HEALTH COMMUNITY WORK AND ELDERLY PEOPLE

Notes from a one day workshop
held at the King's Fund Centre

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London Community Health Resource jointly with
Long Term and Community Care Team, King's Fund Centre

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FOREWARD

This document grew out of a conference held on 18 April 1983, which was organised jointly by the Long Term Care Team at the King's Fund Centre and the London Community Health Resource. It is made up in part of papers presented during the day together with notes from some of the discussions which took place in the 8 smaller workshops but it does not attempt to be a full or static account of what took place.

In the pages that follow we have tried to capture something of the flavour of the event rather than a word for word account and if there are errors and omissions because of this we must take responsibility for them.

Our aim in producing this paper has been to share ideas more widely with others who are interested in the broad field of 'Health, Community Work and Elderly People' and hopefully to encourage future discussion and action. We would welcome comment and suggestions from anyone who wants to carry this work further.

To Malcolm Johnson, the conference chairman, to the speakers and workshop leaders and to the very active groups of delegates, we once again offer our thanks.

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HEALTH, COMMUNITY WORK AND ELDERLY PEOPLE

Introduction

London Community Health Resource is a resource centre in Central London for community groups and community workers working on health. The project has been in existence for 2 years, and in that time we have been building up a network of contacts with community workers and groups, and health professionals who feel they have something to learn from community development. This process is part of a longer term goal of establishing that the achievement of better health and better health care for large sections of our community, especially in inner city areas, is dependent on the active and informed involvement of people in the community. Their involvement in a wide range of decisions affects their health, both directly and indirectly.

This notion is not new, but it is often received with defeatism from people in the community (who may feel impotent to change the conditions of their lives which they know adversely affect their health, and would certainly prefer to remain passive in the hands of health professionals). Equally, it is often regarded with hostility from health professionals, who at worst may see it as a direct challenge to their power and authority, or at any rate, as irrelevant to their professional understanding of what the key issues and problems are.

In some areas of health, and among some groups, there has clearly been progress towards reaching these goals. Women's health is clearly on the agenda, not only amongst women who describe themselves as involved in the Women's Liberation Movement. Many community projects run successful women's health groups; health courses for women are being held at women's centres and community health councils. Health groups for pregnant women, and women with new babies also abound.

It seems a relatively easy area for community workers to get involved in, and also increasingly, it is accepted and welcomed by community-based health professionals, such as Health Visitors, who see their traditional case-work approach as inappropriate and ineffective in addressing the wider definitions of preventive health care and positive health.

The health of elderly people is more problematic. Elderly people are often passionately concerned about their health, and the local health care available, as are their families and friends. We know that elderly people are nummerically one of the largest group of health consumers, that resources are scarce within the NHS, and that the burden of caring for elderly people in the community is increasingly falling on women at home, who often have few or no resources to support them, either financially, practically, or emotionally.

We know that the present government's policy of closing down what often are inappropriate hospital-based facilitied for the elderly, with a view to promoting community care has not been matched by a transfer of resources into the community sector.

It was in this climate that London Community Health Resource became interested in the concern of several community workers we knew in London, who wanted to do health work with the elderly people in their neighbourhood, but

were unsure about the kind of initiatives which were likely to be successful. We didn't know much about what had been done, either, but we shared with them the conviction that the good health of elderly people was dependent not on the blanket term "community care" which all to often hides a total absence of any kind of provision of support. What is needed is a process of active exploration of a wide variety of responses to the health needs of the elderly, which are sensitive and flexible, and most importantly, are matched by generous resources from both the NHS, the local authority and through the voluntary sector.

This is what we hope this workshop will begin to explore. We see it as a learning day, where community workers and health workers engaged in a practical way can learn from each others's experience, and discuss problems and successes in a supportive and informed atmosphere.

We are very conscious of at least one important gap in this workshop. There is a glaring omission of any emphasis on ethnic minority groups and their elderly. We hope that the discussion that flows from this will not make the same error.

Finally, we hope that it will help build a network of people active in the community, and the elderly themselves. We also hope that it will lead to better collaboration between agencies like the GLC, Age Concern and Task Force, the local authorities and District Helath Authorities, and in the end will contribute towards the achievement of better health for elderly people.

OLD AGE - THE AGE OF CHANGE

Dr J A Muir Gray, Community Physician, Oxford

One of the dangers of any day where there are a lot of professionals is that people start talking about 'roles' too early. Where I come from 'rolls' are what you eat for breakfast - and I will leave discussion of that until later. What I believe to be important in working with any group of people is first to make an accurate definition of what we believe the problem to be and secondly to define what interventions we know have an effect on that problem. I am going to try to sumarise what we know about the problems of elderly people, particularly about the physical and mental problems rather that the social problems - though they are interwoven - and the evidence we have that these problems are preventable and treatable. There is clear evidence now to show that a lot of the problems that occur in old age are not the results of the ageing process.

When speaking to older people I often suggest that the best step they can take is to write their own health autobiography. You can do that very simply by drawing a graph with 'age' along the bottom line and 'physical ability' along the vertical line. When we are born we are able to do certain things like breath and suck and co-ordinate some movements but our abilities are limited and we are very dependant. In the phase of growth and development there is an increase in physical ability and mental ability and a decrease in dependence. Then there comes a turning point. For most people that turning point comes in the early twenties and from then on it's downhill all the way. The good news is that the rate at which most people decline is due not to the aging process but to three other processes which we can modify - loss of fitness
- disease
- social change.

Why do people turn this peak and start to decline?

Aging is a normal biological phenomenan which starts as soon as the period of growth and development ends, but in my view it is not aging that causes the decline in ability, it is a loss of fitness. That loss of fitness is usually due to a social change. In my case it was in moving from one university course to another and playing less sport. For many people it is leaving school, for women it is sometimes the birth of a baby or the birth of two babies close together. There is a gap between how able people actually are and how able they could be and that gap gets bigger the older we get. There is interesting evidence that there is no age above which you cannot close that gap between how able you actually are and how able you could be. The evidence we have is that people in their 70s, 80s and 90s can close the gap and I will say a little about ways in which they can do that.

When I use the term 'fitness' this implies doing the London Marathon, playing football and those sorts of activities, but by 'fitness' I mean the the ability of the body to cope with an external challenge. For example looking round the room I couldn't really say who was 'fit' and who wasn't, but if on the other hand I asked you to run to the tube and back I would have a clearer indication, when you got back, of who was able and who wasn't. When we look at very elderly people, their loss of fitness is a very

significant contributory factor in their loss of ability and their dependence on others.

I find it helpful to think of four overlapping circles - Ageing
- Loss of Fitness
- Disease
- Social Change.

Fitness and Ageing overlap because we know that the older we are the more quickly we lose fitness and the more slowly we regain it. If you are fifteen you can sit studying for two weeks, then play a game of football and go to a disco. If you try that at thirty-five you may get through the game of football, but you are unlikely to get to the disco. If you sit about for two weeks at seventy-five you may have difficulty recovering the ability to walk. This has implications for the type of help we give elderly people which assumes they are all disabled, declining and dependent and where the style of work is to do things for them. All the evidence shows that we should be trying to enable elderly people to do things for themselves and that the best way for them to retain fitness is not for us to give them an hour's physiotherapy twice a week but to enable them to stay at home, shop, peel the potatoes, do housework, go to church, to to the pub. The physiological and biological benefits of that are now well proven.

The third circle - Disease. Centainly diseases become more common as we get older, but the overlap between disease and ageing appears to be quite small. We used to think that a lot of diseases were a form of accelerated ageing. Osteo-arthritis, for example is very common in old people. It limits mobility, causes pain and causes functional problems. When I was at medical school I was taught that this was very similar to normal ageing. In some people the body wore out more quickly than others and this was an accelerated form of ageing. We now know that in about three quarters of the cases of osteo-arthritis we can identify factors that were responsible - such as congenital dislocation of the hip, or a poorly set fracture in childhood. The more we look at the health problems and the diseases of old age the more we see that the diseases that cause disability are preventable. Think of the diseases that were once common in childhood that now have permanent disability effects among elderly people - rickets, tuberculosis, polio, myelitis, rheumatic fever and even measles combined with malnutrition which led to septis of the lung and suppuratory ear disease. Some of you will be too young to have known people who have had mastoid operations but when I was a child in Glasgow it was a very common operation. Terrible ear disease and chipping the bone away to draw the puss. Then we look at deafness in old age and say - 'high tone deafness is a function of normal ageing'. It is now quite evident that in many cases it is due to noise and to middle ear infection. Similarly, health problems in middle age can affect ability in old age. Heart disease, strokes, bronchitis and emphysema - these are all preventable diseases.

