

LONG TERM CARE IN TURMOIL

Comparing Britain and America

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The care and support of older people in Western Europe has always been a tension between lofty religious ideals and a desire to punish those who grow to be old, weak and poor. The Judaeo-Christian tradition and theology of respect for age and wisdom faithfully carried out, is one honourable dimension of our collective past. But so too is the often inhuman treatment meted out to the aged poor down the generations. The patterns of health, social care and social security at the beginning of the third millennium reflects this ambiguity giving rise to serious questions about ethics, services and resources.

Christian teachings about the importance of elders within the family have been the enduring foundation of European society. There is good evidence of loving care for the old within the family setting. Yet the historical stereotype of multigenerational families living in harmony in the same dwelling is not one supported by historians. It was one pattern within a spectrum. Those with wealth and surplus accommodation found it easiest to meet the family living ideal. The poor; the majority of the population throughout recorded history, were hard pressed to supply the needs of those who could no longer be productive, did the best they could. But the determining factor has almost always been resources.

To meet the needs of those who were left destitute, two agencies offered support of a minimal kind – the church and the local community. Two moral entities, linked by a shared Christian ethic, but with differing motivations. The Church offered asylum to the frail and the sick. The community offered the lowest level of survival, with regimes established as a deterrent. Throughout the last millennium fear of becoming an elderly pauper permeated the lives of those among the labouring classes who survived into late adulthood. Failure to be able to support yourself or to have the support of kin was seen as sign of social incompetence and failure in the sight of god and men. It was to be punished, if also to be pitied.

During the second half of the twentieth century these philosophies of personal responsibility for poverty and illness were replaced in Western Europe by the welfare concept, which addressed need rather than causation. The welfare state was as much an ethical as a political revolution. Yet now, fifty years later in the midst of great prosperity, the demographic explosion has provoked governments into re-appraising those principles under the pressure of mounting costs.

In the rest of this paper, I attempt to illustrate the issues which challenge European societies in providing Long Term Care, by drawing on the example of Great Britain. I am aware of the different histories and structures which have developed in continental Europe. But it is my belief that there is enough common practice for the lessons to be understood and shared.

The Historical Context

It is never wise when examining any aspect of British social or medical services to ignore history. It would be particularly unwise in the case of long-term care for elderly people. Over the past decade significant changes have taken place which have shifted the balance from public to private and voluntary services. Yet the essential mixture is recognisably one which we have inherited from the Poor Law established by Queen Elizabeth I in 1601 and refashioned during the so called industrial revolution in the Poor Law Act of 1834.

Both pieces of legislation contained elements which can be prominently seen in current policy and practice. They were promulgated out of recognition of the needs of the aged poor who had no viable means of support. Maintenance of life had to be provided for those who could not sustain it for themselves. At the same time there were strict limits to the generosity of this contribution to personal welfare. The motives of the parliamentary drafter were control of both the behaviour of elderly paupers and the financial burden they put on the rest of the population. Therefore access to parish support either in the workhouse or in the ‘out-relief’, which the Victorian legislation brought, was provided only at great cost to personal dignity and with virtual loss of citizenship. Once ‘on the parish’ there was little prospect of independent living. Personal freedom was forfeit.

In *The Last Refuge*, a landmark study of old age institutions, Townsend (1962) showed that those most likely to end up in them were the widowed, the never married, and the familyless. Searching through the historical evidence of occupancy patterns a century earlier, Thomson (1980, 1983) confirms that this is an enduring pattern. Very few elderly couples were ever admitted, for the policy has always been to maintain them in their own homes by providing outdoor pensions (a regular payment to some one living *outside* a Poor Law institution) of a few shillings a week. He also shows that the proportion of elderly people in England living in institutions in 1870 was the same as it was in 1970.

The development of historical demography at the Cambridge Group for the History of Population and Social Structure has totally reconstructed our notion of old age in times past. As Laslett points out, abandonment of elderly people by their families' .. is false because research on the family relationship of the elderly shows it to be so to-day, and because historical work fails to show that familial support has declined over time.' (Laslett, 1984). From the work of the Cambridge Group we learn that pension payments' ... in the late twentieth century are of no greater relative value than earlier twentieth century ones and rather less value than mid-nineteenth century ones' ...(Thomson, 1984). Further, it has been found that in the late nineteenth century, elderly residents in multigenerational households were more likely to be giving care than receiving it. (Robin, 1984). Such evidence is broadly corroborated by Stearns' work in France, which portrays attitudes toward the old as having gone through a 'golden age of age' which falsely idealised their role in earlier centuries (Stearns, 1976).

