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INNOVATIONS IN CARE FOR THE ELDERLY

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INNOVATIONS IN CARE FOR THE ELDERLY

European experiences

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Wim van den Heuvel and Guus Schrijvers (eds)



NIVEL

bibliotheek

drieharingstraat 26

postbus 1568

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telefoon: 030 319946

9 JULI 1986

1986

UITGEVERSMAATSCHAPPIJ DE TIJDSTROOM
LOCHEM - GENT

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ISBN 90-352-1086-7
D/1986/2966/9

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Preface

European countries have witnessed an enormous growth in the relative and absolute number of elderly persons. A further growth of the elderly, particularly of the 'old-old' is expected in the next decades. As a result, a considerable part of the elderly population will rely on professional services for the elderly, especially hospital services.

In the late sixties the growth of institutional care for the elderly led to concern about 'demoralization' and 'depersonalization'. These humanitarian concerns combined with more recent social and economic concerns about the further growth of institutional and professional care are important criteria to look out for in 'alternatives' for care.

Most countries in Europe have adopted the philosophy: 'independent living of the elderly for as long as possible'. In health care there is a focus on primary health care, on health by people instead of health for people. These 'value-orientations' mean a process of de-institutionalization and an increase in 'alternative' out-patient services. So far, actual descriptions and empirical data about this oncoming process are scarce. This book brings together experiences on innovations based on these value orientations in care for the elderly from several European countries. It emphasises the necessity for innovations in care.

Part 1 of this book contains two chapters about methodological problems in research on innovative projects written by Van den Heuvel and Smith. After these two introductions some care innovations within hospitals are discussed in chapters III, IV and V: experiences from Sweden, the United Kingdom and the Netherlands are brought together in part 2 of this book. Alternatives for institutional care or possibilities for this are the topics of part III of this book: experiences and ideas from Norway, Denmark and Holland concerning primary care and family care are given in chapters VI, VII and VIII. The theory of part 1 and the experiences in part 2 and 3 are used as a basis for an innovative model explained in the last chapter of this book.

This book largely results from a workshop at the University of

Groningen (The Netherlands). This workshop was financially supported by the European Science Foundation. J.M. Abma-Hill improved Dutch English into English.

We hope the reader will find some incentives and ideas to innovate existing care systems towards out-patient and informal care.

Wim van den Heuvel

Guus Schrijvers

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I. Evaluative research in the care of the elderly: some considerations

Wim van den Heuvel

1. Introduction

In the mid seventies the field of evaluative studies was regarded as a discipline in itself. The first volume of 'Evaluation Studies Review Annuals' was published in 1976 and dealt with the theory and methods of evaluation. It also presented evaluation studies on different topics such as: education, crime and public health services. The interest in evaluative research is related to the contribution which it is expected to make towards better planning, effectiveness and efficiency.

Evaluative studies of (health) care have also developed rapidly since the 1970's. Major reasons for this development are the growth of expenditure on health services, the growth of medical science and technology and the increased public accountability. Also tools have become available which enable the measurement of the effects of specific actions in health services (Patrick, 1982).

Alternative designs have been developed for evaluations where randomization and experimentation are not possible. The measurement of diseases and handicaps have also improved. An overwhelming amount of literature exists on evaluation and evaluative research. This does not mean however, that there is a conceptual agreement or a uniform methodology. As usual in social sciences, discussions are going on concerning qualitative versus quantitative measurements, pragmatic versus idealistic approaches and descriptive versus explanatory studies.

Evaluative research applies the methods and techniques of the social sciences and epidemiology. It cannot be regarded as a discipline in itself.

The central problem is designing adequate research to show the often and complex effects of an experiment or innovation.

In this chapter we will begin with a description and definition of evaluation. Secondly, the importance of evaluative research will be dealt with, followed by the problems of evaluative research which

generally arise due to the objectives being care systems and patients. Finally the special difficulties in the content of geriatric services will be mentioned.

2. Definitions

Evaluation often starts implicitly when the idea that a specific activity or action (e.g. new therapy, diagnostic instrument, service), is considered worthwhile, or is forbidden because of the possible spread of an infectious disease or prevents institutionalization of the elderly. The idea of evaluation is based on value orientation. For example, it is believed that older people should live independently for as long as possible.

Goals may be formulated which are based on such value orientation e.g. 'older people should live at home for as long as possible'.

Evaluation refers to the general process of making judgements on whether a particular action is really worthwhile (Suchman, 1967). These judgements or assessments of value must be based on the (perceived) achievement of (stated) objectives according to a programme, policy or activity. For example, there is a concept (measurement, analyses) concerning the adequacy of the activity, its acceptance by the target population and its efficiency.

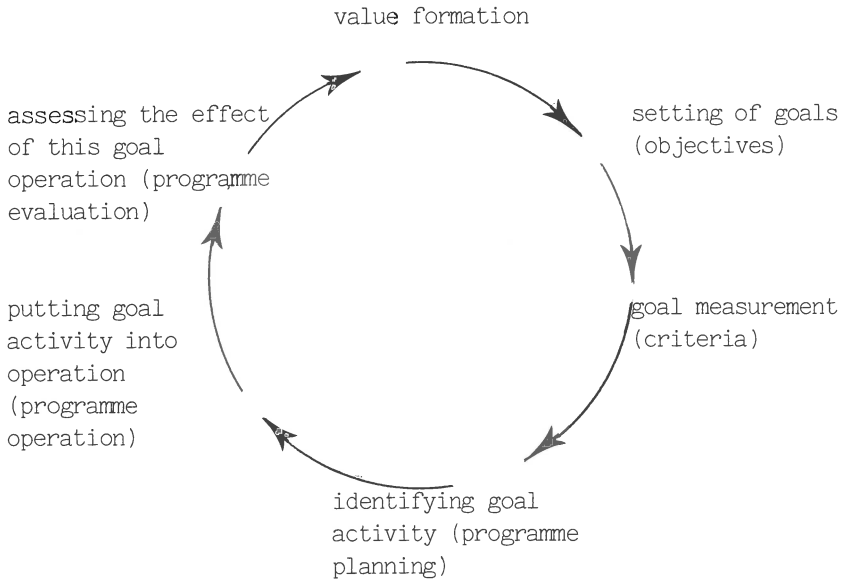
The way in which the general process works may be represented in a circular diagram, as shown in figure 1.

The formulation of objectives (setting of goals) often takes place simultaneously with or even before value formation; the latter may be implicit. The formulation of objectives depends on such aspects as resources (trained personnel), money and effort.

The next question is: which measures are available and how will the effects be shown. For example, do we really know how many elderly people live in institutions? By comparing these figures over a given period of time, i.e. before and after a specific action, the effects may become evident. When no measurements (data) are available (so far), which criteria should be developed? After an agreement has been made concerning known data and which criteria should be used, a programme of activities must be developed in order to realize the objectives. The programme will then be carried out and evaluated.

Evaluation research is (a process of) applying scientific procedures in order to accumulate reliable and valid evidence on the manner and extent to which specified activities produce particular effects

Figure 1. Evaluation process (Source: Suchman, 1967)



(Rutman, 1977, p. 16). Suchman (1967) defines evaluative research as: 'the utilization of scientific research methods and techniques for the purpose of making an evaluation' (p. 7).

The importance of evaluative research

As we will see in the following chapters, in most West-European countries evaluative research is going on in the field of care for the elderly. This research partly concerns the evaluation of innovations in the care for the elderly. Evaluative activities are not always referred to as research, although the systematic gathering and comparison of data against time may well be regarded as such. Evaluative research is especially important in innovative care programmes in order to show which effects have occurred and to make possible amendments to the programme. The results of the research may assist the policy makers with their decisions. In any case they will at least offer arguments and motives for use in the decision making process. However, it is also possible to misuse the results. An analysis of the relationship between policy making and results should be made, i.e. how will the results be used, which aspects

should be evaluated, who defines success, etc. (see Smith). Since evaluation research concerns measuring the effect of a certain activity or programme, some cooperation is necessary (exchange of information) between researcher and programme administrator, care provider or policy maker. Such cooperation is a necessity, but it also forms the main problem (Scheerens, 1983).

The research should be based on sound methodology (valid and reliable data), with special regard to the explanation of the results.

3. Problems in evaluative research

Evaluative research generally uses the same methods, measurement techniques and analysis programmes as the social sciences and epidemiology, e.g. before-after design, case control study, interview techniques, cost effectiveness analysis, randomized control trial. Illsley (1980) states: 'There is no lack of sophisticated methodology'. The topic has been exhaustively explored in evaluative literature. Model designs have been developed for use in field settings. The scientific aims of evaluators in field settings are no different from those of laboratory scientists or of the exponents of randomized control trials. They too are concerned with proof, evidence, validity, reliability etc. The content of such literature however, reveals the nature of their adaption to imposed conditions. Here one encounters such terms as: approximations to knowledge, quasi-experimentation, interpretable comparisons, inductive evidence and causal inference, as enforced substitutes for cause-and-effect experimental proof (cited from Barker, 1983, p. 281).

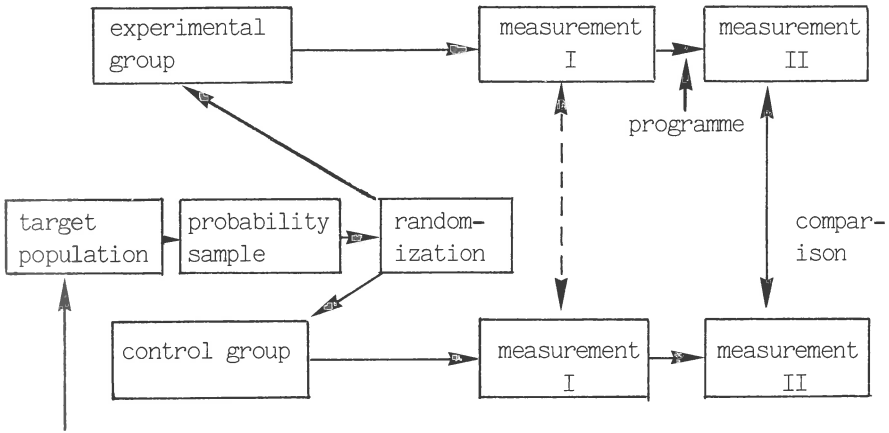
The ideal design for evaluative research is well known (see figure 2).

When patients or care are involved, probability sampling, randomization and the use of the 'programme' in only the experimental group may be difficult. So, variations or adaptations to this design are necessary.

In reality, this ideal design will not be used. The researcher has to design an adapted model.

'The nature of these adaptations to imposed conditions' is the heart of the problem. Problems in evaluative research concern the position of the research worker and the role of the care provider and patient. For example, the researcher may not be involved in the first

Figure 2. Ideal design for evaluative research



stating:

- objectives
- criteria
- description of population
- programme

steps of the evaluation process, which may conceal from him the several parties involved with possible conflicting interests. When a comparison is made between the effect of in-patient services and home services on the well-being of older patients, the hospital management may only be interested in a positive result for the in-patient service. Such interests may lead to hidden policies in programme operations. Therefore, certain data are impossible to register. Because of this, attention should also be paid to the way in which the 'programme' is carried out (process evaluation). This process can be regarded as a clarifying/intervening variable simultaneously with a possible object of evaluation.

There is a classical distinction between process evaluation and effect evaluation. However, the first category of evaluative research seems to form a part of the second, i.e. process evaluation forms a possible explanation of the effect variables. When the evaluation object is a process, effect evaluation and process evaluation coincide. Process evaluation may be an excuse for not wanting to measure effects.

Evaluative research has to be an integral part of the evaluation

process. It is important to know all the phases in the design of the study. Also problems may arise in the organization of the programme which may influence the design or measurements during operation. For example, a geriatric observation and diagnostic department in a general hospital should limit the observation period to 4 weeks in accordance with the programme. In reality, patients remain there for several months because of problems concerning discharge from hospital (no beds available in nursing homes). An additional analysis should be made on this development and extra measurement points are necessary in order to analyse the effect produced by this obstacle. The researcher should be involved in solving this kind of complicating factors because of the consequences they may have on the design of the research.

This involvement may be especially difficult in care situations. The care provider may not wish to follow the protocol in the interests of the patient/client. Without close cooperation it may shortly appear that over half of the patients are judged as 'exceptions'.

On the other hand close cooperation may have disadvantages. The researcher may become too involved in the programme as such. This may lead to the selective use of methods and measurements to the advantage of the specific programme. The researcher should, in my opinion, remain an outsider. This does not mean that value judgements will not be included in the design. They will! But it is a plea for 'methodological diversity' in the design, i.e. quantitative and qualitative data are also necessary and the opinion of the patient/client and the satisfaction of the care providers are just as important as the resulting effect on de-institutionalization. Therefore it must be a pluralistic approach, which Denzin (1970) refers to as 'triangulation' (see also Smith).

Another problem based on the weak position of the researcher and/or his involvement is the tendency to evaluate factors which are easy to study, such as the importance of low prices (as criterium) and to ignore the politically controversial topics. The effectiveness of interventions can be illustrated by using simple indicators but this may be very time consuming, expensive and of an inadequate design. The researcher may also be prevented from pursuing a more complex methodology or better understanding of the effects due to the interests of the planners and the amount of money available for research.

In the field of care, it is well known that care providers have their own fears and uncertainties. These may prevent them from

cooperating in the evaluation study. Ethical arguments are often used for non-cooperation: i.e. 'withholding a service from those who are considered in need of it'. This may be a problem.

However, it will probably be overcome in time. Care providers are not generally familiar with research and therefore do not appreciate all the technical requirements. The solution will be found in considering the researcher as part of the evaluation process.

The last problem concerns policy making. Evaluative research may be used as an excuse or delaying tactic in order to avoid the implementation of a worthwhile idea. The misuse of evaluative research in this sense is difficult to prevent or even to recognise in advance.

The problems mentioned so far may be classified as 'conditional' problems. They must be explored before the decision to carry out an evaluative research project is made.

The question may well be asked as to whether it is possible to evaluate activities at all. Rutman (1976) recommends two steps before starting evaluative research. Firstly, an analysis of the decision making system, intended users, programme activities and objectives (evaluation assessment). Secondly, exploration of the strategy of data collection on the programme's evaluation (formative research).

Although these suggestions may be useful, it is my opinion that researchers should be involved in the total evaluation process (as is already mentioned above), i.e. they should try to make significant 'reconstructions' of the policy making processes which are to be evaluated. Evaluation criteria which are linked as closely as possible to the decision making rules should be used, as laid down by the policy makers of care providers.

In order to overcome the 'conditional' problems mentioned above, the following 9 checkpoints may be used:

- (1). An analysis of the history of the question/innovation/programme.
- (2). Clear specification of the objectives.
- (3). An agreement on the criteria by the various parties involved, including the reasons why certain criteria are not involved.
- (4). A logical relationship between the activities and the goals (causal assumption).
- (5). Registration of the way in which the activities are to be carried out (process).

- (6). The measurements must include several levels of 'objectivity'.
- (7). Differentiation of outcomes into intended and unintended.
- (8). A comparison of the outcomes with changes against time and/or controls.
- (9). The commitment of the policy makers to the results.

4. Special difficulties with regard to the content of geriatric services

The problems encountered in evaluative research are especially relevant to the evaluation of geriatric services. A description of the content will illustrate this.

Description of geriatrics

In the Netherlands the professional community has been striving for a specialization in geriatrics for many years. There are many differences of opinion concerning what is, or should be the content of such a specialization.

Over the last few years various articles in the magazine 'Tijdschrift voor Gerontologie en Geriatrie' have been concerned with the discussion of this topic. What is the difference between geriatrics and the medical treatment which one receives in a nursing home or from the General Practitioner? Various authors have given definitions and/or descriptions of geriatrics. Some refer to 'very old, multiple pathology, disturbed ADL functions, tendency to require care, unstable physical and mental balance and weak basis'.

Others refer to 'the medical treatment for the sake of the elderly, and especially the very elderly, who, through a multitude of ailments, deterioration of physical and mental functions and/or through a disrupted social situation, show a complex clinical picture'. A summary of the factors upon which a patient may be considered as geriatric is:

- old,
- multiple pathology,
- tendency to require care,
- psychological functioning is threatened/deficient,
- social problems.

Geriatrics seems to be mostly concerned with characteristics such as 'old, multiple pathology and tendencies towards needing care'. If these characteristics should be exchanged for illness and/or com-

plaint then the description approaches that of 'integral medicine'. Is geriatrics then not more or less medical treatment from a General Practitioner? Would the knowledge of multiple pathology and continuing tendency towards needing care be typical for clinical geriatrics?

Before specialization occurred, it was split up into social geriatrics, psychogeriatrics and clinical geriatrics. Given the above description these additions seem to be unnecessary. All this says very little about the contents of the care and over the special requirements which must be fulfilled by the care service.

Could it be coincidence that in a relatively short time a range of facilities for elderly people have been announced? The battle over the geriatric patient has begun. In the light of this, it can not be a coincidence that the geriatric ward of a general hospital has developed in regions where there are too many hospital beds.

Policy makers and care providers do not agree on the special requirements which must be fulfilled by the service. Obviously the question arises as to whether there is any clarity over the goal of the care service. Actually, when setting up the facilities one should begin with the fixation of the goal in accordance with the evaluation process circle diagram in figure 1. In the Netherlands it is usual for 'new' facilities to rise up from other existing or partly superfluous facilities.

The following goals are distinguishable, given the description of geriatrics:

- Achievement of the highest possible level of physical/mental fitness.
- Provision of high quality medical treatment.
- Creation of the most favourable environment.
- Contributing to the continuing possibility of being able to live independently.
- Provision of the highest possible quality of nursing care.

These objectives can also supplement each other. Cooperation, coordination and interchangeable expertise are also important objectives.

In practice choices concerning the objectives will be carried out implicitly or explicitly. For the realization of a certain objective there will also be a most suitable form of organization.

Given the different objectives it is obvious that there are various different forms in which geriatric care can be provided. These various forms do exist.

It is not only possible that various forms of geriatric care exist but also services with the same name and legal arrangements can pursue or realize different objectives. The latter is especially true in the case of services which provide more than just geriatric care alone, for example community care, General Practitioner.

5. Conditions for evaluative research in geriatrics

Evaluative research offers countless possibilities, but it also strikes against many problems.

Several conditions will be mentioned which must be fulfilled by investigations such as evaluative research. These conditions are generally a choice of possibilities in evaluative research.

In an evaluative research project in geriatrics this choice is less free, given the difficulties already mentioned concerning content, goal and form of geriatric care. Consequently, the following points may be considered as conditions for a good evaluative research project.

The comparison of different forms of geriatric care

As was already mentioned above, geriatric patients can be admitted to and treated at various locations. The GAAZ (geriatric department in a general hospital) is one such place of residence. However, the diagnostic and treatment facilities offered there can also be realized in other spheres through close cooperation between SGD (social geriatric care organizations), primary care and out-patient clinics. In other words, a GAAZ is not necessarily superior over other forms of care, at least not in theory. During an evaluation, institutionalization and (too) long residence times could possibly act as heavily weighing disadvantages. The possibilities mentioned above can be checked by comparing the various facilities. Control groups are necessary, whereby further differentiation can be made according to the nature of the problem. Also longitudinal measurements are necessary in the same area in order to (by comparison) trace the changes against time. The influence of management policies and other 'natural' changes also play a role here.

Besides the necessity of control groups, the importance of involving other (alternative) forms of care facilities must also be pointed out. In a comparison between for example 5 existing GAAZ situations

no answer was found to the questions concerning whether or not a GAAZ should have its own hospital beds and/or whether the care provided in a GAAZ could not also be realized by nursing homes and out-patient facilities.

The evaluation of only one aspect (e.g. average length of institutionalization) gives an incomplete picture. Other very important factors are the number of resources (e.g. recourse to hospital after discharge to nursing home; recourse to nursing home after discharge home), the burden on the care organizations, the level of satisfaction of the care provider (e.g. sufficient exchange of information), good communication with district nurse, physiotherapist, General Practitioner and in addition to these factors the internal functioning of the department (efficiency, environment), good nursing care and high survival figures. Thus, in a worthwhile investigation a diversity of indicators must be used. The weighing of the various consequences is done by those who are responsible for making the decisions.

Effects on other facilities

The effects which new facilities have on other (adjacent) facilities require extra attention, because they are usually considered as being too far removed from the original theme of the investigation. When employing new staff in a SGD it is not sufficient to consider only the work activities inside the service. Attention must also be paid to the patient flow outside the SGD (e.g. admission to psychogeriatric nursing homes). The same applies for the GAAZ. The effect and efficiency of a GAAZ must be measured against possible shifts in other facilities.

If the problems encountered in primary care change, will intramural care in combination with the SGD be able to cope with the task? If they cannot, then within a short period of time the number of admissions will increase, including the number of 'trivial cases'. Such effects can be demonstrated in relation to hospital admissions, residence in nursing homes etc.

Application of investigation results

Before going over to evaluative research it is advisable to make arrangements about the application of the results. The expectations of the governing body concerning the results must be established as this increases their chance of utilization. A second element is the

assignment of people for the practical work. Generally, this is not only necessary for the success of the investigation (registration, interviews) but it also forms a guarantee that bottlenecks and everyday experiences are involved in the research. This also increases the chance that any potential research results reach all disciplinary levels.

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II. Some methodological suggestions for studying new health services for the elderly

Gilbert Smith

1. INTRODUCTION

This chapter discusses some of the methodological problems which are encountered in evaluative studies of innovation in the care of the elderly. The discussion will proceed in the following way: we begin by reviewing the problems of a soundly based evaluation in view of the fact that

- a) programmes of innovation are constantly evolving and changing,
- b) several separate criteria of 'success' are frequently apparent,
- c) an experimental or clinical trial research design is rarely an option,
- d) evaluative research on the elderly is often, in practice, confined to a case study.

Secondly, we shall draw upon some interviews with staff responsible for caring for the elderly in one new day hospital in the United Kingdom in order to illustrate in some detail one of these problems: i.e. the several criteria used by staff and planners to evaluate the success of the institution. Thirdly we shall draw a methodological conclusion. We shall suggest that a 'pluralistic' approach to innovation is necessary in order to understand how several different groups involved in the care of the elderly use different criteria in pursuit of success in their own interests. We shall suggest that this approach to the study of innovation in health services for the elderly has several advantages. However, we are not complacent and in the final section of the chapter we list what appear to be some of the outstanding methodological issues in this field of research. The studies described in other chapters in the book provide a rich and comparative context in which these issues can be explored.

2. SOME PROBLEMS IN EVALUATIVE RESEARCH

As the studies in this book indicate, the overall research task of many investigations in the field of the elderly is to evaluate the

service and its organization, particularly in the light of what might be regarded as innovations in the care of this client group. Problems have arisen, however, because methodological weaknesses have become apparent, especially in evaluating alternatives to institutional care (Gurland, Bennett and Wilder, 1981), and as Gurland et.al. have pointed out, research results have not had the impact upon policy for long-term care of the elderly which they might have had. Our argument is that the central difficulty lies in the fact that the format of evaluative research is inclined to be deceptively simple.

