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Equality, Ethics, Justice and The Care of Adults in Northern Ireland*

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Introduction

This paper employs the ethics of care debate to present primary qualitative research on the lived experience of care-giving and care-receiving that was conducted under the auspices of The Equality and Social Inclusion in Ireland Project.¹ The ethics of care discourse has been a vibrant debate within feminism, focusing particularly on the socially constructed position of women as carers. The remit of this discourse, however, covers not only discussion about women and care, but about the gendered construction of care in society. It is the ethics of care discourse that has exposed the undervaluing of care in society, because of the association of care with women, which is something that affects all involved in care situations, both care-receivers and care-givers, men as well as women.

In this paper I use the ethics of care theoretical framework for a number of reasons. It makes visible and protests against the gendered nature of care-giving in society while at the same time facilitating a consideration of gender differences in moral orientation. Further, within this debate a challenge has emerged to the dominance of the voices of care-givers in social research on care along with an exploration of the notion of interdependence and a dismantling of rigid categories of care-givers and care-receivers. Finally, it is the ethics of care debate that has challenged the absence of care from political discourses.

I explore these issues as they have emerged in four identifiable strands in the developing (largely feminist) discourse on the ethics of care: the exploitative nature for women of the practice of care in society; the place of an ethic of care in women's moral orientation in contrast to that of men's; the challenge to the dominant voice of carers at the expense of care-recipients in relationships of care and also false perceptions of each of these groups as homogeneous categories; and the enlarging of the remit of care into political space. While clearly identifiable strands, these are not distinct components of the debate; rather they are 'overlapping paradigms' (Williams, 2001: 475).

I consider each of these paradigms in turn, but first some explanation of methods. The paper incorporates both qualitative and quantitative social data on

care from Northern Ireland. Primary qualitative data is here combined with secondary analysis pertinent data in of the 2002/03 *Poverty and Social Exclusion in Northern Ireland (PSENI) Survey*.²

As with any methodological choice, there are, of course, limitations to be addressed and as far as possible overcome. Bryman (1988) points out there is a danger in starting out with a theory already at least partly formulated. He admits that grounded theory allows for deferment of the “conceptual elaboration of data” (1988:11) but goes on to say that grounded theory too has its problems in terms of how the researcher manages theoretical consideration as the research develops and as more and more data becomes available. Nevertheless as grounded theory does allow the possibility of fruitful dialogue between expert and nonexpert knowledge with social research for theory to develop in the course of the study; it is my intention to pursue this approach. The approach is intended to enable common themes to emerge from a number of indepth ‘interviews’ or ‘conversations about care’.

I accessed a number of carers in a range of caring situations. They were either been identified by statutory organisations as carers or have come forward independently and defined themselves as carers. I undertook 26 interviews over 4 weeks. The interviews were transcribed and analysed on an ongoing basis. In this iterative process I expect to draw out common perspectives and themes from the earliest ‘interviews’ informed the conduct of later interviews.

Grounded theory enables a flexible approach to conceptualizing what is taking place in the caring process as experienced by older carers. This meant I did not have to decide a priori whether to conceptualise caring primarily as unpaid work or primarily as a social e.g. familial relationship. Equal I did not have to decide a priori how to deal with the fluidity of carer/cared for person statuses (i.e. caregivers can also be care receivers and vice versa).

“Quantification often makes our observations more explicit....it opens up the possibility of statistical analyses” (Babbie:37)

The qualitative approach, however, allows for a wider range of meanings to be gleaned from the research and enables the researcher to be flexible, in

terms of being able to explore further answers given by respondents. As Fischer (1994) argues

“Qualitative studies ... have rich, descriptive data which offer insights that are not available with survey research alone”(Fischer:5)

Among its advantages are that it allows for flexibility, has the potential to elicit in-depth responses and allows the researcher to engage in a dialogue with interviewees.

As Rubin and Rubin state in Babbie (1998)

“qualitative interviewing design is *flexible, iterative* and *continuous*, rather than prepared in advance and locked in stone”(Babbie:290)

Rubin and Rubin also argue that a qualitative interview is not directionless but

“is essentially a conversation in which the interviewer establishes a general direction for the conversation and pursues specific topics raised by the respondent”.(Babbie:290)

A semi-structured approach allows for some standardisation of the material gathered, but also enables exploration of topics not predicted in advance.

In approaching the topic of caring within the framework of grounded theory, the existing research literature had suggested a number of themes would emerge. I was particularly interested in the dual state of caring and old age. As interviews progressed I found that my findings did confirm many of the characteristics of informal carers' experiences delineated in previous studies such as the gendered nature of the tasks undertaken.

I came to the study with an awareness of the isolation of many older people (which I speculated would be magnified for carers) and the knowledge that older people's contribution to society is undervalued. Ways of coping with the heavy physical tasks which are difficult for carers especially older and disabled carers are being addressed (through the deployment of equipment and

paid care workers, The heavy emotional demands of caring has not been responded to by public services and policy continues

Ungerson has stated that “carers are notoriously difficult to find” (Ungerson:13), so it made sense to try to contact carers through people who were working with them on a regular basis. In so doing the problem of selection bias has to be addressed. Fischer (1994) points out that:

“some people talk more and tell better stories” (Fischer: 3)

Validity is a key concern for qualitative researchers who argue that quantitative studies often lack the understanding in-depth material that can be achieved only through a qualitative approach. Conversely reliability concerns the potential for research results to be replicated if the same study is repeated elsewhere. Taking as its model the natural science experiment, it is argued quantitative research offers the possibility of replication more readily than does qualitative research.

“The quantitative researcher is invariably concerned to establish that the results of a particular investigation can be generalized beyond the confines of the research location” (Bryman:1988:24)

There is a tendency to believe that a quantitative approach, that is one which enables statistical analysis provides for greater scientific truth. However, Mays and Pope (1996) argue that:

“All research is selective – there is no way that the researcher can in any sense capture the literal truth of events....Furthermore statistical representativeness is not a prime requirement when the objective is to understand social processes” (Mays and Pope: 110-111)

They argue that ensuring rigour in qualitative research is based, just as quantitative research, on:

“systematic and self conscious research design, data collection, interpretation and communication” (Mays and Pope: 111)

In pursuing a systematic design, they argue that it should be possible for other researchers to replicate the results of a qualitative study.

There are a number of ethical concerns which need to be addressed in this kind of social research. Fischer (1994) points out that we need to be sure of protecting people if they disclose something which must remain confidential. One way of doing this is if individuals or groups are not identified at any stage in the research process particularly when the researcher uses quotations from the interviewees. Informed consent, given the potential vulnerability of carers and cared for people, is also an issue and in undertaking these interviews the subjects were briefed as to the purpose of the study before consent was obtained. Participants were given a consent form and an information sheet – the latter informed them that their participation is voluntary and that they could withdraw consent at any time without detriment to themselves. It also asked their permission to be recorded by audiotape. As part of the process of preparing for this study, permission needed to be obtained from a Research Ethics Committee within the National Health Service. This process proved useful in ensuring that proper procedures were put in place to ensure both the safety of the respondent and researcher. If the respondent became upset, the interview would be stopped and if necessary assistance would be called.

In targeting carers in this way the issue of gatekeeping inevitably arises. Barbour and Kitzinger (1989) argue that this issue can be difficult to avoid in targeting a research sample. As they point out there is the risk that gatekeepers may choose the most participative or the most likely to keep to the “party line”, that is to give answers which they think are expected of them. It is necessary to use gatekeepers in this instance to access this population, not only because there is the problem of carers defining themselves in this role, but also because there seemed to be potential for greater access if the target group were approached initially by people with whom they were working.

Research Method

The term care-givers is used to refer to people who provide care and assistance to one or more other people on an informal, that is unpaid, basis. Care-receivers are defined as people who require significant extra help with the activities of daily living. Case studies of givers and receivers were completed, these involved a total of thirteen people,³ ten women and three men, eight of whom were care-givers and five care-receivers, involving ten care situations (in three instances both the care-giver and care-receiver in the care relationship were interviewed).⁴ The interviewees encompassed a variety of care situations including: spousal care relationships; care relationships involving parents and adult children (that is, parents caring for and being cared for by adult children); sibling care relationships; carers who themselves have some disability; caring for more than one person and/or for children; and someone providing the majority of care for themselves. In addition, while the focus of my research was on informal care, three interviewees who presented as informal carers also had experience of working as a care assistant or health care professional. Similarly, while concerned with adults, given that some of these care situations had begun while the care-recipient was under the age of 16, five of the interviewees had experience of either receiving care as, or giving care to, children. I have included some reflections from these standpoints as appropriate.

There was also a variety of reasons for needing care and assistance among the care situations in which the interviewees were involved: cognitive and learning disabilities; mental health issues; physical illness; and physical impairment. Further, these were both of long- (for the majority) and short-term duration. The caring settings among those interviewed were in their own family homes, other households, residential settings, and sometimes a mixture of these. Given the relatively small numbers of people interviewed and the small-scale nature of the communities in which the primary research was carried out, in this paper the level of detail of the various care situations reported has to be minimized so that readers cannot identify any particular person throughout the paper. I have, however, endeavoured to use examples and quotations in a way

which is faithful to the narratives and experiences offered by those involved. Reporting the interview material this somewhat restricted way does mean that some of the richness of people's experiences may be lost, but it is necessary in order to protect people's anonymity and confidentiality. This paper cannot do justice to the wealth of capacity, intelligence and character of those I met through this research, nor of the complexities, struggles and joys of their care situations and relationships.