When we look at old age itself we see that there is still scope for the prevention of disease - hypothermia, depression, anxiety, some types of incontinence, some types of fall, and the most common preventable disease in old age latrogenic disease - disease caused by doctors either through incorrect prescriptions or inappropriate communication. It is now quite clear that the fault lies far more often with the professional than with the patient.

What we are seeing is a wide range of problems which are preventable and can be tackled. We see the same for intellectual decline, that what was assumed to be irreversible decline is now seen to be due to a group of factors - the education pattern throughout life, lack of intellectual fitness due to the fact that elderly people are not involved in society. Dementia is clearly not due to an accelerated form of ageing: it has some other cause. We cannot yet prevent dementia but it is not normal ageing.

Finally, the beliefs and attitudes which are of importance. The beliefs with which elderly people grew up have to be taken into account when we are planning any sort of service or any sort of intervention. The beliefs I commonly meet are - "It's my age, what else can you expect", and usually some doctor has previously said the same thing thus providing 'medical evidence' for that belief.
"It's God's will" - a form of religious fatalism tied into the book of common prayer for the sick and a different view of illness from our own "It will never work". Many elderly people have been disappointed so often that it is really much safer to say "I'm alright" than to let your hopes build up and become involved.
"Rest is good for you". They were told by doctors for many years that rest was a good thing. Now we have changed our mind about that but they were brought up for forty to sixty years being told by doctors - "rest", "stay in bed". When I was at medical school there were still people with heart attacks spending three weeks in bed being shaved and fed by nurses. Current practice is to get people out of bed within forty-eight hours. Again these are medically established beliefs. We were the ones who propagated and sustained that belief.

The beliefs of other people are important too. The belief by other people that it is all due to 'old age'. The belief that 'caring' means doing things for elderly people. 'Care' I find a very difficult word that has to be defined 'carefully' because what people mean by 'care' is - "sit down there and I'll put a shawl round you". I believe that one of the reasons people are so paternalistic is guilt. They really feel guilty about the way in which elderly people live, their incomes and so on but instead of campaigning for a real change in the causal problems they prefer to have their paternalistic approach.

Finally I would like to sumarise some research which has implications for community work because it emphasises the importance of a community approach. The first is evidence that it is not ignorant patients but unhearing doctors that are the problem. We don't listen enough to what other people are saying.

Secondly, the need for people to participate both individually and collectively if treatment is to be effective. There is no point in having the best treatment in the world if people do not take the advice that the doctor thinks he's giving. People recall about 50% of what they are told and make mistakes in 30 - 40% of the treatments. That is the professionals' problem not the public's.

Thirdly, the knowledge that <u>any relationship</u> is a medium for health education and that the sixty thousand home helps and all the volunteers and others meeting elderly people are of vital importance in education and change. The expert on high has his part to play but much more important is the person who has a good relationship with the elderly housebound person.

Fourthly, the need for small scale planning. There is a gap between the primary health care team serving around four thousand population and a health authority with four hundred thousand. In our rural area we are looking at matured groups based in small towns and in cities there is a similar need to define what a community is geographically.

Finally, the importance of community work. This is a message which is finally getting across and which a centralised approach to health planning is going to have to live with. There have been two decades in which we have gone for control planning and some central planning will continue but the important thing has got to be planning from the bottom up. By planning I don't mean central but the definition of problems in discussion with other people, the definition of those interventions what will be effective and setting objectives for what you want to do in your own locality.

I am grateful to have the chance to talk to you today. I sit on the Health Education Council and have contact with Helen Rosenthal at the London Community Health Resource through that. This day will tie in with the work which we would like to do on health education in old age and the way in which what we do in the centre will support community initiatives without interfering with the freedom and variety which is the strength of the community sector.

Discussion

a) On the issue of doctors who are pressed for time and may tend to give repeat prescriptions to people who need more attention, who may be depressed and who could benefit by help from other professionals. 'Repeat prescriptions' are one of our top priorities in terms of the health care offered to a whole range of people. One of the most important things we can do is to try to change doctors. It may be important to go for GP or Health Visitor training groups and to aim to influence trainees.

b) The four interlocking circles may omit 'Quality of Environment' and yet for anyone involved in community health work in London this can only be a contributory factor.

The fourth circle - social change - should include the important factors - the beliefs of elderly people, attitudes of others and social and economic environment. Poverty, bad housing and unsatisfactory environment are of fundamental importance. In the Health Education Council we have found a difficulty of saying who is going to deal with the different bits of that. We can call the Health Service a Disease Service and make sure it deals with that effectively but there is no doubt that without adequate housing and a decent environment and income then the demands on the 'Disease Service' are going to be increased. Mental illness is an area where doctors would prefer to ascribe illness to either genetics or early family upbringing because it is then easier not to feel guilty. If poverty plays a part in mental illness than doctors feel guilty because we play a part in the equation by the level of our salaries. Community groups may therefore have an important part to play in looking at the relationship between environment and mental illness and in bringing up unpalatable issues for highly salaried professions.

c) It may be that by joining Family Practitioner Committees as members we may be able to influence the way GPs see the situation of elderly people.

The Family Practitioner Committee has been a means for paying doctors, pharmacists, dentists and opticians and has been basically an administrative body. I believe it can do a great deal more for example in the training of receptionists, or practice nurses. Family Practitioner Committees would welcome some positive ideas, at the present time, and they do have resources to carry out new initiatives.

WATERLOO PENSIONERS' HEALTH GROUP

The pensioners' Health Group started when a student on placement with the Health Project, together with 3 pensioners, organised an 8 week health course. It started in March 1981. At the end of 8 weeks the core of pensioners attending the meetings decided that they would like to continue as a weekly health group. The group had a break over the summer period and continued to meet. The group meets every Thursday morning for an hour-and-a-half at Barley Mow Clinic. There are usually about 6 people at each meeting, although there have, at times, been about 12 people and never less that 4. The group have about 25 on their mailing list. Most live in Waterloo; 1 or 2 live in Kennington.

The first health course was publicised through leaflets prepared by the pensioners. These were put through doors, left at doctors' surgeries, at the local library, local day centres, local clinics and local community centres. The pensioners spent time talking to people they know about the course and the student distributed many leaflets by knocking at pensioners' doors and discussing the proposed course with them. The course was limited to people living in Waterloo.

The 3 pensioners and the student drew up the programme for the course together and the topics included 'water-works', the home-help service, etc. At the end of the 8 weeks the pensioners reviewed the course, decided to continue and drew up a list of topics and interests for subsequent meetings. They usually organised meetings 8 to 10 weeks in advance and produced publicity leaflets each time. Health topics they have discussed and explored include tablets and their side-effects and rheumatism.

They get very angry about comments like: "they're too old to learn" or "it's too late for them to start thinking about health". They are not just concerned with chronic illnesses, death and dying but with the quality of life.

Members of the group feel that pensioners are too often fobbed off by local health workers by being told. "it's just your age". They believe strongly that this attitude needs to be overcome by the Health Service and by pensioners themselves so that more appropriate services could be provided. The 2 sessions on doctor/patient relationships, where the pensioners acted out the doctor/patient situation in the surgery, gave rise to a lot of criticism about the medical profession. Many of the members had no expectation of being examined by their GP. The contact the group has had with health professionals has been helpful in breaking down barriers. The informal approach of the visiting speakers, without the white coat or uniform, meeting 'patients' outside the clinic or surgery have all helped to make the distance between health professionals and patients seem less prevalent.

The group has frequently reiterated the need for more counselling in the health service and has expressed a desire for helath checks for the elderly. The group itself has not begun to be involved in campaigning for improved or alternative services however, several members have become involved in the campaign for more control over the health clinic the group uses and 2 of the demands included a health check-up clinic for the elderly and a chiropody service.

The meetings, which are informal and friendly, usually take the form of a discussion. They have made good use of the skills and expertise of health professionals in the vicinity. Two GPs have visited the group, 1 on a very regular basis, to talk about the heart, drugs, digestive system, chest. Two district nurses from the local GP practice came to meetings about 'water-works', leg ulcers, constipation and the digestive system. The community dietician has also been to a meeting and the health education unit have provided films about particular health projects. A member of the Lambeth and Southwark Mental Health Group has also joined in a discussion about depression. They have also met up with the St Martin's pensioners' health group in Tulse Hill, where they exchanged ideas for meetings and told each other what each group had done. Eight student nurses from St Thomas's Hospital recently visited the group. They make good use of visual aids, including charts, diagrams and models from the health education unit, as well as those they made themselves or made by visiting speakers. The group also has its own collection of books from Lambeth Libraries outreach service.

