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Does Your Carer Take Sugar? Carers and Human Rights: The Parallel Struggles of Disabled People and Carers for Equal Treatment

Luke Clements

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Does Your Carer Take Sugar? Carers and Human Rights: The Parallel Struggles of Disabled People and Carers for Equal Treatment

*Luke Clements**

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Introduction

35 years ago a BBC Radio program came on air in the UK called “Does he take sugar?”¹ The title was provocative, since the subject matter of the program was disability. The title tilted at what it perceived (rightly no doubt) as the prevalent conceptualization 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 program was a symptomatic marker of the journey that 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 program a few legal milestones had been planted, of which the USA’s Rehabilitation Act 1973 was a prominent, if modest, example.

Today the popular conceptualization 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 conceptualized by an increasingly large portion of the population as rights holders: as 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 and even low cost airlines.

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. On the other hand, disabled people needed state support and accordingly were better conceptualized in

1. See B.J. Sweeney, *BBC Radio 4 and the Experiential Dimension of Disability*, 20 *DISABILITY & SOC’Y* 185, 186-94 (2005).

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),² such an analysis is no longer tenable. In individual domestic legislative terms, this new conceptualization 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, color, sex⁴—as if disability was a self-evident category for protection. Indeed it was not.

A while ago I wrote to BBC to suggest that they should broadcast a new program: “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 “dependent person”⁵) find themselves in a position similar to that of disabled people 35 years ago. Today the prevalent conceptualization of a carer is of someone grateful for the services and sympathy⁶ bestowed upon him or her, and for whom the social care authorities have prime responsibility. Few human rights lawyers would conceptualize carers as rights holders, for being a “carer” is an elusive concept and, in any event, is not an innate characteristic (like sex, race and disability). The handicaps experienced by carers are those they assume when they choose to take on

2. The “social model” is used in contradistinction to the “medical model” and sees disability as socially created and extrinsic to the individual.

3. See Theresia Degener, *Disability Discrimination Law: A Global Comparative Approach*, in *DISABILITY RIGHTS IN EUROPE: FROM THEORY TO PRACTICE* (Anna Lawson & Caroline Gooding eds. 2005).

4. For example, Article 14 ECHR 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. See Luke Clements, *Keynote Review: Carers – the sympathy and services stereotype*, 32 *British J. of Learning Disabilities* 6, 6-8.

their caring roles. Therefore, carers' need for support is better conceptualized 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 Article, 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-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

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 Article considers three of these factors: the development of an identity, a narrative, and a creed.

In one way or another, the group needs to "self-identify" as a category of persons oppressed by virtue of a particular uniting characteristic. As Shakespeare has observed,⁷ (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 that 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.

7. See Tom Shakespeare, *Disability, Identity and Difference*, 100, 101 in *EXPLORING THE DIVIDE* (Colin Barnes & Geof Mercer eds. 1996).

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

Identification

As a simple matter of human rights and equality law, discrimination becomes unlawful when a person is treated unfavorably for a “status” related reason, provided it is a recognized 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 substance of power relationships and tribalism: of critical masses and crystallizations. It involves the assigning of a value to a difference, however, in reality, 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 criminalization (as with Gay or Aboriginal / First Nations Peoples).

While 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 reconceptualization may often require a renaming (no longer “cripple” or “queer”), it will invariably be subversive and celebratory. Of Ian Dury, Gay Pride, and sisterhood—the law and social change, like shackled prisoners, move together. The group must, in short, “self-identify.” Its members must embrace sabotage and radicalize 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.

8. Robin West, *The Right to Care*, in *THE SUBJECT OF CARE: FEMINIST PERSPECTIVES ON DEPENDENCY* 98 (Eva Kittay and Ellen K. Feder eds. 2002).

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-asciption, it is also a legally created status. While 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 England and Wales, a liable family rule was formalized in the Poor Relief Act of 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 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 states,¹² (albeit endangered¹³) in India,¹⁴ 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 Greece¹⁶ and

9. It has, for example, been suggested that there are philosophical—rather than simple community cost avoidance reasons for such obligations. See MC Stuijbergen et al., *Filial obligations to elderly parents: a duty of care?*, 14 MED. HEALTH CARE AND PHIL. 63 (2011).

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 Katie Wise, *Caring for our parents in an aging world: sharing public and private responsibility for the elderly*, 5 N.Y.U.J. LEGIS. & PUB. POL’Y 563 (2002); see also Seymour Moskowitz, *Filial Responsibility Statutes: Legal and Policy Considerations*, 9 J.L. & POL’Y 709, 714-17 (2001); C.H.V. Houtven & E.C. Norton, *Informal Care and Health Care Use of Older Adults*, 23 J. HEALTH ECON. 1159 (2004).

12. See generally British Columbia’s Family Relations Act of 1996 § 90; *Newson v. Newson*, 99 B.C.L.R. 2d 197 (B.C.S.C. 1994); The Parents’ Maintenance Act of 1978 § 2 (Saskatchewan); The Parents Maintenance Act of 1996 § 1 (Manitoba); The Family Law Act of 1990 § 32 (Ontario).

13. See generally BRITISH COLUMBIA LAW INSTITUTE, *Report on the Parental Support Obligation in Section 90 of the Family Relations Act* (Mar. 2007); MINISTRY OF ATTORNEY GENERAL, *White Paper on Family Relations Act Reform Proposals for a new Family Law Act* (July 2010), available at www.ag.gov.bc.ca/legislation/pdf/Family-Law-White-Paper.pdf.

14. See Code of Criminal Procedure of 1972 § 125; The Maintenance and Welfare of Parents and Senior Citizens Act of 2007.

15. See Maintenance of Parents Act of 1995 § 167B; see GHY Ting & J Woo, *Elder care: Is legislation of family responsibility the solution?*, 4 ASIAN J. GERONTAL GERIATR 72 (2009).

16. In Greece as Article 21 (and the Civil Code); see Georgios Kagialaris, Tasos Mastrogiannakis & Judy Triantafyllou, *The role of Informal Care in Long-Term Care* (Apr.

Ireland¹⁷ and in the Civil Codes of many states—for example, Belgium,¹⁸ France,¹⁹ Germany,²⁰ Italy²¹ and Spain.²² The Civil Codes of many South American Constitutions contain a similar obligation, including the duty on family members to provide “alimentos” in Argentina,²³ Peru²⁴ and Brazil.²⁵

This obligation is found in China,²⁶ the Civil Code of Taiwan²⁷ and in the customary laws of some African states.²⁸ 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.

2010), available at http://interlinks.euro.centre.org/sites/default/files/WP5_EL_FAMCARE_final_04.pdf

17. In Ireland as Article 41(2); see Alan Brady, *The Constitution, Gender & Reform: Improving the Position of Women in the Irish Constitution* (NATIONAL WOMEN’S COUNCIL OF IRELAND, Working Paper); Joyce O’Connor et al., NATIONAL COUNCIL FOR THE AGED, *The Caring Process: A Study of Carers in the Home* (Sept. 1988), available at http://www.ncaop.ie/publications/research/reports/19_CaringfortheElderly_Part2.pdf.