Typically the description of an evaluative design runs like this: define service goals, specify service outcomes as measures of goal achievement, define criteria of success, isolate the effects of the service from other possible causes, measure achievements, and adjudicate on the success (or otherwise) of the service. This simplicity **is** deceptive because it is based on two broad presumptions which are frequently unjustified.

The first presumption concerns the relationship between evaluation and the social processes which are involved in the making and shaping of health and welfare policy. Lee J. Cronbach and associates make the point:

'The theory of evaluation... has been developed almost wholly around the image of command... Actually, however, most action is determined by a pluralistic community, not by a lone decision maker. Parties having divergent perceptions and aims bear down on law makers and administrators... When there are multiple participants with multiple views, it is meaningless to speak of one action as the rational or correct action. The active parties jockey toward a politically acceptable accommodation' (1980, p. 84).

A rational relationship between policy goals and service outcomes must be questioned. Pluralistic models direct our attention to the several constituencies of service organizations and incrementalist theories (Lindblom, 1959) point to ambiguity and confusion as **typical** rather than unusual features of most agencies. As a good deal of research in hospitals as well as other organizations has shown (Silverman, 1970; Eldridge and Crombie, 1974) objectives vary between and within significant groups. Goals of services for the elderly are also complex, multiple, conflicting i.e. vary over time and between contexts. They are variously interpreted, notoriously

ambiguous, and are sometimes difficult to locate at all. As Cronbach et.al. add:

'References to the attainment of goals pervade discussion of social programmes and their evaluation... (But) this (point of view) seems rationalist to the point of unreality. Consensus on ends and priorities is mostly absent from a context of accommodation.

For rationalists, all thinking starts with a specified goal or purpose. To find a means to the stated end is what it means to 'solve a problem', **but that is not how social action is taken**' (1980, p. 129) (Bold print added).

And Martin Rein has reinforced the point writing in a similar vein:

'Finding out a programme's intent begins with the programme's rhetoric. Getting beneath the rhetoric to the realities of intent and interest is another question. Defining a programme is difficult when there is little agreement on the activities to be included or on the intent that unifies those activities into a coherent purpose. Since the 'activity' to be evaluated is not self-evident, it must be treated as problematic, rather than established' (1983, p. 162).

The second presumption concerns the apparent desirability of experimental or quasi-experimental designs in evaluative research. Cochrane (1972) has been a vocal exponent of the general strengths of this type of study. In the field of the elderly, Goldberg has been a major advocate of the merits of this genre, particularly in the light of her own important example of a piece of evaluative research following a quasi-experimental design (Goldberg, 1970; Goldberg and Connelly, 1982).

The central features of the experiment in the context of evaluating health services have been set out by Illsley (1980). The main objectives of the programme being studied are clarified (or deemed to be clear). The experiment (or randomized controlled trial) tests the intervention against alternatives (including no action). There are precise measures of, and controls over, the inputs to the programme. The criterion of success is uni-dimensional and uncontroversial. And extraneous variables can be excluded or controlled.

In spite of the obvious advantages of the approach both Goldberg and Illsley have pointed out considerable difficulties. Random assignment of clients to different services is seldom possible. There are

ethical as well as administrative objections to randomization. Practitioners learn as they go along, so that inputs to the programmes are rarely stable through the experiment. Even at their most successful such research compares only two programmes rather than the broad range of alternatives, as really required. It is almost impossible in a setting such as services to the elderly, to exclude extraneous variables (e.g. services are reorganized, there are demographic changes, new hospitals are opened, professionals working the service change and so on).

Professionals operating the service become aware of the different treatments which introduces a subjective bias. Usually measures of success are equivocal. And even when finally completed (and even when discounting the problems that we have just mentioned) the experiment or controlled trial can say very little about **why** any changes that may have been detected have occurred.

However, although they largely agreed on the difficulties of the experimental approach, Goldberg and Illsley draw different conclusions from their observations. Goldberg regards experimental designs as 'powerful' and insists that the difficulties are surmountable, with effort, and the rewards considerable. Illsley argues that even if some of the practical difficulties are 'in theory, superable by refinements of technique, design or negotiation' in **practice** that is rarely so. The social world of health and welfare services is simply not the controlled setting of the experimental laboratory. Moreover:

'Four sets of circumstances occur in which limitations on action inhibit the use of rigorous experimental evaluation. These are:

1. inability to determine goals,
2. inability to control output,
3. inability to measure or evaluate output,
4. a combination of 1, 2 and 3' (1980, p. 115).

Illsley thus favours a style of research which he describes as 'illuminative evaluation':

'The data are not cut and dried in the tradition of the natural sciences, instead they trace and reflect what is and must be a fragmented, complex process. The data have to be put together and the process reconstructed with various forms of logical analysis but also with judgements about the relative weight and influence of factors and items. The study, therefore, goes well beyond the normal purpose of a trial which is to confirm or deny a hypothe-

sized relationship between input and output derived from pre-existing theory. The task of relating an input... to output... produces simultaneously an explanatory model of how the system works' (1980, p. 135).

Certainly in our own research in the context of evaluating services for the elderly, we have encountered several specific difficulties arising from the non-rational and pluralistic character of policy planning and from the unattainability of the experimental ideal. To be specific, there is first the problem that the innovation being evaluated is constantly changing and evolving. Thus the research task is that of evaluating a **process** of change. Neither the rationalistic nor experimental approach copes with that. Second, we found that several different criteria of success are apparent within new services for the elderly. Third, the conditions necessary for the experiment, controlled trial or even very meaningful comparison are difficult to attain because of the wealth of relevant related but constantly changing variables. Fourth, the fact that our research, like many similar investigations, was originally commissioned and funded as a case study, adds a further complication. Many relevant factors are beyond the boundaries initially conceived for the project. However, even if evaluation of an innovation is extended to the evaluation of a complete system of care, that system is still located within an unstable and pluralistic policy environment. Therefore, the difficulties that we are discussing remain.

A full adequate discussion of these problems is beyond the scope of a single paper. We can, however, make some methodological suggestions for studying new health services for the elderly by presenting some data on just one of these points: the several and somewhat varied meanings assigned to the notion of 'success' in providing services.

3. ONE PROBLEM ILLUSTRATED: THE MEANINGS OF SUCCESS

During the course of a study in which we were attempting to evaluate the services of a new psychogeriatric day hospital in Scotland we have concluded that at least six sets of criteria for judging the success of the institution are used by different groups, in different ways, on different occasions and for different purposes. On the basis of a set of semi-structured, tape recorded and transcribed interviews with hospital staff and administrators during the early months of the hospital's life, we now set out these different

meanings to provide a detailed illustration of the foregoing general debate.

In summary, these criteria were used to define the success of the hospital in six different ways:

1. Success meaning free patient flow,
2. Success meaning a quality service,
3. Success meaning improved clinical condition,
4. Success meaning a contribution to related services,
5. Success meaning effective organizations of services,
6. Success meaning a service to patients' relatives.

First, there is a set of criteria which refers to the 'flow' of patients through the system of referral, admission, treatment and discharge, into and out of the day hospital and related institutions. Thus the hospital should reduce demand for in-patient beds:

'Well, the main achievement is to keep the elderly as fit and as able as we can in the community and to stop - try and reduce the demand on in-patient beds and to prevent people coming into beds prematurely and keep the patient in the community as long as we can',

shorten waiting lists for these beds,

'We have a large waiting-list of psychogeriatric patients waiting on admission and we have nothing in the foreseeable future to offer them in the way of beds other than hoping beds, we have already, become available in ones and twos...',

prevent and delay admission to in-patient beds:

'... we find that we're getting far too many patients in who should be in the community. Hopefully the day hospital is going to stop them coming in at an early stage. The longer we can keep people in the community the better it's going to be for them and the Health Service as a whole',

facilitate the discharge of patients from Park Hospital, a nearby hospital, by admitting them to the day hospital:

'My hopes, right from the start, would be where there was slack was that we might have had some other in-patients, perhaps the

cream of the in-patients who had potential for discharge, having an opportunity to have the benefits of an intensive sort of treatment regime...!',

improve the use of particular categories of beds by the correct categories of patients:

'... it was hoped that the selection of patients would be such, that there would be patients that we could do something for - hm - it's very easy to take the first ten people that come along, you have to be selective...!',

a more efficient mesh in patient referral to psychogeriatric medical care with other services:

'Y'see, another point is that when a referral comes (here) not all these patients are... admitted... It quite often turns out that (the Social Worker) is able to arrange some other kind of help, such as somebody going for day care in one of the residential units or even exceptionally going into an eventide home... so that - hm - apart from the places we have here, the team... is - hm - really functioning on a wider basis'.

Above all the innovation should avoid 'silting up' both the day hospital itself and other parts of the hospital system to which it relates

'... it was the operational policy to have throughput. Some (day hospitals) are not designed this way. Some are designed as really a sort of pre-war holding operation'.

Generally, as one respondent explained:

'It's rather nice to have some coming in and some going out'.

A second set of criteria for judging the success of the hospital refers to the **quality** of the services. From this perspective, the hospital's success may be measured by pointing to a number of features which are desirable **in their own right**, quite apart from whether there is any demonstrable effect upon the clinical condition of patients or the performance of the hospital as displayed in official admission and discharge statistics. Thus, in summary, the hospital should provide a civilized and caring environment, staff

should convey caring attitudes to patients and relatives should enjoy their time at the hospital. As one respondent explained, the quality of care was featured as a criterion very early in plans for the hospital.

'The Board's officers were very concerned that the existing vehicles for day care really fell more, without being in any way derogatory, into the sense of being **day centres**, the social services concept. It was questionable to what extent they were carrying out a therapeutic function... more they were just caring centres... the day (hospital) was created to try and inject a **new** initiative into the care of the elderly and mentally infirm'.

Quite apart from clinical consequences this initiative had produced results.

'I'm not talking about the clinical side, but the patients seem to be happy. One sat and talked to patients and so on, but whether therapeutically, y'know, it's better or worse than anything else I can't say, but y'know the whole atmosphere it conveys is one of apparent efficiency and friendliness and - y'know, that's something good because you've not got much like that in (this area) y'know it seems to be stimulating, I think that's something that we're all pleased with'.

A third, and perhaps most obvious set of criteria refers to the success of the hospital in improving the clinical condition of patients eligible for admission. Such a view, reflecting a 'disease model' of psychiatric practice, views the conditions from which patients are suffering as akin to other kinds of medical illness and likewise amenable to treatment and cure. The importance of showing improvement on measurement scales, such as the Crighton scale which is used to assess patients as a part of the hospital's regular nursing programme, features particularly in accounts of the use of this set of criteria. As a respondent explained:

'It was hoped that there would be a **clear measurement** of (patients') clinical situation, so that you could get some sort of scale as to whether they were making progress or they weren't, this is the whole idea of this Crighton scale and so on, so that we can begin to **measure** the patients' response to treatment, to medication and so on, and to see whether in fact they're coping...'.

A fourth set of criteria which emerged, refers to the evaluation of the hospital in terms of the contribution which it makes to related services. Such a view dictates that we examine the day hospital as one component in an overall system of health and social care for the mentally infirm elderly. Even if the hospital had no significant and demonstrable effect on the elderly, it might nevertheless be justified in the help it offered to social workers, General Practitioners, district nurses, the home help service, or whatever. Respondents commented upon the way in which they saw the Day Hospital assisting: General Practitioners who could now refer a patient with some hope of admission, the Consultant Geriatrician who could refer on the psychiatric geriatric cases, the Consultant Psychiatrist who saw some hope of relieving demand on beds, social work and other 'community' services which were offered help with the most difficult cases.

One respondent gave an example:

Interviewer: ...how would you describe the service that the day hospital is offering to the patients and their families...?

Respondent: ...Well - one - we offer the community an almost immediate service in that we offer relief for - and I'm talking about GP's and that doesn't always happen in other places... that you get immediate relief. When I talk about immediate relief it can be immediate.. as we did in one particular case that comes to mind, that (the Consultant) saw her in the morning (the Social Worker) saw her the next morning... and she was in the next day. And that's as immediate as it can be, I think. Eh - generally speaking we can '**service**' somebody if you like - hm - within two weeks, that's perhaps the quickest... Now, that relieves the doctor, because it takes the pressure off him, it relieves the pressure from the relatives getting onto him about getting something done'.

The impact of the Day Hospital in this way, it is claimed, may be cumulative, for the effects of service may reverberate throughout the system of care:

'It helped the relatives which was tied up with the pressure - it takes the pressure off the relatives, therefore the relatives take the pressure off the G.P. and consequently off our Consultants and consequently off our bed state'.

The fifth set of criteria which emerged as being significant in considering the success of the day hospital refers to the effectiveness of the organization of services. In this context several aspects of functioning at both micro and macro organizational levels are held to be relevant. Great value is attached to good communication, both within the day hospital and between it and other organizations, the latter being important in developing the co-ordination of the day hospital service with other services with which it has links. Emphasis is also placed on co-ordination and co-operation between the various professions involved directly in patient care. Finally the organization of the day hospital should be such that an environment is created which is conducive to staff deriving maximum job satisfaction. As an example of this perspective one respondent stressed the development of co-ordination between the day hospital and community based services, both medical and social work.

'We're getting a greater liaison going with all the services, that its not nearly as hard now when you phone up for a GP, or a home help or a clinic or a health visitor, they know through the centre, through the day hospital what we're after and how much we can help and how much they can help us. I think... its a focal point to bring all the services together...'

Others stressed the importance of good teamwork within the day hospital.

The final set of criteria advanced concerns the service which the day hospital provides to the relatives of the patients.

'... so many of the relatives were just at the end of their tether, they just didn't think they could cope with the patient and they were really - marriages were beginning to crumble and all sorts of things just because of the strain, and I really think the hospital has helped an awful lot of people that way'.

'I think when relatives get despondent and frustrated and there's no one to turn to, and they're on the waiting-list that's all they'll get doing - eh - I think it's a very desperate situation to be in and I think this is the biggest area of success that the day hospital has provided as well'.

There are several ways in which the day hospital may contribute. By removing the patient from the home for specified periods, it provides respite for the relative from the otherwise constant burden of

caring. Also as well as simply providing some form of custodial care for the patient, the day hospital should give other positive assistance to the relatives in caring for the patient. This is mainly said to be achieved by educating the relatives in how to manage the patient at home more appropriately.

One respondent described in more detail how the day hospital fulfils this supportive function:

'We're offering support to the relatives I think too... even to the extent of, I think, of saving somebody's marriage and somebody's family. I think support is a good thing that they're offered, you're offering comfort, help I suppose, sometimes I think it 's more like eh - throwing somebody a lifeline, a life-belt, y'know, saying: 'well, look, it might not be the best, but it's the best we can do'.

'Supporting is hm - it's knowing what the illness is and y'know letting them (the relatives) know that we know what they are going through, that if they have any problems at all that they just need to contact the day hospital and if there's anything I can do then I certainly will try my best to do that and support them in that way and make them feel comfortable with the day hospital that they can phone anytime and that no-one will shout down the phone and say 'sorry, I can't do anything about that'.

In addition, the facilities and team of professionals available in the day hospital should provide greater opportunity not only for improving the quality of assessment of patients, but also of extending this assessment to the relatives and thus opening up the possibility of responding to the needs of the whole family unit. Certainly for some members of staff the service provided to relatives, is central to any consideration of the success of the day hospital.

4. CONCLUSION: A SUGGESTED APPROACH

In opening this chapter we suggested that several problems arise in evaluating care for the elderly because of the commitment which many studies have to an experimental approach and because of the presumptions that they make about the rational character of the policy process in health and welfare agencies. In the body of the chapter we have illustrated, with data from a study of a psychogeriatric day

hospital, just one of these problems: the way in which **multiple** criteria of success feature in the innovation of services. In conclusion we suggest, in outline, an approach to studying new health services which may avoid some of these difficulties.

We have termed the approach 'pluralistic evaluation'. The central point we are making is that if we are to understand and evaluate the part played by the several different groups involved in the care of the elderly, then we must understand how they use different criteria of success in their own interests and how 'success' thus operates in the social context of its use. Evaluative research must therefore not only evaluate 'success' but also **explore and explain** the hospital (or whatever) and its services. The approach is heavily informed by models of institutional functioning and the policy process which draw upon theories of political pluralism (Hall et.al., 1975) and the important connections between theory and method have been spelled out by House:

'(the pluralist approach involves) collecting the viewpoints and opinions of various people about the programme or policy at issue. The evaluator faithfully records and portrays their viewpoints. In this manner the principles, criteria and weightings of the people involved are used to judge the programme... (T)his... approach is pluralist not only in the philosophical sense of judging on the basis of several principles but also pluralist in the political sense of representing different political interests' (1980, p. 127).

It follows from this standpoint that, first, the research must identify the major constituent groups to the policy initiative and, throughout the research compare them with each other, both in the ideological perspectives that they hold, and in their operational strategies. Secondly, the approach directs us to collect data on these groups' interpretations and perceptions of 'success' in service provision and assign to that data a central place in the evaluative analysis. That is why we have illustrated this paper with data on that point.

Thirdly, the study must document not only the plurality of notions of success but also the different groups' strategies, as they strive to implement their own perspectives in their own interests. We take the view that the attempt to disentangle the meanings **and pursuit** of 'success' is an intrinsic part of evaluation research. Fourthly, evaluative research must then assess the extent to which 'success' (or failure) is achieved on each of the several criteria employed

within the agency and in terms of the several meanings assigned to these criteria. 'Success' is a pluralistics notion. It is not a unitary measure. In consequence, fifthly, pluralistic evaluation must embody the principles of methodological triangulation. Denzin (1970) has argued that any study dependant upon a single data source is 'method bound'. The point of particular relevance to evaluation research is that each data source is interest bound (as tied to the interests of one group rather more than to the interests of another) and also ideology bound (as reflecting one group's perspectives on desirable modes of operation rather more than the perspective of other groups). The constant use of as great a variety of different kinds of data as possible ensures, so far as possible, that the research reflects the full range of interests, ideologies, interpretations and achievements abroad within the agency. Thus, sixthly, pluralistic evaluation offers an ethnography of the way the services develop and an explanation of this development (in terms of the pluralistic interest of participating groups) as well as (some-what complex) conclusions about the success of these services on a range of criteria interpreted in various ways. Our claim is that the attempt to link the problems of an organization as perceived by its constituents, to the performance of the institution's programme of service, is central to evaluating innovation.

Evaluative research embodying these points certainly seems to have some important advantages. It shows that in some ways the day hospital (in our example) is successful and that in some ways it is not. That may seem trite. However, it is an advance on the substantial body of organizational research which shows that most organizations simply fail to live up to their utopian ideals. We need to be more precise than that. There is also the point made by Weiss (1973) who has commented that an inability to show **why** particular failures or successes occur is a frequent weakness in evaluative research. Pluralistic evaluation says a good deal about why some outcomes but not others take place. This opens the way to proposals for change. There is little point in knowing that a service ranks high or low on some criterion, however supposedly 'objective', if we cannot conclude from the analysis how the performance can be improved. It is important to remember that even high levels of success may have significant costs in terms of unanticipated consequences. Many evaluative strategies have no way of detecting these costs. Although the strategy that we have suggested is by no means perfect on this count, its more diverse approach means that it stands a greater chance of revealing the unplanned as well as the planned outcomes of

innovation in service provision.

There is also the question of implementation. Any recommendations for improvement for implementation will depend, at least in part, upon the attitude of agency members to the evaluation exercise. Many evaluations are dismissed because they do not use the criteria which influential groups in the agency themselves employ. While pluralistic evaluation may seem complex and uncertain in its use of multiple criteria, it cannot be dismissed for failing to take at least some account of the perspective of any significant group of participants. While most 'objective' evaluation seeks to remain politically neutral, but in practice becomes hopelessly embroiled in the politics of the organization being studied (even if the evaluators do not always realize what is happening), pluralistic evaluation stands some chance of remaining 'independent' and 'neutral' by having taken sympathetic account of as many perspectives as possible. The irony is that by taking the political process of the agency seriously there is some chance that the politics of evaluation will itself be simplified. As we have argued throughout, little is to be gained by pretending that the processes of pursuing and evaluating success are simpler than they really are.

We mentioned that we are not complacent and certainly many problems remain. In our experience the approach that we have outlined by no means overcomes all the problems of implementation. It is difficult to get health service professionals and administrators to accept a style of research which is different from the stereotype that they may expect (and wish to commission). The detailed links between theory and method must be spelled out more fully if the results of such work are to enter the general corpus of social scientific knowledge on the care of the elderly. Furthermore, much remains to be done in exploring the techniques for managing, analysing and 'triangulating' the substantial volume of both qualitative and quantitative data that the approach generates.

In this chapter we have simply suggested that the approach that we have adopted offers some promise. Too many studies in the field of health care in general and the care of the elderly in particular, complain of the difficulties which we have discussed, yet continue with the methodological approaches from which the difficulties arise.

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Acknowledgements

The data used for illustration in this chapter are taken from the study which is described in much greater detail in the chapter by Cantley in this book. The same acknowledgements apply. Some sections of this chapter are also developed more fully in Smith, G. and Cantley, C., *Assessing Health Care: A Study in Organizational Evaluation*. Milton Keynes, England, Open University Press, 1985.

III. Hospital-based home care: an example of alternative care in Motala

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1. INTRODUCTION

Hospital-based home care is intended to bring hospital facilities to chronically ill patients in their own homes.

In the seventies it was felt in several departments of long-term care in hospitals that chronically ill patients could be sent home when certain guarantees and facilities were available to them. This idea is in agreement with the policy of keeping old people - who are a large part of the chronically ill - at home for as long as possible. Patients themselves prefer staying at home/going home if possible and they feel happier at home.

Moreover hospital-based home care was seen as an alternative to expansion of long-term care departments. When no alternative forms of care are available, such expansion has to be planned because of the increasing number of older people.

In this chapter we describe the development of the hospital-based home care in Motala which was started in 1976. Although the idea was already developed in the sixties, in the hospital-based home care discussed here the service was available day and night, seven days a week. The introduction of night team activity was a new approach in Swedish health care. Nowadays hospital-based home care exists throughout the country.

We begin our account with some background information and the objectives of the hospital-based home care. Next we report the way the care is organized and the characteristics of the patients who formed our objective group. We then evaluate the service by looking at the health care, the family and costs. Finally we draw some conclusions.

2. BACKGROUND OF THE HOSPITAL-BASED HOME CARE

In the mid 1970's the lack of long-term beds was considerable in the district of Motala. A waiting-list of between 200 and 300 persons existed. The internal medicine department was running at 10% above

its capacity. For this reason, among others, it was decided to build a 120-bed extension to the long-term department.

When these plans were well underway a proposal was made to develop day care facilities. Instead of 120 hospital beds for long-term care, extra personnel were employed to develop the hospital-based home care. Later an accommodation for day care activities was also built. At the same time that the extra personnel were employed, a long-term care ward of 30 beds was closed in an old people's home. Part of the savings from this were used for financing the staffing of the hospital-based home care.