The group is now well established and run by the pensioners themselves with minimal support from one of the community workers. They share responsibility for organising speakers; designing, producing and distributing publicity leaflets, drawing up their own programme, making and buying the tea and biscuits, making posters, visual aids and putting newcomers at their ease.

Their interest in health is shown by the fact that the group still meets and is steadily growing. Moreover, they keep coming up with more topics to discuss and many members would like to explore each topic in more depth. An important comment to make is that the group do not just want to talk about illnesses traditionally associated with the elderly, but has a keen desire to discuss all aspects of health and to learn about how their bodies work.

Despite the fact that the health group does not see support as its main function, the very existence of the group helps to alleviate isolation, loneliness and depression. It not only provides an opportunity to meet, but offers a warm and supportive atmosphere for people to share their feelings and ideas.

The group has gone a long way in promoting interest in and an understanding of health and it provides a vehicle for access to health information. Members of the group are beginning to feel more confident when talking to their doctors and they are starting to define their health needs, with several members involved in the campaign to improve local health services.

The weekly discussion group continues with a varied agenda, recently a series on alternative health, exchange visits with other pensioners' groups and more detailed discussion on topics already covered. Individual members are active in supporting other groups who use the clinic to campaign for services to be developed; for example attending meetings and supporting women who are developing ideas for a well-women clinic.

The Pensioners' Health Group and its activities was the subject of a Thames Television 'Help' programme which led to an increase in the uptake of the check-up clinic for the over 60s. Members of the group have contributed to conferences and seminars on health care for the elderly.

The Pensioners' Health Group acknowledges, inevitably, that it involves a limited number of pensioners although it does have a ripple effect amongst the friends of those who are in the group. The group will continue to meet as it does at present. Some of the members are keen to use their confidence and knowledge thay have gained from the group to get involved in issues which affect the wider elderly population, for example the caring of isolated elderly people. Thus the Group is slowly beginning to have a wider perspective.

PENSIONERS' HEALTH COURSES IN BARNET

The Workshop was introduced by 5 representatives from Barnet who all helped to set up the Health Courses discussed.

1. Grahame Park

The speaker worked at Task Force for 4 or 5 years and was co-opted to the Community Health Council. In 1981 talks about the health courses started and small groups of workers set up pilot meetings on the estate, where there were very few activities for pensioners. Some 27 pensioners turned up for the pilot meeting and a working group of 7 was set up. The aims of the course were - demystification; the discussion of preventative care; control of health; and to collectivise experiences. The group met over 3 months in 12 sessions, 8 or which were on various topics with speakers. There was also keep fit, exercise and a film every fourth week. 50-60 pensioners attended each week. The pensioners organised publicity themselves, while the library provided books, etc. A Health Pack was also produced for the pensioners, including summaries of each speaker's topic. The group decided before the end of the course that it would like to continue meeting, and has done so for the last 2 years as a social club. Monthly health talks, keep fit, etc are held and the membership numbers 104 pensioners. It is also financially self-supporting.

2. Finchley Central

This course had a similar start to the one at Grahame Park, but on a slightly different basis. There was no existing activity for pensioners and a health course was seen as a vehicle for getting people together - to discuss ageing, diet, etc - and aiming to try and bring in the housebound. 80 people attended the initial meeting and a working group was set up. Transport was a priority, and a charge of 20p each week was made. The group received a small grant and there was also a lot of support from the Health Education Department and other statutory bodies. Now the group is self-running and centres on social activities with a health input; the programme is decided by members. There is a relaxation course and keep fit is very popular - particularly techniques dealing with stress. The group has been very successful in providing a focus which breaks pensioners' isolation.

3. East Finchley

This health course was set up after a worker from social services was approached by local pensioners and in turn contacted Task Force and the Health Education Department. The pensioners wanted a local course, but the rooms in the neighbourhood centre where it was to be held were very small, with only room for about 20. Pensioners who were known were invited to a planning meeting, a working group was set up (mostly workers with 2 pensioners) and 8 sessions were held. The course was not as well attended as had been anticipated, but broadened out into another course which, although small, was more successful. It was decided to publicise the health courses in the local press, though there are already a lot of competing activities for pensioners in East Finchley, and there are advantages of a small group in that people become involved in discussions. A 9 week course is currently running,

with attendance up to 15 pensioners, but this group will probably not develop in the same way as the others.

4. East Barnet

The East Barnet group is similar to those at Grahame Park and Central Finchley - the motivation was to set up a club right from the start, with a health course to initiate it. At the initial open meeting there was some concern about the health course by pensioners, who felt that there was too much emphasis on health. However, when the final programme was drawn up it included a lot of health sessions. Pensioners now have keep fit sessions every week, although it is hard to find tutors to do this.

Discussion

Withdrawing Workers. After the course came to an end the committee consisted of more pensioners than workers, although one worker still attends the committee meeting. Support started to tail off after 6 months, but is available if the group appears to be falling apart or for new developments.

Transport. This varies from group to group. For example, Waterloo Pensioners' Health Group have access to a mini-van which they can book.

Tutors - eg for keep fit. Difficulties in some boroughs in getting funding and in some no funding is available even from Adult Education.

Roles of Workers. Some health visitors have no experience of group work and at Grahame Park, when the club wanted to continue, the health education worker and health visitor wanted to withdraw because it was not exclusively health-oriented. Problem of jobs overlapping also arises and can affect funding. In some cases, it is possible to play very messy local authority systems - write an application stressing education in one, elderly in another. Getting to know policies of local authority is helpful.

Aims and motivations of setting up courses are very different. Original aims as seen by workers are very grand. Aims of pensioners may be very different (Grahame Park). It is important to be clear from the start on the motivation of people involved in planning.

Topics. Some topics which are not welcome (eg bereavement) were indicated at the initial open meeting. The crux is that the group of pensioners must be involved in the programme. Presentation is very important, eg bereavement - emphasis should be on practical aspects or counselling. One opinion: don't spend too much time on elementary information.

Elderly Men who don't go to classes. This issue was raised. How do we get in touch with them?

What are the Ends? Are the health courses an end in themselves? Could they develop into campaigning groups? Waterloo helped individuals to stand up for themselves (though role-playing in particular - doctor/patient) and campaigned successfully for health checks. Barnet Community Health Council, which has 8 branches of Pensioners' Voice, is trying to set up a group to talk about issues confronting pensioners. It is specifically interested in health, how the health service operates, how it affects pensioners. Issues at present have not been discussed borough-wide.

Final Points. Big is not beautiful as far as health courses are concerned. It is essential that pensioners are involved in planning and running these courses from the start.

COLLABORATION IN THE CARE OF 'CONFUSION'

Ann Rennie Payne, worker at Greenwich Age Concern and Doreen Taylor, a member of the carers group, introduced this topic by describing the range of work carried out in Greenwich. This began with a general interest in campaigning action on behalf of 'confused' people which has developed from a grass roots level. This has included a Day Centre set up jointly with Greenwich MIND where the emphasis is on encouraging users to do as much of the organising at work as they can, or to go shopping or to prepare lunch for the group once a week, and relatives and supporters are invited into see the people they care for relate to others in the centre.

A working group, consisting of people from the Health Authority, Social Services, Housing and Voluntary Organisations, has been formed which, among other activities, has organised an intensive week long programme with open evenings for the public, a day event for social workers and a half day for environmental health officers.

This workshop concentrated specifically on the experiences of caring for a 'confused' relative and the human costs of this.

What Price Caring?

'Confused' Person	Carer	State
1st Year		
Loss of home	Financial cost	No cost
2nd Year onward		
Loss of: dignity independence freedom rights status Role changes Guilt of dependency Distribution of relationships Loss of: hope friends identity	Loss of: job career pension security freedom hope Role change Guilt of resentment Destruction of relationships Loss of: health friends personality	Minimal cost
Final Costs		
Institutionalisation	Breakdown of physical and mental health	Full term care for the person Health care for the carer

Discussion

This was centred round a description of Doreen Taylor's own circumstances as a carer for her 54 year old husband who suffers from Alzheimers Disease. The full account of the discussion will not be set out, but central points should be stressed.