18. See *infra* notes 205-07 (explaining the reciprocal obligation of children (including sons- and daughters-in-laws) to maintain their father and mother or other ascendants who are in need).

19. See Civil Code Articles 205 and 206; see also Mantle & Alderson, *Maintenance obligations for elderly parents under French law*, 2 ELDER L.J. 3, 181-85 (2013).

20. See Bürgerliches Gesetzbuch ¶ 1601 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 Martha Meyer, *National Background Report for Germany* ¶ 2.1.4 (July 2004); see also Robin Means, Sally Richards & Randall Smith, *Community Care: Policy and Practice* 220 (4th ed. 2009).

21. See Civil Article 433; see also Barbara Da Roit, Blanche Bihan & August Österle, *Long-term Care Policies in Italy, Austria and France: Variations in Cash-for-Care Schemes*, 41 SOC. POL’Y & ADMIN. 653 (2007).

22. See Civil Code Article 143; see Arantza Larizgoitia Jauregi, *National Background Report for Spain* ¶ 2.1.3., (July 2004), available at http://www.uke.de/extern/eurofamcare/documents/nabares/nabare_spain_rc1_a5.pdf.

23. See Civil Code Articles 367, 372 and 376.

24. See *id.* at 472, 474.

25. See *id.* at 1694, 1696.

26. See Law of the People’s Republic of China on the Protection of the Rights & Interests of the Elderly of 1996 (as amended Dec. 28, 2012 and effective from July 1, 2013); see also National Human Rights Action Plan of China, Chapter III, Parts 4-5 (2012-2015), available at http://news.xinhuanet.com/english/china/2012-06/11/c_131645029.htm.

27. See Civil Code of 1929 Article 1114 (explaining the mutual obligation of relatives to maintain one another: relatives for this purpose being - lineal by blood; the husband and wife and the parents of the other party living in the same household (father-in-laws or mother-in-laws); brothers and sisters; and the head and the members of a house).

28. See Ghana’s customary laws, for example, make it the duty of the wife and children to support their husband and father. See E.V.O. Dankwa, *Property Rights of Widows in their Deceased Husband’s Estate*, 16 U. GHANA L.J. 7 (1982-85).

Even in those states where such obligations do not exist, or where the obligation is not enforced in practice, the evidence suggests that the dominant social attitudes exert strong moral pressure on family carers to fulfill this role. The assumption is that the family has primary responsibility for care giving. Indeed, it is not so much that the family has this obligation. It is the duty of women to look after sick and frail elderly parents and in-laws.²⁹

In Australia, where no filial responsibility laws exist,³⁰ it is said that there is an “expectation that families will take the primary role in looking after the elderly members”³¹ 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.³²

In much of Asia, it is said that the “Confucian ideal of filial piety is ubiquitous”³³ and highly gendered.³⁴ In Japan, for example, these values create the assumption that “middle-aged women” will provide the home nursing required by infirm elderly relations.³⁵

In the USA, where few of the filial responsibility statutes are actively enforced,³⁶ 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.”³⁷ In similar fashion, in

29. See Means, *supra* note 20, at 218 (describing the UK context).

30. See Michael Collingridge and Seumas Miller, *Filial responsibility and the Care of the Aged*, 14 J. OF APPLIED PHILOSOPHY 119 (1997).

31. Stewart R. Sutherland, ROYAL COMMISSION ON LONG TERM CARE, *With Respect to Old Age: Long Term Care - Rights and Responsibilities* (1999).

32. See Caroline Glendinning, et. al., *Care Provision within Families and its Socio-Economic Impact on Care Providers*, (May 2009) (Social Policy Research Unit, University of York Working Paper No. EU 2342 para 1.2.3) (reporting for the European Commission DG EMPL (Directorate-General Employment, Social Affairs & Inclusion): Negotiated Procedure VT/2007/114).

33. JON HENDRICKS & HYUNSOOK YOON, HANDBOOK OF ASIAN AGING 5-6 (2005).

34. See Heying Zhan & Rhonda Montgomery, *Gender and Elder Care in China*, 17 GENDER AND SOCIETY 209, 210-13 (2003).

35. See Noriko Yamamoto & Margaret Wallhagen, *The continuation of family caregiving in Japa*, J. OF HEALTH AND SOC. BEHAVIOR 164, 172-76 (1997).

36. See Matthew Pakula, *A Federal Filial Responsibility Statute: A Uniform Tool to Help Combat the Wave of Indigent Elderly*, 39 FAM. L.Q. 859 (2006); see also Shannon Frank Edelstone, *Filial Responsibility: Can the Legal Duty to Support Our Parents Be Effectively Enforced*, 36 FAM. L.Q. 501 (2002).

37. See Means, *supra* note 20, at 218-19 (citing WASHINGTON D.C. OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING & EDUC., *Application Guidelines for Long-Term Care*

Germany it is suggested that the “internalization” of the traditional family caring role/responsibility continues to be an important factor for individual caregivers.³⁸ So too in Ireland where, although the Constitutional obligation is not litigated, there exists a moral obligation on families to provide care.³⁹ The position is said to be the same in Spain and Greece where, regardless of the legal situation, women have internalized their role as carers, often with materially adverse impacts on their physical and mental health.⁴⁰

Compensatory Provisions

A significant amount of literature exists that critically examines various examples of positive state action to address the needs of carers,⁴¹ particularly where these take the form of direct financial payments.⁴² 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 (e.g. through the tax or pension assessment systems) or mandate flexible employment rights.

“Carer Recognition” statutes exist in Australia⁴³ and the UK,⁴⁴ and specific measures to support carers have been acknowledged as a political priority in the majority of European states,⁴⁵ with many providing for formal (but generally modest) “carer” payments or “respite” care

Systems (1980).

38. See Means, *supra* note 20, at 220.

39. See Caroline Glendinning, *Support for Carers of Older People – Some International and National Comparisons*, 10 (Audit Commission 2003).

40. See Means, *supra* note 20, at 221.

41. See generally ORG. FOR ECON. COOPERATION AND DEV., *Help wanted? Providing and Paying for Long-Term Care* (2011) [hereinafter OECD, *Help Wanted?*]; see also Glendinning, *supra* note 39.

42. See generally Janice Keefe & Beth Rajnovich, *To pay or not to pay? Examining Underlying Principles in the Debate on Financial Support for Family Caregivers*, 26 SUPPL. CANADIAN J. ON AGING 77 (2007).

43. See *South Australia Carers Recognition Act 2005*; *New South Wales Carers (Recognition) Act 2010*; *Northern Territory Carers Recognition Act 2006*; *Queensland Carers Recognition Act 2008*; *Western Australia Carers Recognition Act of 2004*.

44. See Carers (Recognition & Services) Act, 1995; see generally Luke Clements, *Carers and Their Rights – The Law Relating to Carers* (5th ed. 2012).

