GCPH Seminar Series 11
Seminar 3
23.1.15
Summary Paper

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The Economics of Dignity

Summary

In this talk, Prof Waring discusses what she calls the economics of dignity. She looks at definitions and questions of dignity particularly in regard to caregivers. She then outlines work she and colleagues undertook for the Commonwealth Secretariat on carers of people with HIV and Aids and on social protection. In this work they moved from traditional economic approaches (of using time-use-surveys, quantifying these and then giving this a market value) to the development of a human rights approach to their research based on the Noble Prize economist Amartya Sen’s capability approach. Finally, Prof Waring discusses what this might mean in the Scottish context focusing particularly on young carers and questions around children’s agency, the extent to which they have control over their own lives and destinies.

Defining dignity

Prof Waring began by explaining that the ‘Economics of dignity’[*] is the title of a book that she and three colleagues worked on for the Commonwealth Secretariat. More recently she has been reflecting further on the concept of dignity because of her personal experience of caring for her father for the last fourteen months of his life. During this time he told Marilyn that he had lost both his sanity and his dignity.

‘Dignity’ is an interesting word. It is the most fundamental of human rights as set out in Article 1 of the UN Declaration*: “All human beings are born free and equal in dignity and rights”*. Marilyn’s father knew exactly what he meant when he said he had lost his dignity. She told us of a time when she insisted that her dad be fed but that the response from professionals was that they did not want to undermine his independence. Marilyn’s reply was that her dad wanted his dignity not his independence. As Baroness Hale of Richmond put it in the Alex Comfort lecture in 2008: *“I do think that the human rights values of dignity, respect for individuals’ privacy and non-discrimination have so much to offer in the care of older people. They should inform everything that policy-makers, regulators, providers and carers try to do, difficult though this often is.”*

Dignity is a concept that is hard to put in a nice neat box with a rigid meaning as it applies to our individual lives and all their riot of difference. However, Prof Waring suggested that we all know a loss of dignity when we see it either in an individual or in a community. The concept also needs sometimes to be tied down as we apply it in policy directed towards strategic practical outcomes. We have to move dignity from a concept to a process to a practice to an outcome. To support us in our thinking around this concept Prof Waring outlined two important legal cases which involved dignity and have affected the political momentum for change.

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[*] Waring M, Carr R, Mukherjee A, Shivdas M. Who cares?: The economics of dignity. London: Commonwealth Secretariat, 2011.

The first case centred on gay marriage and a statement from the Court of Appeal in Ontario in 2003: *"The case is ultimately about the recognition and protection of human dignity and equality in the context of the social structures available to conjugal couples in Canada. Human dignity means that an individual or group feels self respect or self worth. It is concerned with physical and psychological integrity and empowerment. Human dignity is harmed by unfair treatment premised on personal trades or circumstances which do not relate to individual needs, capabilities or merits. It is enhanced by laws which are sensitive to the needs, capabilities and merits of different individuals, taking into account the context underlying their differences. Human dignity is harmed when individuals and groups are marginalised, ignored or devalued and it is enhanced when laws recognise the full place of all individuals and groups within Canadian society."*

The second case took place in British Columbia and involved Cheryl Hutchinson, a woman born with cerebral palsy, and her father Phillip Hutchinson, who had been her primary caregiver since she was 13 years old. This case was a major breakthrough in human rights issues in the field of caring and was very instructive as to the part played by loss of dignity in such cases. The tribunal concluded that both Hutchinson's had had their dignity violated by the blanket policy against hiring family members.

Research for the Commonwealth Secretariat

The health sector is a major expenditure for any government. In more advanced economies since the global financial crash the economic imperative has seemed to be for health institutions to develop more efficiencies and effectiveness. One of the chief manifestations of this approach has been to discharge patients earlier from public care facilities. In many countries where HIV and Aids are of epidemic proportions and hospitals cannot cope they just send people home.

In making these kind of policy choices, whether in the west or in developing countries, there is a presumption that at home there is a reserve army of unpaid labour available to immediately resume responsibility for the discharged patient. Alongside this there is increasing pressure for the provision of evermore sophisticated and expensive secondary and tertiary facilities at a time when studies in health economics demonstrate that the best investments in healthcare are those associated with prevention and early detection and treatment. There is growing evidence of the economic costs in respect of the invisibility of the unpaid work in the household. Insufficient or inadequate care at the onset of illness in the home can also exacerbate its severity with costs incurred across all sectors.

So when Prof Waring and her colleagues started their research for the Commonwealth Secretariat on 24/7 caregivers for people with HIV and Aids, they thought they would be looking at the value of all the unpaid work of the carers. However, after an extensive literature review, they realised that the challenges were so complex and diverse from country to country, and almost household to household, that to attempt to do a time use survey and then try and quantify what that was worth and give it a market value was going to be an academic exercise. Instead, they decided that the research focus in the field would be most usefully situated in a rights-based framework, focused on the dignity of the carer, using a capability approach. It highlighted different impacts on carers by age, by cultural expectations, by religion, by sexual orientation, by gender with most of this overlaid by stigma.

