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AGE Concern
INSTITUTE OF GERONTOLOGY
KING'S COLLEGE LONDON (KQC)

# The mentally frail elderly: should we prescribe care?

## Proceedings of a conference held at the King's Fund Centre, London, on 25 March, 1986

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KING'S FUND CENTRE

and

AGE CONCERN INSTITUTE OF GERONTOLOGY

# The Mentally Frail Elderly: Should We Prescribe Community Care?

The proceedings of a conference
on March 25th 1986

to consider the operation and findings of an
action-research project on the
home support of dementia suffers
in Ipswich and Newham

carried out by the
Age Concern Institute of Gerontology

and

The Department of Psychiatry, United Medical & Dental School

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## I Introduction: The Challenge

This seminar is intended to focus on only one among several currrent attempts to explore the realistic potential for sustaining some highly dependent old people in non-institutional settings. The project which we will describe has been targetted at organically mentally frail people and has explored the applicability to this group of an extension of an evaluated community care approach which has developed out of the ideas and earlier work of others. This approach has been used with, for example, young mentally handicapped people or older people who have home care needs but do not present with such complex or demanding symptoms as dementia sufferers. We have thus been trying also to explore the limits to community or domiciliary care and to identify those for whom it might or might not be appropriate. And because we are operating in a real world of expensive alternative approaches to care, we have endeavoured, albeit within a rudimentary framework, to provide care in the community only within a realistic per capita cost.

First though, it is important to place the need for such intensive care in context. If this society describes people as 'elderly' at the age of entitlement to an 'old age pension', we find ourselves including in this 'group' ten million people who have relatively little in common beyond their categorisation as 'elderly'. Most of the ten million people are active, able and alert and do not wish to use, nor have any great need for, health or social services beyond those that all adults require from time to time. They are hugely diverse in their health profile, fitness, social class, personal biography, wealth, income, personality, gender, education and even their age.

In Britain, the 'elderly' population as a whole is fairly static: the number of people aged 65 or over peaked in the early 1980s and will not rise again until those born in the post-war baby boom achieve retirement age. But the growth in their numbers during the 1960s and 1970s will be reflected in a growth in the <u>very</u> old age groups as present cohorts of people in the 60s grow older. Epidemiological data suggest that 10% of the over 65s suffer from organic mental frailties. However, it is the number of <u>very</u> old people which really counts here: there is hardly any

dementia/Alzheimer's disease among young elderly, but data suggest that about 20% of people aged 80 or over suffer from dementia-like symptoms. These old elderly are also more prone to physical disability and chronic sickness though it remains vital to note that most of those who reach their 80s never suffer from any significant organic mental frailty.

Nevertheless this does leave a major challenge to our health and social service providers: up to about one fifth of the very old suffer from an illness that has no known aetiology and no known cure or medical treatment (though orientation and stress reduction may reduce or delay its negative impact). There is also no known means of prevention, except by dying earlier or something else. Dementia prevalence has changed little in an very old population though survival despite it may have increased in recent years. What is increasing - and is alarming governments and service planners - is the total very old population. Between 1980 and the end of the century, there will have been an increase of about 30% in the numbers of people who reach their 80s; pending medical discoveries, this increase in the age group from which dementia patients are largely drawn will mean a 30% increase in people suffering from dementia. Unfortunately, health and social services do not expect the equivalent budget growth which would merely maintain current per capita levels (and types) of service provision.

The challenge is therefore demographic and financial as well as coinciding with changing expectations and a questioning of the universal appropriateness of existing forms of care for this group.

In theory there are several ways in which this society could respond to the challenge. Options, which are not necessarily mutually exclusive, include:

(i) Re-invent the workhouse or asylum: we could, with existing buildings and staffing and using locks and suppressive medication, cram more people into specialist homes and psychogeriatric wards. This retrograde move is unlikely as a policy action but could become a decision by default:

(ii) Rely on - and stretch - caring relatives: again, this could happen by default as relatives notice the declining per capita provision or are deterred by the alternatives and stretch to fill the gap. But, crucially, over one third of these elderly people have no surviving relative and others do not have the resources to fulfil their demands. Dementia is also widely seen to be the condition which people think will make their help unrewarding and stressful, especially if on a sustained basis without respite or support:

(iii) Let people die: people living on their own could be left to damage themselves, fall, be run over or fail to eat. Again, no government would propose this as a serious plank of policy but many people are already barely in contact with any service and some do die:

(iv) Spend more money on existing services: we could promote more of the same Part III, specialist homes, psychogeriatric services, home help, meals on wheels etc. at least to maintain per capita levels. And we should not, in the process, fail to improve on these services in a variety of minor ways:

(v) Be creative: this could be little more than a hunt for panaceas (voluntarism, family care, community care, private care) which would certainly benefit some people but might leave state provision as a low quality 'safety net'. Alternatively this could significantly increase resources by tapping different sources and/or could include a focus onto (for example) more sensitive training, more community tolerance, paid local home supporters, a much-expanded private sector or more use of appropriate enabling devices and technology.

Three years ago, we suspected that what is required is a combination of more resources (because of increasing numbers) with more attention to the voices of individuals and groups of older people to establish their priorities, more assessment to construct services to the particular (rather than the stereotype of an) old individual and more flexibility in using existing revenue budgets to construct individual 'packages' of care, be it at home, with relatives or in a residential or inpatient setting.

In considering these options, we have to take into consideration the limits to spending growth. We must also recognise the fact that existing service provision is often not well sensitised to the needs of the elderly mentally frail person, and that existing services are often available on an uncoordinated take-it-or-leave-it basis with insufficient assessment, understanding, focus on 'enabling' support, individualisation or overall 'case management'. This is in spite of the diversity even of this population in terms of resources (of friends, family, money, household design etc.), knowledge, awareness, physical capacity, and degree and type of confusion and behaviour. Because of this diversity a range of care settings is essential. Some people will wish to live communally, others with family and others will be best in their own homes; no 'prescription' can be either universal or perpetual.