45. See Caroline Glendinning et al., *Care Provision within Families and its Socio-Economic Impact on Care Providers*, (Soc. Policy Research Unite, Univ. of York, Working Paper No. EU 2342, 2009).

arrangements: Finland,⁴⁶ France,⁴⁷ Hungary,⁴⁸ Spain⁴⁹ and the UK.⁵⁰ In Canada, a Compassionate Care Benefit scheme for working carers⁵¹ has been developed as part of the Labor Code. In the USA, the National Family Caregiver Support Program⁵² provides grants⁵³ to states to fund a range of supports designed to sustain the care provided by informal caregivers.⁵⁴ Specific provisions exist for the caregivers of veterans.⁵⁵ Official carer specific measures are not solely a Western manifestation. They can be found, for example, in Taiwan,⁵⁶ South Africa⁵⁷ and India,⁵⁸ and they are being proposed in Columbia.⁵⁹

46. See THE FINLAND FAMILY CARE ACT, 1.7.1992 (312/1992).

47. See Loi n° 2005-102 du 11 février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées (requiring payments for "des aidants familiaux").

48. See THE SOCIAL WELFARE ACT 1993; see also K. Czibere & R. Gal, *Long-Term Care in Hungary*, Enepri Research Report No. 79 (2010), available at <http://aei.pitt.edu/14612/1/Hungary.pdf> (last viewed May 15, 2013); see also Z. Szeman, *Eurofamcare: National Background Report for Hungary* (2004).

49. See SPANISH Law 39/2006 de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia, http://noticias.juridicas.com/base_datos/Admin/l39-2006.html (Dec. 14, 2006).

50. See generally THE REGULATORY REFORM ORDER 2002 S.I. 1457 (CARER'S ALLOWANCE); THE DISABLED CHILDREN ACT 2000 s2.

51. See Canada Labour Code, R.S.C. 1985, s204).

52. See Federal Older Americans Act of 1965, 42 U.S.C. § 3030s; see also, FAMILY & MEDICAL LEAVE ACT OF 1993, 29 U.S.C. § 2601 (providing for up to 12 weeks of unpaid leave for qualifying carers, leaving the qualification requirements as not-inconsiderable).

53. The program provided over \$150,000,000 of grants in 2011.

54. See Erin Giovannetti and Jennifer Wolff, *Cross-Survey Differences in National Estimates of Numbers of Caregivers of Disabled Older Adults*, 88 THE MILBANK QUARTERLY 310, 330-39 (2010).

55. See CAREGIVERS AND VETERANS OMNIBUS HEALTH SERVICE ACT, 38 U.S.C. § 1720G (2010).

56. See PEOPLE WITH DISABILITIES RIGHTS PROTECTION ACT OF 1980, art. 51 (providing services and support to caregivers "to promote the capability of family caregivers").

57. See The Care Dependency Grant Social Assistance Act No. 13 2004 s7(a).

58. See *The Aswasa Kiranam Scheme*, DEP'T OF SOCIAL WELFARE KERALA (2010), http://www.socialsecuritymission.gov.in/index.php?option=com_content&view=article&id=58&Itemid=62.

59. See Senator Yolanda Pinto, *Law Proposal No. 33 of 2009*, http://servoaspr.imprenta.gov.co:7778/gacetap/gaceta.mostrar_documento?p_tipo=11&p_numero=33&p_cosec=23985 (last viewed May 15, 2013).

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-categorization is invariably bound up with the idea of oppression and of “imposition” of a collective identification with unjust subjugation.⁶⁰ 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.”⁶¹ 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.”⁶²

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—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 originate 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. The activism of the Civil Rights Movement acted as a catalyst in the development of Vietnam veterans’ group coherence.

The exponential growth in disabled people’s organizations in the decades following Vietnam is being mirrored by the remarkable growth in carers organizations, alliances, networks and support groups that has occurred in the last two decades. As with disabled people’s groups these

60. 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. See Tom Shakespeare, *Disabled People’s Self-Organisation: A New Social Movement?*, 8 *DISABILITY, HANDICAP AND SOCIETY* 249, 260-63 (1993) [hereinafter Shakespeare] (focusing particularly on critiquing the extent to which “post-materialism” is a core feature of such movements).

61. Shakespeare, at 256; see also Christine Kelly, *Wrestling with Group Identity: Disability Activism and Direct Funding*, 30 *DISABILITY STUDIES QUARTERLY* 562, 563-67 (2010).

62. OECD, *Help wanted?*, *supra* note 41 at 135; c.f. G. Ng, *Study Report of Singapore Family Caregiving Survey* 17, (Nat’l Univ. of Singapore, Working Paper No. 2006-01, 2006).

come in all varieties: local, user specific (e.g. by the nature of impairment, ethnicity, age, or sex), international⁶³ and so forth. The recent proliferation of organizations of self-identifying carers' results from the spectrum of socio-legal factors addressed in this Article, 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 neoliberalism⁶⁴—and its disparagement of dependency.⁶⁵ Nonetheless, it is the coincidence of this political phenomenon with a dramatic growth in the numbers of the "old old" (and to a lesser extent of childhood disability)⁶⁶ that has created the carers tipping point. In many western states, community living programs have accompanied the increased numbers of disabled and frail elderly people. While a debate exists as to whether the closure of large institutions can be attributed to human rights awareness or state "cost cutting,"⁶⁷ the effect has been to increase the demand for "community care."

These two factors—demographic change⁶⁸ and the welfare residualism that comes with neoliberalism—have resulted in a substantial increase in unpaid caring, which in many developed nations is nearing the limits of what families can provide.⁶⁹

However, at the same time in most OECD countries, there has been an even more remarkable increase in female employment rates.⁷⁰ In the USA,

63. Some examples of this include: The International Alliance of Carers Organizations and the European network organization EUROCARERS.

64. This Article uses neoliberal in its political sense; it is a system that adheres to civil and political rights and values, but believes that these cannot be used to limit the "free market." See DAVID HARVEY, *A BRIEF HISTORY OF NEOLIBERALISM* (2006) (stating that the free market is "a natural organic entity that must be left, untrammelled, to flourish and so liberate individual entrepreneurial capacities and thereby create great wealth").

65. Nicole Busby, *A Right to Care?* 42 (2011); see generally Martha Albertson Fineman, *The Autonomy Myth: A Theory of Dependency*, THE NEW PRESS. (2004).

66. See STEVE BROACH ET AL., *DISABLED CHILDREN, A LEGAL HANDBOOK* 14 (2010) (discussing that greater numbers of low birth-weight babies have survived).

67. See Luke Clements, *Disability, Dignity and the Cri de Coeur*, 6 EUROPEAN HUMAN RIGHTS L. REV. 675, 680 (2011).

68. This is true 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 Nancy Folbre & Julie Nelson, *For Love or Money*, 14 J. OF ECON. PERSPECTIVES 123, 124 (2000).

69. See *With Respect to Old Age: A Report by the Royal Commission on Long Term Care*, 1 THE SUTHERLAND REPORT 162 (Her Majesty's Stationary Office 1999).