Those involved in the research were all volunteers who were invited to take part in research through the auspices of independent agencies working in the border region.⁵ While there were specific questions I was exploring in the research in terms of equality issues, each interview began with me inviting the interviewee to tell me about their situation, our conversation following from that starting point. Allowing each person to talk about their own situation in this way, with prompts and specific questions as appropriate, was both important and beneficial. It was important for the interviewee to be able to express their own story in a way that was comfortable for them, and it was beneficial for me in that the way they narrated their own story, in and of itself, revealed something of how each person understood their care experience. In addition, clearly on occasion this approach enabled people to talk about their situation, sometimes surprising themselves with what they were able to contribute. As one woman commented at the end of the interview when asked if she wanted to add anything further, 'No, lucky got that much out!' My thanks are due to all who spoke to me, for the welcome they gave me and their willingness to share their experiences with me.⁶

While the purpose of the research was to explore issues around equality and care, few of the interviewees spoke about or indicated that they thought of their involvement in care situations in terms of equality. The themes of fairness and support needed were evident and certainly there was awareness of difficulties, disadvantages, and restrictions in their lives due to the particular circumstances they experienced as either a care-receiver or a care-giver. While for the most part these were spoken of without specific reference to equality as such, as I demonstrate below, the things they did speak about fit well within

equality discourses. It is possible that the common association of equality with the legislative and formal legal framework in society in terms of both negative (that is, antidiscrimination measures) and positive (that is, promotion of equal opportunities) duties is an odd fit to those involved in care. After all, certainly in informal care settings, care is perceived and experienced in terms of relationship rather than regulation. Law, policy and procedures are, of course, tools of equality, which is a profoundly relational concept. Equality is about relationships between people that are not based on self-perpetuating dynamics of disadvantage and privilege in which some people's empowerment and prospering is gained at the expense of that of others. As will become clear in what follows, care relationships can be exploitative and damaging to the people concerned, but they can also be relationships of mutual flourishing and foster the development and thriving of human personhood.

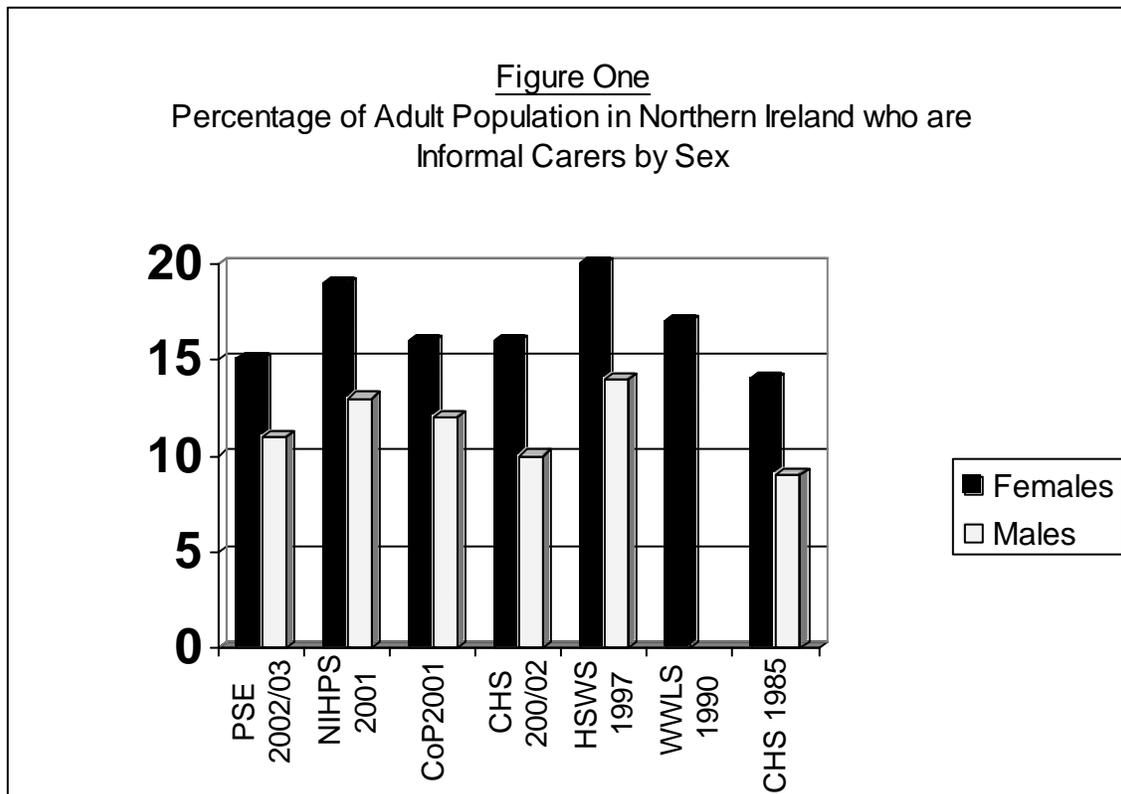
As notes above this paper also incorporates pertinent quantitative data on informal care that is available from a number of population surveys in Northern Ireland: the 2002/03 Family resources Survey (FRS) (DSDNI, 2004); the 2001 Northern Ireland Household Panel Survey (NIHPS) (Evason, 2004); the 2001 Census of Population (CoP Table SO25) (NISRA, 2003a); the 2000/01 Continuous Household Survey (CHS) (NISRA, 2003b); *The 1997 Health and Social Wellbeing Survey* (HSWS) (Mooney and MacNeill, 2001); and *The 1990 Women's Working Lives Survey* (WWLS) (McLaughlin, 1990) and secondary analysis of the 2002/03 *Poverty and Social Exclusion in Northern Ireland Survey*. In this survey out of 3,100 respondents there were 415 informal carers, that is, those providing help or assistance to an adult who requires special help with the activities of daily living on an unpaid basis for someone either in their own or in another household.⁷

The qualitative and quantitative data cited in this paper illuminate differently the issues of equality involved in the ethics of care discourse. I begin by considering the exploitative nature for women of the gendered practices of care in society.

Care as Exploitation

As Mary Daly has remarked, 'Care is one of the original feminist concepts' (2002: 252). From the emergence of its so-called second wave in the 1960s, feminism drew attention to the part that the practice of caring played in perpetuating women's disadvantage in society. Initially focused on women's unpaid domestic labour in families, feminists demonstrated how, in providing for the well-being of their husbands and children, women limited their own employment opportunities and, hence, fostered their economic dependence. This critique was further applied to government policies of community care for people with ongoing care needs. In Britain, since the 1970s, both 'Labour and Conservative governments have seen community care as self-evidently the right way to support individuals who find it difficult to live independent lives' (Graham, 1997: 125). Feminists exposed the gendered and exploitative nature of such policies which were built on assumptions and expectations about caring as women's responsibility and obligation for 'in practice community care equals care by the family, and in practice care by the family equals care by women' (Finch and Groves, 1980: 494; see also Finch and Groves, 1983). It is a self-perpetuating system: 'both the ideology and the practice of community care rests on, and reinforces, gender divisions' (Graham, 1997: 131).⁸

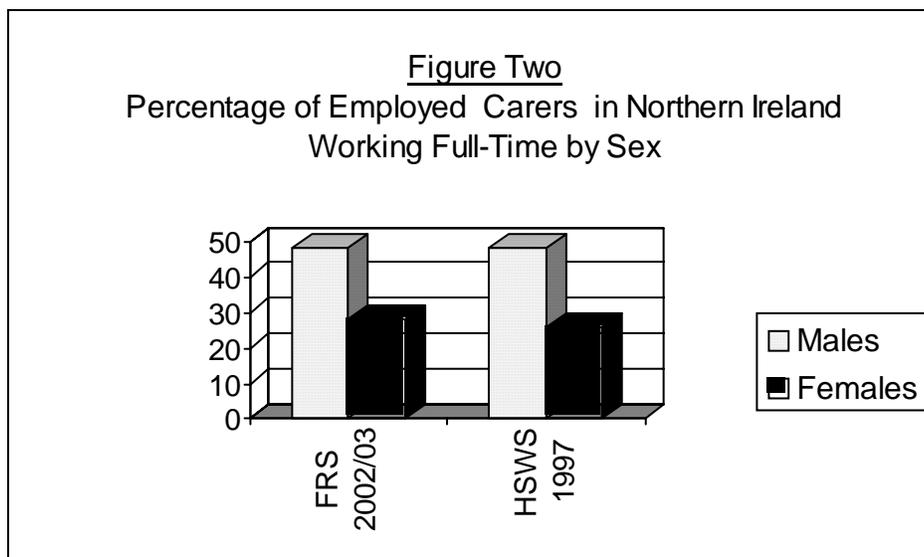
Despite the rhetoric of 'community care', the majority of informal care remains the responsibility of women. In Northern Ireland, statistics from a number of surveys consistently demonstrate a higher incidence of female carers than males (figure one).⁹



The feminist critique pointed out that not only are more women involved in care, but those women who are carers are more likely to be heavily involved in care work than male carers. This has remained the case despite women’s increased participation in the labour force. Writing in 1990 Gillian Parker commented, ‘the evidence of the past 20 years suggests that women do combine the roles of carer and paid worker and that increased labour market participation has not significantly affected the likelihood of women being carers’ (1990: 28).¹⁰ Some women who care are either not in the paid labour force or leave it as a result of care responsibilities. Those women who do combine paid employment and care experience more constraints on the number of hours worked, opportunities for over-time, restricted career development and promotion, and loss of pension rights, all of which affect women’s economic well-being in both the short- and long-term.¹¹

Northern Ireland statistical data reflects this pattern. In the PSE survey, while 53 percent of female carers are economically active¹² compared to 61

percent of their male counterparts, more than nine out of ten (92 percent) male carers who are currently working or had ever worked did so on a full-time basis compared to less than 6 out of ten (58 percent) female carers. A similar pattern is evident in both the FRS and HSWS in which almost half of all male carers work full-time compared to a little over a quarter of women carers (see figure two).