- The level of public and professional ignorance about the nature and consequences of Alzheimers disease and Dementias.

- The powerful messages from individual experiences for the planning and management of health and social services provision.

- The complexity of the pattern of costs and needs which can only be met by collaboration of a variety of agencies and services.

NEIGHBOURS AS A RESOURCE

This Workshop was introduced by Diana Leat, Research Fellow at Policy Studies Institute (PSI), and John Bolton, Community Worker, Wandsworth Social Services.

Diana Leat outlined a 6 month pilot project she had carried out on a part-time basis which aimed to identify people over 75 in 3 neighbourhoods, and to examine the informal help they received from neighbours. The 3 contrasting neighbourhoods were:

a) a council estate in North London (racially mixed with a high turnover)
b) a council estate in Kent (more stable and homogeneous)
c) a middle class, owner occupied area in Kent.

A major problem was getting elderly people to open the door. In the London area, the project was linked with the local Social Services, which to some extent legitimised the interviews. In Kent, the only label used was 'PSI'. This meant nothing to the people interviewed, who seemed less tolerant of strangers than the London people.

Diana Leat made a number of general observations from the study. A distinction has to be made between 'doing things with friends' and 'being helped by neighbours'. The term 'help' tends to be reserved for when people are in a crisis, more usually people do things with or for each other. People 'did things for each other' or helped for complicated reasons, including paying back debts, or believing in helping as a moral duty - they didn't necessarily like each other. Diana Leat used a distinction between 'care' and 'support' to analyse her findings.

Care was an activity like cooking or shopping, carried out regularly on at least a weekly basis.

Support included a wider range of more 'background' activities like chatting on the stairs. Support often provided a basis for the development of care, which was often activated by a crisis.

On the London estate, there was more reciprocal care amongst the elderly. On the Kent estate, people kept much to themselves. Significant in the low level of care in all areas were:

- many people didn't need care
- it was regarded as preferable (and indicated the different available caring options today) to approach a statutory form of care or support (GP, Social Security, etc) than to approach a neighbour when in a crisis
- ideas about privacy and independence were important - "I wouldn't dream of helping unless asked".
- in the middle class area people visited as friends for tea or coffee, but on the council estates this was less likely and 'popping in' was frowned upon
- there was the fear of being seen as a gossip, interfering, etc
- family, daughters and sons would do a lot of caring even when they live nearby, so there was less need for neighbourly caring. People without family were in general worse off, and this was more frequent on the London estate.
- car, 'phones and higher incomes in the middle class area generally made life easier.

A general question posed was whether the vogue for neighbourhood care didn't smack of middle-class assumption that getting on with one'e neighbours is (a) natural (b) a'good thing'.

John Bolton outlined a survey of isolated and vulnerable elderly people, and the agencies providing a service for them, carried out by Wandsworth Social Services in 'The Grid' area of Southfields, Wandsworth. The area is one square mile, mixed housing, though predominantly owner occupied, with a growing Asian community.

Problems with carrying out the survey included:

- being part of the local authority, especially in seeking information from local voluntary and other agencies. Churches, residents' associations, pensioners' clubs, etc felt that the survey represented an implicit criticism of the caring they did, which limited co-operation
- the Southfields Patch Team was not really local, having responsibility for a larger area
- the need for local authority accountability, especially where caring is informal
- the tendency for the professions to be seen to monopolising caring.

The impetus for carrying out the survey was the rapidly increasing number of referrals of isolated elderly people to the Southfield Social Services Patch Team, and a recognition that help offered was often inadequate.

The survey took 9 months, using volunteer interviewers. The questionnaire covered information about age, whether living alone, on the telephone, need of and access to day-to-day support, social contacts, offers of assistance and visits to other people. First a letter was sent to residents, and questionnaires were distributed to elderly people by Home Helps, to those receiving the service, by an Old Peoples' Club, and by volunteers. 60-70% of elderly people were covered, with about 25% af all elderly people in the area responding.

The 2 main areas of unmet needs were the needs of the less mobile and isolated individuals, which could be met by volunteers, and the need for more provision of local activity. In addition to discussion with all existing agencies, a public meeting was held for pensioners involved in the survey who felt that provision was inadequate. Attempts are being made to set up local networks, A meeting was also held for Good Neighbours - a few attended but were mostly giving high levels of care already and were in need of support themselves. Monthly carer's meetings are now held. A new old people's club is being set up on non hierarchical lines, and the new links with voluntary and other agencies are being fostered.

Discussion

There was a lot of interest in the mechanics of using volunteers in the Wandsworth Survey. How had they been recruited? How did they identify themselves when calling on elderly people? Did they become helpers in a longer term sense? Some points which emerged were that existing community projects and schools were good recruiting sources, that they needed support if they were to continue, and that no Asian or black people had been recruited.

There was difficulty in Wandsworth of finding out what was needed by Asians, when the Asian Community Associations wanted to deal with all referrals of Asian citizens themselves.

Confidentiality was another issue. Although gossip on a neighbourhood level is often rife, there is a problem about he State attempting to link into existing informal caring networks. But as professional agencies often tend to make unfavourable judgements about the level of informal caring, it is important for them to gain a picture which is more than impressionistic, of how much and what kind of informal caring exists.

SLOWING DOWN THE BAND-WAGGON

April Whincop and Rodney Mace of the Southwark Adult Education Indtitute introduced a discussion in the field of Reminiscence and Exploring Living Memory. The idea was put forward about a year ago, because there was concern in the Institute that not enough resources were offered to the elderly - 18% of the Southwark population. They are often either housebound or institutionalised, and have little access to educational provision. Moreover, because they are unaccustomed to group learning situations, an attempt was made to personalise the learning/teaching situation. April and Rodney were recruited to set up a course with people in Part 3 accomodation; they extended it to include elderly housebound.

Aims and Objectives

The educational provision aimed at:

- maximising the participation of elderly people in the production of their own historical story
- bringing about involvement between the outside community and the community of the residential home
- improving people's self-image and renewing their confidence in their ability to learn
- making sense of their skills and experiences.

The objectives by which these aims might be fulfilled were:

- to create opportunities for reminiscing about life experiences
- to provide links between the past and the present in terms of the subject matter initially raised.

The initial framework of the project was to revolve around the themes of health and politics in North Lambeth and North Southwark. This area has a colourful political history. The old people's home there used to be the Bermondsey Medical Mission - set up to administer to the local poor, and train medical personnel to be sent out to the empire. However, it was described as "all prayer and pudding" by one resident. Some of the problems encountered came about because of the religious nature of this institution. Also, myths about health were not actually discouraged.

Problems that Arose

1) The problem of extreme isolation is one experienced by many people in the home; additionally, some relationships between residents within the institution are extremely stressful. Difficulties arise in talking about this person's past: the newcomer is perhaps the only person they talk to, who takes an interest in them, who learns about their past. Very strong, intimate links can be established, and a sense of dependency can grow. Both workers found this highly uncomfortable. This doesn't only happen in homes/institutions, it can happen in other situations too, but it is different with the ambulant elderly. It leads to a feeling to concern about some of the reminiscence work going on: is the interviewer/interviewee relationship become a secular confessional, rather than being t he educational situation it purports to be? Nor did they feel equipped to offer the support skills needed in such situations whenever disturbing or distressing memories were

aroused by reminiscence. Even if such distress isn't apparent during the presence of the interviewer, it could accumulate and surface later on.

The crux of this problem is that funded projects are finite: what happens when it is over? The period after withdrawal is potentially hazardous and can cause pain on both sides.

Therefore, the main question becomes; how is the relationship ended? In the case of the work with the Part 3 home residents there was no point in even leaving tape recordings as they were not allowed to have tapes or radios. Some people have literacy problems, others have sight problems. So, without the option of leaving tangible mementoes behind, we would recommend that the withdrawal process must not be sudden, and that there should be a dovetailing of services within an area. Thus, people with supportive skills can work alongside a group of volunteers to maintain continutiy with visits and activities, after the disappearance of the original interviewers.

2) The second major problem lies in the means of entering people's past memories (particularly people who are withdrawn/confused). Ethical problems are raised with the disclosure of information by staff to us. The matron at Bermondsey offered some small bits of information about some of the women. It became obvious that you had to be careful about pursuing what to all intents and purposes might not be true. If 'lies' are told - or fiction - maybe the person is creating something for their own reasons. This is a difficult area, particularly with people who don't have a lot of control over their lives. This was particularly obvious through their lack of possessions: often a deliberate separation from their material past has taken place, possibly imposed by someone else.