70. See Florence Jaumotte, *Female Labour Force Participation O.E.C.D. Economics Department ECO/WKP 30*, (Org. for Econ. Cooperation and Dev., Working Paper No. 376,

for example, women's participation in the labor force has increased dramatically. For women age 55 and older the increase has been 50% in the past 15 years.⁷¹ During this period, average household incomes have not increased⁷²—indeed, they would have declined but for “women joining the workforce alongside their husbands.”⁷³ For many women, much of the additional income from their employment is absorbed in paying for care costs—a process categorized as de-familiarization—where a cost advantage (generally small) accrues by commodifying the care needs of both children and adult dependents.⁷⁴

Many of today's carers, like the Vietnam veterans, are young, 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.⁷⁵ 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” 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 considered and that Australian carers as a whole had an average rating that

2003); *see also* Maria Gutiérrez-Domènech & Brian Bell, *Female Labour Force Participation in the UK: Evolving characteristics or changing behaviour?* (Bank of England, Working Paper No. 221, 2004).

71. This dramatic increase in female employment is mirrored in the UK. *See* METLIFE, *Caregiving Costs to Working Caregivers*, MetLife Mature Mkt. Inst. Nat'l Alliance for Caregiving, & Ctr. for Long Term Care Research & Policy, N.Y. Medical College (2011).

72. *See id.*

73. JOSEPH E. STIGLITZ, *THE PRICE OF INEQUALITY* (2013). *See generally* *Trends in the Distribution of Household Income between 1979 and 2007*, CONGRESSIONAL BUDGET OFFICE (2011), *available at* [http://cbo.gov/sites/default/files/cbofiles/ attachments/10-25-HouseholdIncome.pdf](http://cbo.gov/sites/default/files/cbofiles/attachments/10-25-HouseholdIncome.pdf).

74. *See* Busby, *supra* note 65, at 7 (citing GOSTA ESPING-ANDERSEN ET AL., *WHY WE NEED A NEW WELFARE STATE* (2002)).

75. *Id.* at 18 (citing SUSAN MOLLER OKIN, *JUSTICE, GENDER AND THE FAMILY* (1989) and CAROLE PATEMAN, *THE SEXUAL CONTRACT* (1988)).

classified them as suffering “moderate depression” while 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.⁸¹ In general, “high intensive” caring increased the prevalence of mental health problems by 20%, but in Australia, the United States and Korea, this became “70% or 80% higher.”⁸² UK evidence suggests that carers are a third more likely to be in poor health than non-carers⁸³ and that over half of all carers have a caring related health condition⁸⁴ for which almost 50% have sought medical treatment.⁸⁵

The severity of the adverse consequences experienced by carers is materially influenced by the nature of the state’s welfare support system. Carers in general are less likely to be employed 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.⁸⁶ The prospects of employment bear directly on risks of poverty:⁸⁷ working-age carers—particularly women—experience significantly higher rates of poverty.⁸⁸

76. See Ee H. Kua & Tan Swee Li, *Stress of Caregivers of Dementia Patients in the Singapore Chinese Family*, 12.4 INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY 466–69 (1997).

77. See Means, Richards & Smith, *supra* note 20 at 221.

78. See AC Gratao et al., *The demands of family caregivers of elderly individuals with dementia*, 44 REV. ESC. ENFERM. USP 873 (2010).

79. See Maria Ferrara et al., *Prevalence of stress, anxiety and depression in with Alzheimer caregivers*, 6 HEALTH QUALITY LIFE OUTCOMES 93 (2008).

80. See N. Figved et al., *Caregiver burden in multiple sclerosis: the impact of neuropsychiatric symptoms*, 78 J. NEUROL. NEUROSURG. PSYCHIATRY 1097–102, (2007).

81. OECD, *Help wanted?*, *supra* note 41, at 98–99.

82. *Id.*

83. See *New Approaches to Supporting Carers’ Health and Well-being*, CENTRE FOR INTERNATIONAL RESEARCH ON CARE, LABOUR AND EQUALITIES (S. Yeandle & A. Wigfield, eds., 2011).

84. See *Missed opportunities: The impact of new rights for carers*, CARERS UK 1 (2003).

85. See *id.*; see also Barbara Keeley & Malcolm Clarke, *Carers Speak Out Project: Report on findings and recommendations*, THE PRINCESS ROYAL TRUST FOR CARERS (2002).

86. See OECD, *Help wanted?*, *supra* note 41 at 91.

87. See *id.* at 93.

88. See *id.* at 97.

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 care⁸⁹ and that as a consequence they were (in 2007) on average over £11,000 a year poorer;⁹⁰ that 40% of carers were in debt because of their caring roles (a figure that rose to 50% for parent carers).⁹¹ A 2011 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.⁹²

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 poverty⁹³ and a 2013 study⁹⁴ 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 that have the cumulative impact on lifetime earnings.⁹⁵ These findings are endorsed by USA research—that caregiving in early life significantly raised women’s poverty risks in later life⁹⁶ and that older working caregivers had average pension shortfalls of \$50,000 per person (in total amounting to a loss of nearly \$3 trillion).⁹⁷

89. *The Cost of Caring: How money worries are pushing carers to the breaking point*, CARERS UK (2011), available at http://www.carersUK.org/media/k2/attachments/The_Cost_of_Caring_1.pdf.

90. *Out of Pocket, the financial impact of caring*, CARERS UK (2007), available at http://www.carersuk.org/media/k2/attachments/Out_of_Pocket.pdf.

91. *The State of Caring*, CARERS UK (2011) (involving 4,200 carers).

92. *See id.*; see also *Carers in crisis*, CARERS UK (2008); *Caregiving*, NATIONAL ALLIANCE FOR CAREGIVING and AARP 16 (2009), available at http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf (observing similar findings were noted in the USA research).

93. Somali Cerise et al., *Accumulating poverty? Women’s experiences of inequality over the lifecycle*, AUSTRALIAN HUMAN RIGHTS COMM. (2009), available at http://www.humanrights.gov.au/sites/default/files/document/publication/accumulating_poverty.pdf.

94. *Investing in care: Recognising and valuing those who care, Volume 1 Research Report*, AUSTRALIAN HUMAN RIGHTS COMMISSION (2013).

95. Cerise, *supra* note 94, at 17–19; see also Nancy Folbre & Julie A. Nelson, *For Love or Money*, 14 JOURNAL OF ECONOMIC PERSPECTIVES 124 (2000).

96. C. Wakabayashi & K. Donato, *Does Caregiving Increase Poverty among Women in Later Life?* 47 JOURNAL OF HEALTH AND SOCIAL BEHAVIOR 258–74 (2006).

97. *The MetLife Juggling Act Study: Balancing Caregiving with Work and the Costs*

Poverty is, as Alcock reminds us, “the unacceptable face of broader inequalities”⁹⁸ 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.⁹⁹ Work environments that “far from structurally accommodating or facilitating caretaking . . . operate according to premises that are incompatible with obligations for dependency.”¹⁰⁰ Where “[w]orkers (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).”¹⁰¹

The Politics of Dependency

Dependency work (paid¹⁰² or unpaid) is gendered¹⁰³ and it is this factor that lays 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.¹⁰⁴ In the USA for example, it is estimated that there are over 25 million caregivers of whom between 59% and 75% are women and that

Involved (1999), available at <http://www.caregiving.org/data/jugglingstudy.pdf> (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).