For these reasons, we argued for the need to establish an experimental scheme of enhanced home support for dementia sufferers; and were able to attract funding to establish such a scheme in two areas. We were very keen that one of these should be a relatively poor inner city area, since it is there that the problems of service provision to dementia sufferers are often at their most acute; we wanted it it be in London for ease of access; and we required a place with a psychogeriatric service. We explored a few possibilities but were most swiftly welcomed by the London Borough of Newham. A country town within relatively easy reach of London was our choice of a contrasting area; again we were most quickly welcomed by Ipswich in Suffolk, where several service providers had already got together to think about new projects in this field. The development officers (one in Ipswich, one in Newham) and the research team of three were all appointed in 1983, and our project began to take referrals from April 1984. This seminar describes that project.

We are very grateful to the Sainsbury Family Trusts and the Guy's Hospital Special Trustees for their funding support for our action-research project. We would also wish to thank the staff and members of the health and social service authorities in Ipswich, Suffolk and the London Borough of Newham for their active collaboration in the design and management of the scheme (and, more recently, for the funding to support continuation of local variations of the scheme which have emerged as a result of experience over the past three years).

## II The Home Support Project Concept

Beyond the basic aim of our home support project - to provide a service to elderly mentally frail people which would help those who so wished, to remain at home rather than be admitted to an institution - a number of elements combined to characterise the overall design of the project. The first was that the service should be client-centred, and should provide an individually tailored package of care which would meet the wishes of each client, and fit in with his or her timetable rather than with the service providers. Secondly, it should provide a service which did not match or compete with existing services (whether statutory, voluntary or private) but provided a different kind of service in order to bridge gaps between those already available. Following from this a third aim was that the project should collaborate with existing service providers in order to ensure that there was no overlap or competition with others but that all were working together for the good of the client; and fourth, that our project should, where necessary, coordinate the services available to each client and thus ensure an appropriate and suitably balanced package of care for that person.

Fifth, our intention was to employ local people in order to provide any extra care needed; local recruitment was integral to this plan, whose aim was to build on, or build up, neighbourhood contacts around the client and his or her family. Sixthly, the project should, through the development officers who would manage it, play an educational role, increasing awareness and understanding of mental frailty in old age among professionals, lay carers and local people, thus increasing people's sympathy and confidence in any contacts they might have with elderly mentally frail people.

Finally, the project was to provide a cost effective service, for it was recognised that what would be most welcomed by policy-makers and others was a service that not only helped to keep people out of institutions but did so in a way both acceptable to recipients and less expensive than alternative institutional care.

## III The Action Research: Aims and Design

The special feature of this project is that it is an action-research project: not merely action with research added on, but action designed so that it can be researched. Whilst the emphasis of this seminar is directed towards the 'action', the fact that it was researched is very important, for only by the collection of systematic data can objective answers be given to the question 'Was the action project successful?'

One of the basic aims of the research was therefore to discover whether people receiving the extra home support provided by our two development officers could be kept at home longer (satisfactorily and cost-effectively) than would be the case without extra home support. More specifically, and given the assumption that the 'action' would not work for everyone, the aim of the research was to find out for whom it could be done and for whom it would not work.

The first need of the research, therefore, was to obtain control as well as action samples, for only with matched control samples could we hope to show what difference the action made. Secondly, having drawn samples we needed to collect data from and about them, not only at their point of entry into the project (to see whether action and control samples were indeed similar) but also at later stages in order to discover whether their condition and circumstances changed over time (and if so whether they did so differentially). Thirdly, we needed to cost the care people received at home, by comparison with the alternative form of institutional care, in order to determine whether the extra home support of the action project, when added to the existing services provided, was cost-effective. Fourthly, we had to monitor the course of the project to discover whether any problem or unanticipated consequences of the action arose during its implementation.

The four elements of the research will be discussed in turn.

## THE ACTION AND CONTROL SAMPLES

The samples were achieved by first dividing each borough into Action and Control areas; these areas were carefully selected, so that they were matched as far as possible in terms both of the number of referrals to the hospital psychogeriatric service in the previous year and of census data on the number of elderly people resident, particularly those aged 80 and over, the housing amenities of elderly people and the proportion of elderly people living alone. Then, during the twelve months from April 1st 1984 any persons referred to the psychogeriatric service for the borough and given a diagnosis of dementia became members of our action sample if they lived in the action area, and of the control sample if their home was in the control area (so long as they were also 65 years or over, were not living permanently in an institution, and they or their carers gave consent for their inclusion). Table 1 shows the total numbers of referrals to the psychogeriatric services in Ipswich and Newham in that year, and of those totals the numbers recruited to our samples.

**Table 1:** Referrals to psychogeriatric services in year 1.4.84 - 31.3.85

| | IPSWICH | NEWHAM |
|---|---|---|
| Total Referrals | 301 | 425 |
| Not elegible for project | | |
| - not suffering from dementia | 157 | 204 |
| - have dementia but otherwise ineligible | 39 | 114 |
| Eligible for project | | |
| - but excluded (eg refused, died before seen) | 25 | 21 |
| ACTION SAMPLE | 54 | 41 |
| CONTROL SAMPLE | 26 | 45 |

The total referrals in Newham were higher than in Ipswich because of the greater number of elderly people in Newham (28,500 approximately compared with 18,500 in Ipswich). Because of this difference in numbers we had to exclude a part of Newham altogether from our study, in order to achieve a sample size manageable for our purposes. The only disappointment in our achieved samples was the comparatively small size of the control sample in Ipswich. At the time of this conference our investigations into the cause of the discrepancy are still continuing: there may have been some migration of the elderly out of the control area since the figures we used in our selection were compiled. However, since numbers are small anyway and therefore encourage certain types of analysis rather than others, the shortfall in the Ipswich control sample did not seem disastrous.

In addition the numbers available for analysis will shortly increase through the extension of this project in Newham and by the introduction of the new open-referral project in Ipswich.