Men’s involvement in caring tends to be in relation to spousal care and is more likely to be at a later age in their own lives. More than a third (36.5 percent) of male carers are aged 55 and over compared to just over a quarter (27 percent) of women carers (PSENI 2002/03). The pattern of women’s care work is more of a continuum, first caring for their children and then for elderly relatives. Furthermore, women’s caring roles may often overlap, resulting in competing needs of children, husbands, and other relatives. The stories of the care-givers interviewed for this research reflect these gendered patterns. The male care-giver began his caring role in his senior years, while the seven women care-givers had been providing care in one form or another throughout their adult lives and, in at least one case, while still themselves a child. It is not surprising, therefore, that ‘Generally, female carers have been shown to be more likely to give up their jobs, lose more money and to experience more stress than are male carers’ (Parker, 1990: 93).

Paid employment, of course, may provide not only economic benefits as already indicated, but also offer social opportunities and contribute to personal well-being. 'I couldn't do without the job because it would be losing part of who I am', said one female care-giver adding, 'but financially I couldn't cope either, and that is a big thing'. Another woman spoke of how work had ensured she had an outlet and network outside the home following the death of her husband: 'I was glad that I did [go out to work] because I met so many friends through my work and ... it gives you more confidence being out among people, and ... I think that helped me too [when he died]... Whereas if I hadn't went out [to work] before he died, I wouldn't have went out after, definitely.'

Joan Smyth points out that the gender disparity in regard to care, called by Gillian Parker, 'this very significant inequality' (1990: 93), is built on the 'assumption that women can and should continue to take on most of the caring with little support', an idea which itself 'has been reinforced by the fantasy of an earlier, kinder, more communal provision of care in which "the community" rallied round its elders. Unspoken in this discourse is the hidden agenda "and it didn't cost anything". It did, of course; it cost, and still costs, many women physical and mental health, financial security and a fulfilling social and family life' (in Evason and Whittington, 1995: 1).

Inequalities in informal care provision are apparent among those interviewed. Hazel Quershi and her colleagues (Quershi and Simons, 1987; Quershi and Walker, 1989) suggested that, in terms of care of the elderly, a hierarchy of expectation or obligation exists that determines who cares. This hierarchy is established on the basis of closeness of kinship ties, gender (hence, daughter-in-laws tend to come before sons), marital status, proximity of residence, the strength of labour market attachments, and extent of other caring commitments, for example, for young children. The stories of the interviewees in this paper suggest that, enmeshed in these common factors of gender, kinship, geography and employment, established family dynamics contribute to inequalities in care-giving within families and that, in turn, care solidifies family patterns of relating.

For example, a woman with young children, one of whom has special needs, comes to live near her parents on separation from her husband. As her parents support her in various ways, she increasingly does things for them - errands, paying bills, taking care of household management - so that when the situation arises that the parents are increasingly in need assistance as they get older, the woman becomes the main carer with minimum help from her five siblings (all of whom live relatively nearby), while still having care responsibilities for her now adult child with special needs. Further, she gave up a part-time job when one parent became ill, even though she had two sisters who were not employed at the time, and indeed had never worked outside the home. This woman got into the caring role for her parents because of the family pattern that had been established. This pattern is then solidified through caring and hard to break out of; it is not impossible to do so, but will take disruption to her self-identity and to the lives and relationships of the family. This uneven responsibility for care within families is a familiar pattern, as the woman herself comments, 'I've seen a lot of families the same as me, that there's one person left to [care], you know, and it's expected of them, once they start, [they] just have to keep going.'

Another example is of a woman, the eldest of seven children, whose mother died before she was a teenager. The care she provided her younger brothers and sisters continues when she is older and one of the brothers requires ongoing help and support: 'He looks at me as a figurehead too like, 'cos I always was at home, you know, and I suppose that's part of it too. I have always - I never was away from home or anything, you know, and I suppose he was always used with me there.' One woman became a care worker because of her involvement in caring for a parent who spent time in a nursing home. Approached by one of the staff to consider working in the home, she found herself well suited to the work: 'When I started off I was grand ... I never found it any, any problem at all... It has to be in you or it's not; some people just couldn't do it.' For another interviewee it was the family dynamic that prevented her from taking up a nursing career. Her elderly mother said to her, "'you'll leave me and daddy" - you know what old people would have said - and "what are we going to do?" And then, of

course, I felt guilty and I didn't go.' She did not regret this decision and had found other ways to fulfil the fact that 'I always wanted to be the giver and not the taker ... I get more out of giving than I do out of taking ... I can't say no to anybody.' Indeed, she preferred her home-oriented life to 'holidays and all ... that. I think it's because I always had to look after mummy and daddy and all these old uncles and old aunts.'

One woman recognised the role of family patterns in her own responses. Aware that she would 'have always considered myself as caring for mummy and the rest of the family' and been 'the one to step into the breach' in order to help family cohesion, she further reflected, 'I suppose in many ways, maybe it's myself - no "maybe" about it - it *is* me who puts myself in that position. I allow myself to be, you know, bombarded with all of these emotions and I can choose not to feel that way. But I think for so long I've kind of conditioned myself to be that responsible, you know, pillar of strength for everybody else that there's nothing in that respect that would make that any easier, you know what I mean? Unless I chose not to, and then I think if I chose not to I would feel even more riddled with guilt then - that I was letting people down.'

Whether such family dynamics reflect positive or unhelpful ways of relating, and this will vary from and within each situation and in part be dependent on the 'eye of the beholder', the impact of such established family patterns can lead to inequalities within families as to who carries on caring responsibilities. As domestic relations within families are in and of themselves highly gendered, it is not surprising that family patterns of relating tend to reinforce caring as women's responsibility.

The majority of informal care in Northern Ireland, as in Britain, is of care for a family member rather than of friends or neighbours. The NIHPS, HSWS and WWLS all show that nine out of ten adult carers are caring for a family member (91 percent, 90 percent and 91 percent respectively, Evason, 2004; Mooney and MacNeill, 2001; McLaughlin, 1990). The largest group tends to be care for parents/parents-in-law, which the NIHPS has at 45 percent, the HSWS at 55

percent, and the WWLS (among those caring for one care-recipient) at 65 percent. Care of a spouse or partner accounts for around one fifth to one quarter of care relationships: 20 percent NIHPS, 22 percent HSWS, 25 percent FRS (DSDNI, 2004).

However, if care is left to rest on families then those without family support may suffer in the absence of family or if family relationships are present but antagonistic. One care-recipient interviewed was determinedly maintaining her own independence in a situation that from the outside would have looked supportive but from the inside was not. One interviewee who has experience as a paid care worker commented that their observation was that the medical profession tended to give better attention to patients if family members were present. Hence, those without family support may lack the implicit advocacy of having family members present. Here we see how inequality embedded in the concept of informal care as part of the private family domain impacts those without family support. This raises questions about inequality of the concept of care itself, to which I return below.

Care-giving can be demanding whether provided by women or men.¹³ Two women interviewed had hurt themselves physically – receiving back injuries through lifting – one in her work as a paid carer, one in an informal care setting. Another spoke of a dramatic stress reaction directly related to her caring situation and its emotional demands. She went on to explain, ‘I find that it’s not, it’s not the pressure of doing the ironing and the cooking and looking after a household, it’s not that. It’s the constant, constant, constant, you know, emotional battle that you’re facing... It’s not the practical things, you know, the washing floors and Hoovering, and you know, keeping a house, it’s not that that bothers me, it’s the emotional stuff.’

Care-giving may hinder personal development: ‘I’ve kind of been stunted like, stopped in being able to move on ... I feel that I’ve been there for everybody else, and I done everything for everybody else, that if I don’t ... do something for myself then it’s going to cause me more harm, and as a result cause everybody

else more harm. I'll not be able to, you know, be myself.' Acknowledging that parts of life have 'all kind of been put on hold' through caring responsibilities this woman went on to say, 'not that it's anybody's fault, or, not that you would blame anybody or [have] resentment for that.'