98. PETE ALCOCK, UNDERSTANDING POVERTY 252 (2nd ed. 1997).

99. SUSAN MOLLER OKIN, JUSTICE, GENDER AND THE FAMILY 176 (1989).

100. Martha Albertson Fineman, *Cracking the Foundational Myths: Independence, Autonomy and Self-Sufficiency*, in FEMINISM CONFRONTS HOMO ECONOMICUS 179–191, 184 (Martha Albertson Fineman & Terence Dougherty eds. (2005) [hereinafter “Fineman, *Cracking the Foundational Myth*”]).

101. *Id.* at 189.

102. See Nancy Folbre & Julie A. Nelson, *For Love or Money—Or Both?*, 14 JOURNAL OF ECONOMIC PERSPECTIVES 123, 127 (2000) [hereinafter Folbre & Nelson] (noting 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).

103. See Busby, *supra* note 65, at 2. For Busby, in relation to the conflict between unpaid carers and paid employment, it is “severely gendered.”

104. See Hellen Carr, *Alternative Futures v. NCSC: A Feminist Critique* (2007) (conference paper, European Network of Housing Research Rotterdam). (“[A]ging and caring are gendered in ways that are more nuanced and compelling than the simple fact that women live longer than men.”).

women on average spend 50% more time providing care than male caregivers.¹⁰⁵ This is in line with the evidence from other OECD countries.¹⁰⁶

While 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 opinion¹⁰⁷ have 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 characterize it as unnatural—it is simply “inevitable.”¹⁰⁸ 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.

While the denigration of dependency and the marginalization 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.”

105. Peter S. Arno, Carol Levine & Margaret M. Memmott, “*The economic value of informal caregiving: President Clinton’s provide relief to family caregivers opens a long-overdue discussion of this “invisible health sector,”* 18 HEALTH AFFAIRS 182–88 (1999); and *Selected Caregiver Statistics*, FAMILY CAREGIVER ALLIANCE (2001), available at http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=439. See also Maryam Navaie-Waliser, et al., *When the Caregiver Needs Care: The Plight of Vulnerable Caregivers*, 92 AM. J. PUBLIC HEALTH 409–413 (2002); and Maryam Navaie-Waliser et al., *Informal caregiving: differential experiences by gender*, 40 MED. CARE 1249–59 (2002).

106. See OECD, *Help wanted?* *supra* note 41. See, for example, *Ageing and Carers, Australia: Summary of Findings, 2009*, AUSTRALIAN BUREAU OF STATISTICS DISABILITY (2010), available at <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features12009?opendocument&tabname=Summary&prodno=4430.0&issue=2009&num=&view=>; and *Facts about carers 2012*, CARERS UK (2012), available at http://www.carersUK.org/media/k2/attachments/Facts_about_carers_Dec_2012.pdf.

107. See Fineman, *Cracking the Foundational Myths*, *supra* note 101, at 180.

108. *Id.* at 180.

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.¹⁰⁹ The sphere of the “private” (or what has been termed the “assumed family”)¹¹⁰ 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.”¹¹¹ This is, as Julia Twigg¹¹² has described it, “dirty work” and “hidden work.” It is 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.”¹¹³

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 labor—is self-evidently absurd when applied to a mother’s work in caring for her children. So too with commodification: if one commodifies caring, i.e. touts 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 perspective¹¹⁴).

109. See OKIN, *supra* note 100.

110. See Martha Albertson Fineman, *THE AUTONOMY MYTH: A THEORY OF DEPENDENCY* (2004); see also Fineman, *Cracking the Foundational Myths*, *supra* note 101, at 179–191; and OKIN, *supra* note 100, at 130 (stating 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”).

111. Fineman, *Cracking the Foundational Myths*, *supra* note 101, at 179.

112. See Julia Twigg, *Carework as a form of bodywork* 20 *AGEING AND SOCIETY* 389, 406 (2000).

113. *Id.*

114. See Arno et al., *The economic value of informal caregiving*, *supra* note 106, at 182–188. 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. *But see also* E.R. Giovannetti & J. Wolff, *Cross-Survey Differences in National Estimates of Numbers of Caregivers of Disabled Older Adults*, 88 *MILBANK QUARTERLY* 310 (2010). 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,

Rather than accept the severe limitations of such ideologies, a dustbin dimension is created—the “private” space—into which all awkward facts are piled.¹¹⁵ 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.”¹¹⁶

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 dependent 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 dependent as children.¹¹⁷ 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.”¹¹⁸

Caring and Human Rights

The language of human rights is the most obvious medium by which carers can express and challenge their collective marginalization, and a number of authors have argued persuasively that there is indeed a human right to care.¹¹⁹ By conceptualizing their situation in this way, carers can not only get closer to capturing the essence of their predicament,¹²⁰ but they

“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 & Julie A. Nelson, *For Love or Money*, 14 J. ECON. PERSPECTIVES 123, 125–127 (2000).

115. As Mitt Romney put it “inequality is the kind of thing that should be discussed quietly and privately” (cited by JOSEPH STIGLITZ, *THE PRICE OF INEQUALITY* 27 (2012)).

116. OKIN, *supra* note 100, at 129.

117. See Folbre & Nelson, *supra* note 103, at 137. (“Like other externalities, however, those created by care create an incentive to free ride, to let others pay the costs.”).

118. Fineman, *Cracking the Foundational Myths*, *supra* note 101.

119. See in particular Robin West, *CARING FOR JUSTICE*, (1997); Robin West, *supra* note 9; Mary Becker, *Care and Feminists*, 17 WIS. WOMEN’S L. J. 57 (2002); Deborah Stone, *Why We Need a Care Movement*, *THE NATION*, 13 (Mar. 13, 2000) and Busby, *supra* note 65

120. 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

can also mobilize one of the few forces capable of tilting against the antagonistic political norms that manufacture their social exclusion. As West¹²¹ 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: “[w]hen 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.”¹²²

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 favor of institutionalization and as a political issue, deinstitutionalization is unlikely to be a priority for most voters. However, when articulated in terms of fundamental human rights,¹²³ 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 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 carers¹²⁴ 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. In spite of this,

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 conceptualized 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 labeling 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.

121. See West, *supra* note 9, at 96.

122. *Id.*

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

124. See ANNE ALSTOTT, *NO EXIT: WHAT PARENTS OWE THEIR CHILDREN AND WHAT SOCIETY OWES PARENTS* (OUP 2004).

West argues that we need such a right “to protect caregivers against the pendulum swings of public support and neglect for their work”:¹²⁵ without such recognition, the carers’ needs would be “drowned in a tide of competing needs for scarce public resources.”¹²⁶

Arguably, there are three (relatively) distinct dimensions to the human rights analysis,¹²⁷ 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,¹²⁸ proselytizing,¹²⁹ marching/demonstrating,¹³⁰ 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—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 dependent and in need of care and for many, dependency is not a situation unique to their infancy. Caring has an elemental, non-commodifiable,

125. West, *supra* note 9, at 98.

126. Robin West, *A Right to Care*, THE BOSTON REVIEW (2004) available at <http://bostonreview.net/BR29.2/west.html> accessed 15 May 2013 (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”).

127. See Deborah Stone, *Why We Need a Care Movement*, THE NATION, 13–14. (Mar. 13, 2000). 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.