Table 2 shows that even though small the samples were not badly matched, though obviously more closely on certain characteristics than others.

**Table 2:** **Selected characteristics of the samples**

| | IPSWICH | | NEWHAM | |
|---|---|---|---|---|
| | Action | Control | Action | Control |
| Mean age at referral | 82yrs | 81yrs | 79yrs | 81yrs |
| Proportion female | 76% | 65% | 61% | 71% |
| Proportion married | 14% | 31% | 34% | 19% |
| Proportion living alone at time of referral | 64% | 50% | 50% | 63% |
| Proportion with closely involved relative/friend | 83% | 85% | 72% | 66% |
| Proportion without inside lavatory | 10% | 15% | 29% | 19% |
| Proportion in owner-occupied housing | 68% | 62% | 23% | 20% |
| Mean organic brain syndrome (OBS) score at first assessment | 6.9 | 7.0 | 6.9 | 6.7 |

These figures demonstrate something about the characteristics of people with dementia referred to psychogeriatricians: that they are on average around 80 years of age, mainly women, mainly widowed or single, quite likely to be living alone but not without the involvement of relatives or friends, and with fairly advanced dementia (assuming that this is the implication of a score of nearly seven on scale, running from one to ten, designed mainly to measure impairment of memory). The figures also show something about the difference between Ipswich and Newham: that Ipswich people are more likely to have an involved relative/friend, tend to live in housing with better amenities, and are much more likely to own their own houses. The figures also demonstrate how well matched are the action and control samples: that in both places they were well matched on age, proportion with an involved relative/friend, proportion in owner-occupied housing, and an organic brain syndrome score; they were less well matched on gender and proportion without an inside lavatory (though the difference was not great), and least well matched on marital status and proportion living alone, with the Ipswich control sample and the Newham action sample being more likely to be married and (therefore) not living alone. These factors have to be borne in mind in later analysis.

## DATA COLLECTION, COSTING AND MONITORING

The collection of data by the research team was carried out largely by means of structured interviews. First, data was collected from and about the dementia sufferers at three points: after their initial referral to the project, six months after that. The data collected from the sufferers are discussed below. We also gathered data from 'reliable witnesses' about the sufferer's family, support from relatives and other informal, voluntary or statutory support at home, housing circumstances, physical and mental health (and at later stages any changes of care or other circumstances since referral). Main supporters (defined for our purposes as people who spent at least one hour a day on average with, or doing things on behalf of, the sufferer) were also interviewed on two occasions, using a semi-structured approach, at approximately the same time as the sufferer's first interview, and one year later.

Estimating public revenue costs of home care is an important part of the study. For this purpose the researchers have collected data on types and amounts of all services received at different points during the year. The costs of these services are being estimated partly - and wherever possible - from previous analyses carried out by others, and partly - where a service has particular local features - from our own examination of the services. Precise and detailed analysis of the costs of keeping dementia sufferers at home is not yet complete. Crudely, however, we know from approximate costings made by the development officers (who were required to hold their spending on support workers to a level which kept the total cost of home care below that of the alternative institutional care - see page 16) that spending on only one of their clients appeared to exceed this ceiling, and that for only a short time.

The course of the project was monitored by formal interviews at intervals with the development officers and by records kept of any relevant conversations, discussions or project meetings. Interviews have also been held with other relevant professionals involved with, or affected by, the project and with a sample of the support workers employed by the development officers. Whilst this is not the appropriate place to present details of these data, it is worth emphasising that overall, once started, the project operated without any serious difficulties: for example, there was no difficulty in recruiting support workers or in keeping them, there were no serious conflicts between our project and other services, the project was welcomed by those it sought to help, and the development officers, with a few amendments, were able to carry out the role set for them at the start of the project.

## IV The Choice of Measurement Instruments

The choice of assessment schedules and rating scales for a research study is one of the most important factors in its design. There are a large number of psychological and behavioural instruments available, and the researcher needs to steer a course between the thoughtless use of 'off the peg' schedules and the superfluous construction of new ones. Established scales may be respected and familiar, but if they are not appropriate for the study design, they will give meaningless and misleading results. Conversely, if idiosyncratic schedules are used, it is impossible to compare the findings with those of others, and this severely limits the public value of the study. The following paragraphs outline the various factors that were taken into account when selecting the rating scales for the Home Support Project.

### STUDY FACTORS

The design of a project makes certain demands upon its measurement instruments, and will also impose a number of limits on their usefulness. In choosing instruments we first had to ask: what the instrument would be used for, what was to be measured, who was to administer it and where, and who were the subjects.

The Home Support Project required a schedule that could distinguish between depression and dementia in the elderly, and give an indication of the severity of any disorder present. In particular, a measure of cognitive impairment was to be used as a criterion of entry into the study. The project's design did not require ant refined clinical sub-classification of either depression or dementia, so this was not a consideration when selecting the schedules to be used. Since the subjects were to be followed up, it was important that the instrument be sensitive to changes in the severity of depression and dementia over the time period of the study.

Rating scales for use with elderly people focus on three main areas: cognitive function; behaviour and the activities of daily living (ADL); and mood. Many different clinical questionnaires have been constructed to assess cognitive function, and there is little to choose between them since they all use similar tests of orientation, memory, coordination etc. Unfortunately, they test only one aspect of clinical dementia, and are rather poor at distinguishing between levels of impairment in the more severe cases. Behavioural and ADL assessments measure different disabilities in demented subjects, and give a means of discriminating between cases with a similar score on a cognitive function test.

Assessments of mood can present something of a problem in a study population which is quite severely demented. Mood disturbance in dementia is often stimulus-bound and can vary quickly, leading to apparently contradictory responses to successive questions. However, this study required some assessment of depression, both as a diagnostic screen and as a measure of adjustment.

Some schedules are designed to be administered by medically qualified interviewers. Since the Home Support Project involved both medical and non-medical researchers and interviewers, it was necessary to choose an instrument that could be used by trained non-doctors.