Sometimes the intensity of caring responsibilities results in people just wanting some peace or quiet space to themselves. 'It is nice to get away for a weekend, switch off, do you know what I mean? Now last weekend I just wanted to get away, to switch off from my family ... and watch television and have my wee glass of wine, and that's what [I] did... And I said isn't this wonderful this life, just to lie here and watch the television, you know what I mean? And not have to answer to everybody, you know, and run after everybody.' For another care-giver: 'Sometimes I'd just love to get about two hours peace on my own, no television, no music. [Sometimes I] just love to get up to bed and lie down and just be quiet. ... And I love people, and I love them coming and all that, but I'd just love to just get complete peace.'

While it is in some ways arbitrary to cite these quotations out of context for these people also spoke warmly about their care relationships, it is important not to deny the demands of care-giving.

Criticism of the expectations and cost on women - or men - to care is not the same as criticism of caring in and of itself or of the value of the relationships involved in care. This brings us to the second paradigm of the ethics of care, one that highlights the value of care in women's lives.

Care as Women's Moral Orientation

The feminist discourse on care was not only concerned with the exploitative elements of caring for women. It developed to consider the positive moral significance that caring has in women's lives. Hilary Graham points out that this development is reflected in a change in terminology from domestic labour to caring. 'While the concept of domestic labour captures the work that goes into looking after homes and families, the concept of caring captures the feelings as well' (1993: 462). Further, care was not only about the provision of material

needs, but about the emotional work and investment in others that women do. As Jean Baker Miller encapsulated in 1976, 'If we look at what women have been doing in life, we see that a large part of it can be called "active participation in the development of others"' (1991: xix-xx).¹⁴

The importance of this understanding of caring in forming women's personhood was developed by Carol Gilligan (1993). Her work began as a challenge to existing psychological theories in which women's development was often viewed as immature because it did not complete the established stages of moral development. In her research (originally published in 1982) Carol Gilligan discerned what she described as 'a different voice' among women in which their sense of connection with others influenced their identity and morality. The contrast is between 'a self defined through separation and a self delineated through connection, between a self measured against an abstract ideal of perfection and a self assessed through particular activities of care' (Gilligan, 1993: 35). She conceptualised men's and women's ways of structuring relationships in terms of hierarchy and web respectively. While men's moral frameworks were based on a notion of rights-based, abstract judgements, women's moral orientation rested on responsibility and emotional attachment to others. She argued women operated an ethic of care in contrast to men's ethic of justice.

In identifying this different voice of women's experience Carol Gilligan was affirming women's sense of self built on a moral orientation of care. In contrast to the masculinist value judgements that viewed caring as of lesser importance or even a hindrance to the development of personhood, this was validation of women's way of relating to the world.

However, in contrasting (if not necessarily opposing)¹⁵ the two ethical orientations – that of care and connection with justice and separation – this celebration of women runs into the trouble that all emphasis on gender difference potentially does. Namely, that of subordinating women and their experience in a gendered, dualistic value system that prizes male-identified orientations and

activities and those associated with men, over those identified as female or associated with women. This raised debates about the relationship of justice and care (for example, Mendus, 1993) and of autonomy and dependence.¹⁶ A key concern was how to ensure that an endorsement of women's orientation to care was not used to perpetuate their exploitation through unquestioned expectations that they would take care of care, and do so without complaint or protest. This in turn interrogates the relationship of the public and private worlds, asking whether and how the private world should incorporate justice and the public world embrace an ethic of care for 'isolated from one another, an ethic of either care or justice has its moral dangers' (Tanner, 1996: 172). Further, associating care with women means that care itself becomes feminised, that is, it assumes the lesser value of female-associated attributes within society and this affects all who have care responsibilities, whether male or female.

That an ethic of care is operated by women, that is, responsibility and care for others is their 'normal', is reflected in the lack of identification with the term of 'carer' by women care-givers who were interviewed. As one woman described her relationship with two family members, 'Well, the way I look at it, [he] is my son, do you know what I mean? And there's nobody else going to look after him, I have to do it. I don't have a choice... And then there's just mummy then, mummy was always so good to me ... the two of us always clicked'. Put succinctly by another mother, 'As far as I was concerned, they were my [children] and I was fit to look after them.' Another woman described the care she provides for a family member in terms of: 'You just get up and you do, you just go along and you do whatever has to be done, you don't even think about, I don't even think about it, you know.' Asked specifically if she identified with the label 'carer' having worked as a care assistant, she answered, 'Well, no, not really, I never would have... I did it like for twenty-five years, but I, no, I don't, I wouldn't label myself.' Likewise, in her own family context, 'still never would think that I'm a carer. As I say, just go along, whatever help [my daughter] needs, I would give it and, eh, just don't think, don't think about doing it, you know.'

Similar feelings were expressed by a male care-giver: 'Being a carer, you're an unsung hero. You get up, you do your job and you get on with it, you don't have to cry about it, you just get on with the work. And at the end of the day, you can sit back, watch television and say, well that's one good day, thank God.' His acceptance that 'at the end of the day, the carer has to get on with it, regardless of what happens' echoes the words of a woman care-giver of her care situation: 'it happened and there's nothing I could do about it so I had to cope with it.' The difference, however, is that this interviewee identifies himself specifically as a 'carer' and describes an accompanying lifestyle change on his part as 'a big sacrifice for me'. He has no sense of regret about this and indeed would willingly 'do it all again', speaking of the quality of his relationship with his wife for whom he cares, and is proud to do so. For him, caring has become part of his identity in a conscious way that is not the same for the women quoted above. This makes his care no more or less care than that provided by female care-givers: it is no more care because it was not his norm, or any less care because it involved conscious choices. However, in the wider social context that assumes care is women's 'natural' domain, the care given may be viewed differently in both quantitative and qualitative terms depending on whether it is provided by a man or woman.¹⁷

These particular stories speak to the valuing of care in people's lives, whether provided by women or men. As one woman commented of the support her whole family was providing one family member, 'We'd be there for [her] no matter what. .. Just be delighted to, you know, to help her and to get her through it.' The difference that care as part of women's moral orientation may make, however, is that the hidden nature of much of women's care, that is, their lack of conscious acknowledgement of what they do as care, means that they may not seek additional help that is available to them. One woman caring for both an adult child with special needs and a seriously ill husband remarked, 'The social worker said to me ... you know that [your child] is a handful but you make light of it ... you never looked for outside help.' She added, 'I never would have thought of asking.' These exact same words, 'I never would have thought of asking',

were used by another woman when speaking of how external assessment of her family member's situation by a health care professional had resulted in the family member receiving three and a half hours of outside help on a daily basis. Her lack of identification of her own care-giving as the provision of informal care denied her access to social services that are available for people giving and receiving care in family households. What is needed is a way for people to maintain the relationality of their care-giving while recognising the support that is available to them. A greater valuing of care-giving in society would facilitate such a move, and I return to this below.

The orientation to care does not, of course, mean that caring relationships do not have tensions. Referring to the prospect of a parent coming to live with her that will mean all her caring responsibilities come under one roof, rather than in two different households, one woman reflected, 'In one way it's very good, right, because I won't have that running to do, you know, ... but in other ways, I really will be stuck with her. And that's an awful thing to say but that's the way it will be, that's my feeling.' This same woman was emphatic that she would continue to be the main care provider for her mother and would not consider some kind of residential care setting for her: 'I wouldn't do that ... Except I couldn't, eh, mind her. Right. That's the only time I would ... No, mummy has been too good to me over the years and I love her too much to do that ... It's only that if she became, if she couldn't get out of bed, and I [couldn't lift her], but then I could get a hoist and all that... I don't believe I'd ever put her in a home except I became sick myself, that's the only thing, you know.' Here we see how bonds of affection may sit uncomfortably with the demands of caring referred to in the previous section.

The orientation to and activities of care-giving can be all-consuming. One interviewee was aware of this having heard it said 'time and time again that carers - and like I've seen it once myself ... - that carers who care for, you know, like a partner or something like that, whenever that partner dies then ... when there's that loss of that caring role that they're going to be in limbo because they don't know what to do with their lives. They have spent so long being a carer and

being, you know, there for somebody else and ... they're not being themselves, they're being this, you know, this something to somebody else, and it's not who, it's not the thing that defines them but it's the thing that they kind of allow themselves to be and nothing else and that's what I don't want to happen to me.' Another woman spoke of the experience of her daughter leaving the family home for respite care (on a temporary short-term basis) as 'walking around like I'd lost my right arm' in contrast to her daughter's response to this experience who 'didn't pine her heart out for me'. Through physical injury she found herself having to leave paid employment and see her daughter move permanently into residential care: 'Retired out of my professional job as I was retired out of my caring role and it was like the ground was took from under me in every sense.' She describes the journey she had to go through 'from the notion that nobody can look after this person but you to the point where you can't help her at all' as 'a very humbling experience and a very difficult thing to come to terms with.' She went on, 'I've come to terms with it now ... but at the time it was I'd let her down, you know, I'd put her away.'