   We would recommend more liaison with all the staff before and during tutors' involvement, particularly when working in Part 3 accomodation. This would involve some access by us to case histories. The same seems to apply to working with the housebound elderly.

Positive Features

The residents takng part in the project appeared to enjoy an improved status in the home; the workers enjoyed the contact!

Conclusions

Reminiscence work is very valuable, but certain serious problems have to be overcome. There is a need for continuity: a course starts and ends, so there must be a dovetailing of other roles within a team effort. The question of having access to case files has to be addressed; liaison with staff in institutions such as old people's homes is important. With the housebound, on the other hand, it must be recognised that there are gaps in people's life histories.

Discussion

What is the role of the historian? She/he seeks to record and illusatrate the process of material change; but she/he also promotes a realisation

of the continuity of attitudes and emotional reaction. Perhaps all those involved in such work should contribute to build up a bank of information.

A worker from Lewisham who works with West Indian pensioners described some reminiscence work they do , which is printed in the local paper under the column 'Mama and Papa Talking'. Each pensioner takes it in turns to talk about their childhood in the West Indies.

One should be very aware in this type of work of the importance of returning people's memories to them, once they have been 'captured'. Books, tapes, and the passing on of this information to other generations are all important.

REMINISCENCE WORK WITH HOUSEBOUND ELDERLY PEOPLE

This workshop was introduced by Alan Bearne, whose work with Greenwich Task Force included setting up a Reminiscence Project. He currently works with another Life History Group, and has been involved in the development of 'Exploring Living Memory' Conferences.

Why Encourage the Elderly to Reminisce and Record their Life History?

There are many ways in which reminiscence work and the recording of life history have been used for the benefit of both the individual elderly person and the community as a whole. Some of these benefits are listed below:

The benefits of therapeutic uses (as carried out by staff and elderly people in geriatric wards, day hospitals, day centres, old peoples homes and sheltered accommodation units).

Reminiscing by the elderly, mentally frail can often act as an enjoyable and stimulating mental exercise. This can often be best achieved with the prompting of old photographs.

Reminiscing can often restore a sense of personal value to isolated and confused elderly people and can enable them to retain a fuller perspective of their own lives and hence a chance to relate themselves better to the present day.

Because the elderly become the authorities when discussing the past, it can give them a new found feeling of confidence and can make others respond to them with a greater respect.

Discussing memories can break down barriers and can assist in communication between staff and the elderly as well as between individual elderly people.

Reminiscing can help friends, relations and staff look upon the elderly person more clearly as an individual.

Reminiscing gives people the opportunity to discuss bad memories with others, share their grief and come to terms with past shocks and present day fears of ill health and personal loss (eg death of spouse). This is delicate work but it is rewarding.

Old photos, etc can be stimulating visual aids for speech therapy work and other forms of therapy.

Reminiscing is enjoyable. Those who discuss their memories together seem less likely to be depressed than those who do not participate.

Everyone reminisces whatever their age, but nostalgia can be a subjective indulgence which could lead to self pity and remorse, particularly in the case of isolated, housebound pensioners. A reminiscence project is an excellent way of channelling individual memories into a collective and objective context.

The Benefits of Cross Generation Work (which has taken place in conjunction with schools, youth clubs and unemployment groups).

Joint Reminiscence Projects can break down barriers of age and can reduce stereotyping of age groups.

Joint projects can make young and old realise that they have much more in common with one another than they may first think.

Projects are a good way of getting younsters more interested in history and this, in turn, makes the elderly feel that they have made a worthwhile contribution to those youngsters' education.

Joint projects also break down cultural, social and racial barriers.

Such work can also promote tolerance and patience in both age groups.

Cross generation work can also make youngsters more appreciative of day to day problems faced by the elderly. In some cases, young people have assisted the elderly in some of their campaigning.

The Benefits of Elderly Involvement in Community History Groups. (Nearly all local history/community history groups encourage people of all ages to participate in their activities).

Community history groups can break down age, cultural, social and racial barriers in the localities where they work and this can further help people to understand one another better.

By investigating their local history, people can relate their past experience to present day problems and issues. This has proved of particular benefit to penioners when council services, housing issues and transport cuts have been challenged in their historical context.

Such work can involve pensioners closely with the rest of the community and does not isolate their problems from similar problems shared by the rest of the community.

Community history work can also make people more aware that social and political circumstances have changed little over the years and people may be motivated enough to want to change the situation and press for greater control over their lives in the future.

The work is a good way of collecting and preserving the history of the people in the neighbourhood. Local history is thus recorded by local people for local people.

This type of work is an enjoyable, educational and collective exercise.

The Greenwich Task Force Reminiscence Project 1980-1982

Much Life History work is carried out in institutions because of its therapeutic value, but housebound elderly people also have memories to share. The starting point was an attempt to link these people, who were contacted through Meals-on-Wheels and Home Help Services, into a network of activities based on reminiscence and personal histories.

The idea for the Greenwich Task Force Reminiscence Project came from reading of the work done by Mike Kemp, a DHSS architectural advisor on accommodation for the elderly and mentally infirm, who initiated a Reminiscence Aids Project in 1978. He felt that reminding isolated and confused old people of the past would "restore their sense of personal value and enable them to regain a fuller perspective of their own lives and hence a chance to relate themselves better to the present". So with the aid of old photos,music and relevant narration, the 'reminiscence therapy' was introduced to selected old people homes and geriatric wards. These visits proved that such aids did evoke memories and, in individual cases, after some years of self neglect which had been accepted by staff as irreversible decline, pride and dignity returned.

Although inevitable similarities between the two projects were to arise, without the wealth of equipment, resources and time available. The Greenwich Project was to be more modest in its aims and less defined in execution. Yet this revealed an added dimension to the project for, instead of the material being readily available, it has been the elderly themselves, particularly those who are housebound, who have had to look for and provide the material.

Since the outset of the project, a variety of old photographs, newspapers, magazines and such like have been collected. With this material, files under particular subject headings such as transport, entertainment, street scenes and local history have been compiled and a small, mobile display constructed, the uses of which are described below.

Before putting any of the material into use some of the general issues mentioned above had to be thought through, eg fears of encouraging too much reminiscing, or evoking bad memories. Another reservation was voiced concerning the possible exploitation of the elderly - using them simply as a resource for local and oral history projects. It was possible that workers, volunteers and other relevant groups would become so interested in reminiscence that they would forget the purpose of the project and for whom it was initially set up. To prevent this it was agreed that high priority would be given to informing the elderly about the project's progress and that they would at all times be given ample opportunity to air their criticisms and suggestions. Response to the regular reports sent to housebound pensioners who have contributed to the project subsequently bears out the importance of this. By being informed of the many successful uses of their contributions to the project, their sense of pride and worth in society are maintained.

So with these and other less signigicant observations taken into consideration, the reminiscence material way put to its many uses.

The Uses of Reminiscence Material and Other Work in the Project (abbreviated from the original report)

Reminiscence Socials

Several Reminiscence Socials have been held at old people's homes, sheltered accommodation units, and community centres throughout the borough. At these, residents and local housebound pensioners (brought to the venues by volunteers) looked through the reminiscence files, and mobile display,

commented on local history slides, entered a 'do you remember?' quiz and joined in with music hall entertainment. Besides proving to be enjoyable events, it acted as a stimulus for future initiatives and helped break down barriers between pensioners and staff.

Volunteer Visiting

Greenwich Task Force have many volunteers who visit housebound, isolated pensioners and although, in time, good friendships are formed, the first few visits can be a little difficult. The reminiscence files have been invaluable in breaking the ice and providing a subject of common interest to talk about.

Reminiscence with the Confused Elderly

The reminiscence files and display were used by Age Concern and MIND workers in work they carried out with the elderly mentally frail, some Greenwich pensioners were also involved in being interviewed by an Help The Aged worker for their Recall Project, a tape slide show which, when completed would be used in therapeutic work with the elderly.

School Work

Pensioners have participated in school work at primary and secondary schools. They have taken along the mobile display and discussed their memories with the children. They have also shown local history slides and have talked to youngsters about more topical issues effecting pensioners.

Drama Work

Local Adult Education Institutes and local schools have been jointly involved in some reminiscence drama work.