Many schedules have been designed for used with inpatient populations, and they require close acquaintance with the subject and repeated measurements over a period of time. The Home Support Project was by definition community-based study, so it was not possible to use such instruments. Similarly, it was anticipated that a significant proportion of our subjects would have no involved relative or carer, so schedules requiring information from close informants (such as the CAPE) were also ruled out.

When a study sample is elderly, there are several factors that need to be taken into consideration when choosing or designing a schedule. It should be tactful, conversational, flexible and tolerant of the digressions that frequently occur. Somatic complaints are less significant indicators of depression in the elderly, and this should be remembered when choosing mood questionnaires. Where possible, studies of elderly subjects should use schedules that have been specifically designed for this age group.

## TEST FACTORS

The important factors inherent in any system of rating are its validity and its reliability. The validity of a rating scale - the extent to which it measures what it is designed to measure - is judged by various means; in psychiatric research clinical diagnosis and outcome provide the most usual criteria. One advantage of established schedules is that they have usually been validated in various settings, but ideally the validity of any rating scale should be checked every time it is used in a new context, since unforeseen factors may be influencing subject response. For example, if a schedule was developed on a young adult population, it may not work when applied to the elderly. The Home Support Project asked the local psychogeriatric services in Ipswich and Newham to refer only those patients with a provisional diagnosis of dementia, and this provided a valuable clinical validation of the rating scales used in the research project.

The reliability of an instrument, or the extent to which it measures dependably the same quality on each application, has various aspects: internal reliability, which is concerned with the internal structure and consistency of the scale; re-test reliability, or the reproducibility of the results over a period of time; and inter-rater reliability, which examines the possible sources of disagreement between different raters. Initial training in the schedule and observed interviews at intervals throughout the study period helped to keep this potential source of error low.

Taking all these issues into account, the Home Support Project chose to use the Comprehensive Assessment and Referral Examination (CARE) Schedule[1]. This has been developed for use with community population samples of elderly people, and is a structured interview-based instrument with medical, psychiatric and social factors rated according to interviewer judgement. We used only the validated Organic Brain Syndrome (OBS) and Depression scales, and combined them with other items of our own. In particular, we felt that it was important to have some measure of practical skills, since the CARE OBS Scale would not give a complete description of our subjects' disabilities. The best known of the standardised behavioural assessments is the Performance Test of Activities

of Daily Living (PADL)[2], but for various reasons (cumbersome props, comprehension difficulties, inappropriate tasks) it was not thought to be suitable for the home-based assessments of our subjects. Instead, we developed a 'mini-PADL' based upon the same principles, but having a more portable and natural format.

[1] See Gurland B J., Kuriansky J B., Sharpe L., Simon R., Stiller P. & Birkett P.(1977) The Comprehensive Assessment and Referral Examination (CARE) rationale, development and reliability. International Journal of Aging and Human Development. 8. 9-42

[2] See Kuriansky J. & Gurland B. (1976) The performance test of activities of daily living. International Journal of Aging and Development. 7. 343-52

## V The Action Project in Practice

### 1. The assessment and support procedure

The Home Support Project concept was put into operation by the development officers in Ipswich and Newham in the following way. The procedure started with a referral to the project from the psychogeriatric service in the two areas. On referral the amount of information we were given about each elderly person varied greatly. Often in Newham the development officer would only know the person's name, address and the name of his/her GP. Once a referral was received we set into motion our assessment and support procedure.

(i) Assessment of the home situation was the first task. The development officer investigate the existing level of statutory, voluntary and private care given to the elderly person, as well as the care provided and needs expressed by relatives and neighbours living with or near the client. This was not always an easy task as the elderly person was often unable to remember what help he or she received.

(ii) Action was then undertaken to cater for the expressed and apparent needs of the client if these were not already being met. The first form that this action might take was an attempt to increase the input from other services. This entailed talking to those involved with the other services to see whether they could provide more help. For example in Newham one elderly man was caring for his demented wife and had the help of a district nurse every morning. When the development officer visited him he clearly needed help every evening to put his wife to bed; when approached, the nursing service provided this extra help.

When insufficient help was forthcoming from other agencies, the other form of action might be used. Extra help would be bought in by the project from local people living close to the client. These people were paid on an hourly basis, and were called community carers in Ipswich and support workers in Newham. We will describe below the type of activity undertaken by the carers/support workers. Basically they did anything that a caring relative might do. The ideal situation was collaborative venture where relatives, other agencies and our workers all worked together to provide the care that was needed by an elderly person.

We did not have a limitless budget, and in assessing how much we could spend on a client we had to use as a guideline the estimated cost of a long term psychogeriatric ward hospital bed (at that time approximately £200 per week). As a guide to working out the cost of care we were provided by the researchers with an estimated average cost of other services which we could use to cost each client's care. The way in which we calculated the amount of money the project could spend on each client was to cost all the services a person was receiving from other agenciies and then deduct this from £200. The remainder equalled the amount it was possible to spend per week on home support from our project. In the majority of cases such a calculation showed that at least an extra £100 per week could have been used, but in practice we only spent an extra £45.

(iii) After action had been initiated as appropriate, we acted as coordinators of the package of care. We made sure that everyone working with a client was aware of each other's involvement, and tried to ensure that all had the same goals. In Newham in particular the development officer frequently acted as the key worker for the client.

## 2. The work of the community carers/support workers

As described above, the Home Support Project was set up to fill true gaps in the care of elderly people suffering from dementia, and not to make up for the shortfall in other agencies' services. This was a very difficult rule to operate in practice and we were inevitably drawn into covering for shortfalls in some situations.

Crucial to the operation of the project was the workforce in the two areas, who all lived within or close to the action areas and generally within walking distance of the client. In Ipswich 11 community carers were employed during the project, and 15 clients at some time had the service of such a carer; in Newham 18 support workers were employed, and 17 clients received their services. All our staff were women, and most were aged 30 and 60. We recruited them through word of mouth and local advertising. No special qualifications or experience were required, we simply looked for sensible, caring, ordinary people who were interested

in our work. We paid them £2.59 per hour in Newham and £2.40 per hour in Ipswich (this was for weekday hours worked, we paid extra for evenings and weekends). The average number of hours worked in Newham was 12 per week and in Ipswich 14.

