

Clare Stevenson Memorial Lecture, 2007

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- Thank you for your kind introduction, and for inviting me here today to give the Clare Stevenson Memorial Lecture. I'd especially like to especially thank Laraine Toms, as well as Elena Katrakis and others who have organised the invitation for me today and worked behind the scenes to make it happen. It is a great honour to be invited and to have the opportunity of talking with and to you today.
- *[Recognition of Country]:* I like to start by acknowledging the traditional owners of this land, the Gadigal people of the Eora nation, and their ongoing custodianship of the land.
- *[Clare Stevenson and my life.]* It is a particular honour to be invited today because I knew Claire Stevenson and was inspired by her in many ways when I first started as a fledgling researcher and activist in the field of ageing and care. I first learnt of Clare through her research in 1976, when I was working in my first job as a research assistant for the AAP (Australian Assistance Plan) – looking at services for 'the aged' in SW Sydney. Her research report *Dedication*, was published by the NSW Council on the Ageing that year, and it was profoundly disturbing, and so completely different to anything else I had read on the subject of aged care in Australia at that time. It was so personal and heart wrenching, it made a lasting impression on me, as I suspect it did on all who have read it.

When I first read that report I was impressed not just by the material, the data and conclusion it contained, but by the way it was organised and presented. Here was a researcher and social advocate who listened to people, who encouraged them to write their thoughts, their experiences, their dreams and nightmares down so that others could understand their daily lives and those for they cared – the report was made up largely of personal written accounts of family members who looked after those who were ageing. The methodology was not one I had learned about at the university, and it was simple, effective and impressive. This was also a pioneering piece of research, one that is locally well known and regarded, although I believe it has not, yet, received the international attention and recognition it deserves. Its publication in 1976 pre-dates the establishment of the Carers Movement in the UK by at least two years, and should rank, I believe, as one of the prophetic and foundational studies in a the field of caregiver studies. It certainly laid the foundations for Carers NSW, the first such body in Australia. When a definitive history of the Carers Movement is written, the place of Clare's report, and of the Carers Group set up as part of COTA in the next years, must surely be honoured as world leading.

Later, in the early 1980s, after I returned from three years working in and studying a nursing home in the Netherlands, I found myself on a committee with Clare, and discovered we were, in some ways at least, kindred souls. Clare

knew all about meeting procedure and about framing effective campaigns, and was always a great contributor to the meetings. Getting to know here was truly a privilege and a joy, one that has continued to inspire me to this day.

- *[Inspiration of carers – personal and policy/professional.]* Of course nobody can exist without care. We all have experienced it as child and a very large proportion of all people go on to be providers as well as recipients of care as well. I think I was fortunate, too, in being brought up in family in which care was central, and shared, not through the sacrifice of the life of the carer, as so often happens, but through the fact that my mother was what later came to be called a working woman. My mother was a musician ... Grandparents, maiden aunt, family members, later mother, father... each gave care and each in turn received it.
- In retrospect, it is not perhaps so surprising that I came to do much of my research work around the issue of care – especially aged and community care. For many of the intervening years since I first met Clare Stevenson, I worked as a researcher at the SPRC, studying community care, documenting the work of family carers as well as the operation and performance of services, working to deadlines to finish each project, to obtain funds for the next projects, trying to ensure that we had sufficient funds to keep the research team together. When I accepted an appointment at Macquarie University, as a lecturer, I thought it was time to once again try and write my book. This is not an easy thing for any Australian academic in this field, as Australian publishers don't seem to think that anyone could be interested in topics like community care in Australia. As I looked outside Australia, I discovered that they were even less interested in community care in Australia sought, so I sought to go beyond immediate studies to consider the ideas, philosophy, theories of care, as well as to explore the research literature on different models and approaches to the provision of formal services. In the end, though, there was so much to say about care, so much written that in twenty years I had never known had existed, that it had to become the key focus of the book.

The key argument in my book is that care no longer fits into contemporary society the way it used to. We have been searching for ways of reconciling the competing demands of modern life, with the need for care. Modern life seems to offer almost endless possibilities and vast menus of choice for some, but denies them to so many others. It is this dilemma, I believe, that has led to the creation of the carers movement, first in English speaking countries such as the UK and Australia, but increasingly this is a worldwide phenomenon. Having had a chance to read widely and think deeply over some of the most thoughtful and profound writings I have encountered as an academic, I'd like to now outline first what I think care involves. I'd then like to move on to address the questions that arise from the rise of the carers movement, focussing my discussion on some of the most significant achievements of the first twenty-five to thirty years. Then a number of the challenges that I believe need to be confronted if we are to move beyond the identification of carers as victims and to set an agenda for the twenty-first century.

What is Care?

The essential element of social life.