While this woman described it as 'still a big regret to me that she's in a nursing home', a convincing factor for her in availing of the initial short-term respite was what was happening to her other children who, 'long before they were old enough were taking on caring roles.' So much did their activity as a family revolve around her daughter with special needs that on the first occasion this child was in respite it took some time for her to realise she and her other children could go out of the day: 'We didn't know what we were supposed to do with ourselves, we sat round the table and ... we played board games. This was a real treat. It took me into Saturday to realise we could go out. And, you know, go down into [town] and take the two wains shopping.' Another woman also spoke of the effect of caring for a child with special needs on her other children: 'She is a handful, and the rest of the children had to take second place, because all the time we was focused on [her] ... you don't think these things as a mother until you're told them, and then you feel so bad.' This is not to suggest that either of these interviewees are placing blame on the child with particular needs for the

difficulties they had in caring for the rest of the family. Indeed, if anything, the women blame themselves for being unable to care adequately for all their children. Blame is not, however, an appropriate discourse here. Rather, what the experiences of these interviewees highlight is what can happen in families within a social framework that makes care aberrant and invisible. In such a framework, one that tends to 'abnormalize the physical experience of impairment' viewing relationships within families with disabled members as 'problematic and pathological' (Shakespeare, 2000: 55), matters of care are not taken into account sufficiently to enable families to adequately care for all their members.

Managing the complexities of caring relationships such as these was described by one interviewee in terms of wanting 'to do the right thing to complete the jigsaw'. Yet making the pieces all fit neatly together in a way that fulfills the orientation of care and connection to everyone involved in a family care situation is not always possible. Ironically, the demands of caring that speak to an orientation to care may also mean a loss of the ability to care. Reflecting on the relationship she now has with her grandchildren, one care-giver said, 'I suppose in a way I'm compensating with them what I wasn't able to do with [my own children], you know, those fun kid things. I was very, very lucky that I got an opportunity to do that... I really value that I have that because it was a bit of my motherhood that I lost. I lost out, the [children] lost out, but I lost out too, because I would have loved to take them to the park, I would have loved to take them here and there, loved to have done.'

The value of care in people's lives was spoken of specifically by two interviewees. 'To me, what has happened me in life, I can identify with everybody in their trouble, in any kind of trouble. Em, that's on the good side, that's ... what my life taught me, how to identify, and how to appreciate very little.' Another woman spoke of a cultural tendency to 'look on bad things as blessings, that's how we get round it, it's a coping mechanism. It's a very, very powerful coping mechanism, you know, it might sound trite and sometimes it sounds very trite when you are the one at the receiving end of all these blessings, you know, and less blessings, Lord, would be all right, you know, don't bless me so much

please. *[laughs]*.' She remembered her mother saying of her child with special needs, 'that child is blessed and no doubt about all of that. I didn't have a clue about what she's talking about, but I know now. It was the people I met, the kind of people in the world that I never knew existed, the miracles that I did see, just the miracles of human nature'. She went on, 'You would never chose to be the carer of a person with challenges, with difficult challenges, you know. Chiefly because you don't want to see anybody you love and care about, you know, having to face a difficult life. But having said that, I know that through [my daughter] and I said it earlier, the people I have met, the situation's I've been in, there are times that I've been left ... speechless.' This woman also valued her care situation for 'all the things that it has opened up to me and to [my other children] and the way it has formed their personalities. They may have been poor in some experiences but they are richer... It's an enriching experience, you know, a very painful one in a lot of ways and very difficult but you get to see a side of life that no book is every going be able to teach you, no amount of studying is every going to be able to enlighten you, that you only, only get through the living of it.'

These comments give witness to the positive experience that care relationships can be in the development of human personhood. They also reflect the relational nature of care that care ethics has emphasised and endorsed, despite the disadvantage to women's social status contained within a focus on care as women's moral orientation. Concern for women's identity and social place, however, is not the only objection that has been voiced to this discourse and it is to these other challenges that I now turn.

Ethical Challenges

In addition to the issues discussed above, a number of other challenges to the feminist discourse of the ethics of care have been made. Some have been concerned that the focus on gender and difference leads to essentialist notions of woman. Carol Gilligan herself has been clear that her different voice is one of theme rather than gender. In other words, while the different voices were gender

related, tending to predominate in men and women respectively, she did not suggest this association was absolute and indeed also considered the interplay of the two themes in the development of each sex (1993: 2). However, the difficulty remains that 'feminist ethicists who stress the difference between women and men unintentionally feed the stereotypes that harm women and buttress arguments used to justify their oppression' (Tanner, 1996: 173).

In addition, the category of 'woman' itself was undifferentiated, with the model relating predominantly to White, heterosexual women within marital family networks, which ignored the possibilities of care-giving and -receiving in other family arrangements and in non-family contexts, as well as caring dynamics within different racial/ethnic groups. Jane Aronson, for example, has drawn attention to care-giving and -receiving by lesbians who live much of their lives 'outside kinship structures where exchanges of care and support are not framed by the assumptions and obligations associated with heterosexual kin ties and must, therefore, be navigated in less charted terrain' (1998: 506). She argues that the more conscious attention consequently required by lesbians in relationships of care offers a contribution generally to thinking about 'alternative bases for building nourishing social ties' (1998: 506). Hazel Carby (1982), Patricia Hill Collins (1991) and Evelyn Nakano Glenn (1992) make clear how matters of care and family for Black¹⁸ women and Black communities are profoundly influenced by the legacy of slavery and the experience of racism and may not be subsumed within the dominant model of White families. For while it is recognized that the labour of social reproduction, 'whether commodified or not, ... is 'constructed as "female" ... [!]ess obvious, but equally characteristic, is its racial construction: historically, racial-ethnic women have been assigned a distinct place in the organization of reproductive labour' (Glenn,1992: 6). This distinct place is one in which they disproportionately fill gendered service roles. Black women's identity as mothers caring for their own children, which frequently has to be managed around their paid work providing care for the children and households of White women, is powerful in sustaining their resistance to racial

oppression as they seek to provide better opportunities for their own children than they have known.

A further dynamic in this discourse is the international context and the 'increasing feminization of migration' (Williams, 2002: 513) which has seen a growth in the number of migrant women employed in a variety of caring roles (cleaning, child-care in private homes, and as carers in private care institutions). Often they do so at the cost of being apart from their own children and families. As Fiona Williams suggests, the 'work/life balance for some is being achieved at the expense of the work/family separation of others' (2002: 513). Further, she points out that 'the existence of *diasporas of care*' (2002: 513) that has arisen with not only increased migration but permanently settled second- and third-generation migrants means that caring responsibilities are carried out across international boundaries. She cites an IMF statistic that at the beginning of the 1990s migrant workers were sending home 65 billion dollars, which was 20 billion more than official overseas global aid programmes (2002: 513). Of course, the separation from families has implications for the care needs of migrant workers themselves when the model of family care is dominant.

One of the most striking challenges to the feminist discourse on the ethics of care has been and continues to be voiced from those in the disability movement. They have exposed the silence and invisibility of the cared-for in care ethics discourses. "Caring" is a shorthand way of talking about what carers feel and do rather than what care-receivers feel and do. Thus, when feminist studies refer to "the meaning of caring" and "the cost of caring," when they describe "caring relationships" and "the experience of care," the frame of reference was – and is – typically that of care-providers' (Graham, 1993: 463). There are many repercussions from this.

Jackie Barry points out that accounts of care based on care-giver knowledge of care-receiver needs produce care-giver solutions: 'In constructing those with care-needs as cognitively, physically, and emotionally tractable, and carers as active, effective, and committed, there is no sense of receiver

participation in feminist models of care' (1995: 371). When attention is paid to care-receivers, she argues, it is possible to see that care is a burden also for them, and this must be addressed. She points out that the distinction between 'caring for' and 'caring about' is significant for the care-receiver as well as the care-giver. While optimal care for care-receivers is when both are achieved, if both are supplied in family context, it is possible that the stress of 'caring for' can jeopardise the 'caring about' (1995: 362-363). As Jenny Morris states, many disabled people are aware that 'caring for' in a 'caring about' relationship cannot work unless there is 'real choice based on real alternatives' (1997: 165).

Jenny Morris also comments that engaging with the experience of disabled and older people who require assistance has implications for the meaning of the word 'home', that this should be separated out, 'in a conceptual and political sense' from feminist critiques of the family (1997: 165). In this way, asserting their right to live in their own home would not be equated with disabled feminists endorsing women's oppression in the family. Hilary Graham remarks that paying attention to the experiences of older and disabled people 'opens up questions about the distribution of poor health and disability in Britain. It moves social class and age from the margins to the centre of analysis' (1993: 464).

In the same way that carers are not a heterogeneous group, neither are care-receivers. Nor are care-giving and care-receiving necessarily mutually exclusive categories. 'The dichotomizing of care as given or received also obscures the more blurred reality of many people's lives in which needing and providing assistance and support may occur simultaneously or in which needs, resources, and abilities shift and change over time' (Aronson, 1998: 506). The distinct lines drawn by much feminist research has obscured the extent to which older and disabled women are also carers (Morris, 1997). Jenny Morris argues that the failure of feminist researchers and academics to identify with the subjective experience of those who receive care has meant they have focused on caring situations with seemingly clear distinctions between the carer and the cared-for, often identifying potential interviewees by their established identity as a carer. These are only one type of possible caring relationship, however, and she

argues that if caring is understood to be not only physical tasks but the emotional component of care-giving, then the research of disabled feminists would focus not so much on carers as on caring (1997: 166).