It is not our purpose to dwell on history, but it is instructive to start with it, for it is in the ideas of the past and the human constructions they led to which have shaped British long term care. The Elizabethan Poor Law of 1601 established a framework which has had durable if curious consequences for current policy and practice. It laid responsibility for the relief of elderly people on their children. Only when this system of support failed or proved nonexistent did responsibility fall on the local community in the form of the parish. Once an individual made claim on the parish, he or she could only be an inmate of a poor- house, where a regime of shamed subsistence was the normal if not exclusive pattern.

Because of the rapid urbanisation occurring from the mid-eighteenth century onward, the twin forces of population growth and geographic mobility placed unmanageable strains on the parish system and its institutional provision. The able-bodied poor were increasingly allowed to remain outside the poor-house, existing on the meagre financial support provided under the 1834 Poor Law (Amendment) Act. Here were the origins of our social security system. But for that seemingly irreducible minimum of the old with no means of support (it has remained around 4 percent for the over 65 population for as long as records exist), the institution was their fate. For a small minority, group living was provided by the church and, as the nineteenth century progressed, by a growing array of voluntary societies, which stemmed from Victorian middle-class benevolence. They coexisted with another longer-lived ecclesiastically provided institution, the alms house. Small cottages, usually with one bedroom, were built in a terrace near a church or Christian community which supplied simple but good housing for the infirm but 'deserving' elderly, who received regular aid from clergy and parishioners.

In these early arrangements we can see the origins of state-provided long-term care, the voluntary (nonprofit) sector of residential and nursing homes and of sheltered housing. From the same roots we could observe the emergence of two sorts of hospitals. One derived from the church's healing ministry, which goes back to medieval times; resulting in the voluntary hospitals which grew rapidly in the Victorian era (Woodward, 1975; Davies, 1980). The better known of these hospitals became leading medical schools, but all ultimately became part of the National Health Service (NHS) in 1946. The other grew out of poor-law infirmaries, which provided free medical services to those in or near poverty. Inevitably these hospitals had a clientele which presented more severe chronic illnesses, and they provided many beds for long-term care.

Such hospital care of the elderly people as existed before World War II was to be found predominately in these gloomy places. In the postwar period the hospital-based speciality of geriatric medicine was established all over the United Kingdom (and most vigorously in Glasgow and London) in former poor-law hospitals, which, before their incorporation into the NHS, had for some time been in the hands of local authorities.

The binary pattern of long term care, where hospitals and nursing homes form one major service sector and the social care or residential home form another, has clearly visible antecedents. When local authorities took over responsibility for elderly people by enacting the 1948 National Assistance Act, the Poor Law was terminated. In Part III of the Act local government was required to provide 'old peoples homes'. Indeed this is the origin of the colloquial term used by professionals in the United Kingdom when they refer to such an establishment as 'a Part III home'. Again the inherited stock was made up of large, overcrowded, badly maintained, dehumanising institutions. Townsend (1962), described them with graphic precision and compounded the effect with data from a massive national survey of 800 homes. His work, which closely followed Goffman's *Asylums* (1961), set up a strong reaction against institutional care in all its forms. In Britain the disaffection was further fueled by the publication of *Sans Everything* (Robb, 1967) in which a group of doctors and nurses wrote of their revulsion at the treatment meted out to elderly patients in long-stay care.

Anti-institutionalism in the 1960s eventually provided part of the basis for legitimatizing community-care policies. Yet through-out that decade most of the elderly residents of Part III homes lived in poor-law institutions. Even homes in the voluntary sector were very large and forbidding places. The building of new smaller homes (at first the desired norm was 60 places, falling later to 30 places) began slowly. Local authority homes continued to be the poor – an inferior service for inferior people (Means and Smith 1985).

Anti-institutionalism: the phenomenon described briefly above.

Throughout the story of long-term care, there is a set of themes which, for most of the time, have been in tension. The Poor Law was a benevolent piece of legislation in conception, but its concern for human welfare was predicated on a mixture of financial economy for the provider and social ignominy for the recipient. Social control and humiliation has characterised much of British public social policy. Yet in its execution there has always been the exercise of private humanitarianism. In the 1945-1975 period this heightened concern for the well-being of the person in need became more prominent and official. Since then what had emerged as a set of rights has been redefined to fit within an economic framework where 'rights' are rationed by 'what the economy can afford'. Bornat et al. (1985) put it succinctly: '...elderly people face a special crisis because of the condition facing the construction of social policy in the 1980s. There is a political and ideological attack on the legitimacy of their claim to state support.'