Our service was client-centred in that we employed the carers/support workers to work with particular elderly people and we tried to match the personalities of our carers and clients where possible. Being client-centred had a number of benefits. The project paid for exactly the time worked by carers/support workers and there were no fixed timetables. This meant that we were flexible enough to act effectively in crises: the carers had no other clients to look after so they could stay (and be paid extra) when this was needed, for example if they found the client had fallen or been incontinent. In addition, as the carers/support workers lived so close to the client they could be contacted by the client's neighbours in the event of a problem.

Another aspect of our flexibility was that the carers/support workers were not restricted by preconceived ideas about their role: they did anything that was needed, for example going out with clients on a regular basis if this was necessary, administering and monitoring medication, and holding clients' keys so that others could gain access. This unrestricted role contributed to another important advantage of our client-centred service: the one-to-one relationship built up a strong bond between the client and the carer/support worker who would then act as the client's advocate or negotiator with other agencies, neighbours etc.

## 3. Tasks undertaken by the community carers/support workers

For descriptive purposes, the care given by the carers/support workers can be divided into practical support and psychological support, although in practice most tasks were a combination of both. The following list, while not exhaustive, will give some indication of the kinds of practical support given.

(i) Toiletting/washing: we dealt with people who had short periods of incontinence and, particularly in Newham, with people who were doubly incontinent. Personal hygiene was often undertaken by carers/support workers for clients who were difficult and aggressive towards their relatives. Sometimes it was necessary to get a client up, washed and dressed to enable him/her to be ready in time to go to day care.

(ii) Feeding and making meals: these were common tasks, for various reasons. For example in Newham an Asian client was unable, for religious reasons, to eat meals on wheels. A support worker of Asian origin who understood his needs was recruited to cook for him. In Ipswich a lady refused to accept the strange tin foil container, not understanding that it contained a hot lunch. The development officer arranged for the WRVS to deliver the meal to a neighbour, who put it on one of her own plates and took it to our client as though she had cooked her a meal herself, and this was accepted.

(iii) Control of gas supply: in some cases it was necessary to turn off the main supply and ask the carer/support worker to visit at least four times a day to make meals and hot drinks, disconnecting the gas each time she left. Occasionally, particularly if gas was used for heating and therefore could not be disconnected, the development officer removed the knobs on the gas cooker and the carer/support worker would screw them back on each time she visited. A piece of sticky tape over the knob on the gas fire acted as a deterrent to one client turning it on or off herself.

(iv) Dressing: some of our clients were too physically frail to manage dressing. Others were too disorientated to dress appropriately.

(v) Medication: this is an area not covered by statutory services. The district nurses are far too thin on the ground to visit every day, let alone three times a day to give medication. Home helps are not allowed to monitor or administer medication. Our carers/support workers frequently took complete control of a course of medication, for example a ten-day antibiotic course for a URI or chest infection, or medicine to prevent constipation, or a variety of prescribed medication for other physical ailments. It was often necessary to take the drugs out of the client's home to be sure that only the prescribed dose was taken.

(vi) Helping in and out of bed: there was a group of clients who needed to be helped out of bed and reminded that the day had begun! Also, since dementia sufferers seem to become more active at night (and since we were unable to use Twilight Nursing Services because they cannot hold keys and had difficulty in gaining access to our clients' homes), the carers/support workers had to persuade some clients to go to bed at night.

Other practical tasks were undertaken but these are a few of the most obvious. We think it is fair to say that our carers/support workers met whatever practical needs the client had, as long as the budgetary constraints allowed them to do so. At the same time they offered a range of psychological support, without which the practical tasks undertaken would have been of little value. Some of the elements in this psychological support are outlined below.

(i) Orientating clients to time and place and appropriate behaviour. For example carers/support workers had to remind people to get up in the morning and prepare for bed at night, or to make and eat meals, or to empty their commodes. This task also included making sure clocks and calendars were correct and checking that meals on wheels had been eaten.

(ii) Accompanying clients to social events, medical appointments and everyday outings such as shopping. In one case in Newham an elderly man who frequently lost his way was accompanied daily to a local luncheon club.

(iii) Persuading people to undertake certain self-care tasks eg cooking, eating, shopping, cleaning, turning fires up or on, washing. This was frequently needed as the elderly person would feel that he or she had just washed, cooked or shopped although this might not have occurred for several weeks or months. In one case in Newham an elderly lady was very dirty and dishevelled, so the support worker gradually introduced a bowl of water and a comb to her each day.

(iv) Providing companionship to clients who were waiting for day care transport and who would wander out of their home if left alone.

(v) Providing a sitting service for relatives who needed relief, and who felt that they could only happily leave their spouse with someone who was used to the behaviour related to dementia.

## 4. Differences between Ipswich and Newham which affected the operation of the project

In what we have said so far it has been unnecessary to distinguish between Ipswich and Newham, since the project operated similarly in both places. But there were differences which affected some aspects of the way the project worked.

As Table 2 (page 8) has shown there were some differences between the characteristics of the clients in Ipswich and Newham: a higher proportion of the Ipswich sample were female, were living alone, and had an involved relative or friend, and a lower proportion were married. In Ipswich two-thirds had family members living in the town, but in Newham two-thirds had no family in the borough. The social conditions of the clients in Newham were in many cases far poorer than those in Ipswich. For example, one-third of those referred to the project in Newham were without basic amenities such as hot water, bathroom or inside lavatory: only 10% were without such amenities in Ipswich. In Ipswich owner-occupation was high (68%): in Newham less than a quarter of the clients owned their own accommodation. In Newham the vast majority of the clients or their spouses had been in manual occupations; in Ipswich there was a much greater social class spread.

