁸² and that over half of all carers have a caring related health condition⁸³ for which almost 50% have sought medical treatment.⁸⁴

The severity of the adverse consequences experienced by carers is materially influenced by the nature of the state's welfare support system. Thus carers in general are less likely to be in employment than non-carers – but this difference is less pronounced in modern welfare states (as for instance found in Nordic countries) than those with more residual systems.⁸⁵ The prospects of employment bear directly on risks of poverty.⁸⁶ working-age carers – particularly women – experience significantly higher rates of poverty.⁸⁷

In basic economic terms UK research found that at any one time a million carers have given up work or reduced their working hours to care⁸⁸ and that as a consequence they were (in 2007) on average over £11,000 a year poorer;⁸⁹ that 40% of carers were in debt because of their caring roles (a figure that rose to 50% for parent carers).⁹⁰ A 2011

⁷⁶ EH Kua and SL Tan, 'Stress of caregivers of dementia patients in the Singapore Chinese family' in *International Journal of Geriatric Psychiatry* (1997) 12 466-469.

⁷⁷ Means, Richards & Smith – footnote 19 above p221.

⁷⁸ ACM Gratao *et al*, 'The demands of family caregivers of elderly individuals with dementia' in *Rev Esc Enferm USP* (2010) 44, 873-880.

⁷⁹ M Ferrara *et al*, 'Prevalence of stress, anxiety and depression in with Alzheimer caregivers' in *Health Quality Life Outcomes*, (2008) 6: 93

⁸⁰ Figved *et al*, 'Caregiver burden in multiple sclerosis: the impact of neuropsychiatric symptoms' in the *Journal of Neurology Neurosurgery and Psychiatry*, (2007) 78(10):1097-102.

⁸¹ OECD *Help wanted?* (footnote 39 above) p.98-99.

⁸² S Yeandle and A Wigfield (eds) *New Approaches to Supporting Carers' Health and Well-being* (CIRCLE, Leeds University 2011).

⁸³ Carers UK, *Missed Opportunities: the impact of new rights for carers*, Carers UK June 2003.

⁸⁴ *Ibid* and see also Princess Royal Trust for Carers, *Carers Speak Out Project: Report on findings and recommendations*, October 2002.

⁸⁵ OECD *Help wanted?* (footnote 39 above) p.91.

⁸⁶ *Ibid* p.93.

⁸⁷ *ibid* p.97.

⁸⁸ Carers UK *The Cost of Caring* (2011).

⁸⁹ *Out of Pocket, the financial impact of caring*, Carers UK, 2007

⁹⁰ Carers UK, 'The State of Caring (2011) involving 4,200 carers..

study found that a third were unable to afford their utility bills and that three quarters had cut back on holidays, leisure activities, buying clothes and going out with friends and family.⁹¹

Research by the Australian Human Rights Commission has considered the long-term and gendered impact of the caring role. A 2009 study found that single elderly female households experienced the greatest risk of persistent poverty⁹² and a 2013 study⁹³ found that the average superannuation payouts for women were little more than half of those for men. These differences were attributed to the struggle women experienced balancing paid work and caring responsibilities. Even discounting for the 'accepted' events in a woman's lifecycle (pregnancy, childbirth and caring for children) the Commission considered that much of the difference stemmed from the 'far less recognised' caring relationships (predominantly) undertaken by women and which have the cumulative impact on lifetime earnings.⁹⁴ These findings are endorsed by USA research – that caregiving in early life significantly raised women's poverty risks in later life⁹⁵ and that older working caregivers had average pension shortfalls of \$50,000 per person (in total amounting to a loss of nearly \$3 trillion).⁹⁶

Poverty is, as Alcock reminds us, 'the unacceptable face of broader inequalities'⁹⁷ and in states with (or aspiring to) residual welfare systems, it is inextricably linked with employability. In such states the hostile nature of labour arrangements is a root cause of the adverse experiences of carers: operating as they do, in workplaces based on the notion of an ideal 'autonomous' worker – who it is assumed has "someone else" at home to raise his children'.⁹⁸ Work environments that 'far from structurally

⁹¹ Carers UK *The Cost of Caring* (2011) and see also Carers UK, *Carers in crisis* (2008) and National Alliance for Caregiving and AARP, *Caregiving In the U.S* (NAC and AARP 2004) - where similar findings were noted in the USA research – p.13 and p62.

⁹² Australian Human Rights Commission, 'Accumulating poverty? Women's experiences of inequality over the lifecycle' (AHRC 2009)

⁹³ Australian Human Rights Commission, 'Investing in care: Recognising and valuing those who care' (AHRC 2013)

⁹⁴ Australian Human Rights Commission, (footnote 92 above) para 5.7; see also Nancy Folbre and Julie A. Nelson, 'For Love or Money' in *The Journal of Economic Perspectives*, Vol. 14, No. 4 (Autumn, 2000), pp. 123-140 at p124.

⁹⁵ C Wakabayashi and K Donato 'Does Caregiving Increase Poverty among Women in Later Life?' in *Journal of Health and Social Behavior* 2006, Vol 47: No. 3 258-274

⁹⁶ MetLife *Balancing Caregiving with Work and the Costs Involved* (1999): a research study concerning people aged 50 or over, caring for their parents, undertaken by MetLife Mature Market Institute, National Alliance for Caregiving, and The National Center on Women and Aging.

⁹⁷ P Alcock 'Understanding Poverty' 2nd ed (Palgrave 1997) at p.252

⁹⁸ Susan Moller Okin, *Justice, Gender and the Family* (Basic Books, 1989) p176.

accommodating or facilitating caretaking ... operate according to premises that are incompatible with obligations for dependency'.⁹⁹ Where:

Workers (at least some of them) must shoulder the burdens assigned to the family, while market institutions are relieved of such responsibility (and are even free to punish workers who have trouble combining market and domestic labor).¹⁰⁰

The politics of dependency

Dependency work (paid¹⁰¹ or unpaid) is gendered¹⁰² and it is this factor that lies at the heart of the injustice that carers experience. Caring is not, of course, an exclusively female activity – it is just that the status of caring has been engendered by the fact that it is women who provide the bulk of it.¹⁰³ In the USA for example, it is estimated that there are over 25 million caregivers of which between 59% and 75% are women and that women on average spend 50% more time providing care than male caregivers.¹⁰⁴ This is in line with the evidence from other OECD countries.¹⁰⁵

Whilst dependency is viewed as problematic in many political regimes – in the developed nations it is the neoliberal reification of individual independence, autonomy, and self-sufficiency that so disables and handicaps carers, as well as the people who depend upon them. These are values, which in Martha Fineman's opinion¹⁰⁶ have

⁹⁹ Martha Albertson Fineman, 'Cracking the Foundational Myths: Independence, Autonomy and Self-Sufficiency', in Martha Albertson Fineman and Terence Dougherty (eds) *Feminism Confronts Homo Economicus* (Cornell University Press 2005) 179 – 191, 184.

¹⁰⁰ *Ibid* at p.189.

¹⁰¹ Nancy Folbre and Julie A. Nelson, 'For Love or Money' in *The Journal of Economic Perspectives*, Vol. 14, No. 4 (Autumn, 2000), pp. 123-140 at p127: in 1998 for example whereas women were about 46% of the paid US work force, they constituted over 76% of those employed in hospitals, 79% in other health services, 68% educational services and 81% in social services.

¹⁰² For Busby, in relation to the conflict between unpaid carers and paid employment, it is 'severely gendered' - N Busby (footnote 63 above), p.2.

¹⁰³ As Carr puts it 'aging and caring are gendered in ways that are more nuanced and compelling than the simple fact that women live longer than men' – see H Carr *Alternative Futures v NCSC: A Feminist Critique* Conference Paper to the European Network of Housing Research Rotterdam 2007.