The capability approach was developed by Amartya Sen. It moves beyond the old Aristotelian notion of equality, that all people are born equal, which of course they are not. Capability is about what needs to be put in place for each person to be able to fulfil their humanness in terms of all their human rights, dignity being one of those. The research team didn't think these questions had ever been asked of people who are unpaid carers for someone. Prof Waring described how they used various human rights-based covenants to construct relevant human rights capability questions such as: 'Did you have any choice about becoming the primary caregiver?' (the right to choose); 'Does anyone ever come to give you some rest?' (all human beings are entitled to leisure rest and recreation).

One of the very clear findings was that few carers had human rights. They had no choice at all. They had no time to enjoy their capabilities. The capabilities approach does not assume that everyone is equal and has the same chance. We understand that something has intervened to make it impossible for carers to enjoy the same rights. What the approach says is 'what do we have to do?', 'what has to be changed in this environment so that you can be free to enjoy those rights?'

A second piece of research for the Commonwealth Secretariat took the learning from the HIV and Aids work and looked at social protection. Two schemes they looked at focused on child carers in Swaziland and Kenya. In Swaziland a key project has been to ensure the inheritance rights of children are safeguarded and recognised including land titles and the allocation of land. In Kenya there has been huge disinheritance and asset stripping facilitated by the HIV and Aids pandemic. One women's NGO called GROOTS has addressed this by recruiting and training women in everything to do with land inheritance. When someone becomes terminally ill they go to the village and provide all the information needed. This is a form of anticipatory social protection. There is no need for social protection to be reactionary and responsive all the time; it ought to be far more anticipatory.

Children's agency

In the cases in Swaziland and Kenya, and in other exploratory research in western Kenya, one thing that has been highlighted is that these children manage to mobilise social support. Given the land they engage in income-generating activities. They also move beyond gender stereotypes and we see young boys caring, young women generating income – the work just has to be done. They construct positive identities for themselves in their households despite the tremendous adversity. And a key piece of learning from this research is that it turns out that these things are best mobilised when the children are given agency in their own lives.

So what might the equivalent be in the west? How might we implement this same kind of understanding of the power of agency? The UK's census in 2001 was the first to include a question on health, disability and the provision of care. It showed more than a million people working more than 50 hours a week in unpaid care for family members, friends, neighbours and others because of long-term physical or mental ill health or disability or problems relating to old age. In the UK more than 175,000 children under 18 were acting as carers including 13,000 providing more than 50 hours of care a week. In Scotland 9.5% of the population provided unpaid care. In 2010 a BBC survey of 4,000 secondary school students found an invisible army of 8% working in their households as carers. This is considerably higher than the census figures. Most academics will tell you that the dual stigma of admitting some disabilities and of admitting that children are caregivers means that there is always going to be under-representation in the census figures. The 2007/8 Scottish Household Survey showed 657,000 unpaid adult carers and 100,000 unpaid young carers, much higher than the UK's 2001 UK Census.

Prof Waring is aware of the Children and Young people Act 2014 passed in the Scottish Parliament. She has also been following the various documents and policy changes related to young carers. Compared with elsewhere this is a leading central government effort to put children and young people at the heart of planning and to try and deliver more than just words on a page. So she was interested in the reflections of the Young Carers Project in Stirling where the young carers appear to have the same capabilities issues that they found in developing countries: a lack of transport; a lack of information; a lack of services; few if any shops with fresh produce to enable healthy eating; long school journeys; few or no leisure activities.

Conclusion

Prof Waring ended by describing a number of issues emerging from this new legislation and policy around children and young people and carers which she is interested in. What will the new carers assessments look like? Will they be based on the old clinical approach or might a capability assessment based on human rights be a basic ingredient? She is also particularly interested in the new regulations which set out the circumstances where a supported person can employ a close relative as a personal assistant. At the moment the rules do not seem to pass the 'Hutchinson test'.

Finally, what happens to child carers who effectively qualify for support? At what point in their caring roles are children going to be given the agency to be paid as caregivers? Also every child is going to have a 'named person'. So when we come to assess the impact of dignity on the child carer whose point of view is it going to be? Is it going to be the child's view of the indignity or is the named person going to assume they can speak for the dignity of the child carer? The policy says that carers need to be more involved in decisions about the planning and provision of cared for persons and about support for themselves. Will the child carers be listened to and given agency? Whose dignity counts here?

Prof Waring concluded by saying that she thinks there are some interesting tests ahead for Scotland's new policy. She will look forward to following their development and would be interested to hear any stories about their implementation.