There is a considerable difference between the psychogeriatric services in the two areas. The psychogeriatric team in Newham is geographically very spread out. The psychiatric hospital is outside the borough and the community psychiatric nurses and the doctors are housed separately. The number of CPNs in Newham was less than half that of Ipswich, and the hospital-based social workers did not intervene in cases where a client had not been an inpatient. The result of this situation is that a key worker system for people diagnosed as suffering from dementia does not operate in Newham. In Newham only 17 out of the 35 clients who spent some time at home during the project period had ever been seen by a social worker or a CPN.

In Ipswich everyone was seen, for there the psychogeriatric milti-disciplinary team met thrice weekly for separate conferences to discuss outpatients, day patients and inpatients. All new referrals are discussed by the team and patients with dementia are allocated to either a CPN with special responsibilities to dementia sufferers and their families or a hospital social worker, unless an area team social worker is already involved with the client. All outpatients suffering from dementia and being supported at home are reviewed in conference at least every six weeks. The case of a client with dementia in Ipswich is never closed. This system meant that by the time the development officer received a referral to the project, the decision regarding the patient's care had often been taken by the team. What often led to this situation was the late referral to the psychogeriatrician - frequently at a time of crisis and when family and neighbour support had collapsed. Perhaps partly as a consequence of this, 22 out of 54 clients in the action sample were already in an institution by the time they were referred to the development officer.

Newham has very good domiciliary services provided by the local authority and health authority; these were far more adequate than those provided in Ipswich at the start of our project (though it should be added that all services in Newham are under considerable pressure because of the high level of deprivation in the area; higher levels of poverty, poor housing, unemployment, crime, and so on, mean that there is less time and money available to spend on help to the elderly mentally ill). In Ipswich home help input was only available two or three days a week for one and a half hours at a time, and a financial assessment and payment for home helps had recently been introduced (initially it was not our intention to substitute for home helps; however in Ipswich frequently it was more satisfactory for our community carers to cover both personal and domestic duties for our clients, and it provided a more consistent quality of care for the recipient).

Meals on wheels (organised by the WRVS) were only available two days a week in Ipswich. The Social Services Department has no day care centre, and only minimal provision for day care in a few Part III homes. It does, however, have a Part III home for elderly mentally infirm clients. There is a good day care centre operated by as voluntary organisation. The health authority provides a fuller service, with a day hospital for the elderly at the local psychiatric hospital (which is situated within the borough) and day care provision on two of the long-stay wards; rota beds organised through CPNs are also available on these wards. It should however be added that local authority community provision is improving: the home help service is becoming more flexible and positive moves are being discussed to improve day care facilities in Ipswich.

One final difference between the two places is that in Newham there is no effective private sector providing specialist residential or domiciliary services. This meant that clients in Newham could not choose to buy private services as they sometimes did, particularly through the growing private residential sector, in Ipswich.

## 5. The limits of care

In certain situations encountered by the development officers it was either very difficult or impossible to provide extra care to the elderly people referred. Some caring arrangements broke down, but there were also cases where no extra care was required. The following list outlines some such situations.

(i) Some relatives preferred early admission of their spouse or parent to institutional care, so that the elderly person could be involved in the decision. If admission was delayed and the client deteriorated he or she would be unable to be involved. This was particularly true where private care was envisaged.

(ii) In some cases the elderly person who was referred to the project was only suffering from mild dementia and was already receiving adequate help. Such people were often living with a relative.

(iii) In Ipswich some clients were already paying for extra private care, with which they were quite satisfied.

Circumstances in which caring arrangements broke down include the following.

(i) There were of course occasional severe breakdown in physical health, leading to death or hospital admission.

(ii) Relatives sometimes felt that extra domiciliary care was causing too many extra problems, for example demented husbands or wives blaming spouses for accepting help because they were unable to understand why it was needed. In Newham there was a case of sexual jealousy.

(iii) Some relatives found it emotionally too difficult to accept that strangers could care for their 'nearest and dearest' when they themselves were saying it was all too much.

(iv) A few clients lived alone and were chronically doubly incontinent. This was twice the case in Newham, and in spite of tremendous help and support, the quality of life for the sufferers was so poor that hospitalisation was seen as more appropriate.

(v) If a client was so disorientated that he or she was unable to appreciate being at home and was constantly insisting on leaving, there seemed little point in keeping him or her there.

(vi) Some clients wandered and thus put themselves at risk of accident or illness, especially in the winter months. In some cases this was solved by relatives allowing clients to be locked in. Night wandering could be checked by a night sitter but this provision was beyond the limits of our budgetary resources.

(vii) There was one case in Ipswich of a client wo was visited by a community carer three times a day, seven days a week, and managed to set light to her kitchen between the carer's visits. The client was fortunately unharmed but the bungalow was rendered quite uninhabitable.

## IV Research Perspectives and Preliminary Findings

Did the project succeed? Did it manage to keep at home people who would otherwise have been in an institution? There is of course no one, straightforward answer.

It is important to stress that the kind of data we had to deal with strongly influenced the kind of analysis we were able to carry out. First, our samples were small; second, even though we tried through our research design to hold down the number of different variables, inevitably our samples were far from homogeneous, which makes analysis on an aggregate level extremely difficult. With this kind of sample it is more appropriate to carry out case study analysis using detailed examination of people's circumstances, home care situation, processes leading to institutional care, factors involved in attempts to maintain home care and so on.

Of course we must ask whether people in the action samples were more likely still to be living at home, for example, one year after their referral to the psychogeriatric service than people in the control sample. But whatever the answer to this question, interpretation of its meaning requires further analysis; if the answer is 'yes' one still has to ask whether that difference between the samples might not have happened by chance (given the small size of the samples); if the answer is 'no' it is still very difficult to interpret unless the samples had turned out to be very well matched indeed (which of course would have been very unlikely given the large number of variables relevant to whether or not a person remains at home).