Minnie Bennett Sheltered Accommodation Reminiscence Group

From April 1981 a group of about 15 enthusiastic pensioners have been meeting every Tuesday to discuss their reminiscences with a Task Force worker and a writer from SHAPE, which acts as a sort of clearing house for community theatre workers. These sessions took place at the Minnie Bennet Sheltered Accommodation Unit in Shooters Hill and although most of the group came from the House, others who lived outside the block have been involved.

This was a new venture for all of us and it was decided from the start that the group members' interest and enjoyment were sufficient aims in themselves. However, they felt that they could share their enjoyment with other pensioners by producing a booklet of reminiscence stories.

Because most members of the group suffered physical limitations one of the workers took notes on specific subjects at each session. He then returned the following week with a story based on the information previously given to him by the group. After reading the story to the group, they corrected and changed it according to their wishes and the worker came back the next week with a completed story. If accepted by the group, that story was set aside and another subject taken for discussion. Although this was quite a lenghty procedure, it ensured genuine authorship by the group.

Once enough stories had been compiled, the group approached Help The Aged for funding for the printing of 2000 copies of the booklet which was to be called 'When We Were Young'. Through the Meals On Wheels Service and the Home Help Service, the booklet was distributed free to almost 2,000 housebound pensioners throughout the borough.

It is envisaged that the Task Force worker will shortly withdraw from this group and it will continue to be successfully run by the gruop members.

Conclusion

The Reminiscence Project was started in July 1980 with the primary purpose of involving housebound, isolated pensioners in a worthwhile scheme from which both they and others could benefit. However, as the work progressed it was clear theat the project had wider possibilities. Reminiscence work can break down the most impregnable barriers and this is particularly relevant to organisations such as Task Force who are confronted with the prejudices of young and old toward one another. Reminiscence work can also be used to overcome racial prejudice of the elderly which are, more often that not, based on ignorance. By getting ethnic elderly people to talk about their pasts and comparing them with those of pensioners who have lived in this country all their lives, a greater understanding and tolerance could be achieved.

The benefits of reminiscence work are endless and only some of our achievements have been briefly outlined in this paper. If you are interested to learn about these developments, contact Greenwich Task Force.

Discussion

Four main issues emerged:

Racism and Ethnic Minority Groups

The lack of specific mention of black people - reflected both in the reminiscence work and our overall day's programme - was strongly expressed by a black participant in the group. It was observed that many existing pensioners' groups were racist at some level and that it was therefore difficult to involve black people in these groups, to an extent that token gestures of welcome were insufficient. A Hackney Task Force worker talked about the difficulties and value of exploring together how white people felt in the 1950's during the period of black immigration and how the black people themselves felt on arrival. Working with Greek and Turkish Cypriots when the British played a major role in the civil war raised a further set of difficulties. This worker felt that his most successful mixed group involved bringing together young "up front" blacks with elderly white people. In this situation prejudices were confronted head on with some success.

The Role of the Group Leader

Ideas about the group leader's role included
- trying to include and value all people's experiences, to generalise from them and to build up a shared perception
- to address and acknowledge that reality is based on people's perception of the changes that have taken place during their lives
- not predetermining the direction of group discussion by anticipating the consequences of evoking bad memories.

Sexuality

The question of sexuality tends to be raised obliquely around discussion of sex roles, home births, etc. Institutional provision for elderly people often tends to inhibit sexuality, with younger members of staff frowning on romantic relationships. Discussion in the group may therefore be greatly influenced by the context members live in.

Nostalgia and Grief

Those with experience of this work felt that because group work was emphasised, any tendancy to self indulgence and excessive nostalgia was automatically 'corrected' by the group. Nostalgia may also reflect the genuine alienation felt by some elderly people faced with the quality of present day living. We questioned whether this kind of work could find room for expressions of grief by particular individuals. It was observed that other group members tended to share their similar feelings and experiences and that the group itself controlled the situation.

The Relevance of "Citizen Advocacy" to Community Work with Elderly People

Introduction

Citizen Advocacy is in many ways a difficult concept to get to grips with. As a form of voluntary activity it differs from the service-providing or befriending schemes which are traditionally associated with aid for isolated or disadvantaged people in our society. The idea originated in the United States with the work of people like Wolf Wolfensberger and John O'Brien [1] and has been developed in Canada and Scandinavia.

Until recently I was involved with the first scheme to be attempted in this country which was established by a group of charities for mentally handicapped people under the title "Advocacy Alliance" [2]. As the project's Coordinator I was responsible for implementing and developing their programme and my aim in this short piece is to put across some of the underlying principles of citizen advocacy. It is important to note that the Advocacy Alliance's approach represents only one model and there are many other ways that groups and community networks may wish to take up and develop from the central assumptions.

Before I attempt to define "advocacy" and "advocate" I would like to provide an example which illustrates the aims of my work on the Advocacy Alliance project. The other day I was visited by two friends, Mary and George, who had travelled by car from Epsom to my home in Brighton. There might be nothing unusual in this except that George, who is twenty five years old, has spent all his life in hospital and until recently had never had a visit from anyone outside the institution which is his home. He would probably never have had any contact with normal community life if it had not been for the friendship and actions of Mary who is his advocate.

George is labelled "profoundly mentally handicapped" as a result of extremely damaging lead poisoning which he suffered when he was a baby. The mental handicap hospital where he lives is fairly typical of the large institutions which house people who require long-term care. Food and clothing are often dull; an imposed routine means that residents have little or no choice or say in the way they lead their lives; decisions about treatment and services are taken without consultation or consideration of an individual's needs, wants or expectations. For George much of this is starting to change as a result of his involvement with a citizen advocate.

Mary visits George regularly, usually twice a week. They often go out together and George has got to know her family and friends. Mary tries to ensure that he is properly and fashionably dressed in clothes which do not even hint at institutionalisation. She now attends case reviews on his behalf and is arguing for more effective treatment of the results of George's handicap and years of inappropriate conditioning. The changes in George's life have been dramatic and the improvement in the quality of his experience have been remarkable. It shows in his whole demeanour and appearance and the things that he can now do. A year ago a day-trip to Brighton by car would have been unthinkable.

I could go into a great deal more detail about this and the twenty or so other advocacy relationships which have started during the past year; but this brief account helps to raise the important issues and I am sure that the full story will be told elsewhere [3]. In addition it serves to demonstrate that advocacy can, and must, be concerned with very seriously disadvantaged people who live in difficult, even forbidding, environments.

The definition of Citizen Advocacy

Citizen Advocacy accurs when a private citizen befriends a disadvantaged person and learns to represent their true interests. By providing emotional support, spokesmanship, opportunities to learn new skills and help in obtaining needed

services, volunteers work for the benefit and continuing growth of people who would otherwise remain in a stagnant or deteriorating situation.

Thus, advocacy entails a synthesis of friendship and action with and on behalf of someone who experiences personal disability and institutional control. Mary has not just befriended George she is actively seeking improvements in his life and is attempting to get the health and welfare service agencies to see things from George's point of view. It is not difficult to imagine some of the ramifications of this and the reactions of some professionals and administrators. I shall examine the implications of this controversial new role adopted by Mary and her colleagues later. Before I do so it is essential to emphasize the three sources of Citizen Advocacy.

Firstly, it is recognised that peoples needs can be classified into two categories: instrumental needs, and expressive needs. Fulfillment of instrumental needs ensures that people receive the goods, services and money which should enable them to lead a reasonable life. Provision of the following, or help in attaining such items, illustrate the importance of meeting instrumental needs:-

Welfare Benefits
Accommodation
Transport
Leisure and Recreation Facilities
Voting
Financial Management
Access to Shops, Pubs, etc
Special Medical Care
Dental and Ophthalmic Care
Training and Education

The list is extensive and, for many people living in the community, almost taken for granted. But for most people living in hospitals, or confined in some other way, fulfillment of such needs requires a great deal of effort on the part of someone who recognises their value and importance. One example makes the point. Thousands of elderly people and handicapped people living in various forms of care do not receive their full benefit entitlements. Thousands of others receive benefits but cannot gain access to their own funds which have accrued in large amounts in hospital and social services accounts. In both instances the total amounts involved run into tens of millions of pounds. Help is needed in order that individuals, often desparately short of resources can achieve a better living standard using their own money.

But fulfillment of such material requirements is not everything. People need to express themselves within relationships with others. Expressive needs are:-

Friendship
Companionship
Emotional Support
Warmth
Affection
Attention
Love
Communication
Identity

People who live in institutions are often just as isolated as those who live cut off from family in the community. Starved of real friendship they can only turn to staff, who are paid to be there, and other residents. A situation which inevitably confirms and reinforces their institutionalisation. This is as true for elderly people who live in "Part 111" accommodation and nursing homes, as it is for people like George. Many people react to this situation of little or no choice in human relationships by withdrawing from the social round that does exist.