Apocalyptic Demography and Long Term Care

Long Term Care is yet again in turmoil. Since the great expansion of the early 1980's fuelled by the release of public funds and demographic pressures, there has been a succession of anxieties, atmospheres of collective grievance and claims of injustice. The introduction of the 1984 Residential Homes Act, the associated Code of Practice *Home Life* and the creation of the Tribunal; generated alarm and dismay. Proprietors worried, in public and private about locks on residents doors, ensuite facilities, single rooms, room sizes, night staffing, nurses in residential homes and registration fees. Then it was differential fees, payments for high dependency, different inspection standards, the Fit Person (a legal test of the personal standing of proprietors and managers) and the problems of dual registration. More recently the focus has been on the competing expectation of higher standards with driven down prices, often below the costs of provision. Local authorities in their attempts to manage capped budgets for purchasing care have frequently placed older people in the cheapest rather than the most appropriate care.

Little wonder that those who own and run what is now termed the Long Term Care industry are challenging the government to match its package of policy changes with fair and adequate funding.

In the interim the stock market values of the increasingly influential corporate sector continue to fall and as a consequence new investment has declined. Some parts of the charitable sector continue to flourish and grow on the proceeds of effective fund-raising. The main body of small 'cottage industry' proprietor led homes (still the core provision) mostly struggle to survive. Local authority homes, twenty years ago the largest sector, has dwindled to become the smallest. All too frequently these are places of last resort for the discerning consumer, but given preferential treatment by purchasers from the public purse.

Despite these vicissitudes it is not difficult to conclude that the past fifteen years since the 1984 Act have seen an overall rise in quality for the older people who are residents. Older people have more privacy, personal space, dignity and care. But the average rise, embraces vigorous innovation and excellence as well as facilities and personal services which are intolerably sub-standard. Inspectors and Registration bodies are increasingly skilled at enforcing good care standards. Yet they do their task, largely understaffed, so that the regular monitoring they are charged to undertake is widely neglected. Perhaps most discomfiting to providers is the significant variation in the way standards are interpreted and applied. The government the industry and the registration bodies all have collective voices to express their disquiet. So too have the nurses and the doctors who have all but abandoned old people in homes. The constituency rarely heard even in times where consumer consultation and Charters are in great evidence, are the half million increasingly frail old people who pay an average of over £15,000 a year to live in a residential or nursing home.

Residents do at least have a range of pressure groups to speak as their unchosen proxies. Age Concern, Help the Aged, the Relatives Association and others draw public and political attention to failures in the system which come to their attention. The group which is completely submerged in the clamour is staff. The Royal College of Nursing speaks out for the qualified nurses; but the huge workforce of poorly paid, mostly part-time, unqualified female carers and domestic staff are virtually unrepresented. Nor, significantly do we hear from their managers. Mostly working in single establishment homes with no organised body to represent them managers are often isolated from their peers; engaged in an undoable portfolio of activities and yet bearing central responsibility for the effectiveness of a vital service.

Managers and Staff

There can be little doubt that the greatest net gains to be achieved in the quality of long term care over the next decade will be through improving the effectiveness and skill of staff. There are other domains of improvement which will be complementary - assessment, personal living space, new regulatory frameworks and more equitable public funding - but none will match the efficacy of sound investment in staff. Enhancement of their skills, knowledge, professional self confidence, assessment and recording capability and ability to use knowledge - based practices, will pay high dividends. Yet, given the depressed levels of funding and the poor return on capital across the industry, there can be little prospect of the necessary level of training budgets, to lift the competence quotient significantly above present levels. Even £100 a year per member of staff spent on training would cost the sector more than £60 million. Whilst such a modest training programme would require only the equivalent of £3 per bed per week (or one per cent of average turnover) it is unlikely to materialise at a national level.

Within such a restricted expectation of investment in the workforce it may make more sense to devote a higher proportion of training resource to raise management effectiveness. Reliable estimates of the numbers who might be termed managers are unavailable. In part this is due to the lack of overall workforce statistics in an industry dominated by low paid, part-time and rapid turnover of workers. But even a simple approach produces large numbers. If each home has a manager or matron who takes overall responsibility for the establishment there must be at least one deputy who oversees staff during the second day time shift. In most homes there will be at least one other responsibility post. Add to these, the managers employed by the larger groupings and companies who are senior, with Chief Executive or area responsibilities. On the basis of 31,000 registered homes, there is likely to be around 100,000 operational managers.