Hospital-based home care (HBHC) was started on September 1, 1976, at the department of long-term care in Motala. Similar work had been carried out since the beginning of the 1960's in Linköping, initiated by consultant physician Per Arnander as part of the long-term care organization. In Linköping personnel were employed during the day who could support the very sick long-term care patients in their homes. If more complex medical intervention or night care became necessary, the patient was admitted to hospital.

The difference between the Linköping and the Motala models was that in the latter case working forces were available both day and night. The introduction of night team activity began as part of hospital-based home care on April 1, 1977. The reason that we concentrated on night care so much was that, on going through the records of those patients hospitalized under the auspices of long-term care, we found that 30 patients could have been discharged home if staff had been available for requirements such as turning the patients, care, security and acute medical treatment at night.

Initially hospital-based home care existed only at Motala hospital. Work expanded so that on October 1, 1981, Mjölby nursing home was also equipped with a HBHC-team similar to that at the Motala hospital.

Traditionally, long-term care has been associated with hospitalization. However, in Motala we have systematically thought in terms of differentiated forms of care. This implies that the base resource - the clinic - is complemented by our patient activity, day care activity, allowance distribution, medical appliance stores, nursing homes with day care and last, but not least, hospital-based home care on a 24-hour basis.

Through the systematic achievement of our aim to offer an alternative to hospital care, many patients have only needed to stay in hospital for short periods, and more extensive treatment has been

carried out at home. We have coined the phrase 'long-term care piano', to imply that each key represents a resource. Sometimes one needs to play the complete register; sometimes a couple of notes is enough.

3. OBJECTIVES

From the beginning the objective of hospital-based home care, was to be able to offer chronically ill patients an alternative to otherwise essential long-term hospital care.

During the project this objective was expanded. In addition to the first objective the possibility of offering severely ill patients an alternative to otherwise unavoidable hospitalization arose. This objective introduced a new category of patients, who were so far unknown to the long-term care organization. It now became possible to admit patients directly from their homes after referral by their general practitioner or directly from an acute ward of a hospital. This expansion of objectives has led to a reduction in the dominance of long-term care cases year after year. Instead, a completely new patient category, as far as medical resources and intervention are concerned, has begun to dominate the picture, namely the terminally ill patient. In 1976 100% of the patients came from long-term care units, in 1977 65% of the referrals came from long-term care units, whereas only 35% came from acute hospital wards and general practice.

4. ORGANIZATION

The hospital-based home care is based on a co-operation between several services for the elderly.

Co-operation

In 1984 the department of long-term care in the western health care district in Sweden comprized of 188 clinical beds and 6 acute admission beds. The clinic's chief physician also had the responsibility over a nursing home with 118 beds, 3 kilometres away from the long-term care department.

In addition there was a large nursing home in Mjölby with 160 beds, and other nursing homes in other nearby communities between 15 and 50 kilometres from the base clinic. Close co-operation with the

primary health care system exists. In one of the nursing homes, a general practitioner has the responsibility over both the medical and the administrative duties for 28 long-term care patients. The remaining nursing homes are run by the long-term care physician. The long-term departments cover the on-call night service for all long-term care hospital beds in the district. The long-term care department also has an out-patient department and facilities for day care. Day care is carried out in all nursing homes within the western district. Approximately 22,000 visits per year are paid to day care wards throughout the district, of which half are in the main clinic's day ward.

Access to day care facilities has great importance for HBHC patients, who can thereby receive rehabilitation which otherwise would be difficult in the home, for example, access to bulky training apparatus, swimming pool, etc. Through the combination of hospital-based home care and day care we have been able to gain contact with HBHC patients who need intensive rehabilitation, for example, patients immediately after a stroke and patients with certain neurological handicaps. This combination of day care and HBHC saves a considerable number of hospital beds. During 1983, 16% of HBHC patients in Motala took part in day care activities, the corresponding figure in Mjölby was 20%.

Patients in HBHC do not receive medical attention solely through medically qualified personnel who are provided by the county council but also help from the local council in the form of **home help**. A good functioning co-operation with the local council is important and essential in this context. HBHC provides medical assistance not only to patients living in partially supervised flats but also to those in fully supervised accommodation - old people's homes. In 1983, 38 individuals were registered with HBHC from old people's homes, whereas the corresponding figure in Mjölby was 8.

Financial support

The long-term care clinic also runs a home care bureau where the chief physician of the department is also the director who has the right to grant economic support to patients receiving home care. The bureau has a well-equipped appliance store where up to date appliances (aids) are distributed, by the bureau's occupational therapist, to those needing help or to their care providers. Inquiries concerning possible finance are made to the bureau by district nurses or by the supervisor of the hospital-based home care clinic. Existence of a night service has enabled patients requiring more

complex medical care to be included.

All patients receive medication on prescription and pay for this themselves. Technical aids such as beds, mattresses, lifting machines etc. are borrowed from the store of the home care bureau.

The county council pays for such items as bandages for wound dressing and bed making if necessary. Hospital supplies are used in trials for new medications until a suitable regime is found.

Telephone contact is maintained night and day so that help is available in a critical situation even if the patient is at home. Those seeking help can always make contact with a 'living voice' giving advice and telling them how long it will take for help to arrive.

During the day contact with the patient or helper is maintained through those working in HBHC. At other times contact is maintained by night personnel where the chief on-call physician is contacted first in Motala; the second on-call physician is contacted first in Mjölby. If an emergency call is made at night, the physician responsible, together with the night team, decide which action is required.

Admission to HBHC

All patients living within a geographical radius of 20 kilometres from the base hospital or the nursing home in Mjölby, or living within 30 minutes by car, can be registered. The patient is referred by the district nurse or by a physician from the acute medical department, long-term care department, or general practice, to the chief of the long-term care department in Motala or to the junior consultant in Mjölby. Once the referral has been made, the supervisor for HBHC decides whether it is possible to accept the patient, taking into consideration the patient's medical requirements and home situation, the HBHC staff and resource situation. The patient is then registered and the physician responsible and the supervisor/nurse are informed; the latter then delegates tasks to those under her.

Registration with HBHC is always voluntary and is based on the patient's or possibly a relative's wish and motivation that care should be provided in their own home. Care is offered as an alternative to an otherwise essential hospitalization.

Good information for the patient and relatives is important and time consuming. If the patient is already in hospital the first contacts are made with the patients and relatives on the ward. Then everyone can get to know each other and discuss possible problems before the patient is discharged home.

If a referral has come from another institution or a general practitioner asking for hospital-based home care, a doctor and a nurse make a home visit to assess the degree of assistance required and the feasibility of caring for the patient at home. The patient and relatives are always given the guarantee that immediate admission to the long-term care department is possible day or night, if the need arises. For a few patients registered directly from an acute ward, the same conditions have to be guaranteed, i.e. re-admission to the referring department. It is the previous knowledge that there is a place available at the department which gives the patient and family the confidence to try to cope with a difficult situation at home. Similarly, it is also the knowledge that the resources of the department are at the disposal of the personnel which gives them the confidence to care for seriously ill people in their own homes. Therefore, the availability of a hospital bed is obligatory for home-based care.

Staff

Under the supervision of the chief physician of the department of long-term care, the administrative side is run by a district nurse. Medical cover is provided by specially appointed physicians and by the first on-call at the long-term-care department at night and at weekends, with the second physician on-call having the overall responsibility.

In total, 22.1 personnel posts are available for HBHC in Motala and 13.5 in Mjölby. A minimum of two medical personnel (nurses) are permanently available night and day.

The disciplines (posts) involved in Motala and Mjölby are as follows:

| | Motala | Mjölby |
|------------------------------|--------|--------|
| physicians | 1.0 | 1.0 |
| nurse (supervisor) | 1.0 | 1.0 |
| nurse (assistant supervisor) | 1.0 | 1.0 |
| nurse (SRN) | 2.0 | - |
| nurse (SEN) day | 9.4 | 5.4 |
| nurse (SEN) night | 5.7 | 3.6 |
| physiotherapist | 0.5 | 0.5 |
| occupational therapist | 1.0 | 1.0 |
| medical secretary | 1.5 | 1.0 |
| total | 22.1 | 13.5 |

Transport

HBHC staff travel in 'leased cars' or even in their own cars if the need arises. Patients are transported by ambulance or their own invalid vehicles. In Motala five lease cars are available, in Mjölby three.

The work of the night team

The night team consists of two nurses who begin work at 20.30 and finish at 07.00 the next day. The night team carries out planned home visits and emergency visits whenever required.

The planned visits are the equivalent of the evening round in the hospital and serve to satisfy the patient's need of security, care and prophylactic measures for the night. These measures include help with personal hygiene, dressing of wounds, and turning of the patient. Emergency visits are necessary when there are problems such as difficulty with urinary catheters, unexpected deaths, falls in the home, and acute chest pain. Frequent visits are planned in the case of terminally ill patients at home. When a patient has passed away during the night, personnel prepare the body as is the custom and stay with the family - if so desired - until the day shift takes over.

It is well known that the greatest hindrance in the discharge of patients from hospital is the difficulty of coping at night for patients living alone. The creation of a night team has even made the discharge of gravely ill patients possible from both the long-term care and the acute medical wards which was never the case before. The night team is an indispensable part of the organization which can be set into action by either a direct telephone call or by the doctor on-call if an emergency arises.

Table 1 shows the number of planned and emergency night visits in 1982 and 1983.

Terminal care at home

The following criteria are used to classify a patient as terminal: a definite diagnosis has been made; death is expected within a short period of time; care is focused on symptomatic treatment.

Caring for the terminally ill patient calls for careful observation and understanding of the patient's and the relative's requirements. Decisions about treatment for patients with incurable disease are difficult. It is difficult to decide if active treatment should take

Table 1.

Planned and emergency night visits in 1982 and 1983 in Motala and Mjölby

| | Motala | | Mjölby | |
|-------------------|--------|------|--------|------|
| | 1982 | 1983 | 1982 | 1983 |
| nurse planned | 6017 | 6314 | 1409 | 4089 |
| nurse emergency | 336 | 421 | 122 | 293 |
| nurse with doctor | 156 | 118 | 1 | 4 |
| total | 6509 | 6753 | 1532 | 4386 |

place and even more difficult to stop current therapy. Psychosocial factors play a key role for these patients and relatives as well as for the medical personnel. If a patient needs to receive proper care in his own home the physician must be convinced of the necessity in that individual case. The patient must also be strongly in favour of being cared for at home. Also the family must be able to cope with the situation with the appropriate assistance.

Availability of a hospital bed is an absolute requirement in order to be able to offer a mortally ill patient care at home to the extent that was carried out in 1983 in the western health district. Such a promise is a great security for the patient and the care providers and is indeed essential before a patient dares to go home. It is also important that the personnel are supported and that the communication between staff is kept at a maximum. This applies especially to the need for information between personnel. Every new phase in the patient's condition and every change in treatment policy must be made known to all those involved. The goal is to facilitate as good and serene as possible care for the patient and his family, at all times. The role played by the staff and their emotional reactions is decisive.

During 1983, 62 patients were registered as terminal care cases in Motala. During the same year 58 patients died. Together, these terminal care patients required 2,388 days of care representing 10.3% of the total days and 23% in terms of number of patients. The average age of these patients was 74.2 years. At the time of admission, 42% of the terminal care patients came from acute hospital wards, 19% came from general practice and 26% came from fully supervised accommodation (old people's homes). Only 13% of the terminal

care patients came from the long-term care department. Thirty-five terminal care patients were looked after in Mjölby of whom 31 died in the course of a year. The number of days of care for terminal cases was 1,483. The average age of patients in Mjölby was 68 years. The average number of days a terminal patient was cared for was 41 at Motala and 47 at Mjölby.

Of the 89 patients who died at home in the western district, 12 (13%) had no relatives available. For the majority of patients adequate pain relief was of great importance. This has been largely carried out by means of oral or rectal medication. Treatment by injection has occurred only in exceptional cases.

During the final days of life, HBHC staff have usually made between four and six home visits a day. Sometimes a member of staff has been continually stationed with the patient. Six days was the longest time this occurred with a patient. Pool personnel have been called in on 50 occasions to cope with this type of care, totalling 524 hours, the majority being at night. After death has occurred, support and help are needed for those remaining. We usually visit relatives ten days after the death. The relatives usually appreciate it if one of the nurses involved with the patient up until the time of death makes the visit. A final visit takes place three to four months later.

5. CHARACTERISTICS OF THE PATIENT

In this section some data will be presented about the patients who received hospital-based home care, i.e. how often the criteria were used, where the patients came from, and what kind of care was offered. The data are not exhaustive, but they may give an impression of the functioning of the hospital-based home care.

A small majority of the patients were women, i.e. 56%. For terminal care the number of men was larger than for women. The average length of care was 56.8 days for all patients registered.

In table 2 data are presented on the number of patients, the number of newly admitted, the number of home visits including when and by whom, the number of days of care and the number of discharges for Motala and Mjölby for 1983. In 1983, 367 patients were cared for.

Table 2 shows that some patients were admitted to the HBHC more than once. In Motala an average of 28 patients have been discharged from HBHC and an equal number have been admitted monthly (Mjölby, 12). Over the whole year the average number of patients being cared for

was 62 per day (Mjölby, 35). The total number of patients who were cared for during 1983 was 255 (Mjölby, 112). Of those 255 patients 80 were admitted more than once because of the fact that they were transferred to another form of hospital care and later discharged back to HBHC. It is clearly very important to be connected with the main department. During the different stages of illness a patient may require care in hospital, in the long-term care department or at home.

Table 2.

Some data on admissions, visits and discharges in 1983 at Motala and Mjölby.

| | Motala | Mjölby |
|--|--------|--------|
| total number of patients cared for in 1983 | 255 | 112 |
| number of new admissions | 345 | 141 |
| days of care | 23,062 | 12,730 |
| number of home visits (total) | 26,932 | 16,060 |
| number of home visits by doctors | 1,722 | 316 |
| number of night visits | 6,356 | 4,382 |
| number of discharges | 406 | 174 |

From table 2 it may be calculated that 25% and 27% of all home visits occurred at night. This may be interpreted as a relatively high percentage. The number of doctors' visits were much lower (6% and 2%).

The differences between Motala and Mjölby are explained in the later start at Mjölby. Thanks to this later start, experiences and knowledge from Motala could be used in an efficient way at Mjölby. At the time of admission 41% of the patients were living alone, 40% were living with their partner and 10% with a child/relative.

Where did the patients come from and how were they discharged? These data are presented in table 3.

In Motala 88 patients were discharged from HBHC, representing 22% of the total, because the services were no longer required. The corresponding figure in Mjölby was 21 (12%).

Until now the main reason for discharge from HBHC has been an admission to hospital (12%) or to the long-term department (34%), for a

Table 3.

Place before admission and places of discharge in 1983 in Motala and Mjölby, in %

| | Motala | | Mjölby | |
|---|-----------|-----------|-----------|-----------|
| | admission | discharge | admission | discharge |
| from/to the base/ psychiatric hospital | 21 | 12 | 31 | 23 |
| from/to general practice | 26 | n/a | 24 | n/a |
| from/to the long-term care department | 29 | 34 | 26 | 22 |
| from/to old people's home | 10 | 6 | - | - |
| no more need for HBHC | n/a | 22 | n/a | 12 |
| died | n/a | 10 | n/a | 7 |
| others | 2 | 2 | 1 | 2 |
| transferred | 12 | 14 | 18 | 23 |
| total | 100% | 100% | 100% | 100% |

planned operation or for cytotoxic therapy, or because intensive medical supervision was required for a longer period of time. In some cases a patient was discharged from HBHC because the relatives gave up, because a patient became more ill or because the work load simply became too heavy.

The most frequent diagnoses were cardiovascular diseases (22% and 17%) and neoplastic diseases (21% and 35%).

Medical treatment provided by HBHC personnel in the patient's home have been pain relief, change of catheter, the taking of blood samples (especially in connection with cytotoxic therapy), the making of an ECG, the giving of blood or parenteral nutrition, the draining of fluids from chest or abdomen, TNS pain relief, respiratory physiotherapy, prevention of contractures, prevention of pressure sores, and time consuming wound dressing often with the help of the district nurse.

In addition to the HBHC personnel several other people supported the hospital-based home care. This support is illustrated in table 4, based on the data of Motala in 1983.

Table 4.

Help by HBHC and by others, in %

| | |
|-----------------------------|------|
| home help only + HBHC | 28 |
| relative only + HBHC | 27 |
| home help + relative + HBHC | 12 |
| old people's home + HBHC | 13 |
| HBHC help only | 7 |
| others | 3 |
| <hr/> | |
| total | 100% |

The number of visits paid by a physician in Motala rose by 50% during 1983. An increase in the number of nursing interventions also occurred.

This simply demonstrates the continually more demanding measures that are being taken. Over the years patients have required more medical help as a result of the more serious illnesses which are being treated. Relatives play a very important part in hospital-based home care. The part played by relatives in conventional home care is often not appreciated. Since 1976 the contribution made by HBHC relatives has been between 35 and 50%. This means that some years 50% of the patients have had relatives caring for them; in other years this figure has been less. In 1983, 49% of the patients had relatives who took part in their care.

6. EVALUATION

A strictly scientific evaluation of hospital-based home care has not been done. The question is: is it possible and necessary? To create control groups or to evaluate HBHC in some other way is difficult, not the least on ethical grounds. The organization runs on a local basis so that comparison with other areas in the country is difficult. We must therefore stress that this description of our organization is based on our experiences and impressions, which in turn are based upon how the patients and their relatives experience this form of care.

Health care function

Hospital-based home care takes advantage of the cumulative experience of its personnel. It is complementary to primary care but

naturally does not replace it. Hospital-based home care forms an alternative to an otherwise essential hospitalization if the patient so wishes and if it is medically feasible. In our district this type of care has come to be regarded as a bridge between hospital care and general practice. Patients wishing to come home from hospital and those who can no longer be cared for in hospital are those who are referred for HBHC. However, there are limits.

Geographical separation is such a limitation. In our region we have 87,000 people. With the organization divided between two centres 20 km apart, approximately 80,000 people are eligible for HBHC. The fact that not all patients wish to, or dare to, leave hospital to be cared for at home is also a limitation. One cannot force a person to accept HBHC. Similarly relatives may not wish to, or be able to cope with, a gravely ill person and everything which is involved in home care. Lengthy medical supervision in the home can also be a limiting factor. The longest period that HBHC has been able to provide such special treatment to a patient was 12 days. Addiction to alcohol or narcotics can also be a limiting factor or contra-indication. Relatives with drug abuse are a threat to both the personnel and the patient.

Quality of life

When a new form of health care is developed as an alternative to hospitalization, the quality of life must be considered. The definition of the quality of life and its measurements is difficult. We believe, however, that hospital-based home care provides a good quality of life.

We believe this because:

- this form of care is based on the patient's and relative's wish to be cared for at home,
- the patient and relative are regarded as a single unit and are treated with respect,
- we strive to respect the patient's wish to be cared for at home and equally, the wish that this be stopped,
- we strive to maintain the patient's and their relatives' integrity,
- the organization is based on mutual trust between those caring and those being cared for,
- we always attempt to judge the situation as objectively as possible, both medically and personally,
- this form of care ensures security at all times through voluntary

participation, both medically and socially.

Costs

The total cost of the hospital-based home care is difficult to assess. We do not have all the necessary data available. However, we have tried to assess what the service costs the county council. The expenditures in 1983 are presented in table 5.

Table 5.

Expenditures for the HBHC in 1983 in Motala and Mjölby (Swedish Crowns)

| | Motala | Mjölby |
|---|------------------|------------------|
| Personnel (excl. doctors) incl. further education costs | 2,436,931 | 1,232,714 |
| Internal debits (consultations, social costs) | 1,360,861 | 593,652 |
| Materials (bandages, drugs, petrol for cars) | 182,668 | 81,677 |
| External administrative duties (trips, representation, travelling expenses) | 31,968 | 2,903 |
| Other external duties ('leased cars') | 130,277 | 71,658 |
| Financial obligations (vehicle insurance and tax) | 6,275 | 4,949 |
| Grants for relatives | 142,240 | 107,075 |
| Day care, totalling 1,138 days at 275 Crowns per day | 312,950 | 186,450 |
| Rent for accommodation | 173,800 | - |
| Cost of blood samples and X-rays | 32,755 | 8,434 |
| Doctor's involvement (approx.) | 400,000 | 400,000 |
| Total | 5,210,725 | 2,489,512 |

A small percentage of these costs was reimbursed by health insurance, i.e. a portion of the doctor's visits and of the home visits. The total reimbursement was 1,533,974 Swedish Crowns.

From the 367 patients in 1983, the average cost (minus reimbursement) was 16,800 Swedish Crowns per patient.

7. CONCLUSIONS

About seven years ago we started with the idea of a hospital-based home care service night and day, for older and severely ill people. Now the HBHC idea has spread out all over Sweden. There are now 19 HBHC organizations throughout the country.

Hospital-based home care is carried out under the following conditions:

- that it is the wish of the patient and relatives to be cared for at home,
- that access to a hospital bed and to day care at the referring department exists,
- that there is a good functioning physicians on-call system with a first and second on-call at all times,
- that there is good co-operation with the council's home help organization.

Hospital-based home care must have at its disposal all the resources required to cope with a crisis if security is to be guaranteed for this type of care. For this reason it is important not only to assist with medical equipment, but also to provide medical procedures which normally take place only in a hospital.

An important factor is that the doors between home and hospital are always open and to have such a level of co-operation that hospitalization in the dying moments can also seem correct, not only for the personnel but also for the patient and relatives. It is this hospital back-up system which is absolutely essential when it comes to hospital-based home care. The choice between hospital and home care must always be available. Care for the gravely ill or dying cannot take place outside hospital if hospital resources are not available at all times.

The long-term care department with its many resources, both concerning personnel and equipment, forms the heart of the organization. Not only material is transferred to the individual, but also the hospital routine, i.e. the way in which the care is thought out, carried out and presented. Continuity in health care is important. The physicians from the clinic also look after the patients in their homes. Here HBHC provides a unique possibility for continuity in Sweden's modern health care system.

We know that in Sweden today 85% of deaths occur in hospital-type institutions. With the facilities which are provided by hospital-based home care the wish to die at home can be fulfilled in many

cases. It must also be pointed out that what might at one moment seem to be a suitable form of care might be highly unsuitable the next moment. The patient or relatives may weaken. The important thing in such cases is to always be open for change, to respect the individual's wish and capacity to fulfil a period of care leading to death at home, and to be able to realize when it is no longer feasible to carry out home care.

Care in the last stages of life demands a great deal from those looking after the patient, especially when doctor and nurse involvement is great. The patient and relatives have a great need to discuss medical progress at all times and to experience the satisfaction that what is being done at home is proper and correct, medically, socially and psychologically.

The HBHC organization has its limitations, namely, geographical separation from the organization base, the need for intensive medical supervision over a longer period of time and finally social contra-indications.

However, we believe that hospital-based home care when organized properly and staffed by people with the right attitude, contributes to increasing the quality of life in (older) severely ill people. In our opinion such a service can be provided at a reasonable cost.

