POINTS OF VIEW

WILL CARE SURVIVE?*

The Government's Policy is reputedly based on user orientated provisions, and adequate consumer choice. Its White Paper - "Caring for People" - asks - "What is Community Care?" and says: "Community Care means providing the right level of intervention and support to enable people to achieve maximum independence and control over their own lives. For this aim to become a reality, the development of a wide range of services provided in a variety of settings is essential. These services form part of a spectrum of care ranging from domiciliary support provided to people in their own homes, strengthened by the availability of respite care and day care for those with more intensive care needs, through sheltered housing, group homes and hostels where increasing levels of care are available, to residential care and nursing homes, and long stay hospital care for those for whom other forms of care are no longer enough."

Government Circular HC88:43 "Services for People with a Mental Handicap" and other directives gave policy aims as:

1. "to develop at local level, in collaboration with statutory and other agencies a comprehensive and integrated range of health, social and other services for mentally handicapped people and their families, with provision for assessing and prioritising individuals particular needs for these services.

2. To provide

(a) specialist and generic health care for people with special medical or nursing needs including small residential units in the community and specialist support for people in other settings.

(b) good quality care for mentally handicapped people in all settings, including maintaining and where necessary, improving standards in large hospitals as their population reduces.

(c) the primary aim is not the closure of hospitals but to provide better care. Community care is not a cheap option not an exercise to achieve indiscriminate hospital closures. Hospitals have a vital role to play in backing-up community services and providing respite care.

One can go along 100% with all these aims but the developing situation is far removed from meeting these criteria, and is, in fact, moving away from them at an ever increasing rate.

Within Government circles their stance on the Disabled Person Representation Bill 1985 was clear within 48 hours of its passage through Parliament, when the then Minister, Norman Fowler MP, stated that any parts of the Bill which had financial ramifications would not be activated until funds were available. That as we know is still the position today.

The Government's rejection of the ring fencing of moneys for the care of people with a mental handicap was against widespread opinion, with Health Secretary Mr. Kenneth Clarke MP making the cruel comment that what its supporters proposed was - "interference in the technicalities of local Government finance", an ' interference' justified

**Based on a talk to a conference by the British Society for the Study of Mental Subnormality and the Walsall County Council Health Council, 20th February, 1991.*

apparently for drug and alcohol abuse.

A worrying aspect of the developing situation is the apparent complete lack of accountability at local level of political appointees, and which includes those now sitting unelected on District and Regional Health Authorities. Community Health Councils are in danger of becoming paper tigers instead of public watchdogs, and local democracy is on its way out.

The implementation of the community care policy stands discredited by a host of Parliamentary and other committees.

As financial constraints have increasingly forced local, district and regional health authorities to lower their sights, the once much heralded philosophy, instead of being moulded to meet the needs of all - all are to be moulded to fit a devalued philosophy. Government must put money where its mouth is.

Parents and relatives see only a declining service as hostels, respite care, day and adult training centres, special day and residential schools are being closed instead of expanded to meet the growing need, thereby joining the hospitals to be 'stigmatised', and therefore places worthy only of destruction. Defects within the policy are leading to a reduction in the quality of care afforded those remaining in hospital care so that Health Authorities can pay dowrys. Starved of funds such authorities see hospitals not as centres of multi-disciplinary potential, or purveyors of centralised support services and staff training, but only as capital assets to be sold off in a once and for all drop in the ocean funding operation.

Patrick Daunt, former Head of the Bureau for Action in Favour of Disabled People, within the Commission of European Communities said at an International Conference in 1987: "The prospect for disabled people, above all the mentally handicapped, in the nineties in a world which may be dominated by market forces, is chilling. In these circumstances de-institutionalisation increasingly looks like a trump card in danger of being played at the wrong moment. Professionals and voluntary bodies might do better to hold on to what they've got, keep their powder dry and repel all boarders." Would anyone now question the wisdom embodied in this observation.

People with a mental handicap in their forties and living with ageing parents, are about to flood onto the care 'market' in increasing numbers, drowning the already overstretched service personnel and resources.

For people with a mental handicap the most important factors in assessing their needs is the person's mental age, intellectual capacity, personal characteristics and behavioural habits, all of which can only be accommodated by a wide range of residential and care facilities. To refer to such people as having learning difficulties is to trivialise their needs.