The tasks of management extend far beyond the oversight of care staff and caring work. Rotas, training, finance, purchasing, food and hotel services, building maintenance, health and hygiene, legislative and regulatory compliance and marketing all feature in a diversity of job descriptions. The range of tasks is greatest in the smallest businesses, where the composite of proprietorship and management is common. More specialisation is possible in the larger corporates where conventional line management on functional lines is the norm.

Remarkably little is known in the UK about this key body of staff. Such reports as we have provide sketchy information. Official statistics are strongest on residents, their age gender and dependency levels. Staff are usually described loosely and collectively, but not enumerated. The Audit Commission's *The Coming of Age* (1997) report on care services for older people is much concerned with issues of cost, value and quality, but presents no data on staff and only addresses management in terms of processes and procedures. Plans have been laid out for a new General Social Care Council which will set training standards and regulate the training system to be lead by the National Training Organisation. Clearly this is closer to the staffing of homes for older people; but at this stage the attention is drawn more to the establishment of qualification routes for social workers and other professionals. The untrained army in long term care is part of the planned framework, but still a long way down the line. Managers are equally invisible in this emerging system.

The neglect of staff and management in the institutional care system is as old as the system itself. Long term care has over a century of history of being out of sight and out of mind. Our long stay mental hospitals were staffed with 'orderlies' whose tasks were defined by their title. Custody and control was also the principal task of the poor law institutions out of which local authority residential homes grew. Even the efforts of the Gatsby Group led by Barabara Kahan to improve training in childrens' homes, had only a moderate influence. It resulted in the closure of homes and the abandonment of collective care rather than its improvement. With older people, the 'Home' in its various formats, is one permanent feature of the landscape of support. So attending to the qualities of care staff and the quality of those who manage them is a vital project.

Public Policy in Transition

Fifteen years after the Registered Homes Act 1984 and the accompanying Code of Practice *Home Life* (1984), the institutions and practices which they established are seen to be in need of serious revision. Moreover there is a declared intention on behalf of government to produce a more equitable and better organised set of arrangements for residential and nursing homes. As the public purse currently meets almost seventy per cent of the total costs, it is a matter of expectation that resources are spent well. At the same time it is a matter of concern that demographic pressures and practice trends are increasing the annual expenditure. Thus advances are being made both on the framework for regulation and quality and on establishing future patterns of public and private contributions to the costs of care in homes for older people.

The Single Registered Care Home

The current distinction between nursing and residential homes is based on an historical split between professionally defined models of 'medical' and 'social' care. The regulatory system embodied in the Registered Homes Act 1984 is determined by these two professional models. The current provision for dual registration might have led to the development of a more unified type of provision. In reality, differing regulations, guidelines and procedures followed by health and local authority inspectors have often placed unreasonable regulatory burdens on homes seeking to provide a wide range of care. In consequence, the successful establishment of dually registered homes has been limited.

Resulting from an earlier Rowntree funded study Malcolm Johnson and Lesley Hoyes (1996) proposed an organisational and regulatory framework which would facilitate a broad spectrum of styles of provision enabling a degree of mobility between different styles, which reflects the

changing needs of individuals over time. This was not to advocate a single category of care home catering for any person with support needs. There are powerful arguments against a general mixing of different age and client groups within residential settings. However, instances of couples being split up because of differing care needs are clearly unacceptable and could be avoided with a single registered home.

Equally the proposed system does not imply that all homes would be expected to provide for all levels of dependency. Providers must be able to choose the type of care they are prepared to offer and residents must be able to choose the type of home they wish to live in. The concept of a single care home is about enabling flexibility, not about imposing a universal model of provision.

The aim is a continuum of long-term care, from small family placement schemes for individuals with support needs, through care homes offering a home for life, to establishments caring almost exclusively for frail or sick people with substantial nursing needs. Along this continuum, providers could opt to offer a range of care, some quite narrow, some very broad, which would be clearly set out in their brochures and information for prospective residents.

The detailed proposals are summarised below. Arguments for a single registration include:

- The distinction between nursing and social care which underpins the current separate systems of provision is no longer tenable as residents become older and increasingly frail. Dual registration has not succeeded in bridging the regulatory gap.
- A spectrum of care homes registered under a single system would offer a range of care along a continuum.