That care-givers themselves may be in need of care and assistance is demonstrated in the Northern Ireland PSE survey (see table one). One in four carers (27 percent) have a disability that affects them in one or more of the areas of mobility, personal care, housework, paid employment, and social interaction.¹⁹ One in five carers (19 percent) are affected in two or more ways, with more women in this category than men. These figures are similar for those in the population without caring responsibilities. It is not possible, therefore, to interpret this data in terms of a causal relationship between care and ill-health. Rather the point is that there is not a rigid dividing line between those who provide care and those who require it.

Table 1

Disability among Adult Carers in Northern Ireland (PSE 2002/03)

| | All Carers % | Female Carers % | Male Carers % | Whole Population % |
|-----------------------------------|--------------|-----------------|---------------|--------------------|
| No Limiting Disability | 73 | 72 | 76 | 76 |
| One limiting disability | 8 | 8 | 8 | 7 |
| Two to five limiting disabilities | 19 | 20 | 16 | 17 |

All of the above challenges draw attention to the power dynamics inherent in care relationships, which are manifested in everything from the way care is named to the experience of receiving care. ‘All liberation movements have had to wrest the representation of their reality from those who oppress them’ (Morris, 2001: 5). One such example is the more recent focus on children as ‘young carers’ which further marginalises disabled parents, particularly mothers who are lone parents, by ignoring the social factors such as poverty, poor service

provision or environmental factors (for example, poorly adapted living accommodation) that lead to children assisting their parents. Further, it suggests a role reversal so that, 'If your child helps you put your shoes on ... you have become the child, and your child becomes the parent' (Morris, 2001: 7). Jenny Morris contrasts this disabling attitude with the voice of the disability rights perspective which argues, 'the need for help with daily living tasks does not undermine your ability to love and care for your child' (2001: 7).²⁰ This does not infer that children who have responsibilities in care situations are of no concern. Rather it draws attention to the importance of breaking out of binary distinctions between care-giving and care-receiving.

The importance of listening to the voices of those who require care and assistance was vividly illustrated by one interviewee. He gave the example of how the door to a public building in his town had been widened to accommodate wheelchairs, but that this had been built on a six inch step with no ramp and therefore actually getting to the door was not possible for a wheelchair user, something that a wheelchair user would have pointed out had they been consulted. He commented that architects have 'a strange idea of what a toilet for people with disabilities is all about'. Sometimes this is located within the mother and baby facility with a pull-down nappy changing platform designed to be stored against the wall when not in use. When in its fold-down position, this platform is at face and neck height of a wheelchair user and an injury hazard, as he had experienced himself when attempting to use such a facility after the platform had not been stored away. He went on to describe how a disabled toilet should have access on both sides because some wheelchair users have maneuverability only on the right-hand side of their body, and some on the left. All of these structural failures in material realities result from a lack of consultation with those who require the particular facilities. This lack of voice by those in need of care and assistance occurs not only in regard to environmental factors, it affects all aspects of their lives. Speaking of her daughter with special needs and other children with disabilities, one woman said, 'they are classed as second-class citizens, you know, they don't have any wee speak for themselves at all, even

though probably the majority of them would have wee things they would love to do, but they don't ever get the change of doing it, they're just limited.'

Feminist thinking on an ethic of care as women's moral orientation juxtaposed against a male model of autonomy led to fears that women would be exploited and, hence, the call that caring relationships should be just – but this was with the carer in mind. The disability movement has called attention to the need for justice for the care-recipient and this has involved a critique of the language and understanding of autonomy and dependence.

Defining those with care needs as dependent is to assign them a position of powerlessness in social contexts where autonomy and independence (and the control, choice and self-determination that accompanies this state) are viewed as the norm of adulthood. Susan Wendell goes further: 'Dependence on the help of others is humiliating in a society which prizes independence' (1997: 273). Against this background, she emphasizes the importance of disabled people living as independently as able-bodied persons while knowing that for those disabled people who will always need a lot of help from other individuals because of their particular needs, 'to the extent that everyone considers independence necessary to respect and self-esteem, those people will be condemned to be de-valued' (1997: 273). As Jenny Morris points out, challenging the social construction of dependency is not to deny bodily experience, nor the consequences for the provision of assistance: 'Vulnerability is created by one person having a greater need for physical assistance than the person who is in a position to provide it and by the nature of the assistance required. This is why a focus on human rights is so important in our challenge to the meaning of care' (2001: 12).

Alongside deconstructing assumptions about who is considered dependent,²¹ many in the disability movement redefined independence as choice, control and flexibility rather than self-sufficiency: choice over living arrangements, over how care is provided and by whom, decision-making about most important aspects of daily living, and so forth, as exemplified in the Independent Living Movement. As one interviewee expressed it: 'I like to make

my own decisions ... I feel I need my independence.' The difference having such choice makes was explained by one care-recipient who had moved to a system of direct payments in respect of the paid care assistance they required. Rather than the local social services trust providing the care assistants where it could be 'the one carer one week and somebody else the next week' which 'wouldn't be very good', the care-recipient receives funds directly from the trust and can employ care assistants of their choice from any agency of their choice. In contrast to the previous situation in which 'I wasn't too happy the way that worked 'cos the fact that I wasn't in control', with direct payment, 'I could go to whatever organisation I wanted and pay them myself. The trust give me the money for the care, but how I used it - obviously I had to use it for care - but how I used it was up to me. What agencies I went to, there was no restrictions in that, so that was much better then.'

Having care assistants coming to their homes can be a major adjustment for care-recipients and their families. One care-recipient explained, 'at first it was annoying' having care assistants coming to their house. While they had got used to it and got on well with the carers, they spoke of the difficulty their spouse had that other people have a key to their home. For another person having 'different people coming in and out of the house ... I wasn't terribly keen about it, but I've got used to ... people coming and going now.' While such adjustments are going to be necessary, that should not negate the care-recipient retaining some choice and control in terms of who provides their care and at what times. One person commented about hearing 'horrible stories about people going putting someone into bed at nine o'clock [in the evening]. I wonder how that would work with me because obviously I wouldn't accept that ... I'd want it to be whatever time I'd be feeling tired.' The matter of choice was also raised by a woman who thought it would be preferable to have help within her own home for her elderly mother rather than respite care. This was because she felt her mother would be more able to adjust to being away from her and cared for by someone else if she was in her own home.

Despite these developments in approach, the realisation that, even redefined, autonomy and independence are unattainable goals for some people 'calls into question the value of these in any scheme of virtues and moral goals' (Wendell, 1996: 149). Hence the importance of thinking of all people as interdependent, and engaged in relationships of reciprocity and mutuality.²² This highlights the relational ontology of care, but does not have to mean ignoring the power dynamics in care relationships. This brings us to the final paradigm in the ethics of care discourse.

Moving Care into Political Space

Re-imagining/re-conceiving notions of dependence and autonomy are part of the fourth dimension of care ethics discourse that has developed to enquire how to move care into the public space. Here care and justice are not juxtaposed as a gender binary, but attempts are made to integrate an ethic of care into public ethos and social policy. This is more than a work/life balance, it is about envisioning 'adequate models of loving and working' (Miller-McLemore, 1994: 82) that reflect the fundamental place of care in human existence, but without perpetuating inequalities hidden in care relationships. Two major contributions on this matter have come from Joan Tronto (1993) and Selma Sevenhuijsen (1998).

Building on feminist sensibilities that value caring, Joan Tronto advocates an ethic of care that breaches both the moral and practical confinement of care to the sphere of women. She argues that the promotion of care in society is ineffective when it is based on arguments from women's morality because existing moral boundaries (the traditional division between politics and morality; the notion of morality as an abstract, rational, disinterested and distanced point of view; and the public/private dichotomy) keep women and their experience marginalized. Indeed, care conceived of in this way functions to maintain structural power and privilege (and partial privilege)²³ in terms not only of gender but of race and class. Rather than dismantling these moral boundaries, or simply continuing to promote women's morality, she argues for what she describes as the paradox of stopping talking of women's morality and instead talking of an

ethic of care that 'includes the values traditionally associated with women' (1993: 3). In this ethic of care, care is not viewed as women's identity or domain, but a central concern of all human life. It involves recognizing that the human experience is one of interdependence rather than a binary of autonomy and dependency, and that much of this interdependence is hidden from us because of the way the relatively powerful construct the dominant discourse and practice of care.

Joan Tronto identifies four phases of care: caring about, which is noticing the need to care in the first place; taking care of, which involves assuming responsibility for care; care-giving, the actual work of care that needs to be done; and care-receiving, which is about the response to the care by those who receive it. Arguing that there are subtle dimensions to the relationship of gender, race and class to the power dynamics inherent in care, she comments: 'I think we come closer to the reality when we say: caring about, and taking care of, are the duties of the powerful. Care-giving and care-receiving are left to the less powerful' (1993: 114).