At a local level the watered down policy offers parents only a simple choice of the family home or placement with two or three others in any house in any street. No longer a choice from the wide spectrum of provisions envisaged but a 'choice' only of who provides the 'any house in any street', voluntary, private or local authority - the latter being avoided if possible; and the private encouraged by substantial profits to be gained. This is even less than Hobsons Choice - after all he did have the option of being able to walk away from the horse.

Plans and proposals deal only with the provision of living accommodation, while

abstract reference is usually made to day and support services at some future date, but which fail to materialise. Fall-back facilities are rarely if ever considered, hence the debacle last year at Croydon when a strike by social workers saw their mentally handicapped charges entering St. Lawrence Hospital. The better alternative services are not being provided in the quality and quantity needed, particularly for the more dependent and profoundly handicapped. The policy is certainly not helping those people with a mental handicap who are currently in hospital and who would not benefit from a placement in open society - indeed it is bringing concern and distress to those who express or feel a desire not to move, and their families. Neither is it alleviating the anguish of ageing parents whose ability to cope with their adult child at home is coming to an end. Many parents pray that they do not die before their mentally handicapped son or daughter.

Little wonder that the morale of dedicated staff within the hospital care system is broken as many district and regional health authorities, besotted with the "efficient redistribution of resources" in a cost saving exercise, often against massive local opinion, pursue a retraction policy of ward and service closures resulting in a loss of quality care, and a depressing working environment for the staff. Yet government says the closing of hospitals is not its primary aim.

It is a policy which bears all the ramifications of managerial expediency allied to targets, budgets, bonuses, and the pressure of short term contracts, <u>not</u> the best interests of residents or staff.

What is more worrying for parents and families of people with a mental handicap are recent moves, without prior discussion, to block the registration of establishments for such people to no more than six beds, and to refuse funding to those exceeding that number in what can only be described as bureaucratic anarchy.

For example, inexplicably the North West regional Health Authority social service chiefs in Bolton seek to do just that at a time when their specially DHSS funded neighbourhood scheme is admitted to be in crisis following the end of its three year funding period. The National Development Team in its 1987 report on Bolton's Neighbourhood Scheme included this comment: "The neighbourhood networks offer an exciting variety of types of accommodation for adults but parents are adamant that there is a place for imaginative accommodation for larger groups which offer more protection and local social stimulation than that which is currently fashionable. Eager young administrators and care workers ignore parents' views at their peril in this matter. Current philosophies may fade as their shortcomings are revealed. We ask that any plan be judged in terms of the quality of life it provides rather than conformity to contemporary and possibly temporary theoretical notions."

Bolton's parents and relatives are campaigning for a real choice which does include larger residential communities, as exemplified by the nearby voluntary Brookvale Community with sixty beds which has received Ministerial acclamation.

Bolton's dictatorial proposals are a generalisation which will have serious implications for the long term care of people with a mental handicap, whose often extensive disabilities can only be accommodated by a wide range of residential and care facilities which do offer a meaningful choice. Such

attempts at restricting the size of establishments will seriously and dangerously extinguish choice to the consumer, to their families, and to the professionals seeking adequate placement.

The Minister, Stephen Dorrell MP, last Summer criticised the action of the North West Regional Health Authority. In a letter to its General Manager he says: "There is some concern that the North Western resettlement policy is only diverting dowry funds when ex hospital patients are transferred to small households on the Bolton model and this is unnecessarily restrictive. Peter Thurnham MP and others argue that there are many other suitable arrangements for the mentally handicapped ranging from Brookvale homes (60 persons) to centres of excellence designed for group living of up to 12 or so persons and it would be a great pity if your resettlement policy effectively choked off these ideas through exclusive channeling of dowry funds to a unique model of care in the community. For these reasons I have asked the Chairman to consider the need for a review of the policy to see whether it is too rigid and would benefit the mentally handicapped if it were more flexible".

While being of benefit to those able to get about of their own volition, to relegate all people to small houses in groups of no more than six, places an unacceptable and harsh restriction on those unable to do so. It offends against any meaningful interaction by denying them an adequate social circle amongst their peers, and dictates who will form that limited social circle. For a variety of reasons, not least pressures on staff, their world could well terminate at locked doors with TV as the ultimate tranquiliser. "Idealism", as John Galsworthy said, "increases in direct proportion to one's distance from the problem."