IV. Sustaining innovation: a day care facility for the elderly in the U.K.

Caroline Cantley

1. INTRODUCTION

This chapter describes the planning and early development of a new psychogeriatric day hospital in the U.K. The paper focusses on those features of the day hospital which planners and service providers held to be innovative and it considers the extent to which the institution was a 'successful innovation'. From this account we draw some general conclusions about the process of innovation and the implications which this process has for evaluative research in new service developments.

2. NATIONAL CONTEXT

The development of care in psychogeriatric day hospitals is one aspect of a general policy of promoting 'community care' of the elderly in the U.K. As a broad policy strategy 'community care' has been advocated for around thirty years and has more recently been reaffirmed in numerous government policy documents. See, for example, DHSS (1978) and DHSS (1981). Johnson and Challis (1983) identify five elements in the rationale for the development of this focus upon 'community care'.

Firstly, there is 'the economic push'. In the U.K. since the mid 1970's budget growth has virtually ceased and health and social services have been subject to increasing pressure for greater efficiency and economy. Secondly, there is 'belief in the 'community' as an aspect of political ideology. Thirdly there is the argument based on 'preferences of the old'. The view that the elderly themselves prefer to be cared for in their own homes by their family and friends is widespread, it derives support from both 'common knowledge' and empirical research. Fourthly 'an ageing population', has produced the growing realisation that changes in demographic structure will place unprecedented demands on services. More specifically the proportion of the population of pensionable age in the

U.K. rose from 14.5% in 1959 to 18% in 1981.

This constitutes an increase of 40% in the 65+ age group (from 5.9 to 8.3 million) and a dramatic increase of 89% in the 85+ age group (from 308 thousand in 1959 to 583 thousand in 1981). While the numbers aged 65 or over are not expected to increase much more up to the end of the century it is projected that between 1982 and 2001 there will be an increase of over 75% in the 75+ age group and that more than half of this increase will be in the 85+ group (C.S.O. 1983). Several studies have shown that the incidence of both physical and mental infirmity increases with age (Hunt, 1978), Bond and Carstairs (1982)) and that it is the 'older elderly' who present the greatest demand for services. Finally Johnson and Challis point to 'anti-institutionalism' as an impetus in the growth of community care policies. Disillusionment with institutional provision has been an important factor in a trend towards smaller-scale provision and the belief that it is more desirable and 'normal' for people to reside 'in the community'.

Day care provision has for long been an important element in community care policies. Tibbitt and Tombs (1981) summarise the attraction of day care as a policy option as follows:

'Day services are seen as an attractive area of development in the health and social services for the elderly as an alternative to institutional care, as a convenient means of providing access to a range of therapies and supportive services, and as a means of providing relief to those in the community who are caring day by day for frail or confused elderly relatives. There can be little doubt that day services are an emotional element in a policy strategy which aims to allow the elderly to be cared for in their own homes for as long as possible' (p. 33).

The term day care covers an extremely diverse range of services. The main distinction usually maintained within this range is between day centres, often run by local authorities or voluntary organizations, and day hospitals, provided under the auspices of the National Health Service.

It is within this overall policy strategy that the psychogeriatric day hospital in this study was developed. It was thus not particularly novel concept in national policy terms although at a more local level it was a distinctive new initiative.

In understanding the climate of innovation which pervaded this hospital's development it is important to take into account its location within Scotland. Health and social services in Scotland are administered separately from the rest of the U.K. and Scottish policy and provision provides the main frame of reference for the planners of the day hospital. At the time when the hospital was being planned provision of day hospital places for the elderly mentally infirm was not well developed in Scotland. A survey of Scottish day care found that day hospitals provided 17% of day places for the elderly in 23 units and that only 8 of these units catered specifically for psychogeriatric patients (Tibbit and Tombs, 1981). It was also significant that the establishment of the day hospital coincided with the publication of a major advisory report 'Services for the Elderly with Mental Disability in Scotland' (SHHD 1979) which, amongst other recommendations, concluded that urgent action was needed to develop psychiatric day hospital places for old people. While this was by no means the first policy recommendation of this kind (See for example SHHD 1970) it did help foster the view that the day hospital was at the forefront of service development.

There was one further factor that was particularly important in sustaining the view that this day hospital was a distinctive innovation - the diversity of services that can be provided under the rubric of 'a day hospital'. Several reviews of day hospital provision have noted the variation in aims and service arrangements (Brocklehurst and Tucker 1980, Peace 1980, Tibbitt and Tombs 1981). So even if it was allowed that psychogeriatric day hospital provision was not in itself a novel concept it could still be claimed that this day hospital was innovative in the form of its provision. Below, we shall describe those aspects of the service which staff and planners point to in asserting that this institution is an important innovation in caring for the elderly mentally infirm. We shall then go on to consider the evaluation of those features of the service.

3. PLANNING THE HOSPITAL

The original impetus for building this hospital came from the Area Executive Group (a group of senior officers within the health authority). They were working within overall Health Board policy, and were under considerable pressure from both consultant psychiatrists and senior administrators to increase the provision for elderly

patients with mental disorders in the region. A working party was established to examine urgently the feasibility of establishing day hospital facilities for this category of patients, in the short term. The working party produced a first interim report in October 1978.

From the start of these deliberations it was clear that existing provision was inadequate. Projections based upon 1976 U.K. census data indicated that although over the following ten years there would be an increase of only 48,425 to 50,595 (4.5%) persons over 65 in the Health Board Area and of only 26,614 to 27,857 (4.7%) in the relevant District, the district population over 75 would rise from 9,007 to 13,483 (49.7%).

Moreover the 'risk of psychiatric disorder manifesting itself in the latter grouping is disproportionately high and, due to their longevity, the majority of patients are female'. On this basis it was argued that 120 day hospital places were needed and then only, first, to cope with the current and not project population and, second, to serve as 'a palliative measure to cope with chronic bed shortages which would support patients and their families where no other suitable means were available'. The working party made the point that the use of a day hospital as an **alternative** to in-patient beds departed from the usual practice of treating day hospitals as a **complement** to in-patient and community health facilities.

On the basis of existing waiting-list data a case was made for a 40 place day hospital as an interim measure, pending the establishment of a 120-bedded hospital with a purpose-built day hospital attached as an additional facility. It was estimated that patients using the new Day hospital would be mainly 'patients with chronic brain syndromes i.e. dementias' and 'patients with functional (non-organic) psychiatric illnesses, i.e. depressives, schizophrenics, neuroses of old age', divided female to male in approximately the ratio 5 : 1. Given the level and type of demand it was felt that a significant number of places was necessary to make the venture worthwhile and 'the regime must be geared to rehabilitation, otherwise the number of patients able to benefit will be restricted by a conspicuous lack of throughput'.

It was a very important aspect of the launching of this institution that a considerable air of innovation pervaded the whole planning process. The area in which the hospital is sited is not one known for very progressive health care in the psychiatric field, it has

had some difficulty in attracting well qualified staff to all positions and conveys to the outsider a somewhat culturally as well as a geographically isolated impression. Frequent reference was made to the day hospital not only as a new institution but also a new institution of a new kind; something which was unusual in the area. As such there was widespread support for the view that it should be evaluated.

4. THE STUDY

It was a very important feature of this research that it originated as a collaborative exercise between a research team in a University Department, a health authority and a central government department (the Scottish Home and Health Department (SHHD)). In the autumn of 1979 the Health Board responded to a Health Service Research Committee (HSRC), of the SHHD Chief Scientist Organization, expression of interest in 'naturally occurring experiments in the health service'. A member of the research team was then asked if he would be willing to explore the possibilities for an evaluative study and prepare a research grant application. A small grant was made for preliminary study and in due course SHHD provided support for a team of researchers to conduct a project over two years from January 1981.

The general approach adopted in this research and methodological problems that we encountered have been dealt with elsewhere (Smith, 1982). What is particularly relevant here is the specific sources of our material. In describing the day hospital we draw on data from the following sources:

1. Interview with the nurses, psychiatrist, doctor, social workers and other staff and administrators responsible for establishing and running the hospital. These interviews were semi-structure, focussing particularly on respondents views about the objectives and achievements of the hospital, and were tape recorded and transcribed.
2. Observations of the weekly hospital meetings at which patient admission, discharge and progress are discussed. This meeting also functions as a staff meeting for the discussion of administrative and other more general issues.
3. A review of hospital planning documents and patients records.

4. Observations of the day to day life of the hospital.

5. Interviews with relatives of 25 patients. These interviews were again semi-structured and asked relatives about their perceptions of the patient's problem and their experience of receiving services.

As we have already noted (Smith, 1982) one of the difficulties in studying a new institution is that the service itself is constantly changing and developing. It was therefore necessary that the design remain flexible and a number of adaptations took place as the study progressed. For example when the study began the Relatives Group did not exist and did not feature prominently in the design. Since it came to occupy an important place within the hospital the attention which we gave to data collected through attendance at group meetings and through interviewing a sample of relatives grew over the period of the research.

5. THE HOSPITAL

The outcome of the planning process described above was the establishment of a new purpose built structure in the grounds of a much older and larger institution - Park Hospital - with in-patient wards for geriatric, psychogeriatric and mentally defective patients. The location of the day hospital on the site of an existing hospital had ambiguous implications. The planning papers can be read as implying that the day hospital could as well have been sited anywhere. On the other hand comments about such matters as favourable staff orientations and attitudes, available facilities and treatment of in-patients at the day hospital might be taken to imply that a 'special relationship' was intended between Park Hospital and the day hospital. In the event the interchange of patients, staff and services between the two institutions proved to be very significant in the day hospital's development, a point to which we shall return.

The hospital, which is open weekdays only, has a daily maximum of 25 places and generally caters for some 35 different patients each week. It operates under the charge of a Consultant Psychiatrist but much of the responsibility for day to day management lies with the Sister-in-charge. Other staff include nurses, part-time Medical Officer, sessional chiropodist and physiotherapist, occupational therapist and a social worker employed by the Social Work Department of the Regional Council but operating full-time in the hospital

service.

In the early stages of the hospital's operation about 65% of the patients admitted suffered, in varying degrees, from organic dementia although the proportion of such cases and their severity tended to increase over the period of the research. Patients with depressive illnesses account for about 20% of admissions and patients with schizophrenic, paranoid or essentially physical disorders are represented in small numbers. All patients who attend are ambulant but in other respects their physical and mental condition varies considerably. The problems which they present are described in records as including aggression, wandering, incontinence, inability to cope with the activities of daily living, sleep disturbance, risk with electricity, gas or fires, mood disturbance, hallucinations, general forgetfulness and inability to communicate.

There is considerable variation amongst patients in the type and extent of family support which is available to them at home. Relatives play a significant part in the care of about 75% of patients: about 30% of patients actually live with a spouse, around 25% with other relatives and about 20% live alone but are regularly visited by relatives. In about 25% of cases the patient receives no family support.

Patients, from towns and villages surrounding the day hospital are transported to the hospital by bus. They generally attend on two or three days each week. In exceptional cases patients may attend on all five days each week. The duration of patient attendance varies from one week upward with the span of attendance averaging about 4 months.

6. THE HOSPITAL AND ITS INNOVATIVE FEATURES

There are seven aspects of the day hospital service that staff identify as innovative: avoiding silt-up, assessment and treatment programmes, the role of the social worker, transport, the range of services, the relatives group, quality of the environment. We now discuss each of these features in more detail.

Avoiding silt-up

One of the major features of this hospital is the arrangements that are made to avoid 'silting up' of the hospital population; a well

known problem in institutions of this kind (Goldstein et.al., 1968; Goldstein and Carlson, 1976; McDonald, 1971). Staff point to this as one of the hospital's most innovative aspects and in this connection there are arrangements of several kinds.

Admission procedures are quite rigorous. All referred cases receive a domiciliary visit from the Consultant psychogeriatrician and a social worker attached to the hospital also prepares, in most cases, a background report. All referrals are discussed by the staff group at a weekly meeting in an attempt to establish priorities and admit only 'suitable' cases. In part these are the cases considered to be most serious or cases where caring relatives are in greatest need of assistance. But in part they are cases considered most likely to improve with treatment and thus be discharged from the hospital, so making room for a new admission.

So another mode of preventing any blockage is to discharge patients whenever possible. Given the widely recognised problems which characterize diagnosis and prognosis in the field of psychogeriatric medicine (e.g. Marsden, 1978), it is clear that discharge decision is a topic for considerable discretion. Because it is subject to influence from organizational and other social factors rooted in the needs of staff as well as the needs of patients, patients whose condition has deteriorated as well as those whose condition has improved may be discharged. Goldstein et.al. (1968), in a study of a psychogeriatric day hospital, noted that despite a 42% discharge rate, 'After one year of operation we have not had a single discharge as a result of patient improvement'. Studies by Blake (1968) and McDonald et.al. (1971) also show low rates of 'discharge due to patient improvement', and Goldstein and Carlson (1976) have generally criticised day hospitals which operate discharge policies which are conservative.

A further mode of achieving patient flow is for the hospital to serve as a gateway to other services and some patients may pass along routes to other forms of day care, particularly to social work services provided by the local authority (in the U.K. social work and health services are for the most part arranged administratively quite separately). Alternatively the Consultant may use a small number of the beds which he controls in the adjoining Park Hospital in association with the day hospital and in order to maintain the flow of patients. For example he may alternate two patients each week: one in-patient bed and one day hospital place, or he may use

an 'emergency bed' for a patient taken very ill while attending the day hospital. 'Short term beds' are also used for day hospital patients for in-patient care for strictly limited periods. Such innovative use of beds in conjunction with day hospital places is facilitated by the close physical proximity and staff links between the two institutions.

In practice these strategies have different effects. With 77% of all referrals subsequently becoming day patients staff do not seem to be operating a very tight selection policy. In fact a maximum of 10% of referrals are actually rejected since a proportion of cases fail to become patients by reason of circumstance other than a decision not to admit. Only 6% of patients are discharged to social work department facilities but over 20% of patients attending the day hospital are offered a short term bed in the adjacent hospital. Overall, a high degree of 'turnover' is achieved. At the end of any one year about 68% of the patients admitted during that year have ceased treatment.

The reasons for discharge and the proportion of patients in each discharge category are detailed in figure 1.

Figure 1. Reason for discharge in percentages

| Reason for discharge | Percentage of discharges |
|--|--------------------------|
| Patient and/or relatives refuse to continue attendance | 20 |
| Deterioration in patient | |
| - transfer to longterm bed | 32 |
| - housebound | 6 |
| - death | 6 |
| - transfer to acute bed | 7 |
| Circumstantial reasons unrelated to patients condition | 10 |
| Transfer to other forms of day care | 7 |
| Need for day care eliminated | 12 |

From these figures it is clear that although silt-up is largely avoided there are major qualifications to this point. There is no substantial evidence on the clinical improvement of the majority of patients and the largest group of discharges is to long-term care. There are comparatively few links in terms of patient flow with non-hospital services (especially social work). There is thus little evidence that the hospital has significantly reduced demand for in-patient beds. Moreover the achievement of patient flow involves hospital staff adopting strategies which may well run counter to the interests of other groups of staff and relatives involved in the system of care. This point together with a much fuller discussion of 'patient turnover', is developed at some length in Smith et.al. (1983). But one particular aspect is relevant here. The day hospital staff have effectively used the links with Park Hospital to promote day-patient turnover. This had not been specifically envisaged in the planning of the hospital. Rather the expectation had been that Park Hospital patients would benefit from the facilities on offer in the day hospital. In practice this expectation was overridden by concern to avoid silt-up in the day hospital population.

Assessment and treatment programmes

A second general feature of the hospital which is claimed to be innovative is the arrangements made for the provision of individual programmes of assessment and treatment for each patient. This emphasis reflects a concern to avoid the hospital becoming solely a 'dumping ground for inmates'. In making a claim to innovation on this count staff point to the individual assessment and treatment of patients entailing rating scales, domiciliary, occupational therapy (O.T.) and nursing assessments, individual care plans and regular case reviews. In practice however, the implementation of individualised assessment and treatment programmes is more complicated. Several separate problem definitions are formulated by different staff for each patient within the hospital and brought together in only a limited way. Often decisions are taken without consensus on a clear problem definition.

Indeed sometimes decisions are taken in order to postpone or avoid a definitive account of what the patients problems 'really' are. Often, clearly, the problem in the sense of the patient's clinical condition is only partly relevant since decisions are a function of pressure from relatives or referral agents, or of a range of other social factors. Cross referral does not always take place between decisions, about the grounds of referral, taken at various points in

the patient's career. Thus a definition of problem may vary over time and also between social contexts within the hospital. Decisions are seldom taken on the basis of quantified information about the changes in the patient's condition and in practice the hospital accumulates little specific information on the patient which is **actually used** in determining the path of their career. Happenings without the control of the hospital so often take over the course of events that a climate pervades many decision-making contexts indicating that any precise analysis of the patient's problems is quite likely to be ineffectual anyway.

Overall on the basis of a detailed qualitative review of the case files of a sample of patients discharged from the day hospital, we conclude that even in those small number of cases in which the patient is assessed by hospital staff as having improved there is apparently little quantifiable data on which this judgement was based.

The role of the social worker

Third, amongst the features of the hospital which are claimed to be new, there is the place of social work services. During the course of planning the hospital the role of a social worker was seen as crucial and innovative. As we have mentioned, social work and health services are mostly administered quite separately in the U.K. but in this hospital a social worker employed by the local authority is attached virtually full-time to the hospital. The social worker is rarely involved in 'therapy' or 'counselling' or any other form of direct treatment of the patients themselves. She does not, for example, take part in group work with the patients during the day to day life of the hospital. Principally the social worker's endeavours are focussed on relatives. Essentially she is involved in three kinds of activities in relation to the hospital: first, assessment of home circumstances, second, coping with crises and third organising the Relatives Group (we shall mention this group more fully below).

The role of social worker within the hospital does embody the potential for the treatment of patients to be influenced by continual liaison between patients' relatives and the hospital. In practice however this does not occur as a routine matter. Rather the social worker reacts to a particular crisis. She will visit patient's relatives often at the request of either the psychiatrist or senior

nursing staff when some particular problem connected with the patient's home arises. For example on one occasion she visited the patient at home at short notice when the patient was refusing to get on the bus and the nursing auxiliaries took the view that some discussion between the social worker and the relatives would be useful. Sometimes, too, she will call on relatives if patients have not arrived, in an attempt to find out why this has occurred. Although attachment of a social worker to the day hospital has served as an effective means of incorporating some social work services into the hospital this is not the same as achieving co-ordinated health and social work services. Certainly relatives continue to experience a fragmented and disparate system of services. This arises because integrating social work into the day hospital does not lead to effective coordination of the main health and social work services received from other sources by patients and their relatives.

Transport

A fourth distinctive feature of the day hospital is the way in which patients are transported from and returned to their homes. The point was important during the hospital's development. Experience in other day hospitals suggested that the use of the ambulance service often creates difficulties because patients arrive late and leave early, turning the hospital into what one planner critically described as 'a glorified luncheon club'. Arrangements were therefore made at this day hospital for the transport of patients by coach service operated by a private contractor. This arrangement originated because the Ambulance Service was unable to provide the extensive transport necessary for the day hospital and the Health Board undertook the financing of the bus service. This type of service has proved to be superior to any which the Ambulance Service would provide in several important respects: the hours of operation of the day hospital are not restricted as they would be if transport was provided by the Ambulance Service; there is no risk of disruption of arrangements as there would be with ambulances being called away on emergencies; routes and timings can be arranged to suit hospital staff rather than ambulance staff. The use of coaches also allows hospital rather than ambulance staff, to accompany patients and see something of their home conditions. In spite of the political sensitivity of the arrangement (which arises from the current U.K. Government's interest in the possible privatization of sectors of the health service) the Ambulance Service has now agreed to accept

funding of the present arrangements. It has however, been agreed that the bus service is only to be used for transporting patients between home and the day hospital. Any transport during the day **between hospitals** falls within the remit of the Ambulance Service.

The range of services

Fifth, the fact that the hospital brings together and provides a very wide **range of different** services was significant in its planning and was often described as innovative in the care of the elderly. The following quotation, from one of our interviews with a Consultant gives the flavour of the point:

'We can certainly in the day hospital look at the question of drugs, can't we? And although you cannot really improve somebody's memory, you can often do quite a lot to control things like agitation, which can be the thing that determines whether relatives want a patient in or not. If it's a depressed patient, there again, we're looking at the drug treatment and if it's a paranoid patient we're looking at drug treatment. Of course they can't offer that in a social centre. We can offer occupational therapy in the sense of assessment and training as opposed to diversional. Then physiotherapy - now you don't need a day hospital to arrange physiotherapy, but it's often more convenient to do so and as you know, the physiotherapist attends the weekly meeting and, incidentally, provides some kind of link with the physiotherapy services outside. Diet - there's a number of patients who I think have developed confusional states or at least where the confusion is added to the dementia if you like, through inadequate diet and we can, when we have a dietician, make some kind of assessment of what the patient's diet really is and then try to correct any deficiencies one way or another. Chiropodist - of course we've got, and there again we have quite a few problems with feet. Again these can be dealt with outside the day hospital but sometimes it's more convenient to do so in this setting. Then outside I think that there are a certain number of cases where it just would not be practical to do anything... so we've got a medical aspect to it. Physiotherapy, occupational therapy, chiropody, diet, nursing care of course, in a general sort of way, that can help too. So these are all things we can offer which a day centre can't.'

Despite this emphasis the varied mix of services was not always easy

to maintain. Speech therapy, dietetics, occupational therapy, and dentistry all on occasions were difficult to sustain. These problems arise, at least in part, because the provision of paramedical services and, to some extent social work, are not directly under the control of those immediately responsible for the day hospital. The loss of the occupational therapist at one stage, for example, displayed the rather limited managerial and resource control exercised by the Consultant in Charge of the hospital despite his considerable influence on other matters.

The Relatives Group

Sixth, the hospital is innovative in the context of medical care in the organization of an active discussion group for patients' relatives. The provision of assistance to relatives of patients by means of a support group was not originally envisaged as an integral part of the service when the day hospital was being planned. The idea was not formulated until after the day hospital became operational, the initiative coming from the newly appointed staff. The social worker and sister-in-charge were key figures in promoting this development although other members of staff, including the senior enrolled nurse, the community nurse and secretary, were also involved from a very early stage. The staff on the day hospital itself was generally very enthusiastic about the concept of providing a support group for relatives but administrative staff, who had responsibility for the day hospital amongst other services, showed some caution. This type of involvement with relatives entailed, for them, a departure from the customary model of hospital services in which relatives play no significant part and boundaries between the institution and the home are clearly defined and maintained. However, despite the expression of such concerns by the administrative staff, which caused considerable friction in the formative stages of the Group, there was no effective opposition and the administrative staff eventually accommodated the Group as a feature of the day hospital Service.

In practice the group performs several functions within the hospital. It serves as a forum for the exchange of practical information between patients' relatives and staff. It is used by relatives as a substitute for the individual consultations with medical staff which many of them seek but feel unable to obtain. It is used by staff to convey to relatives a picture of the way in which the hospital's resources are allocated and this, hopefully, will lessen some of the pressure for help which they experience. It is used by both rela-

tives and staff as an occasion on which to 'negotiate' the 'true' nature of the patient's condition. (Our research suggests that staff and relatives have somewhat different perspectives on the 'problem' that they face.) Also, the group is used to provide what staff describe as a therapy for relatives.