From these four phases of care, Joan Tronto identified four ethical elements of care that apply to relationships of care and to a political ethic of care: attentiveness, for we can only address the needs of others if we are attentive to them; responsibility, rather than obligation; competence, in that the care given must be adequate; and responsiveness, as distinct from reciprocity, which 'suggests a different way to understand the needs of others rather than to put our selves into their positions. Instead, it suggests that we consider the other's position as that other expresses it' (1993:136). Moreover, not only should these qualities be applied in the context of the practice of care, they should also inform our practices as citizens: 'If through the practices of giving and receiving care we were to become adept at caring, I suggest that not only would we have become more caring and more moral people, but we would also have become better citizens in a democracy' (1993:167). For example, if attentiveness is part of public values, then the absence of attentiveness to the needs of a group within society becomes a public issue. Such a political commitment to care, however,

requires an understanding of humanity as interdependent beings, all of whom need care at some time in our lives.

This common human condition, that is, ‘the recognition that all people are vulnerable, dependent and finite, and that we all have to find ways of dealing with this in our daily existence and in the values which guide our individual and collective behaviour’ leads Selma Sevenhuijsen to articulate the understanding of care as a civic virtue (1998: 28). She also moves the feminist care ethics debate away from a focus on identity issues (that is, the extent to which women’s identity is formed around a moral orientation to care) to consider the place of care ethics in human agency and morality in the social/political domain, arguing there is a need to ‘judge with care’ (1998:4) how we organize our collective lives.

However, in order to bring care into the domain of citizenship it is necessary to critique the dominant ethical paradigm (of universalism) that views the individual as an abstracted, separated self protected by a rights-based morality removed from the encumbrance of emotional connection with others. ‘In the idea of the atomistic individual, the moral subject is primarily expected to pursue autonomy and independency. In this way vulnerability and dependency easily become separated from the ideal self and localised in, or projected onto others: weak or “needy” people.’ In contrast, a ‘feminist ethics of care, through its image of human nature, is ... better able to situate vulnerability, ambiguity and dependency within the moral subject’ (1998:57). The ethics of care and its central values of attentiveness and responsibility (1998: 61) therefore becomes a matter of public morality (in the sense of the values and norms we use to judge behaviour), and social practice. It ceases to be marginalised as something for the private domain (of women) separated from the political world, but is viewed as a social process that involves us all and is an integral part of democratic citizenship.²⁴

While as already said, the ethic of care involves more than a work/life balance, Fiona Williams sees the emerging discourse about the latter as a response to issues of care and time that is providing ‘an important political space

in which to start to argue for a political ethics of care' (2001: 472). This involves 'more than social policies, it means the development of political principles to underpin a new social environment of care' (Williams, 2004a: 11). For example, she suggests that the language of care ethics is more helpful than the phrase 'family values' to explore what people value in their relationships of care and intimacy, which no longer involve only marital and/or heterosexual relations (2001, 2004a, 2004b, 2005). Similarly, in the North American context of changing family patterns, Martha Fineman states: 'It is time to build our family policy around these emerging norms, to focus not on the form but on the function we want families to perform' (2004: 67), one of which is caretaking. She argues for public policy to reflect equitably that there is a collective responsibility for dependency, which is an inevitable universal experience, but which is often hidden in the private world of families.

Care ethics in political space are the means by which social policy may be both supported and assessed (Daly, 2002; Lister, 2002; McLaughlin and Glendinning, 1994; Sevenhuijsen, 2000, Sevenhuijsen et al; 2003; Wikler, 2002). Anita Silvers, however, warns against 'the regrettable repercussion' of the lack of respect for those cared for that occurs when caring becomes conventional: 'Institutionalizing caring depersonalizes whoever is cared for by shifting the source of the care-giver's motivation from affectional, admirational, or reverential regard of the particular recipient of care to diligent regard for the social role of the care-giver' (1995: 10). Hence, in institutionalized relationships 'the devalued find themselves perceived merely as means for furthering other people's self-regard, not as the valued ends of other people's actions' (1995: 10). Her concern is that the ethics of care, which develops out of asymmetrical power relations in which the disabled have been subservient, obscures the paradigm of equality, which is vital to prevent disabled people experiencing oppression and marginalisation. As Fiona Williams comments, her emphasis on 'disability as a set of socially and historically constructed power relations and as a civil rights movement as significant as those around gender, "race" or sexuality' deserves attention (2001: 481). Jenny Morris, for example, criticises social policy debates for often focusing

on the means rather than the ends of initiatives. The debates are around whether care is formal, or informal, whether cash payments or services should be provided, whether schooling should be mainstream or special, and yet the 'real point is whether these means deliver the ends – which is the protection and promotion of human rights' (2001: 13).

For equality to exist for care-givers and care-receivers in relation to those who currently do not have care responsibilities or need of care and assistance, care must move into political space. That is, care-giving and care-receiving must have a place and identity in public life – it will impact the way that public life is ordered and structured. Interviewees spoke about this with regard to appropriate service provision, financial matters, and physical infrastructures. First, in terms of support provided by social and hospital services, some interviewees spoke very highly of the service provision they received, for example, 'the social services here are brilliant, the social worker keeps in touch with us, if there's anything we need we only phone them up.' For others it was more a case of 'a lot of hit and miss'. As one person put it, 'I was very frustrated with a lot of the services for want of a better word, eh, and I suppose it's only natural - you're a carer, you're there when everybody else comes in and goes out and leaves their instructions and leaves their advice and leaves their opinions and you're left with the situation. And I used to just pray that would they come up here at three o'clock in the morning because they haven't a notion.' The care situations of the interviewees are varied, dealing with a number of different agencies, with experiences over many years, even decades, and it is not possible or my intent here to make an assessment of the adequacy or otherwise of the service provision that has or does exist for the people involved in this study or the areas in which they live. What is clear, however, is the importance of support in terms of proper equipment, day facilities, respite care opportunities, educational facilities and support, consistency of care personnel, and accessibility to and good communication with support services personnel. The difference receiving such support made to people's lives can be transforming; providing mobility, facilitating work and education, and opening up social opportunities.

The second area raised by the interviewees concerned finances. Money, of course, does tend to highlight the overall inequality embedded in caring situations and I discussed this above in respect of employment opportunities for female care-givers. Several interviewees expressed the view that care work was financially undervalued in society, reflected in the pay that care workers received, in the allowances that informal carers were entitled to receive, and in the difficulties they sometimes had in obtaining that to which they were entitled. Certainly, financial entitlements that may or may not be related to employment status were something of a learning curve, for both care-givers and care-receivers. One woman spoke of not being aware that she was entitled to state assistance in regard to the care of her child until the child was eight years old. She thought this was 'because I didn't have a social worker coming, in that, one might come and that same person might've been off on maternity leave or resigned, it could have been a new one that was only filling in for a few weeks... I wouldn't have seen them maybe, maybe only once in a few years, em, so I didn't know [about entitlements], so then I had to go and find out all this.' Given the financial difficulties the family had experienced during those years she added that to have had that financial support, 'would have been great, but we didn't know about it.' A care-receiver spoke about the process of weighing up the advantages and disadvantages to entering the workforce, part of which concerned their financial wellbeing: 'At the start when I got the job I said, will this affect me down way instead of gain way?' Another interviewee commented on the value of help from an independent agency who 'can give you advice on citizen - on your welfare rights and what have you, and anything you need they would put you on the right track.'

Third and finally, a number of the interviewees spoke about the place of appropriate physical infrastructure. 'Just because you have a disability', one wheelchair user said, 'some people maybe say, ach well, they can't get in there because of the steps, or [they can] go in this other way, but why should you, you know? If everyone else is going through the front door, some way or other you should be able to. They don't expect, like, for example, a restaurant doesn't ask

its people that's going to it to pass bins and through the kitchen and through that way so why should a disabled person have to do that, you know, go through that way?' The situation of one wheelchair user who had campaigned successfully to reduce footpaths in their area to a height accessible by a wheelchair can be compared to another interviewee who spoke about being unable to take a wheelchair user into their locality because of the unevenness and height of the footpaths, severely restricting their mobility. The vital importance of transport also was raised, 'because at the end of the day you could have everywhere accessible, like [the town] could be the most accessible city going, but down here, if I couldn't get transport into [it], what good would that be? And I suppose there's a whole lot of other people similar. So, to me, the Discrimination Act, it is important, but the transport ... people never seem to realise how important that part is 'cos if you have no transport you can't get anywhere and that's it.'

Such physical features and infrastructure, along with the use of various equipment and technology,²⁵ enable inclusion and greater participation in society for everyone involved in care relationships but do so particularly for those in need of assistance. In the words of one interviewee, it is about 'a way to participate much more fully in a world that is out there. It's dreadful that, you know, - it's terrible that things have to be put into legislation before it gets to the point where you have a ramp, you have a lift. It was never was alright that unless you could walk you couldn't get up stairs in the cinema or wherever, that never was good.'