Living accommodation alone does not provide an adequate quality of life; it is only acquired by its setting within an area of one's social, leisure and occupational pursuits, plus the freedom and capability to circulate amongst one's peers. This so-called 'integration', which can only quarantine them from the broad cross-section of their peers, is in danger of creating islands devoid of stimulus, surrounded by an ever increasing technically intellectually demanding society

It can often only frustrate the aspirations of such people and that of the staff who care. Reports indicate an increase in stress related illness amongst the staff due to working in the confines of small houses, and an overall staff turnover of 200%.

Why no more than six, why three or four? Perhaps three or four because it avoids planning applications for a change of use or the stringent regulations for a registered home. Perhaps six because housing associations, used increasingly by local authorities, find less than six uneconomical. 'Choice' has become a mockery, it is the provider who is doing the choosing!

Mr. Brian McGinnis, seconded from the DHSS into Mencap's policy department for three years, reviewed a book by Margaret C. Flynn entitled - "Independent Living for Adults with a Mental Handicap - A Place of My Own" which detailed a study of eighty-eight such people living in their own homes. While recommending the book he suggested "that for the most part they are not living independently in any conventional sense of the term." "Many are living very empty and highly dependent lives - not coping very well with finances or with each other and relying for both friendship and advice on their social

workers." "One of the most visibly 'successful' people has no contact with neighbours; needs continuing help with correspondence, money management, health and hygiene, home and household routines and management of his mainly free time. His most frequent visitors are social service personnel."

Ageing parents especially of profoundly mentally handicapped sons and daughters despair for a secure and reasonably stable future for their off-spring and more and more of the younger ones, as their children reach normal school leaving age, find only a vacuum and uncertainty. It is ludicrous to discharge from the education system at the chronological school leaving age people with a mental handicap whose mental age is that of a child of 8, 9 or 10 years. Many parents advocate that the ATC's and other training centres be placed under the auspices of the Education Department who have the expertise to ensure continuity of the process.

We are in danger of allowing an abdication by the State of any meaningful responsibility for the care of those who cannot care for themselves and the three or four or six in any house in any street for all such people hastens that abdication, as private profit-making commercial establishments, so encouraged, abound and flourish. Our children are becoming a marketable commodity - again who can doubt the wisdom of Patrick Daunt's words - "hang on to what you've got!" A household survey by the Charities Aid Foundation in 1987 among 963 households as a cross-section of society, found that 80% of Britons agreed that the Government had a basic responsibility to take care of people who cannot take care of themselves.

Care need not and does not destroy independence as some would have us believe. It just isn't true when that care is geared to creating stepping stones in many directions, taking the recipient to the limit of his or her abilities with dignity, and offering a way back if needs be.

I visited St. Augustine, Gennep, Holland, opened in 1958 with 100 mentally handicapped people, and, with sufficient funding coupled with the will to do so it has developed over the years until today it cares for 500 residents on a 100 acre site.

Its accommodation consists of individualised bedrooms in units of twelve people, with its facilities including a swimming and hydrotherapy pool, exercise room and gymnasium with a variety of modern aids, some specially designed; in house radio and video cable station for requests and films etc.; sports field, church, farm, horse-riding stables, cafe and picnic areas, social club, and a factory workshop employing some 425 residents, including many living with their families in surrounding areas. The factory has many products including the assembly of bicycle wheels, a popular form of transport in Holland, and tasks are broken down to simple functions. The medical and therapeutical provisions and dental clinic leave nothing to be desired and offer a much appreciated outpatient service. Satellite houses have been established for up to eight people, these being administered from the village. Gennep is proud of its 'Institution' and rightly so - the relaxed atmosphere is outward looking and one of continual progression.

Many parents fear that uncritical acceptance of the statement, ". . . it is increasingly recognised that the needs of most mentally handicapped people are largely for social, rather than health care", (Caring for People para 2.14) could result in failure to

adequately satisfy either need. For many individuals these two needs are linked and interact. Both must be satisfied by every agency providing care. The superficial but common argument that mentally handicapped people are not sick and therefore should not be in hospital ignores, among many other things, that many of these places were only named 'hospitals' after they became part of the National Health Service.

The Medical Research Council's study on the closure of Darenth Park Hospital has embraced social care in the objective assessment made of 'quality of life'. In summary, one third of residents moved out enjoyed an improved quality of life. The other two-thirds did not enjoy this improvement, indeed one - third were worse off. A parrallel study by researchers from The London School of Economics concluded that the average revenue cost per person rose by nearly 60% (compared with what it would have been in an improved hospital including a charge for site value). An implication of the MRC findings recorded by the team leader, Dr. Lorna Wing, is that living units in a campus with large grounds and sheltered villages would offer more freedom and opportunities for an interesting life for many than houses in ordinary streets.