In practice relatives' views are not organizationally incorporated as systematically into the hospital as the existence of this group might imply. For generally, relative involvement complicates the day to day work of hospital staff. Indeed much of our data suggest that the group effectively maintains an ideology of service to relatives but effectively limits its practical implementation to a self-contained and rather isolated locale which minimizes the problems of 'relative disturbance' to the organization overall.

Quality of the Environment

Finally then, the hospital was planned as an innovation in the high quality of the environment that it offers to patients. It is a purpose built structure, well furnished and decorated and generally having an attractive appearance. In the context of residential and hospital provision for the elderly in the U.K. the hospital is, in this respect, well apportioned. Amongst our interview respondents there were several who made the point. For example:

'I think that having a reasonable building does help, and very few day hospitals are as nice as this. I suppose you have noticed having been round other ones. They often use discarded accommodation in various places, sometimes it's a ward, sometimes it's been a gym, or something like this, an old sitting room or something, whereas this was built as a day hospital it's not an also... an also ran' (A nursing officer).

Although the high standard of provision is generally much appreciated by patients, relatives and staff of the hospital, such innovation is not without its critics, especially amongst those in other sectors of the health service who feel this may constitute inequity in the distribution of scarce resources. An administrator made this point:

'Well, the thing that impressed me about the day hospital was the standard of **finish** because - hm - although I've been in purpose built day hospitals before in England - hm - I wasn't very im-

pressed by the high standard of finish. I'm not yet clear in my own mind as to whether that high standard of finish was necessary, we have been very criticised for it, you know, there are a lot of people who have said, 'Well, we could have had two for the price of one', and if we hadn't gone for such... it's a very attractive building to go into it. It's a very stimulating building.'

7. CONCLUSION

So far we have outlined the development of a new psychogeriatric day hospital, described its main features regarded as innovative, and discussed their implementation and impact. However, rather than producing a neat evaluation of the day hospital as a service innovation, we are led to present a much more complex picture of both the process and achievement of change in service provision. The process of innovation is far removed from a rational 'top down' planning model in which objectives are clearly defined by planners, and implemented by service providers to produce outcomes which can be clearly measured by evaluators. On the contrary, this study leads us to make some rather different general observations about the process of innovation.

First some innovations may be thwarted in the process of implementation (for a general discussion see e.g., Hill, 1983). For example it was anticipated that Park Hospital would derive specific benefits from its proximity to the day hospital but these did not materialise because of over-riding day hospital interests. Thus since innovation generally occurs in the context of existing service structures and interests, these may have limiting or diverting effects on implementation. This is seen, for example, in the complex interplay of interests in the development of the Relatives Group, in the limited impact of an attached social worker as a means of integrating health and social work services and in the inability of the system to maintain the full 'range of services' within the Hospital.

Second, the planning of innovation may be less certain and more arbitrary than is generally assumed. So some innovations which do occur may not have been entirely foreseen. These may arise through force of circumstances. For example the innovative transport arrangements occurred because the ambulance service could not undertake the work. Alternatively, circumstances may give rise to un-

planned innovation. For example, the siting of the Day Hospital in the grounds of Park Hospital facilitated the novel use of in-patient beds in conjunction with day hospital places. Moreover some innovations may have unanticipated consequences. For example strategies to avoid silt-up had unexpected effects on related parts of the overall system of care for the elderly and the Relatives Group had the effect of further isolating relatives' issues within the hospital.

Third, innovation may have become an objective in itself rather than the means to a desired end. This is a well known feature of the growth of many organizations. For example some aspects of the treatment and assessment programmes had little proven effectiveness but were retained largely because of their significance in maintaining the notion of progressive practices within the hospital.

Finally the existence of 'innovative features' in an institution may function to distract attention away from the basically conservative nature of the service as a whole. For example this hospital was pervaded by a 'rhetoric of success', staff morale was high and there was much talk about the novel nature and the achievements of the institution. However, as we have previously indicated, this was largely maintained by limiting the frame of reference for comparison and by focussing on the Hospital's 'innovative' features to the neglect of aspects of the service which operated within well established confines.

Overall then, 'innovation' is a complex, sometimes arbitrary process, the outcome of which is determined by the interaction of various interest groups in a continuum of planning and implementation. Evaluation of innovative services must take account of this complexity and in particular must avoid assessments of 'innovative features' which fail to understand their relationship to, and impact on, wider services structures.

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Acknowledgements

This chapter draws upon a research project based initially in the Department of Social Administration and Social Work, University of Glasgow, Scotland, and then in the Department of Social Administration, University of Hull, England, and funded by the Scottish Home and Health Department. Valerie Ritman was also a member of the research team in Glasgow. We are very grateful to the Health Board and to the staff, patients and relatives concerned for their assistance. Thanks are also due to Ms. Sue Needham for secretarial help in Hull.

V. Somatic day treatment in the Netherlands: experiences and problems

J. J. van der Plaats, P. Heyendael, R. van Wijhe

1. INTRODUCTION

Based on an account of the first three years' work in a day treatment centre in the Netherlands, the development of a new service is presented. It is a process over a number of years in which presuppositions did not come true, minor aims turned out to be confused with the ultimate aim and, in which by the method of trial and error, a more or less definite working method was achieved.

The new service itself proved to evoke unexpected effects. It also remains to be seen whether one reaches the right target group. Moreover, a new service which is too isolated appears to invite the foundation of more new services. These kind of problems could have been expected.

In this chapter we will first describe the official aims and methods of day treatment with brief references to literature. This results in a description of certain difficulties (paragraph 2). Then we will render the chronological description of the process of change in which, on the basis of achieved, or not achieved results, it became clear how we had to work (paragraph 3). The fourth paragraph gives an evaluation of the cases in the first three years and events thereafter, in order to illustrate the process of change mentioned above. Finally, we shall try to draw some conclusions and point out what we have learned.

2. THE OBJECTIVES OF DAY TREATMENT AND SOME EXPECTED PROBLEMS

Short history

In the Netherlands day treatment resulted from initiatives taken by individual nursing homes. Their experiences were positive, although never scientifically evaluated. They claimed, that with the new service it became possible for potential nursing home patients to stay in their own homes for much longer and that admission to a

nursing home could even be prevented. Politically this appeared to be the most important reason for introducing day treatment in many nursing homes, as happened in 1977. The government published a distribution plan, which indicated that approximately one out of three nursing homes should start day treatment. The number of places available in a nursing home for day treatment could vary from three to twenty-five, as indicated by the government.

Motives and objectives

It is assumed that with day treatment, the frail and disabled elderly are able to live at home longer than without treatment. It is expected that this type of treatment saves nursing home beds. Another objective, which turned out to be important, is the fact that day treatment is considerably cheaper than admission to an institution. Therefore, day treatment should prevent or delay admission to an intramural institution as well as promote an earlier discharge from it. At the same time day treatment was assumed to play an important role, stimulative as well as supportive, in the home based family care system. There was also the idea of rehabilitation: when the patient has improved he could return home again without the assistance of intensive health services. His attendance to day treatment should be limited in time.

The whole idea suits the general opinion that in health services a change should be brought about from intramural to extramural services. The motives are twofold: the quality of life of the disabled elderly person should improve and it should be cheaper.

The means by which the government tries to realize these objectives are as follows: day treatment is officially described as one of the tasks of a nursing home, which offers services to elderly people with impaired health who do not need these services 24 hours a day, 7 days a week. This also became the formal indication for admission. The patients' disabilities must be of such a nature that they need at least three of the available therapies. The admission permit is valid for three months and has to be extended by three months every time this proves necessary.

The locality of the day treatment is in the nursing home, where several rooms and facilities can be used. The staff is a copy of the nursing home staff, with nurses who have only had a two year training. Occupational therapy, speech therapy and social work is available. The demands for physiotherapy are reasonably fulfilled.

It is assumed that the nursing home staff also serves the day treatment, since most professionals in the day treatment work part-time.

The general practitioner remains responsible for the patient when on day treatment. So there must be a good cooperation between staff and general practitioner. Cooperation with other primary health services is desirable and it is assumed that this follows automatically.

The target group should consist of potential nursing home patients whose admission could be delayed or prevented. It is assumed that day treatment attracts potential nursing home patients at a 'somewhat better stage'.

Difficulties

On the basis of the governmental plans and rules, the literature available and the situation in other countries, several difficulties could have been discovered beforehand.

Unfortunately, in most cases the literature was not studied before the innovation started, nor had the situation in other countries been carefully examined. Had this been the case then difficulties could have been prevented and possibly even another plan would have been set up.

The locality

Locality in a nursing home has several consequences. Many nursing homes use the integration model, which means that the day treatment is incorporated in the nursing home, so that a mixing of nursing home patients and day treatment patients takes place.

It is more attractive to work with day treatment patients and they may well form a welcome diversion from nursing home patients. However, the day treatment patients and the people at the home do not require this integration.

Quality of the staff

The treatment implies a universal setting with many possibilities, a 'therapeutic milieu based on socio-therapeutic principles' (Scheffer and v.d. Hout, 1980).

The staff, as it is formed in the official model, does not have the skills for these very important aspects. Actually, there are too many undertrained nurses, not enough occupational therapists, social workers and no psychologists. Also the whole staff is unfamiliar with the philosophy on which day treatment is based; they work according to the nursing home model, attuned to chronic patients who remain in the institution all the time. To improve the patient's functioning and his social network, remedial therapy and family treatment are necessary (Martin, 1976), both requiring a staff

different from the officially required staff.

The admission criteria

Officially, the most important reason for admission is a medical one and many elderly people have medical problems. However, psychological and social problems usually prove to be the real reason (Lössl, 1977; Farndale, 1961).

Since the Dutch situation provides no alternatives between service centre and day treatment, all types of patients are found in the day treatment centre. The reasons for their admission and stay, range from strictly medical to almost completely social reasons: two reasons which require very different approaches. The result is that a large variety of patients continue to make use of the day treatment services or that pre-selection is applied before admission (Martinez, 1984).

The patients

On the basis of practice and literature several reasons can be mentioned why it is doubtful whether the target group is reached. The day treatment centre, or rather the board of the nursing home, expects a different type of patient than workers in primary health care would like to consider eligible (Bootsma, 1976).

In regions with long waiting-lists for nursing homes one sees that too severe cases are admitted for day treatment, and that day treatment only becomes a kind of intermediate station to the nursing home (Bonn, 1982). This happens especially in psychogeriatrics.

In regions where needs are fulfilled with respect to nursing home beds or where there is another service available, for example a polyclinical rehabilitation centre, we notice that the day treatment is inclined to attract a new type of patient (Farndale, 1961).

Discharge

The period during which a patient makes use of day treatment services in the Netherlands increased from 9 months in 1977 to three years in 1982 for 50% of the patients (Van Kesteren, 1982). This problem was already mentioned in the Farndale study in Great Britain in 1961. Discharging appears to be difficult because attention is often paid to the patient only. Problems regarding illness and disability can be managed, but after a certain period especially psychosocial problems present themselves. For this reason home care only, has often become impossible, unless the day treatment centre is able to influence the whole social network at home together with the patient.

Position of day treatment in primary health care

In Great Britain several day care facilities have been developed. These are: day rehabilitation, day hospital, day care, day centre, welfare centre and social club. In this sequence there is a decrease in medical and paramedical treatment and an increase in interest in social activities. This system means that activities can be organized further away from the clinic, with fewer professional and more volunteers involved.

In the Netherlands day treatment is the only service which frail and disabled elderly can attend during the day. The transition to the so-called service centre is far too large or even impossible.

When there is no day centre to discharge to, the period of time that patients receive day treatment increases (Hildick-Smith, 1980).

It has been found that the day treatment innovation stimulated the development of day centres (Brocklehurst, 1970).

Cooperation with other services

A problem described in more recent studies (Bonn, 1982; Van Dijk, 1980; Jongeneel, 1982) is the fact that a good contact is needed with other community care services. Contacts in primary health care are not very extensive, sometimes there are none. In the official statements, no arrangements are made for these, very vital, activities, which ought to be part of the day treatment services.

The cooperation with the nursing home can also cause problems. The day treatment might even form a threat to the nursing home, especially when there is no waiting-list.

From an economic point of view a large day treatment centre is in the interest of the nursing home. But from literature it becomes clear that a small day treatment centre (12-14 places) is much more active and therefore achieves better results than a larger one (20-25 places) (Martin, 1976).

Substitution

It is generally assumed that extending a certain service attracts patients from other services. Day treatment is said to attract 'preference' nursing home patients. So the number of nursing home beds could be reduced. No official measures are being taken by the government to confirm or evaluate the reality of this substitution.

Day treatment proves to be a complementary service with its own type of patients. It merely saves residential home beds on a moderate scale and prevents the readmission of discharged patients to nursing homes (Farndale, 1961).

Day treatment in the Netherlands after six years

In 1983 research was done with respect to the functioning of several day treatment centres in the Netherlands. All of them tried to find a construction in which idealistic motives and practical limitations could be combined. After analysis, there proved to be four working models of day treatment in the Netherlands (Jongeneel and Leenders, 1982).

In the first model somatic, less psycho-therapeutic, treatment is the main objective. The centre of interest is the patient and his pathology. The physician is the most important professional person and straight therapies are emphasized, such as physiotherapy, ergo-therapy and speech therapy. Integration between these professionals is moderate and the treatments are individual. There is little deliberation and the patient's stay is short. The aim is to restore physical disabilities. In many cases there is a forced discharge by the (para)medical professionals.

In the second model the attention is directed not only at disabilities but also to the psycho-social status of the patient as well. The intake is done by more professionals and one of the purposes of the admission is the patient's self-development. Occupational therapy has a central place. There is more multi-disciplinary cooperation. Contact with the patient's relatives at home mainly consists of exchanging information.

The third model implies a more total approach in which the family and the other community services are involved. It is not only a matter of information but also of profound communication. The role of the day treatment is a conducting and supporting one. There is an integration between the professionals and more deliberation in which the patient, the family and other 'outside' workers have an important say. In this model the patient's stay is longer.

The fourth model is one of resocialisation. The main objective is no longer treatment or cure of disabilities but the acceptance of them by the patient and his environment. Communication with the patient's home is essential in trying to improve the quality of life there. Discharge is a long process, which starts when the patient enters the day treatment centre. Often after-care is provided. There is a total integration between the professionals within the centre as well as with those outside.

These models are operational in the different day treatment centres.

However, they might well need expanding in order to serve the needs of patients and their families.

3. AN ACCOUNT OF A DAY TREATMENT CENTRE IN ARNHEM, THE NETHERLANDS

So far we have presented a description of the objectives of the day treatment in the Netherlands. Also we have related some difficulties and problems in the development of such a service. We based these expected problems on some published studies. Despite these studies we started a day treatment centre in Arnhem quite unprepared. A description will be presented of our experiences and of the process of building up such a service.

The local situation and start

As laid down by the government the target group of the service are somatically handicapped patients. In Arnhem the day treatment centre covers a region of circa 250,000 people, including the city of Arnhem with 150,000 inhabitants. In this city there are many other facilities for geriatric services: 5 nursing homes (with an average of 120 beds), two of which are for psycho-geriatric patients, a special ward in a hospital for acute geriatric care, two polyclinical services, a day rehabilitation centre, about 20 residential homes (with an average of 100 places), and two day treatment centres, one for somatic and one for psycho-geriatric patients.

Our main aim was to make it possible for the frail elderly to live at home for as long as possible. Our philosophy on how to achieve this is closest to the third model (total approach), mentioned above. Therefore, we wanted a staff different from that which is officially prescribed. We got fewer inadequately trained nurses, more social workers, more occupational therapists and our own staff. We would have preferred to occupy some building independent of the nursing home, for example somewhere in the city, but the regulations regarding payment would not permit this. However, we did receive separate accommodation in the nursing home, which prevented integration of the patients between the two services.

Since we think that social problems are as important as purely medical-somatic ones, we extended the indication terms with many social and psychological components.

We had also formed some ideas about the discharge of patients. It had to be a meaningful process, in which the patient and his family participated and which would be accompanied by changes at home so

that the whole system could find its own way again without our help. We assumed that the positive changes we brought about in our setting, would automatically have an effect on the home situation. However, in spite of precautions, we appeared to have no idea of what was ahead of us in the following months and years.

Despite our intention to treat the patient and his family 'as a whole', the somatic scope and the specialized exercises proved to be our main objectives. The physician had a central position, physiotherapy and speech therapy were most important to the patients (it seemed their only interest).

We were afraid that the patients might not like our new service, so we made things attractive for them, cosy and pleasant. We also did what they expected us to do. In a short time they behaved as if they were in a hospital, waited passively and inert until we took initiatives for them to undertake something. We did not by far reach the initial objectives which we had in mind.

We had to change our working method, which resembled model 1 (somatic treatment). We had induced the same passivity as observed with chronic nursing home patients. After all, everyone of us had been working in that setting for years. We had to provide a more stimulating environment and make higher demands upon the patients. The daily pursuits should be focused more on reactivation and therefore, the quality of our work had to be improved. To gain this insight the team had to overcome a lot of resistance within itself.

The psychologist who helped us had a major part in this process. Step by step we moved towards another working model, which roughly covers model 2 (occupation). The stimulation we gave was successful, but we lost some patients because we changed the daily activities too abruptly, e.g. the introduction of household activities.

Disappointment grew on another point. We learned that in many cases nothing in the patient's behaviour or in that of the environment had changed at the moment we were planning on discharge. This was the case with ADL-function and mobility. The progress the patient had made in our setting was not noticeable at home. Disturbances in behaviour persisted too, even when they had disappeared in day treatment.

Some important changes were still to be noticed, but these were only due to the fact that the patient was 'going out' (leaving home) a few days a week. He had a regular break, was doing 'something' and had something to talk about at home. The partner had relief and spare time.

However, no changes occurred in the patient's helplessness and the relatives over care and over concern. These phenomena are described in the relevant literature (Farndale, 1961; Van Woerkom, 1981). Medical and physical problems can be solved quite quickly, but this does not mean that the patient can function more independently at home. Psychological and social problems remain.

The situation at home

We had to make home visits, not only to evaluate the home situation but also to stimulate communication with the care providers. The home environment had to change together with the patient in order to see and appreciate the patient's progress. We discovered that most relationships were deeply disturbed.

The principle of 'family care' has many disadvantages. Roles may change completely and people may grow apart (Van Woerkom, 1982).

We were shown a variety of behaviours between care providers and care consumers in the family situation.

In short, we perceived the following stages in the development of their relationship, of which we found parts in the literature (Hermesen, 1982; De Swaan, 1982; Radebold, 1981):

- in the beginning, tender care or even too much care,
- later on, less tenderness and more purely instrumental care,
- strain on the patient, more help-seeking,
- the patient's inadequately in asking for attention, annoying and obsessive claiming,
- strain on the care provider, who in this situation starts remembering unpleasant things from the past concerning the patient,
- the patient as well as the care provider feel neglected,
- slowly growing apart, an expulsion process sets in.

The moment day treatment is requested by the G.P. many of the stages mentioned above have already been passed through.

How can we influence processes in the situation at home when we do not have the skills to manage this. We tried all kinds of professional care and all sorts of therapies. Psychotherapy, together with relationtherapy, proved to be too confronting for the people involved. Counseling by social workers produced results in some cases. Behaviour therapy took a lot of effort and time but was successful. Psychiatric help did not work out well at all.

Anyhow, we discovered thousands of problems with each patient and his situation. It overwhelmed us! We became fatigued and disappointed.

Our attitude towards the patients and especially towards their relatives became more and more negative. We quarrelled in our team and some of us became ill. We were the ones who needed help...!! Again it was a psychologist who worked out our problems with us. Gradually we discovered that we had gathered a considerable know how in our experimental stage. We also found that no services could actually fully handle these kind of problems. We learned how to learn from others and how to incorporate this in our treatments. We also saw that many situations cannot be changed for the better. Small but stable alterations in mutual behaviour at home are often sufficient to improve the quality of life at home. On the other hand, we accepted the fact that the patient, who goes out (leaves home) three times a week, indeed offers a real solution in some cases. Slowly we are moving towards model 3 and 4 (resocialisation). Everyone of us had to reorientate him/herself and, above all, to extend his/her social and psychological skills. We studied together, attended each others therapies and evaluated together afterwards.

From the experiences described above we were able to draw the following conclusions:

1. Regardless of the activities in day treatment, there is an immediate effect merely because of the fact that the patient is away from home several times a week.
2. A new balance is immediately established at home. The family feels relieved; often they do not wish for or need more than this.
3. The patient may value his being under day treatment in such positive terms that he cannot or does not wish to do without it anymore.
4. In the day treatment setting the patient behaves much more positively than at home, the result is a sharp contrast.
5. What is achieved in day treatment is not continued at home.
6. If it is continued, the patient and his family are punished, as it were, with discharge from day treatment.
7. There are motives of interrelative origin, which impede the patient's and his family's changing their care provision/consumption patterns.
8. Making use of day treatment service may cause detachment from the home environment.
9. The family used to be solely responsible for the patient's care. Now they can take advantage of the day treatment: when the end of day treatment approaches, the home environment threatens with

admission to an institution if they have to take full responsibility again.

Statements 1-3 indicate that in some cases the whole range of therapies in day treatment are not necessary (anymore) to improve the quality of life of the patient and his relatives. Especially for patients who need long-term care more services like day centres are sufficient.

Statements 4-7 show that in some situations intensive communication and cooperation with the family is indispensable if results are to be achieved. We do not always have the skill to achieve this.

Statements 8-9 imply that day treatment has negative effects, too. This means that a proper assessment of the underlying problems may cause the decision not to admit the patient, but to do the job in his/her home. However, neither the assessment, nor the work at home are being paid for.

We have not made an exact analysis of the total development of the working methods and results of day treatment. What we saw was that in the course of time more, different treatment programmes were offered to the patients. Physiotherapy and speech therapy were no longer the main activities; a shift came about towards more remedial and group activities and more home treatment.

At discharge, more and more attention was paid to alternatives in the community services and the foundation of the day centre had a sound influence on the discharge policy.

In the course of time the average age became lower, more men came to the day treatment centre and the diagnosis CVA was more often accompanied by agnosia, apraxia and other disturbances in perception.

The period, during which patients were under day treatment, had not increased. This is probably due to the remedial therapies and the presence of the day centers.

Based upon our experiences we developed the following activities:

- Cooperation mainly in the form of **consultation** in complicated cases,
- We **work more in the patient's home**; sometimes we do not even admit a patient to day treatment. The insurance funds are prepared, now, to remunerate this kind of service.
- We organize meetings with small groups of workers in other community services who care for frail elderly living at home.
- We founded a **day centre**, which is more social minded (Hildick, 1980).
- The day treatment became more directed towards remedial work

(Martin, 1976).

- To keep the day centre running we try to attach it to a **social club** or a **service centre**. This might result, in some cases, in a return to independence of former long-term day treatment patients.
- We took the initiative for a **24-hour service** for impaired and frail elderly, who live at home and who do not want to go into an institution. It started in January 1984.
- If possible, we participate in **policy making** in official organizations.