Key elements of the proposed model are:

- *The setting of nationally agreed criteria for initial and on-going assessment of health and social care needs.* Individual care plans would specify assessed needs and would also trigger changes in the level of care. Assessment would be linked to a scale of fees based on provision for individual needs rather than type of home.
- *A level and mix of staffing in each home dependent upon the assessed levels of needs of residents.* Accredited training courses, producing a wider skill mix amongst care staff, would enable a more efficient use of qualified nurses.
- *The development of 'Gerontological Nurse Specialists' who may work as established staff in homes or be based in support agencies, allowing the flexible and appropriate use of specialist nursing skills.*
- *The establishment of an independent and broadly self-financing National Office for Standards of Care to oversee the setting of national standards and the registration and inspection of all care services.*
- *The development of a regionally based registration and inspection system, with a multi-disciplinary core of staff, supplemented by panels of 'lay experts', including service users and carers.*

With or without a single category, the range of provision is already diversifying giving rise to the need for more appropriate skill mixes to meet the needs of a more differentiated clientele and niche marketing on behalf of owners. As a result homes will become more complex organisations as some tasks require more expertise. Managing a more heterogeneous work force will become commensurably more demanding.

Assesment and Care of Older People: The Way Forward

The Government has promised services that are suited to the needs of people not the convenience of providers'. The foci for improving this 'suited' are empowerment of consumers and better commissioning. But there is no mention of the critical underpinning needed to make these improvements work - assessment/care mapping/review. Nor does it address the absence of shared

assessment tools and records for the many workers and providers who now attempt to sustain and improve the quality of life for people in the fourth age.

The diverse and often seriously deficient assessment schemes used by doctors, nurses, social workers, psychiatric nurses, care workers, physiotherapists and occupational therapists have two damaging consequences for older clients. The first is that they are beleaguered by professionals doing assessments, absorbing vast amounts of potential care delivery time and energy. The second is that professionals have no shared assessment tools and therefore no trust in the assessments of others. Nor is there any central file on an individual to which all carers refer and contribute.

Far too much of the already inadequate service to old people is being squandered on poor and often wrongheaded judgements about need. Lack of integration is the fundamental weakness not commissioning - much as that needs attending to. In short old people needs are being neglected. Old people are dying of assessment.

A major problem at present is the lack of a universal means of matching long-term care funding to services and outcomes. Thus there is no way of measuring cost-effectiveness. The relationship between costs, services, standards and quality of care is important and potentially informative, yet presently the precise terms of that relationship cannot be established. (Challis et al 1996). Arguably, comprehensive care provision is only possible through the work of multidisciplinary teams capable of performing specialised tasks. Older people often have multiple needs - medical, psychological, pharmacological and social - which cut across service boundaries. However the multiagency, mixed market system is poorly integrated. This results in: poor and highly differentiated services to clients; wasteful duplication; low cost effectiveness. The lack of a structured and systematic application of standards and quality and regulatory control hinders effective provision and effective monitoring. A common regulatory framework subscribed to by all professionals is needed (Johnson 1996; Johnson and Cullen 1998).

At present there is thus a wide variation in acceptable standards and quality of care. The 1984 Act speaks in broad unquantified terms about quality, adequacy and sufficiency which are open to interpretation. National guidelines do not extend to practical outcome measures or recommendations of skills mix and staff ratios for long-term care homes (Johnson 1996; Johnson and Cullen 1998). The lack of uniformly applied standards renders the measurement of care quality impossible: this obstructs the very processes - building models of best practice, rewarding quality, transferring expertise, promoting cost-effectiveness - by which a better service can be created. (Bowman 1997). But new Regulations if they are to be effective must provide a common framework for assessment and recording.

The key to this coordinated approach is the universal assessment tool linked to agreed quality standards. Given this, the different agencies responsible for care could become part of a structured and integrated framework of care provision. The characteristics of such an assessment instrument would be a standardised link with care planning, providing a holistic account of an individual's need and his or her past medical and social history (Carpenter and Calnan 1997). The *Resident Assessment Instrument* (RAI) operated in the United States meets this criterion. It relates an elderly person's individual needs to an agreed care plan which is benchmarked according to a national standard for quality and outcomes. For the first time care can be costed, and its quality determined at all levels from the individual to the nation. Indicators verifiable against agreed standards have been set (Fries et al 1997).