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

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

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

altruistic quintessence¹³¹ that is perhaps best characterized as a species of the fundamental human right “to give,”¹³² stemming from a collective responsibility for dependency.¹³³ 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 dependent 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.”¹³⁴ 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;” counseling 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, attitudinal for example), it is the need that is relevant—not its provenance, complex as this will sometimes be.

While the scope of this Article is limited to “unpaid” caring, it is debatable whether the absence of remuneration (that the “work” involved in

131. Busby, *supra* note 65, at 7. 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.” See also in this context Nancy Folbre & Julie A. Nelson, *For Love or Money—Or Both?*, 14 JOURNAL OF ECONOMIC PERSPECTIVES 123, 129 (2000).

132. Richard Titmuss, THE GIFT RELATIONSHIP 199 (Ann Oakley & John Aston, eds., 1970).

133. See Fineman, *Cracking the Foundational Myths*, *supra* note 101, at 181.

134. Julia Twigg, *Carework as a form of bodywork* 20 AGEING & SOCIETY 389 (2000).

delivering the care has not been commodified) is of pivotal relevance. Much has been written on this issue¹³⁵ and the constraints of this Article 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 categorization of the activity as a “human right.”¹³⁶ 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 categorized by courts as “family life.”¹³⁷

The Case for Recognition

Human rights treaties/constitutional provisions do not list every right of fundamental importance—for example the right to breathe¹³⁸ 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,¹³⁹ to development¹⁴⁰ or to palliative care.¹⁴¹

135. 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*, 101 COLUM. L. REV. 181, 187 (2001); Mary Becker, *Care and Feminists*, 17 WIS. WOMEN’S L. J. 57, 71–73 (2002); and see also in this context Nancy Folbre & Julie A. Nelson, *For Love or Money—Or Both?*, 14 JOURNAL OF ECONOMIC PERSPECTIVES 123, 129 (2000).

136. See *R (A and B) v. East Sussex CC* [2003] EWHC 167 (Admin), (2003) 6 CCLR 194. [116] where he cited *Niemietz v. Germany* [1992] 16 EUR. H.R. REP. 97, [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.”

137. See e.g., *G v. E, a local authority & F* [2010] EWHC 621 (Fam)—a case in the High Court of England and Wales.

138. See Deborah Stone, *Why We Need a Care Movement*, THE NATION, 13 (Mar. 13, 2000). Indeed, Deborah Stone, in arguing for a Right to Care, states “care is as essential as the air we breathe.”

139. See e.g., *Olga Tellis v. Bombay Mun. Corp.*, [1985] 2 S.C.R. 51 (India).

140. See generally Stephen Marks, *The Human Right to Development: Between Rhetoric and Reality*, 17 HARV. HUM. RTS. J. 137 (2004).

141. See e.g., *Washington v. Glucksberg*, 521 U.S. 702 (1997).

While the formulation of some rights necessitate emphasis on 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 3 (torture, inhuman and degrading treatment),¹⁴² whereas state sanctioned activities that interfered with individuals' sleep has been held to engage Article 8 (private and family life).¹⁴³ In similar vein, the deliberate interference with a person's ability to interact with fellow human beings has been held to engage Article 3,¹⁴⁴ 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 8.¹⁴⁵ This identification of such a latent right to community living within Article 8 (and in analogous terms, in the USA by the Supreme Court¹⁴⁶) 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,¹⁴⁷ the right to associate¹⁴⁸ and indeed the right to family life¹⁴⁹ 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 of the ECHR (non-discrimination) is a classic exemplar. Accordingly, a

142. *Ireland v. United Kingdom* 2 Eur. H.R. Rep. 25 (1978) (concerning interrogation techniques which included depriving suspects of their sleep.)

143. *Hatton v. United Kingdom*, 37 Eur. H.R. Rep. 611 (2003) which concerned the sanctioning of night flights into Heathrow airport.

144. *Keenan v. United Kingdom*, 33 Eur. H.R. Rep. 39 (2001) – in the case of the solitary confinement of a psychiatric patient.

145. *Botta v. Italy*, 26 Eur. H.R. Rep. 241 (1998) (1998) and *Zehnalová & Zehnal v. Czech Republic*, App. No. 38621/97 (2002).

146. *Olmstead v. L.C.*, 527 U.S. 581 (1999) (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").

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

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

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

policy of treating family carers less favorably 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 8.¹⁵⁰

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. While the Human Rights Committee¹⁵¹ 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.”¹⁵² Thus, sexual rights,¹⁵³ environmental pollution,¹⁵⁴ physical barriers to movement,¹⁵⁵ access to files,¹⁵⁶ the denial of citizenship,¹⁵⁷ and information about one’s illness¹⁵⁸ 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.”¹⁵⁹

In *R (A and B) v East Sussex CC*¹⁶⁰ the High Court of England and Wales was asked to give general guidance as to how local authorities

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

151. See for example UN Human Rights Committee, General Comment No. 16 (1988) and S. JOSEPH, J. SCHULTZ & M. CASTAN, *THE INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS* (OUP 2004) (see chapter 16)

152. See, e.g., *Botta v. Italy*, 26 Eur. H.R. Rep. 241, 257 (1998).

153. See, e.g., *Norris v. Ireland* 13 Eur. H.R. Rep. 186 (1988).

154. See, e.g., *Hatton v. United Kingdom* 37 Eur. H.R. Rep. 611 (2003).

155. See, e.g., *Botta v. Italy*, 26 Eur. H.R. Rep. 241 (1998).

156. See, e.g., *Gaskin v. United Kingdom* (1989) 12 E.H.R.R. 36.

157. See, e.g., *Kuric and others v. Slovenia*, App. No. 26828/06 (Eur. H.R. Rep. 2010).

158. See, e.g., *McGinley & Egan v. United Kingdom*, 27 Eur. H.R. Rep. 1 (1998); *LCB v United Kingdom* 27 Eur. H.R. Rep. 212 (1998).

159. See *Pretty v. United Kingdom*, 35 Eur. H.R. Rep. 1, 65 (2002).

160. [2003] EWHC 167 (Admin).

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 regard¹⁶¹ to the Article 8 jurisprudence of the European Court of Human Rights.¹⁶² 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,

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:

I recognize 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 naso-gastric 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.

161. 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).

162. See, e.g., *Botta v. Italy*, 26 Eur. H.R. Rep. 241 (1998).

While this Article has focused 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 Busby,¹⁶³ for example, has provided a convincing analysis on the relatively narrow issue¹⁶⁴ 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

Inherent within all human rights treaties 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 from being undermined.¹⁶⁵ 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.”¹⁶⁶ This may involve the implementation of domestic laws that provide the necessary protection.¹⁶⁷ The positive and negative components, although subject to distinct jurisprudential criteria, are seen as indivisible. In this context, Eva Kittay’s¹⁶⁸ notion of reciprocity in caring is particularly apt: “[j]ust 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.”¹⁶⁹

Kittay coined the word “doulia”¹⁷⁰ 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.”¹⁷¹ For West,¹⁷² such a “right to provide care without

163. See Busby, *supra* note 65.

164. See Busby, *supra* note 65, at 11 (acknowledging that such a right could also exist in EU law for those who “do not engage in paid employment”).