4. EVALUATION OF THE DAY TREATMENT CENTRE IN ARNHEM

After the description of the process we went through from 1980 to 1983, we will now present some data on what happened quantitatively. It presents an additional evaluation to our work.

This evaluation by means of analysis of the patients' files is meant to illustrate the contents of the previous chapters. We have listed patients' characteristics, traced indications and aims and the ultimate results. The data deal with practically all patients who have attended the day treatment from May 1980 until December 1983.

We chose the following parameters:

- reason for admission (which implies the aim of the day treatment),
- the problems (simple = usually somatic, complicated = with psychological and/or social problems),
- the therapies (specialized exercises, maintenance therapy and more socially directed activities),
- improvement (somatically and psychosocially),
- duration of admission,
- discharge home or to an institution.

General characteristics of the patients

In table 1 and 2 we present some general characteristics of the patients and their medical diagnosis. This analysis deals with a total of 80 patients.

Most of the patients need some assistance with all ADL-activities besides eating. It is striking that the number of patients in need of full assistance with some ADL-activities is relatively high. Besides a somatic diagnosis, psychological problems can be mentioned, although they are not accepted by the government as an indication for day treatment. In 30% of the cases such problems were found.

Table 1. Sex, age, civil status and housing conditions of the patients in %

| | | | |
|--------------------|--------------------------|------------------------------|------------------------------|
| sex | male 42% | | female 58% |
| age | 30-60: 15% | 60-75: 65% | 75: 20% |
| housing-conditions | living on their own: 58% | in home for the elderly: 30% | living with e.g. family: 12% |
| civil status | married: 58% | widowed: 38% | single or divorced: 14% |

Table 2. Survey of the most frequent diagnoses in percentages per diagnosis, for all subjects, on an average of 3 diagnoses per patient

| | |
|------------------------------------|-----|
| Hemiparesis/CVA | 53% |
| Decompensation cordis | 23% |
| Aphasia | 18% |
| Diabetes mellitus | 16% |
| Hypertension | 14% |
| Parkinson's disease | 12% |
| CARA | 12% |
| Other focal neurological disorders | 12% |
| Cerebral insufficiency | 10% |

Other diagnoses, occurring in less than 10% of the cases are, among other things: arteriosclerosis, arthrosis, multiple sclerosis and cancer.

Table 3. ADL-activities per category, for all patients, care at home needed, in percentages of the total number of patients

| | no assistance needed | some assistance needed | full assistance needed |
|-----------|----------------------|------------------------|------------------------|
| lavatory | 48% | 38% | 14% |
| mobility | 4% | 77% | 19% |
| eating | 80% | 16% | 4% |
| washing | 4% | 77% | 19% |
| dresssing | 4% | 72% | 24% |

Because of the somatic nature of this day treatment centre no differentiated description of these data is given. In most cases, the psychological problems were referred to in terms like: anxiety, depression, apathy, forgetfulness and cognitive disturbances. More data are available about social problems, which may also lead to an indication for day treatment (table 4).

Table 4. Social indications in percentages for all patients

| | |
|------------------------------------|-----|
| Support/relief of home care | 46% |
| Loneliness/living alone | 20% |
| Support in the home of the elderly | 16% |
| Passivity | 6% |
| None mentioned | 12% |

In this survey the percentage of the indication 'support or relief of home care' (a total of 62%) is remarkably high. The capacities of the home environment seem to be exceeded.

An estimated 20% of all patients have somatic and social problems together with psychological ones. This underlines the need for a multidisciplinary approach to day-treatment patients. What is more important, this means that the staff of a somatic day treatment centre, formed according to the official existing model, cannot handle these problems.

The main reasons for admission are presented in table 5.

Table 5. Main reasons for admission, in percentages per reason, for all subjects, on an average of 2 reasons per patient

| | |
|--|-----|
| Physical rehabilitation | 59% |
| Reactivation/passivity | 41% |
| Support/relief of home environment, home for the elderly | 27% |
| Prevention of admission to hospital/nursing home | 25% |
| Contacts/resocialisation | 12% |
| Support after discharge from hospital/nursing home | 11% |
| Other indications | 10% |

Rehabilitation and reactivation are the most frequent reasons. It is striking that 25% of the patients is, as it were, 'on the threshold of a nursing home'. In all these cases the care providers have indicated that they are no longer able to take the responsibility for the patient's care unless they receive assistance from the day treatment centre or unless the patient's condition improves as a result of day treatment. This particularly applies to those patients who need full assistance with the ADL-activities and to those with complicated problems i.e. somatic, social, psychological.

In 55% of the cases a recent 'important event in life' took place, which lead to an application for day treatment. These events are presented in table 6.

Table 6. Events related to the application for day treatment in percentages of the total number of patients

| | |
|-------------------------------------|-----|
| Discharge from a nursing home | 18% |
| Discharge from a hospital | 12% |
| Recent CVA (less than one year ago) | 14% |
| Falls | 11% |
| No events mentioned | 45% |

According to the official guidelines the treatment is for three months. The average stay, however, proves to be of seven months' duration, ranging from 1-40 months. It should be stressed that the number of days a week that the patient receives day treatment varies from half a day to, under special circumstances, five days a week. Moreover, the team reduces the number of days when the end of day treatment approaches. In 44% of all cases the length of the patient's stay proves to be longer than the team expected at intake. The reasons for ending day treatment can be divided into four categories (table 7).

Table 7. Reasons for ending day treatment in percentages of the total number of patients

| | |
|---|-----|
| As planned by the team | 57% |
| Patient stops on his/her own initiative/ does not come anymore | 18% |
| Deceased | 8% |
| Acute situations like admission to a hospital | 17% |

A relatively large number of patients end day treatment on their own initiative. These are mainly patients who do not feel at home at the centre or who expected more specific therapy, especially physiotherapy. The aim of day treatment is to let the patient function in his own environment for as long as possible.

Table 8 shows where the patients were discharged to and what extra services were used.

Table 8. The setting of the patients, before admission and after discharge, in percentages

| | coming from home environment and discharged to | coming from home for the elderly and dis- charged to | total discharge |
|-----------------------|--|---|--------------------|
| home | 21% | -- | 21% |
| home + physiotherapy | 10% | 1% | 11% |
| home + day centre | 7% | -- | 7% |
| home + service centre | 5% | -- | 5% |
| home + other services | 4% | -- | 4% |
| homes for the elderly | 6% | 20% | 26% |
| hospitals | 10% | 3% | 13% |
| deceased | 5% | 3% | 8% |
| nursing home | 1% | 4% | 5% |

67% of all patients returned to the environment they came from (20% to homes for the elderly and 47% to their own home).

The percentage of patients who came from a home environment and who were discharged to a hospital or have died, is remarkably high. This is noteworthy, especially when we look at the total percentages at discharge. Almost all of the patients discharged to a hospital came from their own homes. This is also the case with the deceased patients. However, nearly all the patients who were discharged to a nursing home initially came from a home for the elderly.

We examined, retrospectively, all the cases and tried to trace the aims which the day treatment team had set for them. In the course of the admission some aims proved to be realizable, others did not. The ultimate result of the time of treatment has also been examined. In this way we came to a classification of 5 rough treatment typologies. They are schematically presented in table 9.

Table 9. Success of the day treatment

| | 1 improve- ment 10% | 2 treatment 10% | 3 meaningful stay 12% | 4 trying 47% | 5 failure 21% |
|---|---------------------------|-----------------------|-----------------------------|--------------------|---------------------|
| simple problems | + | | | | + |
| complicated problems | | + | + | + | + |
| specific therapy | + | + | | + | + |
| maintenance therapy | | + | + | + | + |
| social therapy | | | + | + | + |
| improvement somatically | + | | | | |
| improvement socially | | | + | + | |
| limited period of admission | + | | | + | + |
| long period of admission | | + | + | + | |
| no discharge | | + | | | |
| discharge to original environment | + | | + | + | |
| discharge to institution | | | | | + |

The five types of treatment (1-5) and their characteristics (+). The

improvement-type mainly consists of rehabilitation patients. The treatment-type especially concentrates on postponing admission to an institution; patients are in bad condition and stay very disabled. The meaningful stay-type concentrated on assisting the family; discharge leads to a long stay in a day centre. The trying-type attempts to rehabilitate and resocialize patients. The failing-type includes all types of patients and expectations.

These cases are hard to describe in terms of success or failure. Leaving home, where care of the patient was difficult and conflicts arose, is officially speaking, failure of the treatment. In human terms, however, it might be a good result.

Conclusions

Before starting an innovation, a scientific study is necessary. It is worthwhile to study literature from other countries and that on innovation in one's own country. Many difficulties could be foreseen and a loss of energy prevented, if governments and local authorities would be advised by these studies.

Before starting and in the first periods of working with the innovation, there should be a scientific evaluation too. In this way the registration of patients, treatments and results are adequately and properly done. Without this evaluation it may happen that the new service attracts patients for whom it was not set up and thus creates new needs.

If the innovation aims at reducing services in other institutions, this reduction must be realized at the moment the new project starts operating. As all services are paid for concerning 'full' places or beds, every institution will do its utmost to attract or to keep patients. Admission criteria must be stated in advance and must be controlled.

Nowadays innovations are attached to already existing institutions, so that costs for building and overheads are saved. This does not imply, however, that the organization and way of working has to be exactly the same. This can be a serious inhibition for the new service to realize itself and to do its innovating work.

As far as an innovation in primary health care is concerned, this must be incorporated in a series of services that complement each other. If this is not the case the innovation reveals the gaps. This

becomes clear when the innovation cannot discharge its patients. The result is that the new service starts to select the better patients for admission. A second result may be that another new service is founded.

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VI. Alternatives to institutional care: costs, burdens and quality

Svein Olav Daatland

1. INTRODUCTION

Several studies show that most old people want to live in their own homes as long as they possibly can (Thorsen, 1979; Thorslund, 1981; SPRI S 102, 1978). Other studies have shown that institutional life may have detrimental effects on the inmates (Daatland and Sundström, 1984). Hence, there is general agreement on a policy to promote independent living in old age for as long as possible.

These ideas are far from new. They have been expressed by researchers and policymakers all through the 1950's and 1960's. The question of seeking alternatives to institutional care has, however, attracted increasing attention in the later years, and the most important reasons for this revitalization of the issue is probably financial. The search for alternatives to institutional care has been placed high on the agenda in most western countries, whether or not they have high or low levels of institutional care. What they do have in common is the discontentment over the traditional public care system, the awareness that the problems are growing faster than one seems able to be able to cope with, and the economic crisis. The search for alternatives to institutional care for the aged is motivated by the potential of reducing public expenses in the care sector. The vast growth in costs for the care of the aged, and the growing number of old people in a period of economic recession, have made it vital to look for new - and cheaper - ways of using the available resources.

To what extent is it possible - and if so: advisable - to slow down, or even reduce, the institutionalization rate? What is to be gained by such a policy, and what are the costs involved; costs both in terms of finances and quality of care? While addressing these questions it needs to be noted that there are different parties - and interests - involved. What is good for the public economy is not necessarily good for the elderly, and what is good for the elderly

is not always good for his or her family. A reduction in public care efforts usually means increased burdens on the family, or rather the female family members.

Another point to be made is that institutional life does not in itself have to mean a loss of independence in comparison to living at home. There are old people who are made prisoners in their own homes by disablement and inadequate housing conditions. There are on the other hand institutional regimes which to an exaggerating and unnecessary extent limit the personal freedom for their inmates. A true interest in improving the care of the aged should thus also motivate the search for innovations and alternative actions **within** the institutional sector.

This chapter will address the issues raised above. More specifically three questions will be discussed:

1. Has there been a growth in institutional care for the aged during the last one or two decades?

This question needs to be asked and tested in order to evaluate the background and motivation for the anti-institutionalization policy. Is this policy a reaction to a growth, perhaps an unduly strong growth, in the institutional sector, or has it rather developed despite a decline in institutional care?

2. What are the financial costs of institutional care compared to outside care?

3. To what extent is it possible to reduce the institutionalization rate and the public expenses by increased efforts in outside care?

These questions will be discussed from the point of view of Norway, using data and experiences from Norwegian studies on innovations in care for the aged. Some problems in evaluative research will also be illustrated, and a concluding section will introduce an alternative approach to the issue of alternatives to institutional care of the aged.

2. DEVELOPMENT OF INSTITUTIONAL CARE, NORWAY 1965-1982

What is meant by an 'institution' may be subject to discussion. In

this article I include what Goffman (1961) calls 'total institutions', implying that the inmates are subject to institutional rules of conduct, and form part of a joint household. This includes two types of institutions for the aged in Norway: residential homes (old people's homes) and nursing homes.

The residential homes are regarded as 'social institutions', designed for old people who can generally look after themselves, but need communal living and a limited amount of care. **The nursing homes** are 'medical institutions' intended to accommodate and provide medical care for patients who do not need to stay in a hospital. The latter are the responsibility of the county, while the residential homes are the responsibility of the local municipality. The majority of the institutions are publicly owned, and the private institutions, which for the most part are owned and run by non-profit organizations, are in fact also a public responsibility as they are financed almost exclusively by public means (note 1).

Some institutions, the so-called 'combined institutions', include units of both types, but they are grouped into the two main types for the statistics which are to be presented. Thus, residential homes include the 'pure' residential homes **and** residential home units in combined institutions, and likewise for the nursing homes.

Norway had 14,675 residential home beds and 27,720 nursing home beds by the end of 1982, a total of 42,395, which represent 6.7 institutional beds per 100 of the population aged 65 and older, of which 4.4 are in nursing homes and 2.3 in residential homes. These are fairly high figures compared to countries like the U.K. and the U.S.A., but somewhat lower than Sweden and the Netherlands. It may also be noted that while Norway has the majority of their institutionalized people (2/3) in nursing homes, Sweden has nearly an equal distribution over the two types (medical and social) of institutions, and the Netherlands have an even higher majority (4/5) in residential homes.

Thus, there are large structural differences between countries in the organization of institutional care. If this sector is designed primarily to cover the needs of care in the old population, it seems that such needs are evaluated rather differently in the various countries.

It needs to be underlined that the number of institutional beds is

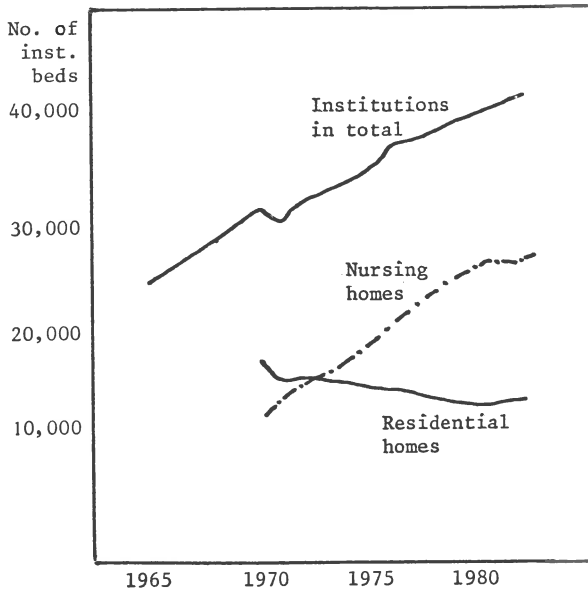
not equivalent to the number of elderly people living in institutions, as approximately seven per cent of the inmates are below the age of 65. I should also mention that close to half of the 4,500 patients in Norwegian psychiatric nursing homes are aged 65 and older, but they are not included in the institutionalized group because of poor statistics, especially concerning the development against time. Leaving this group out will not distort the information presented as there are few psychiatric nursing homes in Norway, including no more than five per cent of all institutionalized elderly. Finally, approximately two per cent of the elderly will be under treatment in hospitals at any given time. Most of them on a temporary basis, but some are in fact patients requiring nursing and waiting for admission to a nursing home. When I include only the patients/clients in nursing homes and residential homes, this is, thus, only an approximation of the level of institutional care in Norway, but it is still an accurate approximation.

There has been a strong growth in **the number of institutional beds** during the last two decades in Norway, which is evident from diagram 1. Note also the shift from social to medical institutions during the 1970's, which may be regarded as a continuation of the developmental line from poor and reformatory institutions of earlier years to the more professionalized care institutions of today. The specific cause of the decline in the number of residential homes and the rise in the number of nursing homes is, however, a financial one, as the national state provides a 50 per cent refund for the running expenses of nursing homes, but not for residential homes. Hence, it has been cheaper for the local authorities to build and run nursing homes.

The increase in expenses has been even greater than the growth in the number of patients, which may be illustrated for the case of nursing homes. The rise in costs was 77 per cent from 1974 to 1979, when evaluated for inflation, while the increase in the number of beds was 59 per cent (Nygård, 1981) (note 2).

The total rise in public expenditure in the health sector was approximately 100 per cent during the 1970's (evaluated for inflation), and it may be this vast growth in public expenditure which has created the belief among the population that there has been a corresponding growth in care efforts. One has talked about the 1970's as the decade of institutional care, which as I shall show, is truly not the case, at least not for the institutional care of the aged.

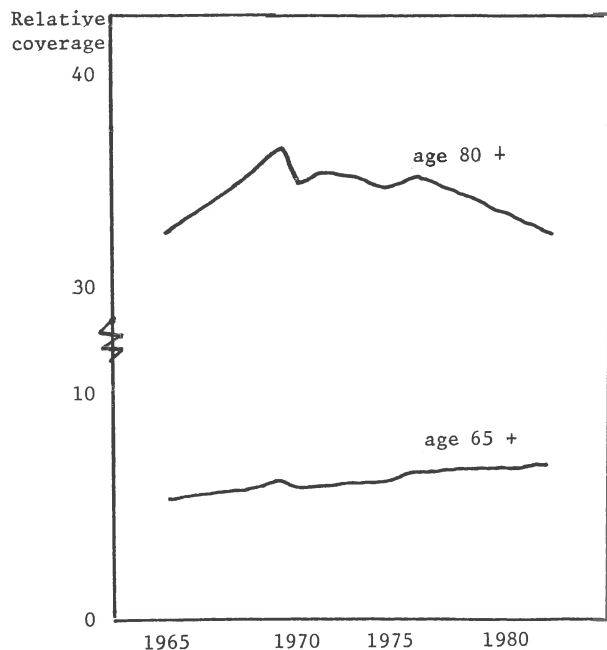
Diagram 1. Number of beds in institutions for the elderly, Norway 1965-1982 (Source; Daatland and Sundström, 1984)



In order to judge how the level of institutional care has developed against time, we must relate the absolute number of institutional beds to an indication of need and need coverage. I shall do so mainly by taking into consideration the number of old people in the population. Has the growth in the number of institutional beds kept pace with the increasing number of elderly people?

I shall employ 'the relative coverage', i.e. the number of institutional beds per 100 of the population, as an indication of the level of institutional care. To be more precise, I shall use two such indications, one relative to the total elderly population (aged 65 and older), the other relative to the very elderly (aged 80 and older), who form the major risk-group in need of institutional care. How the coverage has developed against time is illustrated in diagram 2 (note 3).

Diagram 2. Relative coverage of institutions (number of institutional beds per 100 of the population) aged 65+ and aged 80+, Norway 1965-1982 (Source: Daatland and Sundström, 1984)



Relative to the total elderly population (aged 65 and older) the coverage increased somewhat in the late 1960's, but has been fairly stable in the 1970's, reaching its present level of 6.7 in 1978/79.

Relative to the very elderly (aged 80 and older) there are, however, significant changes. Following an increased care coverage in the late 1960's, there has been a marked decline in care coverage all through the 1970's, from 36.4 institutional beds per 100 people over 80 years of age in 1970 to 32.5 in 1982, a reduction in relative coverage of 11 per cent.

When we assess on the two types of institutions, we find a strong tendency towards more medical institutions. Norway has had an increase in the relative coverage of nursing homes, but an even stronger decline in the care coverage of residential homes accounts for the decline in total (table 1).

Table 1. Relative coverage/80+ in 1982, and change 1970-1982, for institutions in total and separately for residential homes and nursing homes

| | Res. homes | Nursing homes | Institutions, total |
|----------------|------------|---------------|---------------------|
| 1982 | 11.3 | 21.3 | 32.5 |
| Change 1970-82 | - 9.6 | + 5.8 | - 3.9 |

(Source: Daatland and Sundström, 1984)

Another trend to be noted, which is not evident in the data presented above, is that the average age of the institutionalized population has increased steadily over the last 10-20 years. The proportion of the institutionalized over the age of 80 is close to 70 per cent today, while the corresponding proportion in 1965 was around 50% (Daatland and Sundström, 1984).

This means that the decline in relative coverage has first of all resulted in a decreased tendency towards institutionalization among the 'young-old'. **The institutionalization rate** (the percentage actually in institutions) for the 'old-old' has changed very little during the 1970's. It has in fact since then increased somewhat, at least up until 1980, despite the reduction in relative coverage (table 2).

Table 2. Institutionalization rate (percentage in institutions) for the age group 65-79 and the age group aged 80+, Norway 1970-1982

| | 65+ | 80+ |
|------|-----|------|
| 1970 | 2.9 | 20.1 |
| 1975 | 2.7 | 20.9 |
| 1980 | 2.5 | 21.8 |
| 1982 | 2.5 | 21.8 |

(Estimated figures, source: Daatland and Sundström, 1984)

These trends may be judged both as positive and negative signs in the development of public care of the aged in this period. The possible positive side of the development lies in the assumption

that undue and/or premature institutionalization has previously concerned the 'young-old'. We will hope that it is the efforts which have been laid down for improvements in general welfare and outside care services which have 'paid off' in terms of a lower institutionalization rate among the 'young-old', while the necessary standard has been maintained for the 'old-old', the so-called 'pay off hypothesis'.

An alternative explanation is that the provision of institutional care has **not** kept up with the growing number of people in need of institutional care. Thus,

1. when the average age of the institutionalized population has increased,
2. the institutionalization rate among the 'young-old' has decreased, and
3. it has remained fairly constant for the 'old-old'.

These trends are the result of scarcity in the institutional care sector. They are consequently an indication of the necessity to give priority to the oldest age group and those in most need of care, the so-called 'scarcity hypothesis'.

Which of these two is the most correct hypothesis should be judged on the context of an evaluation of the possible unfulfilled need for institutional care today as compared to the situation 10-15 years ago. This is beyond the scope of the present article. However, a general idea as to which explanation is the most valid may be indicated as follows:

Resources like health (William Olsson and Svanborg, 1984), economy (Trier, 1980), and housing standard (Trier, 1983), have improved over the last years and have probably strengthened the possibility of staying outside institutions in old age. So also has the growth in outside care services like home help and home nursing (Daatland and Sundström, 1984). These services have, however, expanded primarily in order to provide such services for more old people, thus not by offering more help to each client (Daatland and Sundström, 1984). The service has hardly been able to cover the heavy burden of care for old people on the verge of institutionalization (Daatland and Sundström, 1984). There has also been a growth in the number of old people's flats. Close to 4% of the elderly live in such flats today (1982). Most of these flats offer no additional services over residence in an ordinary housing area. The priority given to service houses in the last couple of years appeared after the decline started in the residential home sector. The development of service

houses, the introduction of programmes like 24-hour home help and day care centers/institutions, should be regarded more as attempts to compensate for the earlier shortcomings, than as a true effort to increase the already established level of care in the early 1970's. In support of this conclusion there is a growing number of waiting-lists for institutional care, particularly in the larger cities (note 4).