Thus, advocacy is concerned with identifying and meeting basic needs. In practice this means that advocates become both friends and representatives. The Advocacy Alliance's approach assumed that no-one could be a successful advocate without first becoming a friend of the individual resident.

The second source of Citizen Advocacy is the "principle of normalisation" (4), which is now being taken up and developed in the mental handicap field but may equally well be applied to services for people who are elderly, or mentally ill, or children in care, and so on.

This principle calls on us to "use means which are valued in our society in order to develop and support personal behaviour experiences and characteristics which are likewise valued". For a host of historical, social and political reasons, people who live in care are often treated as if they were less valuable than other human beings. It is a central purpose of advocacy to demonstrate that such people must be regarded as equal members of the community not to be demeaned or degraded in any way.

The final source of Citizen Advocacy is freedom from conflict of interest. This suggests that advocacy programmes should be independent from the agencies which provide the services for people who are or have become dependent on some form of residential care. Professionals often feel that they advocate very successfully on behalf of their clients. But they do so within very severe constraints imposed by their employing organisations and their professional peers. Independent advocates can challenge institutional assumptions and practices which are taken for granted, and their presence should ensure that a true dialogue can take place whereby individual residents' needs and wants are represented whenever day-to-day or major decisions are being taken which directly affect their lives. For instance Mary's visits to the ward where George lives and her attendance at case conferences have helped to shift the emphasis of routine and procedures away from the convenience of staff and the generally low expectation of what George could achieve.

In summary, Citizen Advocacy is a synthesis of friendship, protection and representation in the context of an independent programme which assumes that everyone should have valued experiences.

The Role of the Advocate

An advocate is a willing, committed member of the community local to the hospital, hostel or home where they have befriended a resident. The advocacy relationship is a one to one friendship, plus. There are organisations which advocate on behalf of groups of disadvantaged people but the Advocacy Alliance project concentrated on introducing volunteer advocates to single hospital residents. In an interesting development a married couple decided to advocate as a partnership for one resident. At present it is not envisaged that advocates will befriend more than one resident.

The central theme of the advocacy relationship is advocate loyalty. It means that the advocate's primary loyalty is to the resident not to the advocacy programme, other residents, the institution's staff, or the service agency. Advocate loyalty implies:- mutual interest - it is not a one-way beneficient relationship;

equal partners - advocates do not dominate or control their friends, or dictate what is best;

direction - there is always something happening which is extending or improving the resident's experience and quality of life.

Thus, the advocate's role is a complex, positive one. It entails:-

i) Providing friendship and emotional support.
ii) Practical help in day to day living.
iii) Enabling social integration.
iv) Helping with financial management.
v) Pursuing statutory entitlements.
vi) Assisting with access to services, leisure facilities and employment opportunities.
vii) Securing necessary treatment and education.
viii) Cooperating with staff on individual treatment and therapy programmes.
ix) Intervening in instances of neglect or abuse.

This means that an advocate does not merely build a relationship with an isolated person. They have to consider a wide range of issues and together with the resident working towards constructive change. Inevitably they must examine a list of circumstances which may have been stagnating for years. For example:-

Living situation (privacy, food, bedding, etc)
Personal appearance (clothing, hair style, etc)
Social communication (speach, leisure activities etc)
Independence (self-reliance, lack of choice, etc)
Physical skills (occupational and social)

In order to achieve change in any of these areas advocates must achieve a set of tasks:-

Getting all the information
Deciding what you both want to do
Finding out where the support is
Knowing about rights and responsibilities
Building a working relationship with staff, without compromising their independence
Beginning to change the way things are (5)

The example of Mary and George illustrates this very well, thus,

An advocate is an competent volunteer representing, as if they were his or her own, the interests of another citizen who is impaired in his or her instrumental capacity or who has major expressive needs which are likely to remain unmet without special essential steps towards establishing and advocacy programme.

How can such people be brought together and an effective Citizen Advocacy project attempted ?

There is not space here to describe the implementation of the Advocacy Alliance proposals (6). However, it is possible to outline the steps which were taken which resulted in the first advocacy relationships in this country. I am certain different strategies could well be adopted, but this step by step account raises the crucial issues.

ESSENTIAL STEPS TOWARDS ESTABLISHING AN ADVOCACY PROGRAMME

(ALWAYS RETAIN INDEPENDENCE)

1) DEVELOP AND SUSTAIN VIABLE AGREEMENTS WITH THE RELEVANT AUTHORITIES AND MANAGEMENT.

2) BUILD GOOD UNDERSTANDING AND WORKING ARRANGEMENTS WITH STAFF EMPLOYED AT THE "SHARP END".

3) OBTAIN SUPPORT AND BACKING FROM INFLUENTIAL LOCAL GROUPS AND VOLUNTARY ORGANISATIONS.

(CLEARLY IT IS IMPORTANT THAT PROGRAMME STAFF EDUCATE KEY PEOPLE THEY MUST ALSO BE "POLITICALLY" SENSITIVE)

4) RECRUIT AND SELECT POTENTIAL VOLUNTEER ADVOCATES.

5) ESTABLISH A COHESIVE TRAINING PROGRAMME WHICH,

a) DEVELOPS AND INDEPENDENT ORIENTATION.
b) PROVIDES GOOD INFORMATION ON RIGHTS, SERVICES AND BENEFITS.
c) PROMOTES ADVOCATE LOYALTY.

6) PROVIDE AN ADVOCACY OFFICE WITH STRONG LINKS WITH THE LOCAL COMMUNITY AND WHICH IS A CENTRE FOR DEVELOPING ADVOCACY.

7) FACILITATE A CONTINUING EVALUATION OF THE PROGRAMME.

8) INVESTIGATE THE NEED FOR ADVOCACY BY IDENTIFYING THOSE INDIVIDUALS WHO WOULD BENEFIT FROM ITS INITIATION.

9) MAINTAIN SUPPORT FOR EXISTING ADVOCATES THROUGH:

a) REGULAR MEETINGS (GROUP WORK)
b) BUILDING SUPPORT NETWORKS OF INTERESTED LAY INDIVIDUALS AND PROFESSIONALS.
c) FURTHER TRAINING AS NEW NEEDS ARISE.
d) AMEND EXISTING ARRANGEMENTS AS ADVOCATES ACHIEVE CHANGE.

Conclusion

Recent Government reports have emphasised official commitment to improving services for the elderly, mentally ill and mentally handicapped people. But circumstances, especially in long-stay hospitals and other residential accommodation, indicate that change will take a long time. It has also been demonstrated that many people who receive long-term care are very isolated. Some are never visited by family or friends. My experience was that forty per cent of the residents in the hospital where George lives had not seen someone from outside for years. I am sure the situation is even worse in our so-called "psychogeriatric" services, and is probably just as bad in private sector and social services homes.

Clearly, there is a need for intervention and it must come at the local level. Policy change will be a long drawn out business which will necessarily ignore individual needs and focus on shifts in emphasis, for example, from institutions to community care. Somehow active, committed members of the community have to be encouraged to take an interest in others who are experiencing the serious deficits that long-term care appears to bring. Citizen Advocacy promotes recognition and support for individuals who would otherwise disappear from view inside our institutional systems. Because it values people positively and provides volunteers with a constructive role it poses a difficult yet exciting challenge.

Advocacy Alliance demonstrated the need for advocacy for people with mental handicaps. It has also started to show that the challenge can be met within long-stay hospitals - a most difficult environment. We now need to think of ways in which similar schemes can be developed for elderly people; for if the need is extensive in the mental handicap field it is enormous where older people are concerned.

Ways have to be found to establish networks which will facilitate the recruitment, training and support of independent advocates. Existing agencies such as C.A.Bx. and Councils of Voluntary Service may help, or alliances of committed organisations might be established at a local level. The aim of this paper has been to stimulate interest among people involved in this field. I do not underestimate the practical difficulties and I would be very interested in the response of those who wish to explore the possibilities further.

Notes

1) See, W. Wolfensbeger & H. Zauha "Citizen Advocacy" National Institute of Mental Retardation, Toronto, 1975

   J. O'Brien "Building Creative Tension" - a paper to be published by the King's Fund Centre.

2) The Advocacy Alliance consists of MIND, MENCAP, One-to-One, The Spastics Society, and Leonard Cheshire Foundation.

