V. INVITED ARTICLE IV

Statutory and Informal Care Partnership Policies: a United Kingdom Perspective

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Introduction

In the U.K., the 1990 National Health Service and Community Care Act (NHS and CC Act) (DH 1990) was the first major legislation to acknowledge the importance of a partnership between State and individuals in assessing and responding to the need for care in the community, most of whom are older people. Local Authorities (LAs) had a duty to consult with the older person and their family in order to set up costed "care packages" of social service provisions which enabled older people to remain in their home for as long as possible. The most recent social care reform legislation allows for direct payments to individuals who have been assessed as needing services, in lieu of social service provisions. The aim of a direct payment is to give more flexibility in how services are provided. By giving individuals money in lieu of social care services, people have greater choice and control over their lives, and are able to make their own decisions about how their care is delivered. This article examines the development of the policy decisions in the U.K. which have altered the emphasis from State-led to person-led response to care needs, and speculates on how successful this shift has been in the 21st century.

The balance of responsibility between the State and the family in caring for vulnerable persons, regardless of age, depends upon the welfare policy ideologies of the Nation State and its incumbent government. The principal drivers of welfare policy decisions are reflected in the political weighting attached to concepts such as citizen rights and responsibilities, equality and equity, independence and choice, control and flexibility, and to what extent benefits can be afforded and sustained within that society. The recent global recession has challenged the budgetary and fiscal policies of all Welfare States.

Welfare State ideologies

Esping-Andersen⁴³ described three main types of welfare régimes within capitalist economies: corporatist régimes which are work-oriented and based on individual contribution; social democratic régimes which favour universalist values and liberal régimes which tend to be residualist. The U.K. can be described as having a foot in the last two camps: some welfare is provided to all citizens as a right, whilst other provision is needs-based (assessed) and means-tested. A prime example of this dichotomy is the historical division between health and social care. Health provision by NHS is funded from general taxation and free at the point of delivery for all citizens. Social care on the other hand is the responsibility of social services within LAs, and largely dependent upon local taxation and provision is rationed. When "care" is discussed in this article, it refers to "social" care and not "health" care, since the latter is universally available and although there are current debates as to the quality of health delivery in the U.K., these are not at issue here. Nevertheless, it is the most vulnerable people in society who blur the boundaries between health and social services. For the purposes of this article I will be referring to vulnerable adults who have physical or mental disabilities, the vast majority of whom are elderly and cared for by family and relatives.

As in most Christian-based societies, the concept of family care is predicated on the organising principle of "subsidiarity":

It is a fundamental principle of social philosophy, fixed and unchangeable, that one should not withdraw from individuals and commit to the community what they can accomplish by their own

Esping-Andersen (1990).

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enterprise and industry. So, too, it is an injustice and at the same time a grave evil and a disturbance of right order, to transfer to the larger and higher collectivity functions which can be performed and provided for by lesser and subordinate bodies. In as much as every social activity should, by its very nature, prove a help to members of the body social, it should never destroy or absorb them. Quadragesimo Anno: Para 79, 1931 (de Torre, 1997))

There is therefore an expectation that families will provide the major share of caring for their vulnerable members in their own home, whether non-resident or co-resident, and only call on the statutory bodies when they encounter serious difficulties and/or are no longer able to look after their relative(s). Figure 1 offers a simplistic model of the ideal share of responsibility for caring within the community.

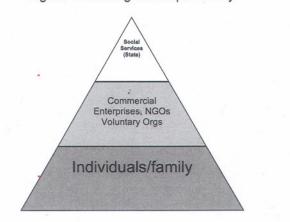


Figure 1. Sharing the responsibility

The apex of the triangle represents the minimal (and diminishing) formal State provision for vulnerable elderly people and includes LA residential care homes and sheltered accommodation (assisted living) and some domiciliary care. In the middle, an increasing proportion of non-family support, such as domiciliary care has been "outsourced" through competitive tender to commercial enterprises—the need for these services are assessed by Social Services and means tested. Private (for profit) and not-for-profit organisations (such as NGOs) have undertaken a greater involvement in residential provision and domiciliary care and again, payment depends on the capital and income of the person in need. Included in the middle section are those organisations whose voluntary members carry out a vast amount of unpaid work, aid and support for vulnerable people in the community. Often, the organisations get grants and funding from local authorities and parish councils, but the majority of the funding is from donations and they depend on the goodwill of the volunteers. Interestingly, the majority of these are retirees themselves, wanting to "give something back to the community" and of course, tend to have the time to do so.