I believe there is a case for reviving the essence of a proposal considered some years ago by establishing a single agency to oversee all provision for mentally handicapped people. It could be the channel through which all national funds would be allocated to bodies offering services locally - NHS, local authority, voluntary etc. If a grant or allowance was attached to each mentally handicapped person the opportunity for choice to influence service provision, rather than planning from the top down, would be clear.

A succession of Ministers have given approval and support for village communities and their evolvement within existing hospitals. On the 26th June, 1989 the then Minister, Roger Freeman MP in the House stated: "Residential or village communities may be part of the new range of facilities that will be built in the future. As long as these villages or residential communities for mentally handicapped people are not isolated or inward looking they will have an important part to play . . . I accept that some of the institutions that are being run down currently are physically in the community and I am sure that some of these facilities can be re-used."

Since 1965 some 25,000 residential places have been lost overall to people with a mental handicap, and it is not without significance that in the year 1988/89 the cases of inmates of prisons suffering mental disorder and handicap, rose by 4712 at a time when the prison population has shown a slight decline.

The need for residential care is increasing as the prevalence of the malady is not falling, multiple handicap is increasing, longer life is now usual, and many who would have benefited have, since 1983, been denied the long-term residential care provided by hospitals. I would suggest that from DHSS statistics alone some 350,000 residential places could be the minimum provisions needed for adults. I conclude that we must immediately stop destroying such residential places already available in hospitals, with their valuable and needed associated services. Instead we must consider how their well known weaknesses can be overcome.

We should be improving and expanding the resources we've got to meet the growing need not losing them.

Of greatest concern to parents has been the failure to grasp and understand the needs of the most severely mentally and multi handicapped people of our population. The failure to see that the medical, surgical, social, preventative, legislative, pharmaceutical and other advances which have wiped out the causes of certain handicaps, ameliorated the effects of others, and prolonged life in general, have also resulted in a growing population of those so dependent. For this swelling category there can be no careless evasion of the concept of lifelong care for lifelong needs; there can be no careless or optimistic release into open society, nor an assumption that they need only the type of care which can degenerate into warehousing.

With the Social Services Inspectorate's Report last year criticised the chronic shortage of day services and the poor management of those existing, there is little wonder that more parents, relatives, and professionals are seeking, for their charges, the sheltered care of residential or village communities only to find that the few communities have waiting lists of years. Such sheltered provisions can be provided on the scale required by their gradual evolution within suitable existing hospitals retained for this purpose, a concept which has Ministerial acceptance.

Many parents envisage such villages as having purpose built small living units replacing existing wards, and providing a high degree of autonomy. The existing extensive support services, educational, occupational, recreational, therapeutical,social, spiritual etc. would be available not only to their residents but also to those living in the surrounding districts. It has been impossible to provide specialist services on an individual basis to clients scattered throughout the populace. This has proved to be the case for the majority cared for in the family home.

Respite care would be more readily available, and satellitite housing outside the village and administered from it, would provide flexible responsiveness to changing individual needs. Operating on a revolving door principle they would offer a passage out for those able to cope in open society and entry for those unable to do so. They would accept and accommodate completely the whole spectrum of mental disability including challenging and unsociable behaviour, and enforce a transformation of management thinking from hospital to home. As centres of excellence and expertise, as part of and serving society as a whole, they would provide assessment, ongoing monitoring and advice, respite care and research into the alleviation and prevention of the disability. Above all, in addition to their viability in financial terms, the village has the more important potential to provide good quality permanent care for people with a mental handicap, difficult to achieve elsewhere, with rewarding employment in satisfying and progressive careers for staff in a community that has assured stability. They provide the feeling of togetherness, a sense of belonging, freedom of space and movement unhindered, the pleasures of individual or group activities, and most important the freedom from being condemned as different. With such residential places available in sufficient quantity, and in spite of the increase in the number of ageing parents, no longer would the question - "What will happen when I die?" go unanswered.

R. S. Jackson
Parent and Hon. Chairman RESCARE
(The National Society for Mentally Handicapped People in Residential Care)
23 Higher Hillgate, Stockport. SK1 3ER