165. See Comm. on Econ., Soc., and Cultural Rights, *General Comment No. 12: The Right to adequate food (Art. 11)*, ¶ 15, U.N. Doc. E/C.12/1999/5 (May 12, 1999) (discussing an obligation to “to facilitate, provide and promote” the right); see also Velásquez Rodríguez v. Honduras, Inter-Am. Ct. H.R. (ser. C) No. 4 (July 29, 1988).

166. See *X & Y v. Netherlands*, 8 Eur. H.R. Rep. 235, para. 23 (1985).

167. See *A v. United Kingdom*, 27 Eur. H.R. Rep. 611, para. 22-24 (1998).

168. Eva Feder Kittay, *LOVE’S LABOR* (1999).

169. West, *supra* note 9, at 107.

170. From the ancient Greek word “doula” which signified a female servant or slave.

171. See Kittay, *supra* note 168, at 77.

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 characterized as “derivative dependency,” i.e. where one person “assumes responsibility for the care of an inevitably dependent person.” Her aim is to capture:

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. . . . [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, channeling our beliefs and feelings about what is considered natural and what are appropriate institutional arrangements.¹⁷³

Fineman argues that we share a “collective or societal debt” for this fundamental caretaking role,¹⁷⁴ and with it an obligation to challenge the prevalent socio-economic mores that are not only inimical to dependent people, but also to carers. Far from “structurally accommodating or facilitating caretaking,” societal institutions and workplaces “operate according to premises that are incompatible with obligations for dependency.”¹⁷⁵

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*,¹⁷⁶ 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: “[t]he 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.”¹⁷⁷

172. West, *supra* note 9

173. See Fineman, *supra* note 101, at 184.

174. See Fineman, *supra* note 101, at 182.

175. See Fineman, *supra* note 101, at 183.

176. 34 Eur. H.R. Rep. 1285, 1296 (2002).

177. *Id.*

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 marginalization created by their 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 Malherbe¹⁷⁸ 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, counseling, financial assistance and respite care"¹⁷⁹ and that "persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities."¹⁸⁰

In addition, Malherbe cites General Comment 5 of the Committee on Economic, Social and Cultural Rights.¹⁸¹ Comment 5 stresses the importance of "social security and income-maintenance schemes" for persons with disabilities. Reflecting on this, Malherbe 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 Child¹⁸² that States should afford the family "the necessary protection and assistance so that it can fully assume its responsibilities within the community" for the care of children.¹⁸³ General Comment 9 of the Committee on the Rights of the Child¹⁸⁴ (which

178. Kitty Malherbe, *The social security rights of caregivers of persons with disabilities in ASPECTS OF DISABILITY LAW IN AFRICA* 181-181-94 (Ilze Grobbelaar-du Plessis and Tobias van Reenen, eds., 2011).

179. *Convention on the Rights of Persons with Disabilities*, G.A. Res. 61/106, U.N. Doc. A/Res/61/106, at art. XXVIII (Dec. 13, 2006).

180. *Id.* at pmb1, para. x.

181. See Comm. on Econ., Soc., and Cultural Rights, *General Comment No. 5: Persons with disabilities*, para. 28, U.N. Doc E/1995/22 (Dec. 19, 1944).

182. *Convention on the Rights of the Child*, pmb1., Nov. 20, 1989, 1577 U.N.T.S.3.

183. *Id.*

184. Comm. on the Rights of the Child, *General Comment No. 9: The rights of children*

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 dependent people’s rights means that a failure to provide compensatory measures to enable the dependent person to live with dignity may subject their carer to intolerable hardship, which itself can be articulated in terms of breaching their rights (for example, to respect for their private and family life and their right not to be subjected to degrading treatment). The English case of *R (Bernard) v. London Borough of Enfield*¹⁸⁵ concerned a claim by a disabled applicant and her carer that their human rights 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 that made it virtually impossible for them to have any meaningful private or family life for the purposes of Article 8.”¹⁸⁶

Carers and Inequality

As noted at the outset of this Article, 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

with disabilities, U.N. Doc. CRC/C/GC/9, para. 13 (Feb. 27, 2007).

185. [2002] EWHC 2282 (Admin), [32]-[33] (Eng.).

186. See also *R (Hughes) v. Liverpool City Council*, [2005] EWHC 428 (Admin), [35]-[39] (Eng) (determining that support for a disabled person was not a violation of that person’s “Article 8 rights” solely because of the extraordinary efforts made by his carer, a burden the judge considered to be “intolerable”).

is not a “choice” and the options available to a person in this situation will be dictated in large measure by the welfare arrangements that the state chooses to offer.¹⁸⁷ The situation has been described as “non-coerced yet not voluntarily chosen”¹⁸⁸ although “compulsory altruism” is perhaps a better description.¹⁸⁹

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 formalized 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)¹⁹⁰ 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, and the rights of children. 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 such as 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

187. See Fineman, *supra* note 101, at 185 (“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.”).

188. Alan Deacon, *Civic Labour or Doulia? Care, Reciprocity and Welfare*, 6 SOCIAL POLICY AND SOCIETY 481, 484 (2007),

189. Kittay, *supra* note 168, at 133 (citing P. Taylor-Gooby, *Welfare State regimes and Welfare Citizenship*, 1 JOURNAL OF EUROPEAN SOCIAL POLICY 93 (1991)).

190. See *supra* notes 16-26.

14. Acknowledging this state of affairs, the Human Rights Committee referred to the “inequality in the enjoyment of rights by women [as] . . . deeply embedded in tradition, history and culture,” stressing 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.”¹⁹¹

Similarly, the UN Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) requires states to promote measures that “enable parents to combine family obligations with work responsibilities and . . . participation in public life,” which “eliminate discrimination against women in all matters relating to marriage and family relations.”¹⁹² The CEDAW Committee 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.”¹⁹³ At a regional level, the Council of Europe has echoed this. The Council 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.”¹⁹⁴

The New Zealand case of *Ministry of Health v. Atkinson*¹⁹⁵ concerned a blanket policy applied by the Ministry of Health to exclude family members from payment for the provision of various disability support services 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. The appellate court found that the policy was discriminatory and consequently it fell on the government to establish weighty reasons to justify its retention. In endeavoring 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. While the court considered that this might be tenable relating to the care of young

191. See Human Rights Comm., *General Comment No. 28: Equality of rights between men and women*, paras. 4-5, U.N. Doc. CCPR/C/21/Rev.1/Add.10, (Mar. 29, 2000).

192. G.A. res. 34/180, at 193, U.N. Doc. A/34/46.

193. Committee on the Elimination on the Discrimination against Women, *General Recommendation 21: Equality in marriage and family relations*, U.N. Doc. A/49/38 (1994).

194. Eur. Consult. Ass., *Committee of Ministers to member states on policy to support positive parenting*, 28th Sess., Doc. No. Rec(2006)19 (2006).

195. [2012] NZCA 184.