¹⁰⁴ P Arno, C Levine and M Memmott, 'The economic value of informal caregiving' in *Health Affairs* 1999 Mar-Apr;18(2):182-8; and Family Caregiver Alliance *Selected Caregiver Statistics* (Family Caregiver Alliance 2001) and see also M Navaie-Waliser, P Feldman, D Gould, C Levine, A Kuerbis & K Donelan, 'When the caregiver needs care: The plight of vulnerable caregivers' in *American Journal of Public Health*, (2002) 92(3),409–413; and M Navaie-Waliser, A Spriggs and P Feldman, 'Informal Caregiving: Differential Experiences by Gender' in *Medical Care* Vol. 40, No. 12 (Dec., 2002), pp. 1249-1259.

¹⁰⁵ OECD *Help wanted* (footnote 39 above) and see for example, Australian Bureau of Statistics Disability, 'Ageing and Carers, Australia: Summary of Findings, 2009' (2010) and Carers UK, *Facts about carers* (Carers UK 2012).

¹⁰⁶ Martha Albertson Fineman, 'Cracking the Foundational Myths: Independence, Autonomy and Self-Sufficiency', in Martha Albertson Fineman and Terence Dougherty (eds) *Feminism Confronts Homo Economicus* (Cornell University Press 2005) at 180.

attained sacred and 'transcendent' status: but which are a myth: for 'all of us were dependent as children, and many of us will be dependent as we age, become ill or suffer disabilities'. Dependency is hard wired into humanity: it may be a challenge but it is absurd to characterise it as unnatural – it is simply 'inevitable'.¹⁰⁷ The core creed for the carers' movement is, therefore, the 'politics of dependency': just as we have created environments based on the needs of non-disabled people, so too have we created environments based on the mythology of independent people. Caring, like disability, is not in itself a handicap: it is the socio-legal context in which it is practiced that renders it so. The principal politically engineered handicap experienced by carers is that their care is uncompensated and – as Fineman and others have articulated so clearly – it is uncompensated because it is gendered.

Whilst the denigration of dependency and the marginalisation of dependency work is the aspect that most clearly explains the injustice that carers experience, a compounding role is played by the context in which it is generally practiced: the context of 'privacy'

A daunting literature exists that critically analyses the way that states have sought to create a socio-legal space – the space of the 'private and the family' – into which expansive 'public' notions of justice and equality should not intrude.¹⁰⁸ The sphere of the 'private' (or what has been termed the 'assumed family'¹⁰⁹) is an ideological construct that validates the severance of 'individual dependency, pretending that it is not a public problem'; it is (Fineman once more) one that 'masks the dependency of society ... on the uncompensated and unrecognized dependency work assigned to caretakers'.¹¹⁰ This is, as Julia Twigg¹¹¹ has described it, 'dirty work' and 'hidden work' – hidden:

because it deals with aspects of life that society, especially modern secular society with its ethic of material success and its emphasis on youth and glamour, does not want to think about: decay, dirt, death, decline, failure. Careworkers manage these aspects of life on behalf of the wider society.

¹⁰⁷ Ibid p180.

¹⁰⁸ see for example, Susan Moller Okin footnote 98 above.

¹⁰⁹ See for example Martha Albertson Fineman, 'The Autonomy Myth: A Theory of Dependency' (New York: The New Press, 2004) and Martha Albertson Fineman, *Cracking the Foundational Myths* (footnote 106 above) at 179 – 191; and see also Okin. that 'the very notion that the state has the option to intervene or not to intervene in the family is not only mythical but meaningless. In many ways the state is responsible for the background rules that affect people's domestic behaviors' Susan Moller Okin footnote 98 above p130.

¹¹⁰ Ibid (*Cracking the Foundational Myths*) at 179.

¹¹¹ Julia Twigg, 'Carework as a form of bodywork' in *Ageing and Society* 20, 2000, 389-411 at 406.

The creation of a different legal sphere from which many traditional legal principles are exiled, is essential to the maintenance of gendered systems. For neoliberalism, it is of particular importance since without the public / private delineation, key tenets would fall away. The dogma of ownership, for example – the right to own and sell the product of one’s labour – is self-evidently absurd when applied to a mother’s work in caring for her children. So too with commodification: if one commodifies caring – ie tots up the cost that carers should be paid for their caring work – then one ends up with very large sums indeed (‘unaffordable’ sums from a neoliberal perspective¹¹²).

Rather than accept the severe limitations of such ideologies, a dustbin dimension is created – the ‘private’ space – into which all awkward facts are piled.¹¹³ States can then avoid accusations of injustice when failing to ensure that carers are properly compensated – and let individual carers bear this cost. Such an approach enables states to ‘ignore the crucial fact that much human labor, energy and skills is *not* devoted to the production of things that can then belong to their producers.’¹¹⁴

The radicalization of the carers’ movement is a consequence of the heavily gendered injustice at the heart of the current political settlement: a system that enriches those without impairments or caring responsibilities and consigns dependant people (children, elderly and disabled people) and their caregivers to poverty. A system that enables those without dependency to free-ride on the freely given care they received when dependant as children.¹¹⁵ For Fineman this injustice is currently ‘the most compelling’ problem facing our society: where ‘winners and losers become winners or losers in large part because of benefits and privileges or disadvantages and burdens conferred by family position and unequal distribution of social and economic goods.’¹¹⁶

¹¹² In the UK a sum estimated as £119 billion pa L Buckner and S Yeandle Valuing Carers (Carers UK 2011) and in the USA (using different criteria) in 1997 it was estimated that the national economic value of informal caregiving amounted to \$196 billion – see PS Arno, C Levine and MM Memmott, ‘The Economic Value of Informal Caregiving’ Health Affairs (1999) 18, 182-188 – but see also E Giovannetti and J Wolff, ‘Cross-Survey Differences in National Estimates of Numbers of Caregivers of Disabled Older Adults’ in The Milbank Quarterly Vol. 88, No. 3, September 2010, 310-349. Folbre and Nelson suggest that ‘valued solely on the basis of labor inputs’ it accounts between 40 per cent and 60 per cent of the total value of all U.S. output. As they observe, ‘even this striking estimate contains a sizeable down-ward bias, since the market wages being imputed to women homemakers are lowered both by discrimination and by the time and effort put into nonmarket work’ - see Nancy Folbre and Julie A. Nelson, ‘For Love or Money’ in The Journal of Economic Perspectives, Vol. 14, No. 4 (Autumn, 2000), pp. 123-140 at p125-127.

¹¹³ As Mitt Romney put it ‘inequality is the kind of thing that should be discussed quietly and privately’: cited by Joseph Stiglitz in *The Price of Inequality* (Allen Lane 2012) p27.

¹¹⁴ Susan Moller Okin footnote 98 above p129.

¹¹⁵ ‘Like other externalities, however, those created by care create an incentive to free ride, to let others pay the costs’ – see Nancy Folbre and Julie A. Nelson, ‘For Love or Money’ The Journal of Economic Perspectives, Vol. 14, No. 4 (Autumn, 2000), pp. 123-140 at p137.

¹¹⁶ Martha Albertson Fineman, ‘Cracking the Foundational Myths’ (footnote 106 above) pp179 – 191.

Caring and human rights

The language of human rights is the most obvious medium by which carers can express and challenge their collective marginalisation, and a number of authors have argued persuasively that there is indeed a human right to care.¹¹⁷ By conceptualising their situation in this way, carers can not only get closer to capturing the essence of their predicament,¹¹⁸ but they can also mobilise one of the few forces capable of tilting against the antagonistic political norms that manufacture their social exclusion. As West¹¹⁹ argues, it is only through the rights discourse that we can protect those facets of the human condition that we have come to understand as essential to our individual and collective ability to flourish and which ‘the political process is unlikely to confer on us’. In her opinion, rights are necessary:

When for some reason, the sphere of life, service, freedom, activity, or identity that is protected by the right, and so necessary to flourishing, might nevertheless be systematically undervalued, underappreciated, or underprotected by standard political processes.¹²⁰

In the context of the struggle by disabled people, the articulation of a right to community (or ‘independent’) living is such an example. In many regions a good economic argument can be made in favour of institutionalisation and as a political issue, deinstitutionalisation is unlikely to be a priority for most voters. However, when articulated in terms of fundamental human rights¹²¹ the question is translated into an entirely new language – from one defined by the vocabulary of political and economic pragmatism to one of moral imperatives, urgency and repugnance. In precisely the same way, there is

¹¹⁷ See in particular Robin West, ‘Caring for Justice’ (New York University Press, 1997); Robin West (footnote 8 above); Mary Becker, ‘Care and Feminists’ in 17 Wisconsin’s Women’s Law Journal 57 – 110 (2002); Deborah Stone, ‘Why We Need a Care Movement’ in *The Nation*, 13 March 2000, at 13 and N Busby (footnote 63 above).