Also, the trend in the residential homes sector seems to be that the clients are becoming older and more ill, which makes the distinction between residential homes and nursing homes more vague. Long waiting-lists for nursing home care have probably lead to the necessity of admitting patients in need of a large amount of care to the residential homes which were not originally designed for this (Harraldsen and Nygård, in press).

The reason behind this seemingly growing need of institutional care, in spite of the improvements in general welfare and outside care services, is probably first of all the vast increase of single households among the elderly, particularly among the 'old-old'. Single elderly people have a 5-10 times higher probability of being institutionalized than married couples, according to Danish and Norwegian studies (Daatland and Sundström, 1984). Another Norwegian study shows that 85 per cent of the patients discharged from a nursing home over a five year period were dependent upon family care in addition to public home help and/or home nursing (Romoren, 1984).

Despite the fact that it is difficult to assess the joint effects of all these changes for the need of institutional care, it seems fair to conclude, albeit rather tentatively, that the institutional care of the aged has stagnated, perhaps even declined, in Norway since 1970. This seems to be only partly explained by the increased efforts in other sectors of care and welfare for the aged. Thus the growing interest in searching for alternatives for institutional care may **not** be understood as a reaction to a period of strong growth in this sector, but rather the opposite: such a policy has developed despite of a standstill, or even a decline, in institutional care efforts in relation to the needs.

3. COSTS OF INSTITUTIONAL AND OUTSIDE CARE

The second question to be discussed concerns the comparison of costs of institutional and outside care. Two Norwegian studies from the

middle of the 1970's have addressed this issue. More specifically, one calculated the number of hours of home help and home nursing which it was possible to provide for an old person against the costs of institutional care.

The first study (Jensen, 1977) reports on the basis of an analysis of the costs of the care of the aged in all municipalities of Vest-Agder and Aust-Agder, two of the 19 Norwegian counties. All nursing homes in these two counties were included in the study, and a sample of 10 of the residential homes (a sample which was drawn among the more modern and expensive residential homes), in order to draw conclusions which were relevant for residential homes of a standard which might be built at that time (1974).

The second study (Helland and Pettersen, 1979) reports from Ski, a municipality close to Oslo, which at that time had approximately 17,000 inhabitants.

Thus the two studies are not representative for the whole of Norway, but both these and other studies (f.i. Nesvåg, 1984) show that the level and exence of the care of the aged varies greatly between municipalities. The data presented provides only a general idea of the cost of institutional and outside care. The results are presented in table 3.

Table 3. Number of hours of home help and home nursing a week which equals the cost of institutional care, Norway 1974/1975. Average cost per institution

| | Vest- and Aust-Agder county (Jensen 1977) (1) | The municipality of Ski (Helland/Petterson 1979) (2) |
|------------------|---|--|
| Residential home | 15 | 21 |
| Nursing home | 28 | 35 |

1) Presupposes a distribution of 20% home nursing, and 80% home help hours.

2) Presupposes a distribution of 33% home nursing, and 67% home help hours.

For the cost of a week's stay in an averagely priced residential home one might pay for 15-21 hours a week of home help and home

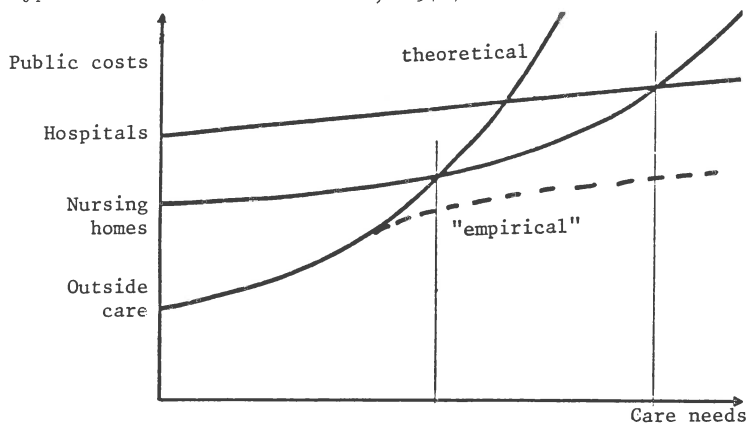
nursing. The cost of nursing home care is higher, and the corresponding number of hours in outside care of equal average cost to a nursing home bed, is between 28 and 35 hours a week.

All these figures relate to the situation in 1974/75, and the analysis has been corrected for the living expenses if one was living in one's own home. However, not accounted for are the costs of other medical and social services which an impaired elderly person living at home might make use of. The actual number of hours which were possible to provide in outside care for the cost of institutional care may therefore be somewhat lower than indicated in table 3. But still, there seems to be large potential in outside care. The average number of home help hours per client at that time was between two and three hours a week (national figures). Thus one might increase the efforts in outside care tremendously within the costs of institutional care.

On the other hand, if the old person is in need of daily care at a degree which might require institutional care, even 28 hours a week may be too little. This will give the patient about 4 hours of help each day, and leave him/her to him/herself and/or possible family care providers for the other 20 hours.

It seems that outside care is a cheaper alternative compared to institutional care if the care needs are not too high, and when there are family care providers able and willing to carry out the major tasks of the care efforts. In conclusion the following diagram (diagram 3) might theoretically illustrate the relationship between public expenses and care requirements according to the different types of care:

Diagram 3. Public expenses in care requirements according to the types of care (Source: Grund, 1978)



With moderate needs of care, outside care will be cheaper than institutional care. As the need for care increases, institutional care will become relatively more competitive costwise, and eventually even cheaper, than the cost for adequate outside care.

The solid line for outside care (diagram 3) represents the logical, or theoretical, level of expence if outside care were fully provided by the public care system. The actual, or empirical, level is probably more like the dotted line, as the public efforts in outside care will often be merely of an assisting nature, and supplementary to the care efforts from family care providers when the burden of the care is heavy.

4. OUTSIDE CARE AS AN ALTERNATIVE TO INSTITUTIONALIZATION

The third question to be answered is: to what extent is it possible to reduce the institutionalization rate and the public expenses by increasing the efforts for outside care?

Judging from the comparative cost of institutional and outside care (table 3) there seem to be potentials, in particular when we speak of people with moderate needs of care (diagram 3). However, theory is one thing, the complexity of real life situations is another. A Norwegian study which set out to measure the effects of interventions in outside care may provide some answers.

The aims of the study were:

1. to analyse the effects of public services and the care to old people,
2. to analyse whether a better primary health and social care system can improve the functional ability and reduce the need for institutional care,
3. to analyse the positive and negative factors affecting the improvement of the care of old people at home and
4. to make practical proposals towards better care for old people in the future (Rø, 1983).

A team consisting of one medical practitioner, one nurse, one social worker and one ergotherapist (half-time) participated in the project for three years. This included an 18 month intervention period of medical examination, intervention and mediation between the elderly and the public service system. The project included interviews and research, and an additional staff of 1-4 persons took part in cleri-

cal and assisting functions during parts of the period.

The subjects were old people living at home, aged 80 years and older, in Oslo. An action or intervention group (n = 456) was compared with a matched control group (n = 562) after the intervention period of 18 months, among other things with regard to their consumption of institutional care, which is the issue to be addressed here. The results, comparing the number of days of institutional care between the intervention and control group during the 18 month period, are presented in table 4. The table presents figures for institutional care in total, and separate figures for the different types of institutions. Sex differences are also indicated.

Table 4. Average number of days of institutional care in an 18 month period for the intervention group (IG) and the control group (CG) according to sex and type of institutions, for a sample of people aged 80+ in Oslo 1980

| | All insti- tutions | Somatic hospitals | Nursing homes | Residen- tial homes | Other in- stitutions |
|---------------|-----------------------|----------------------|------------------|------------------------|-------------------------|
| interv.group | 39.8 | 20.6 | 10.8 | 5.0 | 3.4 |
| control group | 50.5 | 24.6 | 17.7 | 5.4 | 1.7 |
| IG-CG, total | - 10.7 | - 4.0 | - 6.9 | - 0.4 | + 1.7 |
| women | - 15.8 | - 5.9 | - 9.2 | - 1.0 | + 0.3 |
| men | + 3.4 | + 1.0 | + 0.5 | + 1.2 | + 1.6 |

(Source: Rø, 1983)

The intervention group spent an average of 39.8 days in institutional care during the 18 month period, 10.7 days (21%) less than the control group. Note that this is only the case for women, while the men in the intervention group consumed **more** institutional care than the men in the control group did!

The fewer days of institutional care for the intervention group (in total) is judged by the project team as resulting from the intervention process.

Let us accept this conclusion without further scrutiny for the moment. What, then, is gained, or rather saved, in terms of institu-

tional care and public expenses by such an effort in outside care? Savings for the cases of somatic nursing homes and somatic hospitals, which are the two major settings (see table 4), are presented in table 5, calculated over a **one year period**:

Table 5. Estimated savings in days of institutional care and net working expenses for a one year period for hospitals and nursing homes. Comparison of intervention and control group

| | hospitals | | nursing homes | |
|-----------------|-----------------|----------------------|-----------------|----------------------|
| | days in instit. | net working expenses | days in instit. | net working expenses |
| interv.group | 4,843 | 4,368,882 | 2,018 | 605,535 |
| control group | 5,909 | 5,320,357 | 4,241 | 1,272,390 |
| control interv. | 1,066 | 951,475 | 2,223 | 666,855 |

(Source: Rø, 1983)

The results seem impressive at first sight. The estimated savings are 1,066 days in hospitals and 2,223 days in nursing homes, a total calculation of 1.6 million Norwegian kroner on a one year basis.

However, this 'gain' constitutes no more than $(1,066/365 =)$ 3 hospital beds and 6 nursing home beds a year. It may be added that the days saved in hospitals did not reach significant levels (i.e. the difference between the intervention and control group was not significant). One might also question to what extent the difference between the groups as regards nursing home stay, was in fact significant, as one study included refusals (non-participants) in the intervention group, and the refusals (which were originally sampled for the intervention group) had a particularly low consumption of institutional care.

If we still assume that these are actual gains due to the intervention, these savings of cost in institutional care must be compared to the cost of the intervention in outside care:

The intervention group ($n = 456$) constituted about $1/31$ of the population over age 80 living at home in Oslo. One might gain a total of $(6 \times 31 =)$ 186 nursing home places in Oslo, a number which represents 3.7% of all nursing home beds in the city. In order to

achieve this, one would need, and pay for 31 intervention teams like the one behind this particular project, i.e. one would need 31 medical practitioners, 31 nurses, 31 social workers plus assisting staff. Even though one could probably manage with a smaller staff if the arrangement was properly organized and if one might use all resources in the intervention, not only research, there still seems to be vast effort needed in order to produce rather modest savings in the institutional sector. Another way to illustrate this is by looking at the relative coverage of nursing homes, which for in the case of Oslo is 5.5 beds per 100 of the population aged 65 and older (4.4 for the country in total - see p. 94). The saving of 186 beds through interventions like this in all parts of Oslo would imply that one could lower the coverage only by 0.2, from 5.5 to 5.3.

Besides, this would probably be only a theoretical saving as the need for institutional care seems to be far higher than that which is provided. Close to 2,200 old people were at that time (1980) on waiting-lists for admission to nursing homes, and another 2,000 were on waiting-lists for residential homes. Although not all of them are judged to be in acute need of institutional care, any place saved through interventions in outside care, would immediately be replaced by someone from the waiting-lists.

An even more pessimistic, or rather realistic, conclusion is reached when we carefully scrutinize the basis for the intervention team's own evaluation of the effects. Strictly speaking one has merely observed the difference between the control group and the intervention group, a difference which might have been there from the start of the intervention period. However, the two groups were carefully matched with regard to background information like sex and age, which probably rules out the reason for doubts concerning their conclusions. But as they could not follow a before-after design for ethical reasons, measuring **the change** produced by the intervention process, means that the conclusions may still be questioned on these grounds.

A more serious objection may be raised on the basis of possible effects of the ideology and policy of the intervention team itself. They started out to reduce the institutionalization rate. As they did not formulate and design an **impact model** in which hypothesis of cause and effect of specific actions were delineated (cfr. Estes and Freeman, 1976), their results may, at least partly, be produced by their stated intentions. Needless to say, intervention projects can

hardly ever be carried out as carefully designed experiments, but the current study's general relevance is weakened by the inadequate control of many of the elements involved, which makes it hard to judge which action produces which result. Part of the problem is the multiple goals of the project and the multiple effects which must be measured, of which consumption of institutional care is only one.

A possible bias in the results produced by wishful actions on behalf of the intervention team itself, is partly admitted when they point out in the report that they were restricted as regards hospital admissions, but were keen to prevent long hospital stays for the intervention group. They justified this aspect by stating that they, through a more careful examination of the patient's total life situation than is usual, adopted a more correct practice than is normally the case. On this basis they also 'explain' the difference between men and women: if the team's intervention produced a correct institutionalization rate, then the **lower** institutionalization rate for women after the intervention, plus the **higher** rate for men (see table 4), means that old women in **general** must have too high, and old men too low, institutionalization rates in Oslo!

This is a type of self-verification reasoning which conceals that which the intervention team regards as a correct institutionalization rate and also implies certain attitudes and values concerning the family responsibilities in care. A lower institutionalization rate in the intervention group may have been produced by increasing family efforts in care, which in fact is admitted indirectly by the team's stating that more disabled old people were kept and cared for at home in the intervention group than in the control group at the end of the intervention period. This may, of course, be according to the families' own wishes, as they may have found it possible to provide care for their impaired elderly when they have the additional support of an intervention team. However, the possibility should not be overlooked, that they felt forced to take on more care burdens than they preferred because of the intervention team's restrictive practice regarding institutionalization. A moral issue is also involved: what happens after the project has ended and the families no longer have the practical and moral support from the intervention team?

Another critical point to be raised is that the intervention team applied for admission to institutions for some people in the intervention group who were **not** admitted to institutional care because of

the shortage of institutions in Oslo. Hence, the institutionalization rate in the intervention group was lower than the team itself judged as necessary.

Thus there are several reasons why one might question the conclusion that this intervention in outside care **produced** a lower institutionalization rate. In summary, judging from experimental study in intervention:

1. there seem to be minor economic savings gained by increased efforts in outside care,
2. savings will only be effective if the care provided for institutional care are close to coverage, and
3. significant savings in the institutional sector implies that efforts and responsibilities are delegated to the family care providers.

Interventions in outside care may also prove expensive, as one might uncover unfulfilled requirements and thus contribute to increased consumption of both outside and institutional care services, if they are available.

5. AN ALTERNATIVE APPROACH

The search for alternatives to institutional care is motivated by the discontentment over the traditional public care system, the wish to reduce public expenses, and the wish for a better care system and a better life for the elderly. The data and studies presented illustrate that there are no easy solutions to these problems. Will efforts in outside care provide alternatives to institutionalization on an aggregate level, without just escaping the responsibilities or lowering the standards. It is imperative that firstly an adequate baseline is established in the institutional sector. This calls for a realistic, not a pessimistic, attitude to the care of the elderly. It should not prevent us from looking for alternatives to institutional care. An individual elderly person may be helped and gain a better quality of life through outside care which may prevent his or her premature institutionalization. Families may also be willing and able to provide care for their impaired elderly family members, if and when, they are properly supported by provisions in outside care.

However, the issue of alternatives to institutional care is obscured by unclear conceptualizations. The discontentment with institutional

care, both in terms of the cost and the quality, is transferred to a discontentment with public and professional care. Thus alternatives to institutional care are often conceived as private, i.e. family, care. But a lot of impaired elderly people are already cared for at home, mostly by partners (wives), children (daughters), and to some extent siblings. Shanas (1979) reports that the frail and bedridden aged cared for at home in the United States outnumbered the institutionalized elderly by two to one in 1975. The higher institutionalization rate in Norway probably implies a lower, but still considerable, proportion of family care (Daatland, in press). This informal care is 'the black box' we manipulate if and when we do not provide sufficient capacity through public efforts. It is only possible to achieve significant savings in public expences by letting the black box grow. This situation creates a moral dilemma: on what basis and, to what extent is a policy justified which shifts burdens and lack of welfare from one group to another? It may not even be possible, as the vast growth in the number of old people, and the changing family and work patterns, reduce the family capacity for care compared to the situation two or three decades ago (Sundström, 1983).

There are, however, other alternatives, although they may not seem as financially rewarding for the public economy in the short-term perspective.

Alternative actions in the care of the aged involves several dimensions, of which two of the more important concern:

1. **the type of care** (institutional or outside), and
2. **the responsibility for care provision** (public or private).

These two dimensions are wrongly considered as one whole like sometimes occurs when the alternative to our present type of institutional care is considered as outside care in a family setting.

Old people with merely moderate needs of care and support will probably be able to stay in their own home longer than they often do today, provided their capacity for self-care, both in terms of managing their daily chores and their feelings of insecurity are properly supported through a combination of support and help from family, network and the public care systems. Such efforts will probably not be sufficient for the growing number of old people with severe, or heavy, care requirements, and among them the fast growing number of mentally demented elderly. The most viable alternative to our present institutions for this group, is to introduce the qualities of outside care into institutional-like settings, **and** at the same time retain the public responsibility for care provision. There

are already experiments in this direction, f.i. in Eindhoven and Emmen in the Netherlands, where ordinary houses in the community are being used for accommodation and care for senile demented patients. Such houses are 'semi-institutions', and provide not only care, but also a home, for the few patients living there. The houses are properly staffed for this kind of work and responsibility, involving a staff of about the same number as the number of patients. Thus by avoiding the institutional character of the setting, household members (the patients) are offered a more normal, and probably also a better quality of life. The public will also be rewarded by somewhat lower expenses than those for traditional institutional care.

Equally important is that this more informal structure may lower the barriers between 'the institution', the patient and the family. The traditional institution takes over, or substitutes, the family's and the patient's responsibilities in such a way as to often prevent cooperation. The patient's capacity for self-care is often counteracted, making him more helpless than necessary. The family, willingly or not, can find no 'natural' way of contributing to the care. This is a form of **competing** substitution which must be replaced by a **relieving** form of substitution, in which the three parties are made able to interact in a cooperative and complementing fashion (Daatland, 1983).

It is not clear just who and how many of the elderly with severe needs of care may receive adequate assistance through this kind of alternative service. However, improvements can be realized within the present limit of resources, i.e. through a radical revision of the institutional sector. The public responsibility and efforts in the institutional care sector should not be reduced. This would imply a poorer quality of life for the aged and their families and a lower standard of care in general. What is called for, in order to reach a better and relatively cheaper form of care, is not a reduction in the public's responsibility towards care, but serious evaluation and revision of the way in which we presently manage this responsibility.

Notes

1. The clients/patients contribute to the financing of the institutions. Their contribution amounts to 20-30% of the cost of residential home accommodation and is somewhat lower for nursing home accommodation.

2. The relatively higher growth of expence compared to care units is even more evident in Denmark: between 1972 and 1980 the number of institutional beds increased by 17%, while the number of employees increased by 61% (Jørgensen, 1983).

3. The 'relative coverage' is a theoretical construction which shows the percentage of the relevant age group which might have been institutionalized **if** the institutions were reserved for this age group. As some of the institutionalized will be under the age of 65 and 80, respectively, the relative coverage will provide us with a figure which is higher than the percentage actually living in institutions (the institutionalization rate).

4. The waiting-list for nursing home care in Oslo has approximately 2,200 names, which represents an additional 40% of those already living in nursing homes. Not all the patients on the waiting-list are in acute need of nursing home care, but the list is recorded and approved by the local authorities and is based on the social and medical reports of each client.

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VII. Extended home care for the elderly: some Danish experiences

Björn Evald Holstein, Gert Almind

1. INTRODUCTION

This chapter discusses two innovative approaches to extended home care for the elderly: First acute home care to meet acute needs and secondly the 24-hour home care service to meet long-term needs for extended care. The last innovation can be seen as an extension to nursing home services in the private homes of the elderly. The objective is to prevent or delay institutionalization into nursing homes for identified groups of seriously disabled or chronically ill elderly.

The acute care nursing is an extension of some of the functions of both hospitals and primary care systems, i.e. the capacity to deal with acute health problems. This service is directed towards a group of elderly with health problems not necessarily known to the health care providers prior to the acute episode. The objective is to achieve earlier diagnosis and intervention in order to prevent unnecessary disability and institutionalization.

Both these innovations are examples of tertiary prevention but they intend to deal with different types of problems and different groups of the elderly. The 24-hour home care service is organized mainly to deal with needs for long-term care. It is, then, directed towards known or well defined **risk groups**. The acute care nursing, on the other hand, deals with the need to cope efficiently with acute illness or acute problems. This service is not directed towards known groups of the elderly but towards **risk situations** in the total population of elderly. The rationale of dealing with risk situations is described in paragraph 2.

These services can be organized in many ways, based in institutions (hospitals, nursing homes), or in the community (in connection with home care services). Community-based demonstration projects from Denmark regarding these services are evaluated by research investigations. The results are presented in paragraphs 4 and 5.

2. RISK GROUPS AND RISK SITUATIONS

The prevalence of physical, mental, and social problems is high in elderly populations. This is documented as 'known' illness (diagnosed by the health care system) as well as undetected illness (by the health care system). Screening procedures among the elderly usually identify vast amounts of symptomatic but undetected problems (Svane, 1972; Almind et.al., 1983). It is, almost contradictory to these findings, also documented that most elderly living in their own home are generally well-functioning and 'unproblematic' regarding health and social conditions (Almind et.al., 1979; Agner et.al., 1980; Hickey, 1981; Platz, 1981).

One question frequently asked by health planners and researchers during the last decade, is whether screening programmes to define and detect risk groups of elderly followed up by individual intervention are beneficial to the elderly. The answer seems to be that screening does not provide an efficient basis for the identification of problems. Taylor, Ford and Barber (1983), in their study from Aberdeen based on a random sample of 619 people older than 65 years and conducted in 1980, defined a number of groups of the population at risk for illness, breakdown, and institutionalization. These groups are shown in table 1.