All the different agencies responsible for care have access to a set of evidence-based criteria by which their input is governed, and their precise role within the multiagency context is made clear.

When an older person enters nursing or residential care his or her needs are assessed according to a set of indicators of functional ability which covers all aspects of mental and physical health. This standardised assessment is enshrined in the *Minimum Data Set* - a matrix of all possible care needs

of an older person. All care providers understand and use the same assessment. The Resident Assessment Protocols (RAPs) are a crucial accompaniment. These indicators guide the assessor in working out a care plan by flagging up what kinds of functional problems are likely to benefit from what kinds of care intervention. They act as an aid to goal-setting and care planning. While not normative, they are admonitory. Thus if the RAPs were to recommend a particular intervention and an assessor did not follow the recommendation, s/he would have to justify this in terms of the specific individual needs of the client.

The aims of the proposal are to:

- an improved means of uniformly assessing - on an individual basis - the needs of older people resident - or likely to become resident - long-term care establishments in the UK
- relate needs to practicable and achievable standardised actions or care plans

Cost, Value and Price

Since the transfer, by the last Government, (commencing April, 1993) to residents in long term care homes, from the Department of Social Security to local authorities, there has been a growing downward pressure on fee levels. The shift of this component of social security payments - which now amounts to more than £7 billion a year - to Social Services Departments was soon accompanied by a capping of the budget. This has simply meant that the growing number of older people needing to enter care has (i) been restricted by the unavailability of funds - waiting for the beds of claimants who have died, and (ii) led to attempts by local authorities to pay below national rates for care to provide for more people (iii) resulted in policies to place elderly people wherever possible in lower cost residential rather than higher cost nursing homes.

The local authorities were placed in a situation which required them to do more with less. In the contemporary world this is a familiar challenge. It immediately, requires the pressed budget holder to consider whether better value can be obtained from the expenditure. Almost immediately the commissioning units began to explore the possibilities of better deals for their block purchasing power. New rules were constructed around the country which placed residential and nursing homes in new forms of price competition. Fairly rapidly it became necessary for proprietors to accept publicly funded residents at below current Department of Social Security (DSS) rates. Initially such reduced rates were exceptional and set within packages of substantial business delivered by the local authority.

As the movement for Best Value, sponsored by the Audit Commission and the National Audit Office was diffused into local authority Commissioning' practice, the national guideline prices were increasingly breached. The 'set price' practice which had prevailed for many years was quickly diluted by local Commissioners anxious to demonstrate their negotiating skills and to maximise the number of older people accommodated within the capped budgets.

. As a consequence the tariff of prices has become something of a managed lottery. Those whose costs are met by the local authority may be placed in homes at prices below the marginal cost i.e. at a loss. Proprietors are increasingly left with the option of taking loss making residents or risking the loss of their contracts with the local authority. In other cases residential homes feel obliged to accept residents whose case needs would properly place them in a nursing home - but the placing social workers are under instruction to avoid placements in higher cost nursing homes as far as possible. The same social workers were also required to place as many old people as possible in local authority or block contracted homes previously owned by the LA to ensure maximum occupancy rates - despite the much higher costs in many of these establishments.

A report for the London Government Association (Kenny, 1997) *Influencing the Market: Negotiating fees with Independent Homes*, highlights the impact of the cost containment strategy. Overall, the average prices paid for residential and nursing home places were within the upper and

lower DSS rates for residential homes in 1996 when the survey was done this range was £207 to £221 per week. However these averages contain very wide disparities, with some highly specialised cases costing £2000 a week and some at the lowest end alarmingly and irresponsibly low. For example in the Midlands the average fee for residential care was £221; the highest was £436. But the lowest end was £83. The lowest paid to a nursing home was £190.

A wider consideration of disparities in market rates for state funded residents was carried out by William Laing for the Joseph Rowntree Foundation (Laing, 1998). He draws attention to the circumstances above, but adds that 52% of residents with preserved rights have to pay top-ups to meet the disparity between the fees payable and the DSS higher rate. Of local authority supported residents 14% have to find top-up funds. Laing estimates that these top-ups for the poorest residents on a state funding cost £80, million a year.

It is almost standard practice across the industry to charge private payers a higher rate than is accepted for state supported residents. Thus those who are paying from their personal savings or from the equity from their house are systematically subsidising the majority.

Laing's reasonable conclusion is that there is a overall under funding of long term care, over and above the shortfalls which result from the diversity of fee levels. His estimate that a further £600 million a year is needed to re-establish proper rates of return to what is now a predominately private sector industry.