¹¹⁸ The ‘carers rights’ discourse has attracted a number of cautionary qualifications: Tronto for example suggests that it is within the idea of ‘an ethic of care’ that the analysis should take place (J Tronto, ‘Beyond Gender Difference to a Theory of Care’ *Signs: Journal of Women in Culture and Society* 1987, vol. 12, no. 4 pp. 644-663 at p662) and Knijn & Kremer consider it better conceptualised as a dimension of inclusive citizenship (T Knijn and M Kremer, ‘Gender and the caring dimension of welfare states: towards inclusive citizenship’ in *Social Politics* (1997) Fall, 328–61 at 330). Important as these perspectives are, they do not undermine the idea that there is a ‘right to care’. Caring occupies a much larger and more profound space, than simply being a human right, but by so labelling it, it does not diminish this larger meaning: no more than referring to the right to religion in the language of rights can be said to restrict or compromise its value.

¹¹⁹ Robin West (footnote 8 above) p96.

¹²⁰ *Ibid.*

¹²¹ See for example, Article 19 UN Convention on the Rights of Persons with Disabilities and Article 26 Charter of Fundamental Rights of the European Union.

every reason to believe that until the adverse treatment of carers is understood as the proper subject of human rights, it will continue to be interpreted as a regrettable but economically inevitable fact of life.

It has been suggested that a quasi-contractual / public law duty to secure compensatory support for carers¹²² is all that is required to address the impoverishment and hardships they experience: that the establishment of a right is superfluous. Of course the acceptance of a right to care, without a corresponding social support mechanism is of little value – but as West argues, persuasively, we need such a right ‘to protect caregivers against the pendulum swings of public support and neglect for their work’:¹²³ without such recognition, the carers’ needs would be ‘drowned in a tide of competing needs for scarce public resources’.¹²⁴

Arguably there are three (relatively) distinct dimensions¹²⁵ – and these will be explored in the succeeding section. The first concerns the proposition that there is such a thing as a substantive human right ‘to care’. The second concerns the extent of a state’s positive obligation to compensate carers for the adverse consequences of their caring roles. The third looks at the human rights of carers through the equality lens: that through this prism their adverse experiences can be seen as discriminatory.

Caring as a substantive human right

Civil and political human rights’ treaties protect various activities: expression;¹²⁶ proselytising;¹²⁷ marching / demonstrating;¹²⁸ and so on. Although the essence of each activity has a platonic core, capturing this is generally problematic: political demonstrations are forms of expression; religious meetings necessitate association –

¹²² See for example, Anne Alstott, ‘No Exit: What Parents Owe Their Children and What Society Owes Parents’ (OUP 2004).

¹²³ Robin West (footnote 8 above) p98.

¹²⁴ Such ‘rights, if they exist, must be given content by legislatures through the normal mechanisms of democracy, not by courts through the extraordinary means of judicial review’ - Robin West, ‘A Right to Care’ in *The Boston Review* April / May 2004 at <http://bostonreview.net/BR29.2/west.html> accessed 15 May 2013.

¹²⁵ Other compartmentalisations have been advanced - for example, Stone argues for three facets of such a right, namely: (1) that families are permitted and helped to care for their members; (2) A right to care means, second, the right of paid caregivers to give humane, high-quality care without compromising their own well-being; and (3) a right to care must mean that people who need care can get it. See Deborah Stone, ‘Why We Need a Care Movement’ in *The Nation*, 13 March 2000, at 13 -14.

¹²⁶ ICCPR Article 19; AmCHR Article 13; AfCHR Article 9; ECHR Article 10.

¹²⁷ ICCPR Article 18; AmCHR Article 12; AfCHR Article 8; ECHR Article 9.

¹²⁸ ICCPR Article 21; AmCHR Article 16; AfCHR Article 10; ECHR Article 11.

and the extent to which these activities warrant protection can be graded in terms of their value: not all expression takes the form of the Gettysburg Address.

From a jurisprudential perspective, it is difficult to differentiate between the notion (or the 'value') of a right 'to care' and that of a right 'to expression' or 'to belief'. All humanity arrives in this world utterly dependant and in need of care and for many, dependency is not a situation unique to their infancy. Caring has an elemental, non-commodifiable, altruistic quintessence,¹²⁹ that is perhaps best characterised as a species of the fundamental human right 'to give':¹³⁰ of a collective responsibility for dependency.¹³¹ It is the pre-eminent, indispensable and emblematic activity of a civil society – the absence of which is the acid test of inhumanity: of Brave New World and 1984.

To define 'caring'- and hence the scope of the right – presents as great a challenge as defining 'expression' or delimiting the notion of 'privacy'. Fundamentally, it involves providing care to meet the needs of a dependant person. The caring may be a physical, an emotional or a purely cerebral activity. It may involve intense intimate care: 'dirty work', 'bodywork' which may 'involve inflicting embarrassing or painful procedures' ... out of sight and in the back bedrooms'.¹³² Even if physical, it may be relatively impersonal – for example changing bedclothes or keeping a home clean for an elderly relative. It may be highly charged in terms of emotional support – of trying to keep a person from descending into depression; of 'keeping their spirits up'; counselling and so on. It may consist of nothing more than 'being there' to ensure that the other person does not come to harm – of 'keeping an eye' on a young child or an elderly relative with dementia. Caring in this context is what the carer does – it is their physical or intellectual or emotional activity that makes it caring. The recipient may be grateful or ungrateful; oblivious, unconscious or simply indifferent: it is in this sense a classic gift relationship.

The person for whom the care is provided must have some element of need for that care. This may be due to the consequences of age (a young child or a frail elderly person) or that person's impairment – be they mental or physical disabilities. Although the need may arise because of socially engineered barriers (physical, administrative,

¹²⁹ Busby refers to the 'intrinsically intimate nature of the exchange that takes place between a carer and a recipient of care' that demonstrates 'the inalienability of certain aspects. This central component of the relationship is crucial to the well-being of both parties and is, thus, non-commodifiable' – N Busby (footnote 63 above) p7; see also in this context Nancy Folbre and Julie A. Nelson, 'For Love or Money' *The Journal of Economic Perspectives*, Vol. 14, No. 4 (Autumn, 2000), pp. 123-140 at p129.

¹³⁰ Richard Titmuss, 'The Gift Relationship' (George Allen & Unwin 1970) p.199.

¹³¹ Martha Albertson Fineman, 'Cracking the Foundational Myths' (footnote 106 above) at 181.

¹³² Julia Twigg, 'Carework as a form of bodywork' in *Ageing and Society* (2000) 20, 389-411.

attitudinal for example), it is the need that is relevant – not its provenance, complex as this will sometimes be.