Three main components.

1. **Disposition** - thought for the wellbeing of others.
2. **Activity** - purposeful activity
 - physical, bodily work undertaken to assist another;
 - Requires capability/competence - knowledge, skill and conscious attention.
3. **Social relationship** - an intimate/personal relationship; professional/occupational; social concern/social capital.

Key elements include gender, identity, responsibility, commitment over time.

A Successful Social Movement

There can be no doubt that, internationally, the carers movement is more than a traditional interest group, an organisation formed with the intention of advocating benefits from government for its members. It is, I contend, a successful social movement.

When we speak of social movements in sociology, we refer to more ambitious, larger scale undertakings that extend beyond the membership of single organisations. Instead of a handful of members, a social movement encompasses a diverse, amorphous population that participates in a range of different sorts of activities, many of which may not even be recognised by the individuals concerned as involving membership of an organisation. Many may be equally unaware that the activities and way of life involved has any formal organisation behind it. We think of such movements as feminism and the environment movement as social movements, because of the massive cultural, social, political and even economic impact that they have sought through their activities, and to an extent have achieved. Yet there is no single organisation to which all feminists or environmentalists belong. Although there is a common core of beliefs, there is no single doctrine to which all members adhere, either. Instead, social movements aim at achieving broad social change, and legislative changes, acts of government, as a long-term goal. In the meantime, a key to social movements is the immediate change of the behaviour of participants, or perhaps better said, that members enact or embody as they become the change they seek to implement. That is, the most immediate impact of social movements is the change they bring about in the identity and behaviour of their adherents.

Feminism, for example, is not simply about achieving legislative changes such as equal opportunities, even though these sorts of reforms are important. Feminism is also about the identity of women have not just the right but seizing the opportunity to live a life in which individual women are not subordinate to men, but are their equal, some might even think, better. Similarly, environmentalists are known not simply for their

advocacy of broad changes in policy that favour the environment, but through their search to live their own lives in ways that are in harmony with the earth.

Carers, too, have advocated, and achieved policy concessions and services from government, but to try to understand carers organisations, or better still, the carers movement as being concerned solely with winning political concessions would, I believe, be to seriously misunderstand carers. Instead, there is a core personal identity based around caregiving, a search for recognition of what caring involves. And there is a sense of dedication, to use Clare Stevenson's term, to the enactment and embodiment of care, to living a life that involves being a caring person who takes her (or his) responsibilities seriously and who is dedicated to the intimate acts of caring for another as an essential part of their being.

Now there are, of course, a great number of significant achievements of the carers movement. Each on their own is significant, if not enough. But put them together and it's possible to see just how much has been achieved in what is only a short historical time.

Some of the most significant achievements include:

The creation of *organisations for members* – now in each State, as well as at the National level in Australia, and also in a great many localities – through self help and various carer groups, educational programs, and so on.

Significant *impact on government policies* – in Australia this has been achieved under both Labor and Coalition governments. The outcomes include *Benefits* – Carer Pension; allowances, bonuses; as well as *Services* of various kinds for those in need of care that take as a key part of their mission, in words if not always in deeds, the provision of support in ways that assist and support carers.

An impressive and truly extensive body of *research* – produced both directly by Carers organisations, and that produced by academics and other researchers that has been inspired by, or addresses, the concerns and situations of carers.

And increasingly, *a new generation of services aimed directly at carers*, not just the recipients of care – for whom it might be, and is, argued, that there is a rightful claim to direct support in their own regard.

But the achievements go well beyond relatively tangible outcomes – complex and difficult as policy change has been. The achievements go to what we might call the heart of a social movement – the achievement of cultural change. Foremost amongst these has been the recognition not just of carers, but of the existence of and plight of primary carers. Similarly the claim of the very term 'carer' is itself a huge achievement. It's important to recognise just how recent this term is. When Clare published her report *Dedication*, the term carer was not in common use. Instead, the first use of the term is recorded by the OED as being in 1978!

Imitation is, of course, the greatest form of flattery— and now the term carers, itself a major contribution to the English language, has widely copied and used for range of occupations – including paid staff, parents guardians or carers, and even animal handlers. And in a real sense, I believe, they are right to call themselves carers – because they too, like primary carers operating within a bond of family, marriage or intimate friendship, give care and have as this as a key element of their own personal, and occupational, identity.

A significant feature of the work of the carers movement has been portrayal of care as involving a series of continuing deficits: Care as a burden. Think, for example, of the recent findings of the Deakin study of Carers in the *Carer Health and Wellbeing Study* by the Australian Centre on Quality of Life, Deakin University, with Australian Unity and Carers Australia (Cummins, Hughes, et al., 2007). Think too of the study of carer numbers in undertaken by NATSEM, in which decreasing numbers of carers are projected from 2001-2031 (Percival and Kelly, 2004).