Price and Quality in Tension

There is good reason to further raise quality standards in homes, through regulation, audit and training. It is also right that those who work as care staff should be properly paid and provided with appropriate employment facilities. The introduction of the minimum wage will not affect most of the bigger providers, whose lowest pay rates are already above the £3.60 minimum. But many homes have employed staff at less than £3 an hour and the legislation will Laing and Buisson estimate that following its introduction in April 1999, there will be an addition to industry costs of £90 million a year.

Commissioners and purchasers as well as a better informed clientele are driving up expectations of quality. Following the drive for single rooms and ensuite facilities, there is pressure to demonstrate staff training and the capacity to deal with increasingly dependent residents who are likely to experience progressive dementia and memory loss. Activities and the introduction of complementary therapies are also more demanded.

From government there is a significant assortment of new requirements in the making, most of which are listed earlier in this chapter. Amongst the ones which are troubling providers is the *National Required Standards for Residential and Nursing Homes For Older People* prepared by the Centre for Policy on Ageing for the Department of Health. Focus has already gone onto minimum room sizes - 12 square metres for new build homes and 10 square metres for existing homes. Reaching the required size for existing homes will add considerable costs and in some cases will lead to closure.

Changes in legislative requirements personnel regulations, training and quality are not peculiar to long term care. Nor is the need to respond to the market. But care services for the vulnerable old are not ordinary businesses. Rapid turnover of staff, home closures and underfunding are matters of public policy and widespread social concern. So these changes present those who own and run homes with complex and difficult tasks. Perhaps this explains why in his 1998 market review Craig Woolam (1999) reports that one in four home owners plan to quit the market within the next three to five years.

Balance between ethics, services and resources

It is always the task of politicians to make judgements between competing priorities. Increasingly in a globalised world the main task of governments is to regulate practice, set standards and ensure good value for its citizens. Yet in this account we have observed the changing position of our most vulnerable citizens. It is one in which traditional patterns remain dominant, in large measure because society is unwilling to meet the real cost of quality care.

Here are some of the ethical issues we now face:

Ethical dilemmas

- Does it meet the requirements of a human rights society that staff are largely under trained, underskilled and under managed?
- Can we honestly sustain a system in which there is no common base for assessing needs – but standard regimes and charges.
- Is it acceptable that Long Term Care is organised on historical grounds rather than needs based.
- Is 10 square metres or even 12 square metres enough space for an older person to live in ?
- Is it ethical to make higher charges for those who pay for themselves, in order to subsidise those who are paid for by the state?
- Is a service largely devoid of skilled medical involvement, one which marks out long term care residents as the worst group in terms of health care?
- Can it be justified that Long Term Care homes neglect the process of dying and death.
- Is it defensible that there is an anxiety on behalf of proprietors that knowing more about resident needs means that known but unmet needs makes them legally culpable.
- Is it morally defensible for governments to drive down the price paid for care below the level where it can be competently provided?
- Are we breaching the intergenerational contract by taking all the assets of those above the £16000 threshold?
- Is the policy of home care ethically and socially right a) because of the burden it places on carers b) because it raises the threshold of entry to a total care environment?

Long Term Care in the U.S.

An informed audience such as this will not require a detailed account of developments in Long Term Care in the USA. Nonetheless, I offer some reminders of the key events and issues, before comparing developments in our two systems.

- **Milestones and Developments.**
 - Introduction of Medicare and Medicaid 1965
 - growth of LTC beds
- **National Health Planning**
 - slowing the growth of beds
 - shifting the case mix to the more disabled
- **Mid 80's**
 - abuses of Medicare and Medicaid
 - debate about who should pay: public or private
- **Introduction of MDS/RAI**
 - Expenditure controls
 - Remuneration based on RUGS

Milestones and Developments (2):

- Assessment/Quality/Skill mixes management/Remuneration
- Impoverishment resulting from long stays. Spending down
- Quality standards
- Nursing Homes (skilled nursing facilities) versus uncertified lower disability homes)
- Assisted living
- Home care
- Caring for the carers

Commonalities and Differences UK/US

- Same proportion of over 65s in LTC (approximately 4.5%)
- Largely publicly funded
 - US 60%
 - UK 70%
- 95% of older people live independently at home
- Bulk of old age care provided by family and friends
- Increasing regulation concerned with cost control and quality
- Quality and price in tension