Whilst the scope of this paper is limited to ‘unpaid’ caring it is debatable whether the absence of remuneration (that the ‘work’ involved in delivering the care has not been commodified) is of pivotal relevance. Much has been written on this issue¹³³ and the constraints of this paper enable it to avoid this contested and wide-ranging question. That said, the mere fact that aspects of an activity are capable of being priced does not in itself render the process without value. Arguably commodification in the context of social care is better understood as an ethical or political discourse: tangential to the potential categorisation of the activity as a ‘human right’.¹³⁴ Whether or not the process undermines and devalues is a mature debate – from blood donation to foster parenting: but the availability of blood engages a state’s obligations in relation to the ‘right to life’ and foster children’s relationships with their foster parents are categorised by courts as ‘family life’.¹³⁵

The case for recognition

Human rights treaties / constitutional provisions do not list every right of fundamental importance – for example the right to breathe¹³⁶ or to feel the caring touch of the human hand. Instead, the relevant Articles are treated as living instruments within whose reach all rights essential to human flourishing are capable of being identified – be they (for example) the right to a livelihood,¹³⁷ to development¹³⁸ or to palliative care.¹³⁹

¹³³ For a critical review of the literature, see Katharine Silbaugh, ‘Commodification and Women’s Household Labor’ in Martha Albertson Fineman and Terence Dougherty (eds), *Feminism Confronts Homo Economicus* (Cornell University Press 2005), and see also Katherine M. Franke, ‘Theorizing Yes: An Essay on Feminism, Law, and Desire’ in *Columbia Law Review* (2001) 101, 181 – 208, 187; Mary Becker, ‘Care and Feminists’ in *Wisconsin’s Women’s Law Journal* (2002) 17, 57 – 110, at pp71-73; and see also in this context Nancy Folbre and Julie A. Nelson, ‘For Love or Money’ in *The Journal of Economic Perspectives*, Vol. 14, No. 4 (Autumn, 2000), pp. 123-140, p129.

¹³⁴ This issue was addressed by Munby J in *R (A and B) v East Sussex CC* [2003] EWHC 167 (Admin), (2003) 6 CCLR 194. at para 116 where he cited *Niemietz v Germany* (1992) 16 EHRR 97 at para [29] where the Strasbourg Court stated that there was no reason in principle why the ‘private life’ protected by article 8 “should be taken to exclude activities of a professional or business nature’.

¹³⁵ See for example *G v E, a local authority & F* [2010] EWHC 621 (Fam) – a case in the High Court of England and Wales.

¹³⁶ Indeed, Deborah Stone, in arguing for a ‘Right to Care’, states ‘Care is as essential as the air we breathe.’ see Deborah Stone, ‘Why We Need a Care Movement’, *The Nation*, 13 March 2000, at p.13.

¹³⁷ See for example, *Olga Tellis v. Bombay Municipal Corporation* (1985) Indian Supreme Court 2 Supp SCR 51.

¹³⁸ See for example Stephen Marks, ‘The Human Right to Development: Between Rhetoric and Reality’ in *Harvard Human Rights Journal*, Vol. 17 (2004) 137 – 168.

¹³⁹ See for example, *Washington v. Glucksberg* (1997) 521 U.S. 702.

Whilst the formulation of some rights necessitates emphasis of provisions at the socio-economic end of the human rights spectrum, this is not the case in relation to the right to care. In this context, the Strasbourg Court's approach to arguments concerning the existence of a 'right to sleep' and a 'right to social interaction' is informative for present purposes. Deliberate interference with a person's sleep has been held to engage Article 3¹⁴⁰ (torture, inhuman and degrading treatment), whereas state sanctioned activities that interfered with individuals' sleep have been held to engage Article 8¹⁴¹ (private and family life). In similar vein, the deliberate interference with a person's ability to interact with fellow human beings has been held to engage Article 3¹⁴² whereas a state's failure to take action to remove barriers that handicapped a disabled person's ability to 'participate in the life of the community' has been held to have the potential to engage Article 8.¹⁴³ This identification of such a latent right to community living within Article 8 (and in analogous terms, in the US by the Supreme Court¹⁴⁴) has of course been followed by its explicit recognition in the UNCRPD, Article 19.

The classification of a 'right to care' as a human right might be challenged on the ground that it is binary – involving as it always must, another. On analysis, however, conjoined rights are not unusual: the right to marry,¹⁴⁵ the right to associate¹⁴⁶ and indeed the right to family life¹⁴⁷ are not wholly egoistic or autonomous rights. Just as a right to care is contingent on there being a person 'in need' of care (or a 'protected class' in the language of rights) certain fundamental rights are contingent on another right being engaged – the so called parasitic rights, of which Article 14 ECHR (non-discrimination) is a classic exemplar. Accordingly, a policy of treating family carers less favourably than non-family carers was held by the High Court of England and Wales to constitute differential treatment based on a family relationship – and (in the absence of justification by 'counterbalancing factors of a compelling nature') to violate Article 14 in combination with Article 8.¹⁴⁸

¹⁴⁰ *Ireland v UK* (1978) 2 E.H.R.R. 25, which concerned interrogation techniques which included depriving suspects of their sleep.

¹⁴¹ *Hatton v UK* (2003) 37 E.H.R.R. 611 which concerned the sanctioning of night flights into Heathrow airport.

¹⁴² *Keenan v UK* (2001) 33 EHRR 39 – in the case of the solitary confinement of a psychiatric patient.

¹⁴³ *Botta v. Italy* (1998) 26 E.H.R.R. 241 and *Zehnalová & Zehnal v. Czech Republic* (2002) Application no 38621/97.

¹⁴⁴ *Olmstead v LC* US Supreme Court (98-536) 527 US 581 (1999) – of perpetuating 'unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life ... which severely diminishes [their] everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.'

¹⁴⁵ ICCPR Article 23; AmCHR Article 17; ECHR Article 12.

¹⁴⁶ ICCPR Article 22; AmCHR Article 16; AfCHR Article 10; ECHR Article 11.

¹⁴⁷ ICCPR Article 17; AmCHR Article 17; AfCHR Article 18; ECHR Article 8.

¹⁴⁸ *R v Manchester City Council ex p L* (2001) Times, 10th December: [2002] 1 FLR 43: para 90.

Source / foundational human rights treaties

A right to care rests most obviously within the generic ‘right to private life’: Article 17 ICCPR, Article 8 ECHR and Article 11 AmCHR. Whilst the Human Rights Committee¹⁴⁹ and the Inter-American Commission on Human Rights have given only a limited steer as to their interpretation of the notion of privacy, this has been more than made up for by the Strasbourg Court which has described the notion of ‘private’ in the most expansive of terms: including a ‘person’s physical and psychological integrity’ for which respect is due in order to ‘ensure the development, without outside interference, of the personality of each individual in his relations with other human beings’.¹⁵⁰ Thus sexual rights,¹⁵¹ environmental pollution,¹⁵² physical barriers to movement,¹⁵³ access to files,¹⁵⁴ the denial of citizenship,¹⁵⁵ and information about one’s illness¹⁵⁶ have all been held to come within its reach. In the context of the needs of disabled people, the Strasbourg Court has been particularly attracted to the notion of dignity – declaring that the ‘very essence of the Convention is respect for human dignity and human freedom’.¹⁵⁷

In *R (A and B) v East Sussex CC*¹⁵⁸ the High Court of England and Wales was asked to give general guidance as to how local authorities should seek to resolve the relative interests of two disabled people (to be lifted safely and with dignity) and their paid carers (to avoid risks of injury from manual handling). In its analysis, the court had particular regard¹⁵⁹ to the Article 8 jurisprudence of the European Court of Human Rights.¹⁶⁰ Having identified the fundamental importance of disabled people being lifted safely and with dignity, Munby J (as he then was) observed that this needed to be put into context: the context that carers had corresponding rights. In his opinion such claims ‘are necessarily affected when the individual brings his own private life into contact or close connection with other protected interests’, adding (para 118):

¹⁴⁹ See for example UN Human Rights Committee General Comment No. 16 (1988) and S Joseph, J Schultz and M Castan, ‘The International Covenant on Civil and Political Rights’ (OUP 2004) chapter 16.

¹⁵⁰ *Botta v Italy* (1998) 26 E.H.R.R. 241.

¹⁵¹ *Norris v Ireland* (1988) 13 EHRR 186.

¹⁵² *Hatton v UK* (2003) 37 E.H.R.R. 611.

¹⁵³ *Botta v Italy* (1998) 26 E.H.R.R. 241.