3) Ms Robin Harris, a researcher at St George's Hospital Medical School, is conducting a research evaluation of the Advocacy Alliance project.

4) See, "The Principle of Normalisation" John O'Brien and Alan Tyne, published by The Campaign for Mentally Handicapped People (C.M.H.) 16 Fitzroy Square, London W.1.

5) I am grateful to Michael Libby of Leonard Cheshire Foundation for many of the ideas contained in this section which we developed for the advocacy training programme.

6) I am writing about the problems of implementing Citizen Advocacy in a paper for the King's Fund Centre, to be published with John O'Brien's piece (see (1) above).

Bob Sang

October, 1983

SOME IDEAS AND THOUGHTS ARISING FROM THE CONFERENCE

While the full sessions and workshops focussed mainly on specific issues and initiatives, several underlying themes emerged, which help to provide some prespectives on the otherwise fragmented world of health, community work and the elderly.

Malcolm Johnson, Chairman of the conference, identified 7 overlapping catagories of activities from the work of the conference participants.

* Health Groups and Courses with different froms and shapes but sharing the central idea that older people believe that health matters. While some of us may feel that services of all kinds for elderly people focus too much on health and that doctors play too large a role in the lives of older people. None the less, the contributions showed that elderly people were concerned enough about their health to meet together on this issue. They want the whole-hearted attention of professionals, want explanations in terms they could understand, and want to know what they can do about it - not what doctors or professionals can do. They are interested in health as a medium for other things since being healthy means a capacity to pursue a generally active and interesting life.

* Counselling - and in particular Bereavement Counselling was an activity taken up by several projects represented.

* Screening Activities of two kinds - both screening for physical and psychological themes and 'screening' for social security and welfare rights issues. This double sided approach to both physical and economic health' has obvious advantages though it needs stressing that people will not talk openly to strangers about money unless they are very clear that the strangers are 'on their side'.

* Keep Fit and Exercise. Older people think this is an important issue. We may need to keep in mind the question - fit for what? - and to maintain the present variety and individuality of schemes which are aimed at very different groups of elderly people with different ends in mind.

* Managing Hospital Discharge continues to be a major issue where professionals have all but failed and which now emerges in the context of self help, voluntary help and support systems of various kinds.

* Community Transport and Dial-a-Ride Schemes represented now fairly common ways to help elderly people exercise some control over what they do.

* Supporting the Supporters with an emphasis on taking care to meet the very different meeds of both elderly people and their supporters.

Alongside these direct service giving activities Malcolm suggested 4 other themes from the day.

- Promoting self esteem and confidence of older people. While services are important ultimately the target should be to help older people regain what the stereotypes of old age take away -

their self confidence and their belief that they are important to to other people and can stand in their own eyes as members of a community.

- Caring professionals are seen as separated from the caring networks and see a need to be drawn in. They lack the time, contacts and local knowledge to bridge the gap. Community workers were suggested at the conference as one answer to this and the work they were 'allocated' included network building, identifying leaders in the community, key people to provide support and information.

- The lack of representation of non white elderly people was a major issue in some of the workshop discussions and the final session. The area was not directly represented in any of the sessions of the day which many people regretted. There was a clear message that issues of racism in this field should be tackled by ensuring that it is on the agenda of future workshops and that it is dealt with in the context of other issues effecting elderly people not set up apart in 'specialist' conferences or meetings. The topic itself is not taboo or ignored and there is useful work being done, for example, at the Policy Studies Institute (Social Services Departments and Ethnic Minorities Research) and at the Age Concern Research Unit (Elderly People in Ethnic Minorities Report). Malcolm suggested that part of the problem lay in the fact that few community workers are concerned with elderly people and those there are, are almost all white. This however was strongly challenged by a number of people in the audience.

- Action by older people. Much of what we do will only be changed when older people themselves become much more politically influential than they are now. The contrasts with the impact of the Grey Panthers in the USA can be seen as showing a need to encourage older people in Britain to have the confidence, the capacity and the information to do the same sorts of things. There is a question though, of whether we really need more organised pensioners' groups in Britain or whether the problem is that the British groups are not listened to and have no access to decision makers. There may be a challenge to professionals here to find better ways to listen.

Finding Frameworks. From the day as a whole, there was plenty of evidence of a huge, lively diversity of projects being set up and a strong demand for real opportunities for information and sharing of ideas. This diversity is a strength because it allows people from very different backgrounds and interests to be involved - from Historians to District Nurses - but there is a strongly felt need for a more consistant set of overall philosophies or theories to help make sense of the 'piecemeal' picture we have at present.

Because so few projects have any clearly set out principles, it is hard to know whether one effort complements and supports another and how small scale practical projects relate to important 'idelolgical' questions - the promotion of rights for disadvantaged elderly people, the relationship between voluntary effort and the 'Welfare State'. The Workshop 'The Community and the Institution' highlighted this issue very sharply. Bob Sang's model of Advocacy for individual elderly people which is drawn directly from principles of 'Normalisation' shows how a clear explicit basis to your work can provoke a great many questions about the value of other

accepted 'good practices' in voluntary and statuatory services for elderly people. We seem to have barely begun the process of setting out shared - or alternative - frames of reference comparable with 'Normalisation' which could be used to analyse the range of activities being carried out. This must be a high priority for the future.

The Power of Individual Personal Experience came through very clearly in the day. The Workshop on 'Collaboration in the Care of 'Confusion'' devoted a fair amount of time just to listening to an account of one carer's experience. The two Workshops on Reminiscence projects of course based firmly on a belief in the value for the individual and society of sharing personal life experience in an organised and professional (in the best sense) way. Dr Muir Gray offers hints that we can link small local experience into large scale service planning activity, but we still have a great deal to learn about how to use the undoubted power of individual human experience most effectively to change the present 'system' of planning and resource allocation.

Elderly people (like everyone else), express many contradictory things about their health and health needs. They may want both help, which can lead to dependence, and autonomy. A home-help may help someone stay independent, or at any rate less dependent than being cared for in a home, hospital, or by relatives. But even to get a home-help requires pleading to people in authority that help is urgently needed. It is those people in authority (social workers, GPs, or relatives) to whom that elderly person may fiercely resent demonstrating even a small degree of loss of autonomy. There may be a fear that the request will be misinterpreted, that the help offered may not be what is asked for, and that it could entail still further loss of independence. Asking for help may injure that person's pride.

Contradictory things are also expressed about GPs. Either "it's good to have a GP, but my GP's hopeless", or "GPs can't do anything, all they'll offer is more pills, but mine is wonderful".

Both attitudes may express a recognition of powerlessness, or a fear of confrontation, since the reality is that the GP is one of the very few people in a position of power to whom anyone has relatively easy access (in theory!).

These contradictory espressions underline the need for help and helping services to be offered on the terms of the person needing the help. The manner in which help is offered is of great importance, and there needs to be space for negotiation about how, where and when the help is given.

Another contradiction appears between some popularly held views about what kinds of support and help are likely to be most acceptable to elderly people, and their own views. One example (see workshop on 'Neighbours as a Resource'), is the widely held belief that the support or help of neighbours or relatives, both practical and financial, is generally more acceptable than 'state handouts', or the services of the Welfare State. Elderly people are commonly perceived as too proud to accept 'charity! Yet one view expressed by an elderly person interviewed by a researcher suggested that to approach a GP or the Social Security Office at a time of crisis was regarded as preferable to having to depend on neighbours or relatives. The welfare state has widened the choices available to people. We can speculate that while for some elderly people for whom

the Welfare State was something new, it was suspect and threatening to their pride, while for the next generation of elderly people who have grown up with the Welfare State, its benefits, while inadequate, are no longer necessarily perceived as stigmatising. Attitudes to different kinds of support are now informed only by inherited beliefs, but also by experience of objective social developments.

Another recurrent theme was how often health was an issue for elderly people around which their activity could be maintained over any length of time. Health courses which attract large numbers of elderly people may develop as social clubs, either consciously or in an unplanned way. This can be seen as a successful integration of 'health' with 'life', but for professional health workers who are involved, it can present problems. Their definitions of 'health work' may have clear and narrow limits, and to persist in spending time with a group of elderly people whose apparent reason for meeting is more to do with combatting isolation than health, may seem to dilute and threaten their specific professional competence (see the Workshop on the Brent Pensioners' Health Course). This raises important questions about the purpose of some community health initiatives. Are they in the end more about breaking down isolation than about education and health, and if so does this matter?