So it is clear that despite the daily experience of shortfalls in policy, and ongoing limitations and frustrations in achieving policy changes, the carers movement has been very successful. But isn't its task fundamentally different to that the other social movements I identified? Weren't there some who felt at least a little uncomfortable with my classification of carers as somehow aligned with radical change agents such as feminists and environmentalists? Feminism did not seek to maintain the existing status quo of patriarchy, of the subordination of women to men in society. It sought, essentially, to overthrow that. Similarly, the environment movement has sought to change the basis of our interaction with the environment. While there is often an almost nostalgic, conservative tendency amongst some conservationists to return the world to some sort of earlier, more idyllic period of harmony between man and the environment, it is clear that the task of conservationists and environmentalists is not seen as a conservative, status quo preserving one, but one involving a fundamental, even radical redirection of social energies and direction. Carers, on the other hand, are often seen in more traditional terms, as following a more conventional sense of duty and moral commitment to provide care to someone they love or someone for whom they feel responsible. But I want to argue that there is a strong link between the potential of the different social movements – and not just because environmentalists care for the forests and the air in the same way that carers care for other people. The links between the carers movement and feminism are more readily discernible, and continue to provide a deep, if hidden underpinning. While few carers would set their sights on radically changing the world, I believe carers are seeking a very different sort of social contract. In the final section of this talk, I want to return to address a question that arises as a response to my argument that care no longer fits into modern life the way that it has in the past. How can care be made central to modern life?

Challenges

I argue in my book that the long established forms of care –heavily reliant on the family at home, usually meaning unpaid work by women who forgo careers outside the family– came unstuck in the wake of feminism on one hand, and the rise of the welfare state, on the other. They did not disappear, but as women sought a life of their own outside the home in the final decades of the twentieth century, care went public too and increasingly became a matter of public interest and public responsibility.

The Ethics of Care

One of the most important and interesting traditions in the care literature concerns the ‘ethics of care’, a morality that some feminists, following the work of Carol Gilligan, say underlies care and which, they argue, needs to be brought into the public arena and made a public ethic, too. An ethic of care involves seeing responsibility for the wellbeing of others as a keystone of our behaviour. This is an approach that its proponents believe is until now most strongly associated with the feminine and the private world of the home – but which must become a key ethical principle, like that of justice or fairness, in the public realm as well.

The approach first developed in the USA in the 1980s, but as it crossed the Atlantic and began to be taken seriously by researchers and activists there, it became formulated increasingly as a political ethic of care, as a claim for a set of rights concerning care. These are surprisingly simple and elegant to state:

- the right and the opportunity to *give care*
- the right to *receive care*
- the right to *care for one’s self*

(Williams, 2001; Knijn, 1997; Sevenhuijsen, 1998; Morris, 2001)

Note that each of these is important. Care can not simply be about giving, important as this is, nor about receiving. Nor can care be solely directed towards others. What is required, instead, is to see care as creating a balance, in which we are not alone, but nor do we cease being an individual with right to nurturing of our own possibilities.

Paid Care

A second and very fundamental issue, itself implied in the idea of a political ethic of care, is the importance of acknowledging paid and formal care providers and especially care workers of the various kinds and levels. The term carer has been claimed for unpaid caregivers in a way that emphasises their dedication and personal, unpaid commitment. Informal care has also been showcased as an ideal model of care – one to which professional caregivers now increasingly also strive. Yet partly because of this advocacy, and perhaps partly through the conservative idealisation of the family, there remains a gulf between advocacy for unpaid carers and that for paid and professional care staff. This belies their commonality and complementarity. Unpaid and informal care does not replace paid and professional formal care, but complements and extends it. Given the working conditions, pay and existing and potential shortages of care workers, for the carers movement to strike common cause helping to support and develop services, professional opportunities and standards of care must be seen as a logical extension of the carers movement.

Let me finish on a note of hope with a quote from the final passage of my book.

As Guy Standing, from the ILO (International Labour Organisation) points out, the twentieth century was the first in human history in which the performance of work, as employment, was elevated to a social right (Standing, 2002: 17). Work was, of course,

important before that time, but the idea that citizens would be seen as having a right to work or to financial support if that was not achievable, would have seemed peculiar to most social observers in the nineteenth century. The challenges of care in the twenty-first century present the prospect of building on the nested dependencies that human vulnerability represents. Demographic, political and economic developments make the search for different sources of care and the development of new social solidarities imperative. The challenge to those who seek to see a more caring society in future, is to work towards the realization of this ideal, not through personal sacrifice, but through the promotion of care as a foundational principle of citizenship and social solidarity (Fine, 2007: 225)