¹⁵⁴ *Gaskin v U.K.* (1989) 12 EHRR 36.

¹⁵⁵ *Kuric v. Slovenia* (2010) Applic no. 26828/06 13th July 2010.

¹⁵⁶ *McGinley & Egan v UK* (1998) 27 E.H.R.R. 1; and *LCB v UK* (1998) 27 E.H.R.R. 212.

¹⁵⁷ *Pretty v. UK* (2002) 35 E.H.R.R. 1 at 65

158 [2003] EWHC 167 (Admin), (2003) 6 CCLR 194.

¹⁵⁹ Other provisions it considered to be of relevance included Article 3(1) of the Charter of Fundamental Rights of the European Union (the right to respect for ... physical and mental integrity).

¹⁶⁰ Notably *Botta v Italy* (1998) 26 EHRR 241.

I simply do not see how in this almost uniquely personal context persons in [the disabled persons] situation can seek to rely upon the rights afforded to them by article 8 without allowing that their carers have, at least in some respects, corresponding rights which have to be brought into the equation. If article 8 protects [the disabled persons] physical and psychological integrity – and it plainly does – then equally article 8(2) must ... protect their carers' physical and psychological integrity. And if article 8 protects [the disabled persons] dignity rights – and in my judgment it does – then equally article 8(2) must protect their carers' dignity rights.

Having so determined, Munby J observed (para 120):

I recognise of course that the compassion of the carer is itself a vital aspect of our humanity and dignity and that at a very deep level of our instinctive feelings we value and need the caring touch of the human hand. ... Even those who do not believe in any God know that a human being is more than a machine consisting of a few rather basic chemicals operated by electric currents controlled by some animalistic equivalent of a computer located in the skull – and that, no doubt, is why we have an instinctive and intuitive preference for the touch of the human hand rather than the assistance of a machine. As disabled persons or invalids our instinctive preference is to be fed by a nurse with a spoon rather than through a nasogastric or gastrostomy tube.

At the very least the *East Sussex* judgment confirms that the caring role is the proper subject for human rights discourse. In so doing, it uses the elemental language of rights – that ‘the compassion of the carer is itself a vital aspect of our humanity and dignity’ – language indistinguishable from that deployed by the scholars considered above.

Whilst this paper has focussed on the ‘right to private life’, it is not the only human rights provision that could be construed as protecting a substantive right to care. Nicole Busby¹⁶¹ for example has provided a convincing analysis on the relatively narrow issue¹⁶² of how a ‘right to care’ can be identified within European employment law, as a mechanism for reconciling the conflicts and adverse consequences experienced by those involved both paid work and unpaid care.

Carers and the right to support the ‘*doulia*’ right

¹⁶¹ Nicole Busby (footnote 63 above).

¹⁶² While acknowledging that such a right could also exist in EU law for those who ‘do not engage in paid employment’ – *ibid* p 11.

Inherent within all human rights treaties¹⁶³ is the obligation on states, not merely to refrain from interfering with the substance of the protected right (the ‘negative’ obligation) but also to take action to prevent the right being undermined. In the European context this positive obligation requires that states take effective measures to ‘secure respect for private life even in the sphere of the relations of individuals between themselves’¹⁶⁴ and which may involve the implementation of domestic laws that provide the necessary protection.¹⁶⁵ The positive and negative components, although subject to distinct jurisprudential criteria are seen as indivisible, and in this context Eva Kittay’s¹⁶⁶ notion of reciprocity in caring is particularly apt:

Just as we have required care to survive and thrive, so we need to provide conditions that allow others – including those who do the work of caring – to receive the care they need to survive and thrive.¹⁶⁷

Kittay coined the word ‘*doulia*’¹⁶⁸ to explain the reciprocal nature of dependency in such cases – that without a positive obligation to support carers, those for whom they care ‘will continue to remain disenfranchised’ and their carers ‘will continue to share varying degrees of the dependents’ disenfranchisement’.¹⁶⁹ For West¹⁷⁰ such a ‘right to provide care without risking impoverishment or dependency is comparable in importance and priority to the widely recognized core liberal rights of privacy, speech, property or contract.’ For Fineman the relationship is best characterised as ‘derivative dependency’ – where one person ‘assumes responsibility for the care of an inevitably dependent person’. Her aim is to capture:

¹⁶³ As an obligation to ‘to facilitate, provide and promote’ – Committee on Economic, Social and Cultural Rights, General Comment 12 (1999) to the International Covenant on Economic, Social and Cultural Rights para 15 – and see also for example, *SERAC v Nigeria* (2003) African Commission on Human and Peoples’ Rights Communication No. 155/96, and *Velásquez Rodríguez v. Honduras* (1988) Inter-Am.Ct.H.R. (Ser. C) No. 4 July 29, 1988.

¹⁶⁴ *X & Y v. Netherlands* (1985) 8 E.H.R.R. 235. para 23.

¹⁶⁵ *A v. UK* (1998) 27 E.H.R.R. 611, paras 22 & 24.

¹⁶⁶ Eva Feder Kittay, *Love’s Labor* (Routledge 1999).

¹⁶⁷ Robin West (footnote 8 above) p.107.

¹⁶⁸ From the ancient Greek word ‘*doula*’ which signified a female servant or slave.

¹⁶⁹ Eva Feder Kittay, *Love’s Labor* (Routledge 1999), p77; see also, for example, H Arksey and M Morée, ‘Supporting working carers: do policies in England and The Netherlands reflect ‘*doulia* rights?’ in *Health and Social Care in the Community* (2008) 16 (6), 649–657; and Alan Deacon, ‘Civic Labour or *Doulia*? Care, Reciprocity and Welfare’ in *Social Policy and Society* (2007), 6 : pp 481-490.

¹⁷⁰ Robin West (footnote 124 above).

the simple point that those who care for others are themselves dependent on resources in order to undertake that care. Some of those needs are for monetary or material resources, whereas others are more related to institutional or structural arrangements.¹⁷¹

Derivative dependency is, she argues:

culturally and socially assigned in an inequitable manner according to a script rooted in ideologies, particularly those of capitalism and patriarchy. These scripts function at an unconscious (and therefore unexamined) level, channelling our beliefs and feelings about what is considered natural and what are appropriate institutional arrangements.

Fineman argues that we share a 'collective or societal debt' for this fundamental caretaking role,¹⁷² and with it an obligation to challenge the prevalent socio-economic mores that are not only inimical to dependent people, but also to carers: that far from 'structurally accommodating or facilitating caretaking', societal institutions and workplaces 'operate according to premises that are incompatible with obligations for dependency.'¹⁷³

What is being described here is a social model of exclusion – similar but even more subtle and 'unconscious' than that we have come to associate with the experiences of disabled people. In *Price v. UK* (2001)¹⁷⁴ Judge Greve gave what has come to be considered a classic statement of the positive obligations owed to disabled people under civil and political human rights provisions – the duty to take action to 'ameliorate and compensate for the disabilities faced' to the extent that 'compensatory measures come to form part of the disabled person's bodily integrity'. In so finding, she noted:

The applicant's disabilities are not hidden or easily overlooked. It requires no special qualification, *only a minimum of ordinary human empathy*, to appreciate her situation and to understand that to avoid unnecessary hardship ... she has to be treated differently from other people because her situation is significantly different.

Although in contrast the handicaps and social exclusion experienced by carers are all too easily overlooked – this cannot in itself diminish a state's obligation to take compensatory measures to address the injustice and marginalisation created by their

¹⁷¹ Footnote 106 above at p.184.

¹⁷² Footnote 106 above at 182.

¹⁷³ *Ibid* p.183.

¹⁷⁴ (2001) 34 E.H.R.R. 1285.

derivative dependency. The fact that states with a neoliberal or similar gendered bias see this as the natural order cannot – in the court of fundamental human rights – be an adequate excuse. No more than it can excuse the exclusion of gay, illegitimate, or disabled people.