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 the ICCPR and the UNCRPD, as well as on the Canadian High Court decision of *Hutchinson v British Columbia (Ministry of Health)*,¹⁹⁶ involving 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 characterized 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 objectively reasonable justification for the difference in treatment. This 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.¹⁹⁷ 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*¹⁹⁸ (a case concerning state policies which prejudiced the “illegitimate” family):¹⁹⁹ “[w]hen 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 the argument that protected statuses should be reserved for those with immutable or “innate” traits, there exists the challenge of the social impacts that are experienced by those in the out-group, i.e. 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),²⁰⁰ a case before the

196. 2004 BCHRT 58 (Can.).

197. See *Price v. United Kingdom*, 34 Eur. H.R. Rep. 1285, 1296 (2002).

198. 2 E.H.R.R. 330, 341 (1979-80).

199. *Id.* at 346.

200. Case C-303/06, *Coleman v Attridge Law* 2008 E.C.R. 1-5603 (2008).

European Court of Justice (ECJ), the Advocate General referred to the “more subtle and less obvious ways” of adverse treatment: one of which was to target not the person with the protected characteristic (i.e. the black or disabled person), “but third persons who are closely associated with them and do not themselves belong to the group.”²⁰¹ 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 dealt with the interpretation of an EU Directive, which prohibited discrimination where a “person is treated less favorably than another” on grounds of religion or belief, disability, age or sexual orientation.²⁰² The applicant claimed she had been constructively dismissed from her employment because she had sought time off work to care for her disabled son.

Her claim was problematical under the then UK anti-discrimination law²⁰³ because 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 favorably “because of disability”: that the Directive protected individuals from “associative” discrimination of this type.²⁰⁴ The UK has since brought its legislation into line²⁰⁵—and carers are now effectively protected from such adverse “associative” treatment. A similar process has resulted in protection for carers in France²⁰⁶ and in Ireland.²⁰⁷ Protection of this nature is found (for example) in Peruvian antidiscrimination provisions,²⁰⁸ is under discussion

201. *Id.* at paras. 12-14.

202. *Id.* (citing European Union Employment Equality Directive, 2000/78/EC, at art. 2).

203. Disability Discrimination Act (1995), <http://www.legislation.gov.uk/ukpga/1995/50/contents>.

204. 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 Centre Ltd. v. Owens*, [1983] UKEAT 29_83_2810, [1984] IRLR 7, [1984] WLR 384, [1984] ICR 65, [1984] 1 All ER 836, [1984] ICR 962, [1984] 1 WLR 384, *available at* http://www.bailii.org/uk/cases/UKEAT/1983/29_83_2810.html.

205. Equality Act, 2010 (Eng.), <http://www.legislation.gov.uk/ukpga/2010/15/contents>.

206. 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.”

207. Employment Equality Act, 1998, s2(1) (N. Ir.), <http://www.irishstatutebook.ie/1998/en/act/pub/0021/>; Equal Status Act, 2000, s2(1) (N. Ir.), <http://www.irishstatutebook.ie/2000/en/act/pub/0008/index.html>.

208. Peruvian law no. 29973, *available at* <http://www.conadisperu.gob.pe/web/documentos/2012/politica/ley29973.pdf>.

in Australia,²⁰⁹ and a duty to consider reasonable adjustments for working carers has already been enacted in New Zealand.²¹⁰

Conclusions

This Article 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 were enacted, 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.²¹¹ 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 recognizing 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 million²¹² "informal" carers²¹³ and for this to be put "at the top of" each member state's policy agenda.²¹⁴ In 2009, this had resulted in carer support being acknowledged as a political priority in at least half the member states.

For neoliberal governments, in particular, the handicaps experienced by carers" pose particular problems. Ideologically, such governments

209. See Australian Human Rights Commission, *Investing in care: Recognising and valuing those who care* (2013), http://www.humanrights.gov.au/sites/default/files/document/publication/UnpaidCaringVolume1_2013.pdf.

210. See Employment Relations Act, 2000, §6AA, (New Zealand), <http://www.legislation.govt.nz/act/public/2000/0024/latest/DLM1398200.html>; see also Ministry of Social Development, *Caring for New Zealand Carers* (July 2007), <http://www.msd.govt.nz/documents/about-msd-and-our-work/work-programmes/policy-development/carers-strategy-consultation.pdf>; see also Ministry of Social Development, *The New Zealand Carers' Strategy and Five-year Action Plan 2008* (April 2008), <http://www.msd.govt.nz/documents/about-msd-and-our-work/work-programmes/policy-development/carers-strategy.pdf>.

211. THERESIA DEGENER, *Disability Discrimination Law: a Global Comparative Approach*, in *Disability rights in Europe* (Anna Lawson & Caroline Gooding eds., 2005).

212. See Glendinning et al., *supra* note 39, at para. 7.2.1.

213. EUROPEAN COMMISSION, *Long-term Care in the European Union* (April 2008).

214. Glendinning et al., *supra* note 39, at para 1.2.3.

espouse the “small state” and are committed to 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 Stiglitz²¹⁵ and others have observed, in such states women re-joining the workforce have only averted a fall in middle class household incomes. These changes have occurred at a time of dramatic increase in the numbers of dependent elderly people, and for whom institutionalization 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.²¹⁶ 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.²¹⁷ While these papers have attracted considerable publicity for different reasons,²¹⁸ what is most 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,”²¹⁹ and the “severe penalties” that result from the “forces impelling women” to take paid work.²²⁰ 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”²²¹

As this Article has highlighted, the general response of neoliberal governments since that time has been tokenistic. It involves 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

215. STIGLITZ, *supra* note 74.

216. MARK DRAKEFORD, *Social Policy and Privatisation* 103 (1999).

217. Simon Demissie, *Files from 1982 – Renewing the Values from Society*, THE NATIONAL ARCHIVES (Dec. 28, 2012), <http://blog.nationalarchives.gov.uk/blog/files-from-1982-renewing-the-values-of-society/>

218. Alan Travis, *Margaret Thatcher’s Role in Plan to Dismantle Welfare State Revealed*, THE GUARDIAN, Dec. 28, 2012, <http://hereisthecity.com/2012/12/28/margaret-thatchers-role-in-plan-to-dismantle-welfare-state-revealed/>.

219. The National Archives, *supra* note 216, at 89.

220. *Id.* at 148-49.

221. *Id.* at 12.

little on no strain on the public purse. As Levitas has observed, “recognizing the value of unpaid work . . . means not recognizing its full economic value, since its cheapness is its main recommendation.”²²²

In his seminal paper concerning the impact of Americans with Disabilities Act of 1990, Samuel Bagenstos (while 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.”²²³ 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.”²²⁴

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. At its heart, it must be a progressive social welfare system.

While 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, only when disabled people have full independence will carers have full equality.²²⁵

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 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

222. RUTH LEVITAS, *The Inclusive Society? Social Exclusion and New Labour* 37 (1998).

223. Samuel Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1 (2004).

224. Martha Albertson Fineman, *Cracking the Foundational Myths: Independence, Autonomy, and Self-Sufficiency*, 8 AM. U. J. GENDER SOC. POL’Y & L. 13 (2000).

225. 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*.

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 compensate for such impacts because 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 ourselves. A carer's feelings of compassion, guilt and duty do not, however, sanction adverse treatment.