Tables 3 and 4 therefore, which provide an answer to the questions of whether more of the action samples remained at home or spent more time at home than the control samples, should be seen as a first stage in analysis, and should be treated with caution. (One further reason for caution is that our fieldwork has not yet finished; the following analysis is therefore based on incomplete data).

**Table 3:** <u>**Where dementia sufferers living one year after referral to psychogeriatric service**</u> - PRELIMINARY FIGURES
(for all still alive at one year and who have had their third assessment)

| | IPSWICH | | NEWHAM | |
|---|---|---|---|---|
| | Action | Control | Action | Control |
| | % | % | % | % |
| At home | 32 | 58 | 50 | 34 |
| In Part III accommodation (old people's home) | 52 | 33 | 27 | 37 |
| In psychiatric hospital | 16 | 8 | 23 | 19 |
| Total | 100 | 99 | 100 | 100 |
| Number: | 33 | 12 | 22 | 32 |
| % of original sample who had died by one year | 30 | 42 | 41 | 18 |

**Table 4:** <u>**Total amount of time spent in institutional care by dementia sufferers throughout the one year from referral to the psychogeriatric service**</u> - PRELIMINARY FIGURES
(for all still alive at one year and who have had their third assessment)

| | IPSWICH | | NEWHAM | |
|---|---|---|---|---|
| | Action | Control | Action | Control |
| | % | % | % | % |
| No time in institutions | 21 | 25 | 32 | 19 |
| Less than 6 months | 24 | 42 | 32 | 25 |
| Six months or more | 55 | 33 | 36 | 56 |
| Mean number of months | 6 | 3 | 4 | 6 |

These figures appear to show that in Newham the project worked as we expected (with action sample people more likely to be at home than those in the control sample) but that in Ipswich this did not happen. However, as stated above, such a conclusion cannot necessarily be justified. It is important to go beyond these crude aggregate data. A much more useful question, for example, is 'Are the kind of people still at home after one year more 'disadvantaged' etc in the action samples than in the control samples?' In other words 'Was the project helping to keep at home people whose circumstances or condition was so poor that if they had been in the control sample they would have been in an institution?' If the project was found to be doing this then one could assume that over a whole population more people would be kept at home with such support even though our small sample in Ipswich does not show it.

In order to see whether 'more disadvantaged' people were sustained at home in the action samples it is necessary to examine the nature of these 'disadvantaged'. What factors either facilitate or impede home care? For instance a basic assumption of our action project was that the services of a development officer and support workers would facilitate home care. In the course of our project, and through particular attention to accounts of decisions taken either to institutionalise or keep someone at home, we have been able to identify many other possible factors. Because we cannot give them a more objective existence we define them as factors used by people involved in decisions about home versus institutional care to explain what aided or hindered home care. Many of them have already been mentioned at this conference. They are listed below (although not in any order of priority and not as an exhaustive list).

**Table 5:** **Factors seen to aid or hinder home care**

| HINDERING HOME CARE | AIDING HOME CARE |
|---|---|
| Being unable to manage essential personal care on own (including incontinence, not eating, inability to administer own medication) | Being able to manage essential personal care on own |
| Being unable to manage care of environment on own and having no help/insufficient help (including having no home help or insufficient home help hours) | Being able to manage care of environment, or having help to manage it |
| Being lonely at home (including no strong commitment to remain at home) | Not being lonely at home (including preferring to remain at home) |
| Being unable to manage/negotiate environment safely (including behaviour which risks own or others' lives/health) | Being able to manage/negotiate environment safely (including not wandering, not fire or gas risk) |
| Being directly physically aggressive/harmful to others (including assaulting, sexual aggression) | Being unagressive to others |
| Being emotionally burdensome/harmful to others (including being demanding, uncooperative etc) | Not being emotionally burdensome/harmful to others |
| Causing inconvenience/disruption to order of others' lives (including being noisy at night) | Causing no inconvenience/disruption to order of others' lives |
| Behaving in a way which deters help from others (including being unwilling to accept help) | Allowing, welcoming help from others |
| Not having involved, capable relatives, friends, carers in close proximity (including voluntary or statutory service providers) | Having involved, capable relatives, friends or carers in close proximity |
| Being physically frail or ill (including being immobile, liable to fall, in need of nursing care or vulnerable to attack) | Being physically fit |

These factors are of course over-simplified; for example, and most obviously, they are not discreet but continuous variables, so that people amy possess them to a greater or lesser extent, and one still has to determine at what point possession becomes an aid or hindrance to home care; also - because the factors are often closely linked - it is not possible to consider one in isolation from another. This makes it virtually impossible to scale the items, or to measure the extent to which a person possesses 'aiding' or 'hindering' factors, or to assess the ratio of one to the other.

However, some assessment of people's home care potential is necessary. For what our action project has done is to add 'factors aiding home care'. It has done this mainly by helping people's personal and environmental care to be managed, helping them to be less lonely, less at risk, encouraging them to trust others and accept help, and by providing the nearby involved carer. (Incidentally, we have said that ours is only one among a variety of possible schemes to promote home care among the elderly mentally frail - others may work more closely on other factors or combinations of factors; for instance some may more strongly emphasise the emotional burden on carers by instituting a carer support scheme).

Because our project has added factors aiding home care it follows that we would expect: a) similarly disadvantaged people not receiving such an input (ie in the control sample) to be less likely to remain at home; and b) control sample people remaining at home for as long as those sustained in the action sample to possess more 'aiding' and fewer 'hindering' factors than would the action sample people in the absence of our project. In other words we would for instance expect control sample people still at home one year from their referral to the psychogeriatric service to be less disadvantaged in home care terms than action sample people still at home (or rather perhaps, than action sample people would have been without our project). If this is so then it is reasonable to conclude that over a large population a project such as ours would sustain at home more dementia sufferers than could be kept at home without it.