Kitty Malherbe¹⁷⁵ has identified a number of human rights provisions that relate to the notion of a state's positive obligations to mitigate the adverse consequences that arise from assuming a caring role. These include requirements in the UNCRPD on States to provide support for persons with disabilities 'and their families' for 'disability-related expenses, including adequate training, counselling, financial assistance and respite care'¹⁷⁶ 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 disabilities¹⁷⁷

In addition Malherbe cites General Comment 5 of the Committee on Economic, Social and Cultural Rights¹⁷⁸ which stresses the importance of 'social security and income-maintenance schemes' for persons with disabilities and then notes:

... the support provided should also cover individuals (who are overwhelmingly female) who undertake the care of a person with disabilities. Such persons, including members of the families of persons with disabilities, are often in urgent need of financial support because of their assistance role.

Also of relevance in this context, is the requirement in the UN Convention on the Rights of the Child¹⁷⁹ that States should afford families 'the necessary protection and assistance so that it can fully assume its responsibilities within the community' for the care of their children.¹⁸⁰ General Comment 9 of the Committee on the Rights of the

¹⁷⁵ Kitty Malherbe, 'The social security rights of caregivers of persons with disabilities' in Ilze Grobbelaar-du Plessis and Tobias van Reenen (eds), *Aspects of disability law in Africa* (Pretoria University Law Press 2011).

¹⁷⁶ Article 28(2)(c).

¹⁷⁷ Preamble paragraph (x).

¹⁷⁸ Committee on Economic, Social and Cultural Rights, General Comment No. 5, Persons with disabilities (Eleventh session, 1994), U.N. Doc E/1995/22 at 19 (1995) para 28.

¹⁷⁹ Convention on the Rights of the Child, G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989),

¹⁸⁰ Preamble.

Child¹⁸¹ (which concerns the support for disabled children) stresses the need for action to ensure that disabled children and their 'parents and/or others caring for the child do receive the special care and assistance they are entitled to under the Convention'.

The reciprocal nature of carers' and dependant people's rights means that a failure to provide compensatory measures to enable the dependent person to live with dignity, may subject the carers to intolerable hardship, which itself can be articulated in terms of breaching their rights to respect for their private and family life and their right not to be subjected to degrading treatment. *R (Bernard) v London Borough of Enfield* (2002)¹⁸² concerned a claim by a disabled applicant and her carer that their human right had been breached by the failure of the local authority to take positive measures (by way of community care facilities) 'to enable them to enjoy, so far as possible, a normal private and family life'. The claim succeeded because the council's failure to act 'condemned the claimants to living conditions which made it virtually impossible for them to have any meaningful private or family life for the purposes of Article 8'.¹⁸³

Carers and Inequality

As noted at the outset of this paper, in the 1970's the proposition that disabled people were the proper subjects of equality legislation was met with a degree of incredulity. However, within two decades their claim came to be seen as 'self-evident'. Today a similar incredulity exists in relation to carers: being a 'carer', it is suggested, is not an innate characteristic and the handicaps they experience are those they assume when they choose to take on their caring roles.

Many carers do not articulate their experience in terms of choice: many speak of it in similar terms to the way disabled people describe their experience of impairment. The assertion of 'choice' does not of course vitiate the need for rational thought. Different societies offer different choices: being the parent of a disabled child or the child of a disabled parent is not a 'choice' and the options available to a person in this situation

¹⁸¹ Committee on the Rights of the Child, General Comment No. 9, The rights of children with disabilities (Forty-third session, 2007), U.N. Doc. CRC/C/GC/9 (2007) para 13.

¹⁸² The High Court of England and Wales, [2002] EWHC 2282 (Admin); 5 CCLR 577; [2003] UKHRR 148, paras 32-33.

¹⁸³ See also *R (Hughes) v Liverpool City Council* [2005] EWHC 428 (Admin) 8 CCLR 243 paras 35 - 39. where a similar failure to provide support for a disabled person was held not to amount to a violation of that persons 'Article 8 rights' solely because of the extraordinary efforts made by his carer (a burden the judge considered to be 'intolerable').

will be dictated in large measure by the welfare arrangements that the state chooses to offer.¹⁸⁴ The situation has been described as ‘non-coerced yet not voluntarily chosen’,¹⁸⁵ although ‘compulsory altruism’ is perhaps a better description.¹⁸⁶

The ‘non-innate’ argument is also suspect for a number of other reasons, not least due to the existence in many states of legal obligations on carers to provide care and the moral coercion that exists in those others where no statutory liability remains. It is also undermined by protected status being accorded to ‘religious belief’: plausibly, it could be argued that ‘religious belief’ is no more immutable a characteristic than being a ‘carer’. Indeed, given the advances in medical technology (retina and cochlea implants, for example) the retention of disability has itself the potential to become a chosen characteristic.

Direct and indirect discrimination

It is arguable, that the almost universal presence of legal, social and moral obligations on family carers has created a formalised public status of being a carer: one that transcends the private and the personal. Such a status may not be ‘innate’ but it is nevertheless very real. It is a role that falls disproportionately on women (expressly so in some states)¹⁸⁷ and has undoubted negative health, financial, and well-being impacts.

In the language of human rights, such legal/social obligations engage – indirectly, at the very least – several protected statuses: sex, disability, birth / family, the rights of children for example, and in consequence demand of states, especial vigilance. Indeed such laws, policies and mores do more than ‘engage’ such statuses – they have a disproportionately adverse impact upon them, and constitute *prima facie* unlawful discrimination contrary to many international treaties: for example the ICCPR Articles 2 and 3; the African Charter on Human and Peoples' Rights (AfCHR) Articles 3 and 18; the AmCHR Article 24; and the ECHR Article 14. Acknowledging this state of affairs,

¹⁸⁴ As Fineman observes ‘We ignore the fact that individual choice occurs within the constraints of social conditions. These constraints include ideology, history, and tradition which funnel decisions into prescribed channels, often operating in a practical and symbolic manner to limit options’ – see M Fineman, ‘Cracking the Foundational Myths’ (footnote 106 above) at 185: or as George Elliot put it in Middlemarch, ‘there is no creature whose inward being is so strong that it is not greatly determined by what lies outside it’.

¹⁸⁵ Alan Deacon, ‘Civic Labour or Doulia? Care, Reciprocity and Welfare in Social Policy and Society (2007), 6 pp481-490, 484.

¹⁸⁶ Eva Feder Kittay, *Love’s Labor* (Routledge 1999) p133 attributes this to P Taylor-Gooby, ‘Welfare State regimes and Welfare Citizenship’ in *Journal European Social Policy*, 1 (1991) 93-105.

¹⁸⁷ See footnotes 16 and 26 above.

the Human Rights Committee referred to the 'inequality in the enjoyment of rights by women [being] ... deeply embedded in tradition, history and culture' and stressed the need for States to 'take all steps necessary ... to put an end to discriminatory actions both in the public and the private sector which impair the equal enjoyment of rights'.¹⁸⁸

In similar vein, the UN Convention on the Elimination of All Forms of Discrimination against Women¹⁸⁹ (CEDAW) requires states to promote measures which 'enable parents to combine family obligations with work responsibilities and ... participation in public life' and which 'eliminate discrimination against women in all matters relating to marriage and family relations'. The CEDAW Committee¹⁹⁰ has noted that in 'all societies women who have traditionally performed their roles in the private or domestic sphere have long had those activities treated as inferior' and that 'even where de jure equality exists, all societies assign different roles, which are regarded as inferior, to women.'¹⁹¹ At a regional level this has been echoed by the Council of Europe which has called for 'the removal of barriers to positive parenting, whatever their origin' and for employment policies that 'allow a better reconciliation of family and working life'.¹⁹²

The New Zealand case of *Ministry of Health v Atkinson* (2012)¹⁹³ concerned a blanket policy applied by the Ministry of Health to exclude family members from payment for the provision of various disability support services¹⁹⁴ to their adult disabled children. The policy was challenged on the ground that it constituted unlawful discrimination against them on the basis of their 'family status'.¹⁹⁵ The Court of Appeal found that the policy was discriminatory and in consequence it fell to the Government to establish weighty reasons to justify its retention. In endeavouring to discharge this evidential obligation, the Government raised a number of arguments, all of which were held insufficient by the Court. One of these being that a 'social contract' existed between families and the state, under which families had the primary responsibility for providing care to family members. Whilst the court considered that this might be tenable in relation to the care of

¹⁸⁸ Human Rights Committee *General Comment No. 28: Equality of rights between men and women (article 3 International Covenant on Civil and Political Rights: 29/03/2000. CCPR/C/21/Rev.1/Add.10 paras 4 and 5.*

¹⁸⁹ UN G.A. res. 34/180, 34 U.N. GAOR Supp. (No. 46) at 193, U.N. Doc. A/34/46 Articles 11 and 16.