Commonalities (2)

- Bulk of older people's care provided by family and friends
- 95% of older people live 'independently' at home
- Public policy focus on maintaining independence
- Push towards Assisted Living (better and cheaper?)
(In UK – residential homes/very sheltered housing)
- Staff – poorly trained; low esteem; very low pay levels;
Recruitment and retention problems
- Systems historically bounded

Differences

- In UK greater mix of LTC providers
Local government/charities/private companies
- UK more of a cottage industry – few commercial corporates
- National Health Service mitigates impoverishment

- UK an older population with more experience of demographic pressures, but less ethnically mixed
- US LTC more professional, better managed, involves physicians better
- US more responsive to the Gay Vote

As if by collusion, this week the UNC Institute of Medicine published its *Long Term Care Plan for North Carolina*. Its conclusions are highly congruent with my analysis – though perhaps less far-reaching. The Report concludes:

“Ideally, long-term care services would be provided by home and community-based programs or families on behalf of their loved ones. These services should enable individuals to live as independently as possible without casting them into poverty. Without adequate private long term insurance or public funding, some individuals in need of long-term care services are faced with three options: (1) find a family member to provide unpaid care; (2) pay a caregiver out-of-pocket; or (3) enter a long-term care facility where, as they more quickly use up their resources to pay for institutional care, they are more likely to qualify for public subsidies. This raises questions of the availability of services and financing needed for people to live independently without institutionalization.

The state’s long-term care policy should be to support older adults and people with disabilities and their families in making their own choices with regard to living arrangements and long-term care services that will result in appropriate, high-quality, cost-effective care provided in the least restrictive setting. The state’s policies and program activities should strengthen the capacity of families to serve as caregivers; however, individuals in need of additional long-term care services should have access to certain core services across the state. North Carolina’s long-term care system should be accessible and understandable for both public and private pay consumers, and uniform for all in need of these services.”

Conclusions

- Is Long Term Care inevitably a service which provides a basic existence – plus service, for those at the end of life?

What are the appropriate models for a late of life care which might be called ‘best practice’

Older people in the fourth age are defined by their biological, physical and psychological losses

We meet the physical tolerably well.

The next task is to learn how to acknowledge the human, biographical losses and help to create a wholeness out of the life.

At present, the unfortunate ones who go into LTC, all too often fall off the end of life in a 19th century state of less eligibility.

In the ‘good’ home there is a constant atmosphere of enjoyable activity. Not a uniform, structured regime; but where in different parts of the Home – both in the public areas and in private rooms, human engagement goes on. Where the activities are spontaneous the staff nurture them gently with friendly enquiries, humour and the service of a good cafe.

Where there is the potential for depressive inactivity, excessive sleeping or lost ability to self activate; staff are active listeners, visitors provide interest and stimulus, counsel is given in

addressing bereavement or biographical pain; spiritual issues are addressed, personal problems explored; reality orientation given.

As part of a more structured framework we need to fundamentally re-think what the last months and years of life require to still be good life.

As a professional observer, I note that what characterises a ‘good’ home is one where staff and residents spend their days in a seamless mixture of functional and human interchange, which nonetheless reflects the slower rhythms of the last stages of life.

What I most often see is ‘good-enough’ care which provides an agreeable and safe environment with capable personal care and decent food. In such places the staff work in a series of activity peaks which are functionally oriented (getting up and dressed, bathing, medicating, eating, toileting, going to bed) followed by lengthy periods of virtual inactivity, occasionally punctuated by a brief therapeutic intervention or an occasional group activity.

This leaves the long hours of the day for most residents as stretches of somnolent agitated idleness. In such circumstances memory loss and disorientation or depression flourish in a human environment bounded largely by visits to the bathroom, the dining room and the arrival of the drugs trolley.

A new paradigm

My lecture has had two themes – (1) the persistence of a historical model of minimal provision within a framework of latent punishment
(2) the technical debate about efficiency, quality, regulation and price

I would argue we need to break out of this bounded thinking -
in the Kuhnian sense – make a Paradigm shift.

- Listen to people about what matters to them.
- Make LTC more of a human centred service.
- Recognise that the cost issue should be more about good value than lowest price.
- Think about the ‘who pays’ issue more imaginatively. (A national bank for equity release?

Top slicing pension funds?)

Let us use the energy and enterprise of the baby boomers to be the energy force to create a decent Fourth age.

We must do it – for soon we too shall be old

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