In order to demonstrate the validity of the above propositions it is necessary to examine in detail people's home care position, and the extent to which they possess factors which either aid or hinder it. Detailed case analysis is the most appropriate method to apply, but it is not of course easy to present analysis in a form of this kind within a very limited time period and with as yet incomplete data. However, we can present some data about those people whom we know to have been still at home one year from their referral.

In Ipswich one can take three people from the action sample, still at home and with considerable support from our project. The first is an 87 year old widow, with an OBS score of 8, living on her own in a local authority flat; she has very poor mobility, is subject to falls, and has an increasing tendency to incontinence. She cannot manage her own personal care, nor the care of her home. She has children living nearby but they give only limited assistance; she also has a home help. A project community carer visits her daily to ensure that she eats, and to help keep her clean and safe. The second is also an 87 year old widow, with an OBS score of 8, and living alone in her own house. She needs help to walk on stairs but is otherwise mobile, she wanders, and is doubly incontinent. She cannot manage her own personal care or care of her house, and is known to be at risk when on her own. She has a very involved son and daughter-in-law but both go out to work and therefore cannot manage continual care (although she has respite hospital care two weeks in six). A project community carer visits to help with her personal care and play a safeguarding role at times when other care is not available. The third person is an 81 year old widow, again with an OBS score of 8, living alone in her own house. She is unable to manage her food preparation or heat regulation and is at some risk from gas and on roads. She has no involved carer apart from our project community carers who prepare meals and handle other aspects of her personal and environmental care as required.

In the Ipswich control sample there was no-one living at home at the end of one year whose home care potential (without project supporters) was as poor as that of those three. For instance only two were living alone, and

both these people had much lower OBS scores than the three being supported by our project (one had a score of 3 and the other of 5); they were also able to manage much more of their own care than the former group. The woman with the score of 3 is perhaps better described as eccentric and slightly confused rather than anything else; she cares for herself independently; the woman with the score of 5 is more disadvantaged (including requiring an aid to walk indoors) but she lives in sheltered housing, and does receive some support from the warden as well as a home help, community psychiatric nurse and neighbours. The others still at home in the control sample live with very involved spouses or children, who share the care with day care centres and temporary admissions to homes or hospital.

In Newham the picture is more complex, though on the whole similar to Ipswich, with the project tending to support people living on their own whose demential is advanced or who for other reasons cannot manage their own care, and/or need some safeguarding care. We have data on 4 people form the action sample still at home one year from referral and with project support workers. They are very similar to the Ipswich group: all are women; all live alone; only one has a closely involved relative (and like the similar Ipswich case it is a daughter, who goes out to work and needs help to care for her mother at certain times during the day). In other ways they vary: 3 have very high OBS scores, are unable to manage much of their own personal and environmental care, and need safeguarding, the other one has a lower OBS score (4) but such poor mobility that she is physically incapable of doing much for herself.

In the control group there were 4 people still at home at one year who live alone and without closely involved relatives. If our expectations are to be upheld they should either have low OBS scores and be able to manage a good part of their own care, or they should have good support from other sources. Two of the women (again they are all female) do have relatively low scores of 5, are mobile, and can manage to care for themselves and their homes to a large extent. They both also have other support: one in the form of day care, a home help and social worker; the other in the form of a home help and a very involved social worker who manages her finances for her. However the other two have scores of 7 and 8. One has good mobility, is not incontinent, receives day care, home

help and help from a son and daughter (who visit once a week even though they do not live closeby). However we would expect this situation to be difficult to sustain for long, and indeed this woman was admitted to permanent institutional care three months after the year ended. The other woman's competence belies her relatively high OBS score, in that she generally manages all her own personal care and care of her house (apart from shopping, which is done by a nephew). However she has poor mobility in that she needs an aid to walk indoors and is liable to falls; she is also so emotionally burdensome to her nephew, and unwilling to have other help that we would expect this situation to break down.

These cases merely give an indication of the kind of analysis most fruitful for this type of study. Though as yet incomplete we hope they begin to demonstrate the combinations of factors which contribute towards making home care viable or not, and show how our project operates particularly effectively to sustain at home those who have only little capacity for self care and comparatively little support from other relatives and friends.

## SUMMARY OF DISCUSSION SESSION

In the wide ranging discussion which followed the presentation considerable enthusiasm was expressed for projects of this kind. For example Elaine Murphy mentioned the value to very many dementia sufferers of remaining at home; Ken Boyce talked of the value of a service provided by a non-statutory organisation which could mediate between the Social Services Department and the Health Authority, and was seen as having 'no axe to grind'; such a project could also act as a catalyst to other service providers; and was good for the elderly people involved because its sole focus was on this particular group of clients. Peter Laycock and Martin Stevens were enthusiastic for the way in which the project filled gaps in service provision which the statutory authorities could not cover, and in particular for the amount of time the project could make available in which to talk to and provide services for the clients.

The limitations to care were discussed, with some participants anxious for more details about the kind of people who are not sustainable at home. They were assured by project staff that such information would eventually become available and would be augmented by additional data through the forthcoming extensions to the projects.

Some points were made about the apparent differences between Ipswich and Newham. Martin Stevens suggested that there might have been some differences between the action and control areas in Ipswich which could have helped to account for the small size of the control sample there. He also suggested that general practitioners were more ready to refer patients living in the action area to the psychogeriatrician because they soon learned that the project existed for people in north Ipswich. The apparent opposite of the expected difference in outcome between action and control groups in Ipswich (as compared with Newham) was discussed; one suggested explanation for instance being that Ipswich statutory authorities provided such an extensive service anyway that the control sample was very little worse off than the action sample and might even have been better off because the work of the development officer in the action area released the community psychiatric nurses to operate more fully in the control area. Project staff however warned again that the figures on outcome needed careful interpretation and that detailed case analysis suggested that

a greater number of more disadvantaged people were being sustained at home in the action samples than in the controls in both Ipswich and Newham.

In conclusion David Hobman suggested that projects such as this remind us of the worth and scope of community care support; elderly people need more choice, and dementia sufferers in particular need advocates and supporters to help them retain that choice.