¹⁹⁰ CEDAW General Recommendation 16, Unpaid women workers in rural and urban family enterprises (Tenth session, 1991).

¹⁹¹ CEDAW General Recommendation 21, Equality in marriage and family relations (Thirteenth session, 1992)

¹⁹² Recommendation Rec (2006)19 Committee of Ministers on policy to support positive parenting, adopted on 13 December 2006.

¹⁹³ CA205/2011[2012] NZCA 184.

¹⁹⁴ Provided under the New Zealand Public Health and Disability Act 2000.

¹⁹⁵ Contrary to the Human Rights Act 1993, s20L(1) as inconsistent with the New Zealand Bill of Rights Act 1990, ss 5 and 19 which protect, amongst other matters, the right to be free from discrimination on various grounds, including family status.

young children it found it decidedly unattractive to suggest that parents were obliged to care for their disabled adult children ‘for the remainder of their lives on a full-time basis, subject to respite care.’

In *Atkinson* the court placed reliance on New Zealand’s ratification of (amongst other human rights treaties¹⁹⁶) the ICCPR and the UNCRPD,¹⁹⁷ as well as on the Canadian High Court decision of *Hutchinson v British Columbia (Ministry of Health)*¹⁹⁸ which involved a similar policy of prohibiting state support payments to family members caring for adults with disabilities.

Absent formal recognition – that it is unlawful to discriminate against a person simply by virtue of their caring status – such adverse treatment will fall to be characterised as indirect discrimination based on grounds of birth, family status or sex.

In response to claims by carers alleging unlawful discrimination (such as in *Atkinson* and *Hutchinson* above) states will be required to establish objective and reasonable justification for the difference in treatment. This in turn is likely to require evidence of the measures they have taken to ‘ameliorate and compensate’ carers for the handicaps they experience as a consequence of their caring role.¹⁹⁹ In Strasbourg jurisprudential terms, the placing of status responsibilities of this kind, creates direct obligations on contracting states – as the court observed in *Marckx v Belgium*²⁰⁰ (a case concerning state policies which prejudiced the ‘illegitimate’ family):²⁰¹

when the State determines in its domestic legal system the regime applicable to certain family ties ... it must act in a manner calculated to allow those concerned to lead a normal family life.’

Associative discrimination

Even if one accepts uncritically the argument that protected statuses should be reserved for those with immutable or ‘innate’ traits, there exists the challenge of the

¹⁹⁶ The Court also referred to the similar provisions in the International Covenant on Economic, Social and Cultural Rights Article 2.2, also ratified by New Zealand.

¹⁹⁷ In particular ICCPR Articles 2 and 26, and UNCRPD Articles 5, 12, 19(a) and 23(5).’

¹⁹⁸ *Hutchinson v B.C. (Ministry of Health)* (2004) BCHRT 58; affirmed as *R v Hutchinson* 2004 BCSC 1536, (2004) 261 DLR (4th) 171: n this case a violation of the British Columbia Human Rights Code 1996, s6. See B Bunn, ‘A New Class Of Employees: Family Members Aiding The Disabled’ in *University of Pennsylvania Journal of Labor and Employment Law* [2006] Vol. 8:2 505-521.

¹⁹⁹ Adopting the language used by Judge Greve in her concurring opinion in *Price v. UK* (2001) 34 EHRR 1285, albeit that the case related to a disabled person.

²⁰⁰ (1979-80) 2 E.H.R.R. 330 para 31.

²⁰¹ *Ibid* para 41.

social impacts that are experienced by those in the out-group – ie people who associate with those who are protected.

A person may experience overt adverse treatment as a consequence of their ‘protected status’, without being subjected to explicit ‘direct discrimination’. In *Coleman v Attridge Law* (2008),²⁰² a case before the European Court of Justice (ECJ) the Advocate General²⁰³ referred to ‘other, more subtle and less obvious ways’ – one of which was to target not the person with the protected characteristic (ie the black or disabled person) ‘but third persons who are closely associated with them and do not themselves belong to the group’. In the Advocate General’s opinion ‘a robust conception of equality entails that these subtler forms of discrimination should also be caught by anti-discrimination legislation’.

Coleman concerned the interpretation of an EU Directive²⁰⁴ which prohibited discrimination where a ‘person is treated less favourably than another’ on grounds of religion or belief, disability, age or sexual orientation. The applicant claimed she had been constructively dismissed from her employment because she had sought time off work to care for her disabled son: that her employer had treated her less favourably than employees with non-disabled children.

Her claim was problematical under the then UK anti-discrimination law²⁰⁵ since its prohibitions were limited to actions against ‘disabled people’ and it was the applicant’s son, not herself, who was disabled. The ECJ ruled however that she had been treated less favourably ‘because of disability’: that the Directive protected individuals from ‘associative’ discrimination of this type.²⁰⁶ The UK has since brought its legislation into line²⁰⁷ – and effectively carers are now protected from such adverse ‘associative’ treatment. A similar process has resulted in protection for carers in France²⁰⁸ and in

²⁰² *Coleman v Attridge Law* (C-303/06) (2008) All ER (EC) 1105 ECJ (Grand Chamber) Judgment 17 July 2008 at <http://curia.europa.eu/jurisp/cgi-bin/form.pl?lang=EN&Submit=rechercher&numaff=C-303/06> accessed 15 May 2013.

²⁰³ Opinion of Advocate General Poiares Maduro delivered on 31 January 2008 Case C-303/06 S in *Coleman v Attridge Law and Steve Law* at para’s 12 – 14.

²⁰⁴ European Union Employment Equality Directive 2000/78/EC, Article 2.

²⁰⁵ The Disability Discrimination Act 1995.

²⁰⁶ Discrimination by association is not a new concept – particularly in relation to discrimination on the grounds of race: in the UK, for example, see *Showboat Entertainment v. Owens* [1984] 1 All ER 83.

²⁰⁷ Equality Act 2010 s13.

²⁰⁸ Article L 1132-1 of the French Code du Travail has been held to apply, not only to ‘victims, directly or indirectly, of discrimination by reason of their [protected statuses enumerated in the Equal Treatment Framework Directive 2000/78/EC and transposed in the French law with a few additions], but also to any person who is closely associated to them’ – see CPH de Caen, 25 nov. 2008, F 06/00120 – see <http://blog.dalloz.fr/files/2010/11/Caen-21-10-2008.pdf> accessed 15 May 2013; see also Haute Autorité de Lutte contre les Discrimination et pour l’Egalité (HALDE) Délibération n.2007-75 du 26 mars 2007, p.3-4 at http://halde.defenseurdesdroits.fr/IMG/pdf/Deliberation_26_mars_2007.pdf accessed 15 May 2013.

Ireland.²⁰⁹ Protection of this nature is found (for example) in Peruvian antidiscrimination provisions,²¹⁰ is under discussion in Australia²¹¹ and a duty to consider reasonable adjustments for working carers has already been enacted in New Zealand.²¹²

Conclusions

This paper has sought to highlight the many parallels between the struggles waged by disabled people and by carers, in challenging their social exclusion. From the first domestic provisions addressing disability discrimination (most famously the USA's Rehabilitation Act 1973) it took almost 30 years before concrete international legal provisions came on stream, such as the EU Equal Treatment Framework Directive 2000/78/EC and the UNCRPD. The period following the 1973 Act saw an exponential growth in states adopting specific disability discrimination legislation:²¹³ action that formed the basis for effective universal recognition of the rights of disabled people.