Having care as part of political space requires us to address our understanding of and attitude to disability, and of the vulnerability of the human condition. As one care-recipient put it, 'it goes down to very simple terms what equality is, and it's an awful lot about attitude, you know, the attitudes of people ... attitude's a big thing, it's one of the biggest things of all.' He described how in the training role of his job people would bypass him and direct questions to his colleague: '[she] hasn't got a disability and it was amazing how people were asking her the questions and, you know, it was actually my job and she had a few times say, well this is [his] responsibility, and it was all about attitudes.' This speaks of the need for what one interviewee described as a shift to a 'significant

intelligence about disability' among society that 'disability isn't an abnormality, there isn't a deviation here, that ... it's normal to be disabled, that there's nothing, you know, there's nothing strange about it. Now that's asking a lot of people.' Speaking in an upstairs room overlooking a public area, she went on, 'It's not that "oh yes, we welcome the disabled" or "we have disabled facilities", that's not it. [It's about] if we have open access up here [*points to her head*] as well as down there [*points to street*].' Such open access in the way we think, behave and organise would mean society 'tuning in to the person [with the disability] rather than the person having to do all the tuning in.' The end result of this would be that 'you're not diminished by your disability, I think that's what needs to happen, that you're not diminished by your disability. Be diminished by your behaviour, be diminished by your attitudes, be diminished by things you have a choice over and if you let yourself down, yes. You lose respect, it's yours to lose, but if you can, as I say, take that diminishing out of disability.'

In taking the diminishing out of disability, we also take the low status away from care-giving. For our understanding of and the value we place on care-givers is bound up with our understanding of and the value we place on those in need of care and assistance, and both rest on a proper assessment of human vulnerability and interdependence.

Conclusion

So often, as the ethics of care discourse highlights, advocacy for the needs and perspectives of care-givers and for those who are in need of some form of care and assistance appear to sit together incongruously. Indeed, even in the writing of this paper, I am aware of the tension, for example, of in one place writing about the exploitative elements of care for women, and indeed potentially for all who provide care in a society that has feminised care in a gendered social order, and in another place speaking about the invisibility of care-receivers in so much thinking about care. While it is not acceptable to ignore the views and choices of care-receivers, nor is it right to deny the amount of care provided on an informal basis and the associated costs to the care-givers. It is vital, however,

that the approach taken to address care situations is not one in which greater equality and social inclusion for either care-giver or -receiver results in less equality and social inclusion for the other. Rather, it should be the case that greater equality for care-givers and care-receivers in relation to those who currently do not have care responsibilities or need of care and assistance would assist the equality within care relationships. If needing care and assistance was accepted as part of the human condition, albeit in varying ways at varying stages in life – some fairly predictable and some much less so – the concept, practice and/or experience of care would not have to compete to be included as part of normal life. Rather the focus could be on how best to accommodate this facet of human existence in society or, put another way, how best society can ‘tune in’ to the realities of care.

¹ This paper concentrates on the ethics of care in regard to the care of adults. For issues around parental care of children researched by the project, see McAuley, 2005.

² The PSENI was directed by Paddy Hillyard, Eithne McLaughlin and Mike Tomlinson. Thanks to OFMDFM and the directors for permission to use the data set prior to its public archiving.

³ The interviews took place between March and August 2005. Interviews were taped and then transcribed. In one case, the recording equipment failed at the beginning of the interview so I took notes and wrote them up immediately after the interview.

⁴ The initial objective of the study was to explore the lived realities of care for all those involved in the care relationship - the care recipient, primary carer, and a secondary carer. The intention was to explore situations of spousal care, of non-spousal family care, and of institutional care. In the end, despite initial favourable indications, I was not able to negotiate access to residents within care institutions. It was also difficult to find situations where both care-givers and care-receiver could agree to talk to me. In one instance, the health of a care-receiver who was very keen to talk to me, along with their carer, prevented the receiver from taking part in the research given the timeframe within which I was working. One avenue of contact that I pursued that offered the possibility of interviewing all those involved in several care situations was not productive due to unforeseen circumstances of the particular contact. In the end, as already stated, there were three cases where both care-receiver and care-giver were interviewed and I concentrated on ensuring I had interviews with both care-receivers and care-givers regardless of whether they were in the same care

relationship or not. On reflection, given the relatively small numbers of interviewees and the small-scale geographical area in which the research was carried out with the associated issues of anonymity outlined below, exploring all the relationships in a care situation was an ambitious initial objective.

⁵ I am grateful for the co-operation of the following independent agencies: Disability Action; Newry and Mourne Carers Centre; Newry and Mourne Senior Citizens Consortium; NHS Retirement Fellowship; Phab NI; Out and About, Armagh.

⁶ Each person interviewed was sent a copy of an earlier draft of this paper for their information and comments.

⁷ I created a new variable for informal carers based on two questions in the PSENI survey: (i) *dep* Do you provide help or assistance to an adult (e.g. friend, neighbour, relative) who requires special help with the activities of daily living?; (ii) *paid* Do you get paid for this work? The 38 respondents who got paid for the care work they provided were excluded from the total of 453 of those who responded 'yes' to the first variable (either 'Yes, another person in the household' and 'Yes, a person in another household'), giving a total of informal care-givers of 415.

⁸ Hilary Graham argues that it was this context (the critique of government community care policies) that concentrated the feminist response in Britain to a narrow focus on informal care rather than dealing with 'the broader swathe of caring relationships and activities that keep individuals, communities, and society going' (1993: 462) and which are discussed below.

⁹ The question wording and sampling bases between the surveys differ so the data does not constitute a time series. The data does demonstrate, however, that higher proportions of women than men undertake informal care activity. Source for CHS 1985 is McLaughlin (1993). I include data from WWLS here even though the survey only deals with female carers in order to indicate the consistency of high levels of caring by women.

¹⁰ Her research review focused on the care of the elderly, of children with disabilities and of adults of working age with disabilities or chronic/serious illness and excluded the care of non-elderly adults with mental illnesses (Parker, 1990: 12-13).

¹¹ Referring to data from the 1990 Northern Ireland WWLS Eithne McLaughlin states: 'Although these associations between caring and increases in part-time employment rates and lowered employment rates are reasonably clear from the data, direct causality cannot be inferred. It may be that it is women whose labour market attachment is already weak who find themselves "selected", or are self-selected, from within the family circle to fulfil the role of carer' (1993: 181).

¹² Includes those who are both employed and unemployed.

¹³ To say that care is demanding is to recognise that care-giving requires mental, physical and emotional resources. I distinguish this from the notion of burden, which can imply that the care-receivers are themselves burdensome. Only three interviewees used the term burden: one person in need of care and assistance of herself, expressing her wish that she did not become a burden to her children; one care-giver with reference to the financial concerns that some carers, not herself, experience; and one care-giver in regard to the weight of emotional responsibility that carers can feel.

¹⁴ In describing women's care of others as 'active participation', Jean Baker Miller is challenging the masculinist view which does not see women's care of others as activity precisely because it involves others and is not in pursuit of their own goals (1991: 54).

¹⁵ Carol Gilligan spoke of 'two views of morality which are complementary rather than sequential or opposed' (1993: 33).

¹⁶ A debate that not only looks at the relationships of these concepts but considers how each concept is reconceived in the light of the others. For example, Jean Keller (1997) argues that care ethics' relational model of moral agency provides the basis for criticising the philosophical tradition's model of autonomy and for rethinking autonomy in relational terms.

¹⁷ In similar vein, in reviewing research data on stress levels for carers, Gillian Parker (1990) notes that one of the difficulties of measuring stress is that the experience of stress may be socially or culturally mediated to some extent - depending on social expectation about what carers do and who should care. Hence, if caring is seen as less appropriate for a man than a woman, then it may be perceived as more stressful for men than women to do certain tasks. This may be a perspective taken by carers themselves and by service providers with accompanying ramifications.

¹⁸ The term 'Black' is a politically collective term. Evelyn Nakano Glenn (1992) uses the terms 'women of color' and 'racial-ethnic women' to refer collectively to African, Japanese and Mexican American women

¹⁹ This includes those who answered that their main health problem affected them in this area either 'quite a lot' or 'very much' and excludes those who responded 'varies' or 'not at all'.

²⁰ She also states that, against a background of discriminatory professional attitudes in which the ability of disabled people to be fit parents is questioned, disabled parents can be reluctant to ask for assistance for fear of having their children taken away.

²¹ For example, why depending on help for getting dressed and making meals should be different to depending on local services for clean water on tap rather than each household collecting and purifying rain water, or to buying vegetables in shops rather than people growing their own.

²² Susan Wendell comments that if we acknowledged ‘the realities of our interdependence and the value of depending on others and being depended upon’ we might improve the status of children and/or reduce the fear and shame associated with dependency in old age (1996: 151).

²³ Partial privilege operates alongside exclusion to maintain the position of the most powerful in society. Those with partial privilege – for example, women who benefit from the advantages of their education, economic condition, skin colour, religion, and/or sexual orientation – come closer to the centers of power. ‘Because the boundary lines between the center and periphery are not clearly drawn, they can be continually obscured and admit some to partial privilege’ (1993:16).

²⁴ She applies this in particular to the matter of child custody and to Dutch health care policies.

²⁵ A number of interviewees spoke about making use of mobility and other equipment aids, information technology including voice recognition software for computers, and having modifications to housing.

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