The base of the triangle represents by far the largest contribution to caring for vulnerable adults from neighbours, relatives and family, and the informal care of people over the age of 65 is estimated to save in excess of £60 billion per annum to U.K. taxpayers.⁴⁴

Care in the community

During the neo-liberalist Conservative government of the U.K. in the 1980s, there was an increasing awareness that this "reserve army" of carers should and must be acknowledged and consulted if they are to be retained to continue their cost-saving (to the state/tax payer) labour. Originally, Care in the Community directives were central to Mental Health policy as the numbers of inpatient beds in psychiatric institutions declined dramatically from the 1970s, principally because of the development of effective psychotropic drugs. There was a need to support and monitor ex-patients, not only for regular and appropriate medication use but for their accommodation, safety and well-being. In the 1980s and 1990s, the remit took in all vulnerable people in the community including people with disabilities and older people. The problem was that-people with disabilities, many of whom were also old, had complex

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health **and** social care needs, but the NHS (centralised) and Social Services (localised) did not communicate with each other. Hitherto, the "top-down" approach from health and social services professional meant very little input was considered or encouraged from the older person and their family, especially for example on discharge from hospital once the medical condition had been treated or ameliorated. The NHS and CC Act (1990) attempted to address this dilemma and set up communication channels between these two welfare giants. The enormity of this total paradigm shift is reflected by the fact that the Community Care component of this vast legislation was enacted three years after the NHS element, in April 1993. Nevertheless there was a firm commitment to personalising services and to consult not only the older person themselves, but also their carers including family, friends and neighbours—anyone involved in their care on a regular, frequent basis—within certain timescales of hours per week.

Health and social services are enormous bureaucratic organisations and have quite different methods of information collection through forms, questionnaires, procedures and storage of data. Take the example of an older person who had a fall requiring hospitalisation for a fractured neck of femur (broken hip) and subsequently discharged home or into special living accommodation after physiotherapy and occupational therapy (OT). They may be on several databases—general practitioner, hospital (medical and physiotherapy and OT), district nurse, health visitor and Social Services. This person would most likely have been asked the same questions about his or her medical and social history for each of these services, and as pointed out above, little or no inter-provision communication. One of the methods employed to address the problem was the instigation of the "Single Assessment Process" (SAP)⁴⁵ which aimed at ensuring integrated commissioning arrangements between health and social care. This entailed the generation of a standard form holding basic information which followed the older person from one section of service provision to another. The underlying philosophy is to ensure not only continuity of care but the opportunity for older people as individuals to make choices about their care, and for all the professionals to know the wishes of the older person and their carers.

Since the NHS and CC Act (1990) there have been a flurry of government directives, too numerous to mention here, but in essence they share the ambition to enable people to live their own lives as they wish, confident that services are of high quality, are safe and promote their own individual needs for independence, well-being and dignity. Probably the most important recent protocol is "Putting People First" (December 2007). This is a collaborative document which addresses all adult services, but recognises the demographic reality of an increasing ageing population. This ministerial concordat establishes the collaboration between central and local government, the sector's professional leadership providers and the regulator. It sets out the shared aims and values which will guide the transformation of adult social care, and recognises that the sector will work across agendas with users and carers to transform people's experience of local support and services.⁴⁶

People want, and have a right to expect, services with dignity and respect at their heart. Older people, disabled people and people with mental health problems demand equality of citizenship in every aspect of their lives, from housing to employment to leisure. The vast majority of people want to live in their own homes for as long as possible. (Putting People First, 2007, p. 1).

Developing from "Putting People First" was the introduction of "Direct Payments" in 2008.⁴⁷ Direct payments are local council payments for people who have been assessed as needing help from social services, and who would like to arrange and pay for their own care and support services instead of receiving them directly from the local council. A person must be able to give their consent to receiving direct payments and be able to manage them, even if they need help to do this on a day-to-day basis. They are a success for those who have them. Unfortunately many people are simply not being offered them when they should be. There are wide variations in uptake, both between local council schemes and across the different groups of individuals. Nevertheless, it is an important step in the direction of "marrying" formal and informal care in the U.K. and a belated recognition that services should be "bottom up" and not "top down", that is client rather than professional led.

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Counting the cost

The partnership of formal and informal caring within the community envisaged a saving on costs: the longer people stayed in their own home, the less had to be spent on institutional care. It is estimated that approximately 5 per cent of the older population (over 65) are in care homes or long-stay hospitals, although this does increase to about 20 per cent of people over the age of 85. These data demonstrate that people who do enter residential care are older and frailer and are thus more likely to require costly care. Also, about 75 per cent of people in care homes have some level of dementia, again needing specialised care.⁴⁸ The demographic realities—increased longevity and chronic morbidity, lower fertility and the greater expectations of the baby-boomer generation for their parents and themselves—mean that a call for increased rather than decreased State support is likely.

Added into the mix is the fall-out from the recent worldwide recession. Governments are looking for ways to cut public funding. Older people on fixed incomes, diminishing value of pensions and/or dependent on savings will have suffered disproportionately from the economic downturn. Since social care is means-tested, they will require more, not less State support. And so in the time of recession and the post-recession recovery, there are more questions than answers in the formal-informal care debate. How can we afford to keep the partnership balanced and fair for all citizens (tax payers and recipients of care)? How do we address the social and political dilemmas for prioritising funding for vulnerable people in the community?

Since the middle of the 20th century and the inception of the post-World War II welfare state in the U.K., welfare provision is driven by a shared commitment to social justice. Therefore, I remain optimistic that within our social-democratic ideology, older people will be listened to, responded to and that the experience of growing old will be improved by a continued obligation to care for the most vulnerable members in society.

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48 www.carehomesguide.com.