We are now witnessing a similar 'global' trend in domestic legislation recognising the rights of carers. Carer specific provisions and 'associative discrimination' measures exist in almost every continent.

In Europe, for example, the EU has stressed the need for increased support for its 32 million²¹⁴ 'informal' carers²¹⁵ and for this to be put 'at the top of' each member state's policy agendas.²¹⁶ In 2009, Glendinning et al²¹⁷ considered that in at least half the member states this had resulted in carer support being acknowledged as a political priority.

²⁰⁹ Carers have formal protection (under the Family Status ground) in the Employment Equality Act 1998, s2(1) and the Equal Status Act 2000, s2(1).

²¹⁰ Article 8.2 Law 29973 General Law of Disabled Persons at <http://www.conadisperu.gob.pe/web/documentos/2012/politica/ley29973.pdf> accessed 15 May 2013.

²¹¹ See Australian Human Rights Commission, 'Investing in care: Recognising and valuing those who care' (Australian Human Rights Commission 2009) at

http://humanrights.gov.au/sex_discrimination/VUCW_australiaResearchPrj/index.htm accessed 15 May 2013.

²¹² The Employment Relations (Flexible Working Arrangements) Act 2008 and see also Ministry of Social Development, *Caring for New Zealand Carers* (2007) at www.msd.govt.nz/documents/about-msd-and-our-work/work-programmes/policy-development/carers-strategy-consultation.pdf and the Ministry of Social Development, 'The New Zealand Carers' Strategy and Five-Year Action Plan' (2008) at www.msd.govt.nz/documents/about-msd-and-our-work/work-programmes/policy-development/carers-strategy.pdf - both accessed 15 May 2013.

²¹³ T Degener 'Disability Discrimination Law: A Global Comparative Approach' in Lawson L & Gooding C (eds) *Disability Rights in Europe: From Theory to Practice* (Hart Publishing 2005).

²¹⁴ Glendinning et al footnote 43 above at para 7.2.1.

²¹⁵ EC (2008) *Long-term Care in the European Union*, European Commission DG Employment, Social Affairs and Equal Opportunities p1.

²¹⁶ Glendinning et al footnote 43 above at para 1.2.3.

²¹⁷ Ibid.

For neoliberal governments, in particular, the handicaps experienced by carers' pose particular problems. Ideologically such governments espouse the 'small state' and are committed to a reducing the public provision of social welfare support. Unfortunately, in the developed Western nations this brand of economic liberalism has not (even before the financial crash of 2007) produced material benefits for the bulk of the population. As Stiglitz²¹⁸ and others have observed, in such states a fall in middle class household incomes has only been averted by women re-joining the workforce. These changes have occurred at a time of dramatic increase in the numbers of dependent elderly people, and for whom institutionalisation is no longer considered appropriate. Carers – and they are preponderantly working women – are the elastic that has accommodated the contradictions in neoliberalism: a dogma that advocates work as the only route out of poverty but simultaneously holds to the belief that social care is primarily a family or charitable responsibility.²¹⁹ Carers are now stretched to breaking point, and these governments are aware of this.

At the end of 2012, Cabinet papers from the first Margaret Thatcher administration were released, under the 30 year rule.²²⁰ Whilst these papers have attracted considerable publicity for different reasons²²¹ what is striking is the Cabinet's concern about sustaining 'family caring': its preoccupation with 'the increase in the proportion of women' in paid work; the 'reduction in the ratio between the number of "typical carers" (women aged 45- 59) and the number of elderly people';²²² and the 'severe penalties' that result from the 'forces impelling women' to take paid work.²²³ The policy direction of the government is summed up as 'how to encourage families ... to reassume responsibilities taken on by the state e.g. responsibility for the disabled ...'.²²⁴

As this paper has highlighted, the general response of neoliberal governments since that time has been tokenistic: involving in large measure the enactment of opiate legislation – for example, of the relatively bland 'carer recognition' type. These are essentially rhetorical measures, heavy on process and exceedingly light on substance: responses that place little or no strain on the public purse. As Levitas has observed

²¹⁸ See footnote 72 above.

²¹⁹ M Drakeford *Social Policy and Privatisation*: (Longman 1999) p.103.

²²⁰ The National Archives *Prime Minister's Office files (PREM)*: Home Affairs. Family policy group; renewing values of society Catalogue ref: PREM 19/783 Date: 1982 May 26 - 1982 October 29

²²¹ Not least for their revelation as to the chilling intent by that government to dismantle the welfare state – see Alan Travis *Margaret Thatcher's role in plan to dismantle welfare state revealed* The Guardian, Friday 28 December 2012 page 2.

²²² The National Archives (footnote 216 above) at p89 - paper prepared by Secretary of State for Social Services (Norman Fowler) 7 September 1982.

²²³ *Ibid* at p148-149 - paper prepared by Secretary of State for Transport (David Howell) 27 August 1982.

²²⁴ *Ibid* at p12 - paper prepared by the Central Policy Review Staff FPG (82)2 November 1982.

‘recognising the value of unpaid work ... means not recognizing its full economic value, since its cheapness is its main recommendation’.²²⁵

In his seminal paper concerning the impact of Americans with Disabilities Act 1990 Samuel Bagenstos (whilst celebrating the Act’s achievements) concluded that it had had ‘little, if any, positive effect on the overall employment of people with disabilities’ and little impact on eliminating ‘the deep structural barriers to employment that people with disabilities face’. In his opinion these problems could only be overcome by the government adopting ‘more direct and sustained interventions such as the public funding and provision of benefits’.²²⁶ For Fineman too, neoliberalism has no answers: the ‘approach to resolving this type of inequality is not found in simplistic and hypocritical prescriptions and ideological placebos of independence, autonomy and self-sufficiency’.²²⁷

For carers and disabled people alike, the answer lies in the state providing decent support services for disabled people and by removing the barriers that handicap them. For this to happen a new political settlement is required: one that does not predicate everything on work – or work of the autonomous non-disabled model – but has at its heart, a progressive social welfare system.

Whilst the path that carers are treading towards the goal of a right to equal treatment is analogous to that taken by disabled people, it is not the same and indeed it has a different destination. The Disabled People’s movement seeks to create a society that is fully accessible and for which their different needs are accommodated and respected. Simplistically it is only if this struggle succeeds, that carers can have true equality: only when disabled people have full independence will carers have full equality.²²⁸

Simple as this assertion may be in theory – that if disabled people have a fully accessible environment and decent support services then carers will be able to have undisturbed lives – in practice it is not so. The reality is, of course, that the turbulent experiences of disabled people will always spill over and on to those close to them: it is the consequence of the human condition that we are affected by those closest and dearest to us. This impact (no matter how active, benign and universalist the state’s role) will always be capable of articulation in the language of disability and handicap, or alternatively in the language of experience and the loss of innocence. No state can

²²⁵ R Levitas *The inclusive society?* (Palgrave 1998) at p 37.

²²⁶ Samuel Bagenstos, ‘The future of disability law’ in the *Yale Law Journal* 114.1 (Oct 2004) at p1.

²²⁷ Martha Albertson Fineman, ‘Cracking the Foundational Myths’ (footnote 106 above) at 189.

²²⁸ For those caring for children or frail older people, the ‘need is for a fairer society: one that does not just tolerate or (at best) ‘accommodate’ dependency, but one that regards it as central: as its *raison d’être*.

compensate for such impacts since we will always have within ourselves an innate sense of our duty to care: a feeling that will inevitably open itself to exploitation by others – or indeed ourselves. A carer's feelings of compassion, guilt and duty do not however sanction adverse treatment, anymore than a woman's maternal feelings justify treating her less favourably.