Table 1. Risk groups defined in a population older than 65 years in the city of Aberdeen. Percentage, N = 619

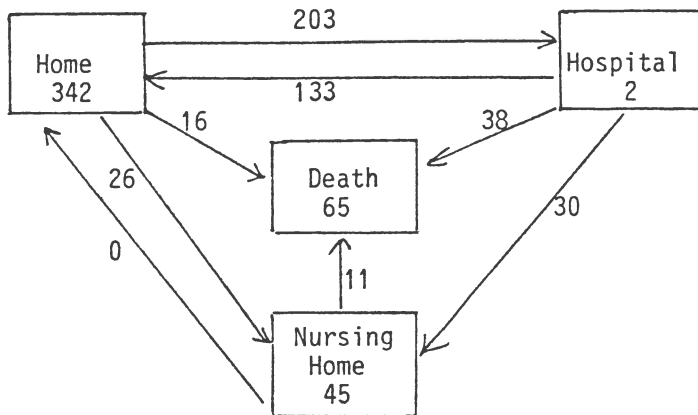
| Group | Percent |
|-------------------------------------|---------|
| Very old, over 80 years | 14 |
| Recently discharged from hospital | 13 |
| Minimum income | 15 |
| Living alone | 35 |
| Childless | 20 |
| Single | 11 |
| Isolated | 9 |
| Recently moved (change of dwelling) | 14 |
| Social class V | 8 |
| Divorced/separated | 4 |
| Recently widowed | 8 |

This study demonstrates that these groups, generally speaking, rated low in terms of health, psychological functioning, confidence, activities, support, and material well-being. At the same time these

groups only account for a relatively small proportion of the total number of cases of poor health and psychological functioning etc. Most cases of poor health and functioning are recruited from non-risk groups. Therefore, despite the significant association between being at risk and being a 'case of poor health or functioning' this association is of low practical or clinical relevance to the providers of health and social services: They know that some minor groups of the elderly population are at risk and do cause a high demand on service provision. But they also know that most of their cases are recruited from non risk-groups of the population.

Almind and his associates described health conditions, functional capacities, and social welfare among the very old (over 80 years) in Holbaek, a Danish community (4). Almost the total population of very old, 454 persons, living in private homes, were visited and interviewed. A follow-up investigation two years later describes the movements into and out of home, hospital, and nursing home (Almind), see figure 1. Movements from nursing home to hospital were not registered.

Figure 1. Movements among 454 very old citizens of Holbaek in the two year period 1977-1979. Absolute numbers



About 75% (342 persons) remained at home at the end of the two year period, less than 1% were in hospitals, 10% in nursing homes, and 14% had died. 143 people experienced a total of 203 admissions to hospital and 62 of these people were still living at home at the time of the follow-up study. Of the old people still living at home, 280 had avoided hospitalization during that period.

By combining the base-line data from 1977 with the data on death and institutionalization during the two-year observation period, Almind was able to determine risk factors for death and institutionalization. Data on some of these self-reported risk factors are provided in table 2.

Table 2. Risk factors and outcomes for 454 people over 80 years of age living in Holbaek

| Risk factors in 1977 | Per cent with each outcome 1977-1979 | | |
|---|--------------------------------------|------------------|------------------|
| | Hospitalized | In nursing home | Dead |
| Reduced functional capacity (N=108) | 46*** | 23*** | 22* |
| Daily use of more than six medicines (N=89) | 43*** | 15 ^{NS} | 23* |
| Home help and/or district nurse (N=212) | 40*** | 20*** | 17 ^{NS} |
| Poor memory (N=80) | 47*** | 24** | 19 ^{NS} |
| Shortness of breath (N=100) | 40* | 11 ^{NS} | 22* |
| Stomachaches (N=50) | 44* | 22* | 28* |
| Headaches (N=34) | 38 ^{NS} | 24* | 12 ^{NS} |
| One or more health complaints (N=119) | 34* | 13 ^{NS} | 17* |
| Per centage of all 454 old people | 32 | 12 | 14 |

NS = no significance, * indicates p 0,05, ** p 0,01, and *** p 0,001 by chi square test

Although it was possible to identify risk factors in this study

Almind concluded that the risk factor approach was of little practical and clinical relevance: most people with these risk factors, even with many risk factors in combination, stayed in their own homes throughout the whole period. Moreover, most cases of death and institutionalization took place in groups without these risk factors. Last but not least, the majority of the risk groups had frequent contact with providers of health and social services and were, thus, under surveillance. Almind therefore suggests that intensified intervention in known risk groups might be a waste of resources. A change in focus from risk groups to risk situations might be a more beneficial way of intensifying intervention in the Danish elderly population.

This change in focus is illustrated in paragraph 4. Paragraph 5 (which is about 24-hour home care service) demonstrates a special case of the risk group approach, discussing alternative services for elderly who qualify for nursing home admission.

3. THE DANISH SETTING

14% of the 5.1 million inhabitants of Denmark are over 65 years and about one third of these are over 80 years. The health and social services of the elderly are based on three basic policies:

1. the old-age pension,
2. the housing policy,
3. comprehensive and free health care and social services, organized and financed by the local and regional authorities.

1. Old-age pension is received by every citizen over 67 years of age (in some cases from the age of 55). The monthly amount is approximately (December 1983) \$ 320 with some reduction if alternative incomes exist.
2. The housing policy is based on the principle that elderly should have the opportunity to stay in their own home for as long as they wish and can. The rent is subsidized, so that an old age pensioner without additional incomes pays no more than 15% of the pension for housing facilities of fair size and standard. 7% of the pensioners live in nursing homes and 5% live in service flats.
3. Medical treatment in hospitals, general practice and home nursing is free of charge. The General Practitioner is a key person in the health care system regulating admission to hospitals and consultation of specialists. Emergency physicians are available

during the night free of charge. Dental care, physiotherapy, and medicine are subsidized significantly for pensioners without additional incomes. Aids for the disabled are free of charge. Home help is free of charge for pensioners without additional incomes and subsidized even for more wealthy pensioners if the need is extensive. Hobby-, leisuretime-, recreational- and educational activities are subsidized too and available at low cost.

Hospitals and general practice are administrated and financed by the county authorities whereas pensions, home care and nursing home services are administrated and financed at the local (municipal) level. This decentralized structure of planning, financing and administering services causes a considerable amount of poor coordination. It also procudes a significant variation in the amount and standard of services for the elderly across the nation. Moreover, innovative initiatives in care of the elderly are based on local entrepreneurship. The principles described in points 1-3 above are the core of the national regulations regarding the welfare of the elderly (The elderly commission, 1982).

4. ACUTE-CARE NURSING

The project - background and objectives

Based on the rationale that efficient support in risk situations can often prevent acute breakdown and institutionalization, a research and demonstration project was launched in Holbaek, Denmark, in 1981. Holbaek is a community with 30,000 inhabitants of which 20,000 live in a city, the rest live in rural settings. 11% of the population is older than 70 years of age. The welfare and health services for the elderly probably rate about average for Denmark, perhaps slightly above average. In the city there is a regional hospital with approximately 400 beds. There are 18 General Practitioners, and, mainly for care of the elderly, 13 community nurses and 150 home helpers. 250 elderly, almost all over 70 years of age, live in nursing homes and 150 live in service flats. No elderly people stay in hospital beds after completion of medical treatment.

The objectives of the project are:

1. to describe the course of illness in three types of risk situations: acute illness, discharge from hospital, and being on the waiting-list for hospital admission,
2. to intervene in the content and organization of service provision

on the basis of the research findings,

3. to evaluate the benefits of these interventions (Almind et al 1983).

The research investigation analyzes the support provided by and the interaction between

1. General Practitioners,
2. home care providers (nurses, home helpers, etc.),
3. hospitals,
4. informal social support networks, and
5. self-care activities of the elderly.

These supports are analyzed in relation to the needs and desires of the elderly. The central hypothesis of the project is that it is possible, without additional costs, to improve the care for the elderly by changes in the provision of services and by strengthening the interaction and coordination between the various sources of support.

The project is organized in three parts along with the three types of risk situations,

- A. acutely ill over 75 years of age living in private homes,
- B. elderly over 70 years of age discharged from hospital to their own homes, and
- C. elderly over 70 years of age on waiting-lists for hospital admission.

The elderly in project A and B were interviewed as soon as they were recorded/discharged and were reinterviewed after two weeks. Individual intervention was introduced if needed and desired, immediately after the first interview. The elderly in project C were interviewed every second week until admission, at discharge, and two weeks after discharge. Table 3 shows the number of respondents. 99.5% of the

Table 3. Elderly in risk situations interviewed in Holbaek 1981-84

| Project | Period 1 (before intervention of the community) | Period 2 (after intervention of the community) | Total |
|---------------------------------|---|--|-------|
| A (acutely ill) | 157 | 117 | 264 |
| B (discharged from hospital) | 111 | 106 | 219 |
| C (waiting-list) | - | 50 | 50 |
| Total | 268 | 263 | 533 |

reported people were interviewed, and 88% were reinterviewed two weeks later.

This chapter discusses some of the data from project A and B (N = 483). The data on social networks, self care, psychological coping with illness and interaction with providers of help and services are not reported here.

Monitoring elderly in risk situations

In order to discover the cases and then define the population in the research- and demonstration project three recording systems were established:

1. All professionals working with the elderly (physicians, community nurses, home helpers) were asked to report acutely ill elderly aged 75 or older to the community-nursing unit of the municipal. This opportunity for reporting acute illness was even taken advantage of by some elderly or their relatives. Acute illness was defined as new confinement to bed for more than two days due to acute or chronic disorders or acute reduction of functional capacity.
2. All patients aged 70 years or older discharged from the Holbaek Central Hospital to their own homes were reported to the home-nursing unit. Such communication is not usual in Denmark.
3. All patients aged 70 years or older on a waiting-list for hospital-based medical treatment were reported to the community-nursing unit by their General Practitioners.

The average number of cases reported monthly were 17 cases of acute illness, 14 discharges, and 4 additions to a waiting-list. The recording of discharged patients and waiting-list patients is believed to be complete, whereas the reporting of acute illness is probably not complete. Some causes for non-reporting could be:

- that some elderly become acutely ill without having any contact with professional providers of health or social services to report the illness,
- that the providers of services are often uncertain as to whether cases should be reported,
- that it is sometimes easier not to report the case,
- that some care providers disagreed with the idea of reporting acutely ill elderly.

The actual completeness of the reported cases is unknown. However,

based on an experiment with open admission to acute care for the elderly themselves in a residential area, resulting in no admissions at all, it is believed that the reporting is fairly complete. Table 4 indicates the number of reported cases.

Table 4. Number of reported cases and proportion of the elderly

| Age group | Number in own homes | Acutely ill* | | Discharged* | |
|-----------|---------------------|--------------|-----------|-------------|-----------|
| | | N | % of pop. | N | % of pop. |
| 70-74 | 873 | - | - | 62 | 7.1 |
| 75-79 | 791 | 118 | 15.0 | 81 | 10.2 |
| 80+ | 693 | 146 | 23.3 | 76 | 10.9 |
| Total | 2,357 | 264 | 16.7 | 219 | 9.3 |

*) During a sixteen-month period

The organization of acute care

The acute care nursing was organized from the community-nursing unit. A research nurse with several years of experience in community nursing conducted all visits, interviewed the elderly and initiated individual intervention when needed.

The acute care nursing was from the beginning not intended to be a permanent service for the elderly, but a tool for data collection. It became, however, a permanent service when the practical outcome of the first period of data collection showed its perceived and obvious benefits to the elderly.

The objectives of the acute care nursing are indicated by the task description.

1. The task is usually to perform **one or two visits** to acutely ill and recently discharged old-age pensioners.
2. During the visit the nurse will assess the needs of the elderly person and offer adequate help and support.
3. The assessment of needs must include functional capacity and well-being and should be based on the nurses professional assessment as well as the elderly's subjective assessment.
4. The care provider must then perform nursing care requirements, give health education, information on any relevant service available, and organize services needed by the pensioner (e.g. home help aids, and meals-on-wheels).

5. After the visit she should report adequate information to relevant providers of health and social services regarding her reassessment of the pensioners needs. A few days later she should check whether the required help, support and care are being provided.

This function, of course, challenges the coordination and flexibility of the provision of services from the health care system and the social welfare system.

The task is performed by one full-time district nurse. In weekends and evenings the functions are taken over by the nurse actually on duty. Since this service became permanent in October 1982 the average number of elderly visited per month is 54.

The clientele and their needs

The general health status (i.e. before the actual problem) of the patients is described by means of a self-rated health status, by ADL index and by the capacity to communicate. 21% of the population assessed their general health as excellent, 28% good, 39% fair, and 12% poor. 27% of the population had no problems with seven specific daily activities; 40% had problems but managed without help; 33% needed varying amounts of help. Moreover 27% suffered varying degrees of sight impairment, 32% hearing impairment, and 16% memory impairment. The patient populations were heavy consumers of health and social services: 73% had home help, 27% home nursing, 55% handicap-compensating aids, and 72% had been in contact with their general practitioner during the last month. Despite this extended contact with providers of services heavy additional needs were discovered.

The causes for reporting acute illness were recorded as the elderly persons' subjective description of the problem. This type of data illustrate a typical pattern of symptoms and signs of illness in an elderly population, dominated by a multitude of more or less well-defined problems. These data reflect the difficulties in distinguishing the acute problems from the aggravated chronic conditions, and the difficulties in distinguishing illness from the weakening and additional needs in general. Some categorization of the subjective problems are indicated in table 5.

Table 5. Indicated, subjective problems among acutely ill elderly and recently discharged elderly, %

| | Acutely ill | Recently discharged |
|--|-------------|---------------------|
| Acute or chronic | | |
| Acute illness or loss of functional capacity | 63 | 61 |
| Aggravation of chronic condition | 43 | 41 |
| Symptoms | | |
| Pain | 74 | 82 |
| Reduced mobility | 73 | 63 |
| Fatigue | 22 | 15 |
| Anxiety, nervousness | 5 | 4 |
| Dizziness | 20 | 6 |
| Incontinence | 8 | 3 |
| Fever | 21 | 20 |
| System | | |
| Cardiovascular | 12 | 16 |
| Respiratory | 35 | 19 |
| Digestive | 13 | 16 |
| Sensory | 18 | 2 |
| Fractures | 1 | 9 |
| In/Out of bed | | |
| Confined to bed all day | 18 | 5 |
| Out of bed all day | 58 | 89 |
| Alternately in bed/out of bed | 24 | 7 |

An alternative description of the acute needs is the description of the individual intervention decided on at the home nurse's visit. Intervention was needed in 61% of the cases among the acutely ill elderly and in 51% of the discharge cases. The intervention was based on the community nurses' assessment as well as the respondents evaluation of required help and support. Table 6 indicates the type and number. These interventions ranged from minor adjustments to the services provided or making contact with a relative, to major efforts in restoring the total living situation of an elderly person with extended needs for care. In many cases the interview and the individual intervention required almost a full days work. At the follow-up visit two weeks later it sometimes appeared that necessary

interventions had not been put into practice, sometimes because of subsequent hospitalization, sometimes because of lack of organizational flexibility and capacity.

Table 6. Acute individual intervention in 486 visits to acutely ill and recently discharged elderly, %

| Intervention | Acutely ill elderly | | Recently discharged | |
|---|---------------------|---------------------|---------------------|---------------------|
| | % need | % put into practice | % need | % put into practice |
| Acute care (Additional) home help service | 13 | 13 | 19 | 19 |
| Regular home nursing | 28 | 20 | 16 | 9 |
| Handicap compensating aids | 11 | 8 | 8 | 7 |
| Contact with general practitioner | 19 | 12 | 13 | 11 |
| Contact with others | 14 | 9 | 14 | 12 |
| Other forms of intervention | 21 | 14 | 15 | 13 |
| | 9 | 4 | 6 | 4 |

Evaluation

The project was planned without a control group because of ethical considerations: no elderly person included in the study who was in acute need of help would be denied the help needed. Objective data on waiting-lists, institutionalization, consumption of health care services, and even mortality, are in principle available but not used here.

The evaluation is based on three sets of data:

1. whether or not necessary interventions were actually put into practice (data given in table 6),
2. the elderly's subjective assessment of the benefits of these interventions, and
3. the research nurses' assessment of the services provided.

Follow-up data were recorded two weeks later from 88% of the respondents visited and re-interviewed at this point in time. They answered questions concerning actual condition, recovery, received and needed services, etc. By that time 20% said that the acute problem was over, 47% said that their condition had improved, 27% were

unchanged, and 6% said that their condition had become worse. Table 7 indicates some key results from this visit two weeks later.

Table 7. Patient description and evaluation of provision of help and support in relation to acute illness

| Source of support | % receiving this support | % of receivers receiving it within 2 days | % of receivers finding it helpful | % of the total group missing this support |
|--|--------------------------|---|-----------------------------------|---|
| General practitioner | 57 | 16 | 37 | 8 |
| Additional community nursing | 22 | 84 | 78 | 0 |
| Additional home help | 22 | 69 | 82 | 11 |
| Other services* | 21 | 69 | 67 | 6 |
| Additional help from informal social support network | 49 | 59 | 95 | 5 |

*) Incl. handicap-compensating aids, physiotherapy, pedicure, welfare visit, meals-on-wheels, etc.

As an additional evaluation the research nurse has made her own assessment of:

1. the general provision of help in relation to the needs of the elderly, and
2. the aggregate effect of the various forms of help and support.

These evaluations are indicated in tables 8 and 9. Although these data are based on intense and extended interviewing by a skillful nurse, they are also of a subjective value. Despite their 'soft' nature these data seem to be important; they are significantly and strongly associated with other main variables in the investigation. Adequate help is associated with: active self-care; active psychological coping with the illness episode; autonomy and internal locus of control; supportive social network; positive self-assessed health; functional ability of above average.

Table 8. The nurses' evaluation of the general provision of help in relation to needs, %

| | First visit % | Second visit % |
|---|------------------|-------------------|
| Too much help provided | 5 | 9 |
| Sufficient help in relation to needs | 61 | 76 |
| Inadequate help | 34 | 16 |
| Total | 100 | 101 |

Table 9. The nurses' evaluation of the aggregate effect of the various forms of help and support, %

| Aggregate effect of total help | First visit % | Second visit % |
|------------------------------------|------------------|-------------------|
| Improving functional capacity | 51 | 71 |
| Maintaining functional capacity | 30 | 20 |
| Aggravating functional capacity | 20 | 9 |
| Total | 101 | 100 |

Table 8 indicates that the general provision of help (not necessarily related to the acute problem) becomes better adjusted to the needs of the elderly person after the individual intervention, although there seems to be a tendency to give too much help. Table 9 shows that the aggregate effect of several forms of help might not be beneficial to the functional capacity of the older person. This might happen for instance when an old person receives so much home help that there is no incentive to stay fit; or when the General Practitioner and the relatives give contradicting advice; or when various providers of services try to accomplish contradictory treatment programmes.

5. TWENTY-FOUR HOUR HOME CARE SERVICES

As indicated in paragraph 3 the local administration in Denmark organizes home care for elderly and disabled persons. These services include community nurses, home helpers, handicap-compensating aids, and in most communities also meals-on-wheels, physiotherapy and a variety of other services. Several Danish local administrations (municipalities) have introduced various forms of 24-hour-alert home care services during the last five or six years. The services are aimed at supporting old people with extended needs for care in their own homes for as long as possible, thus reducing the need for nursing homes. Because of the local autonomy in organizing home care services these innovative services vary considerably from one community to another. The factors on which they vary are:

- whether they include service all around the clock, or only home care extending into the evening hours (e.g. 7 a.m. to 11 p.m.),
- whether they are based on home helper, community nurses, or both groups,
- whether they are 'closed systems' requiring medical assessment on entry, or 'open systems', in principle open to everybody in need, without previous assessment.

Moreover, major variations are seen in the practical arrangements regarding transportation, calling-in, and staffing. One uniform characteristic is that this service is always based in the municipal community nursing organization and is thus outside the hospital system. The 24-hour services in several cities and local communities are presently being evaluated, e.g. Viborg, Naestved, Aabenraa, Copenhagen and Frederiksberg. Data regarding Viborg and Naestved are now available.

The organization of 24-hour home care service

Viborg is 25% larger than Holbaek (population of 38,000) and very similar regarding demographic characteristics and provision of services for the elderly. In 1978 the 24-hour home care service was established. The objectives are (Hansen et.al., 1984):

- to improve well-being and security by providing 24-hour care in ones own environment,
- to necessitate old peoples wishes regarding staying in their own home,
- to relieve the pressure on institutions,
- to reduce the expense of building institutions for the elderly.

The basic elements of this service is **staffing** (2 nurses and 2 home helpers in the evening hours, 1 nurse and 1 home helper during the night) and a coordinator calling in the staff. The system is open to new (acute) admission during the night.

Naestved is a community of 45,000 inhabitants, with a demographic and service-provision structure rather similar to that of Holbaek and Viborg. The 24-hour service was introduced in 1982. The staffing consists of: 2 nurses and 9 home helpers in the evening hours, 1 nurse and 2 home helpers during the night. The system is open to new (acute) patients during the night. The objectives are to increase the opportunity for elderly people to stay in their own home, to increase the well-being of the elderly and to save the financial expenses of institutional care (Hansen et al., 1984).

The clientele and their needs

a) Viborg

During the first year 284 patients were admitted to the 24-hour home care service in Viborg and 595 patients in Naestved. The age distribution is presented in table 10 (Anderson, 1980).

Table 10. Age distribution of patients from the first year, Viborg and Naestved

| Age | Viborg % | Naestved % |
|-------|----------|------------|
| < 64 | 25 | 22 |
| 65-79 | 46 | 35 |
| > 80 | 29 | 43 |
| Total | 100 | 100 |
| N = | 284 | 595 |

The majority of these patients were visited at least once every evening/night in addition to the day visits over several months. More than 12,000 visits were carried out during the first year in Viborg, equaling 1,764 yearly visits per 1,000 people aged 60 years and older, or 43 visits per client. Of these visits 70% were carried out in the evenings, and 30% at night. 85% of the visits were planned, the rest were acute, primarily among patients already admitted to the system. The acute visits in Viborg were dominated by

the following types of service provided, calculated in relation to number of visits:

- general observation 40%
- injection 15%
- nursing care 13%
- change of clothes 8%
- colostomy 6%
- medication problems 7%

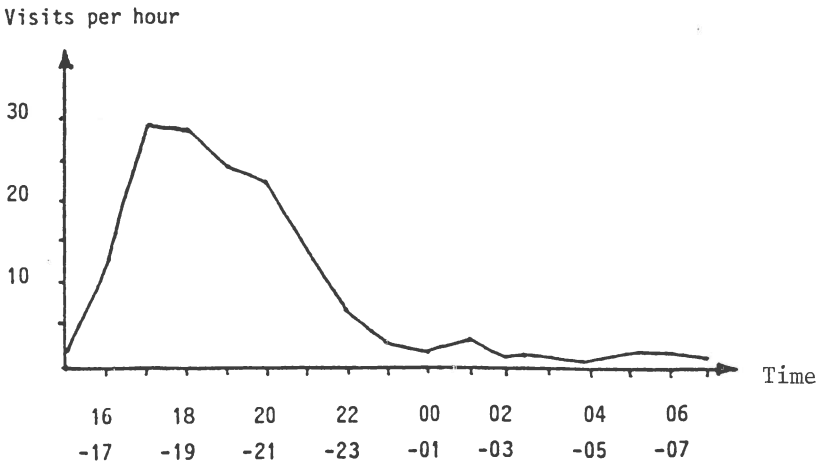
Similar data are not available for the planned visits.

A rough indication of the type of client is shown in the fact that 42 of the 284 patients died during the first year and 8 were admitted to a nursing home.

b) Naestved

During the first year of the 24-hour home care service in Naestved 595 patients received 51,000 visits during the evening hours and 4,000 visits during the night. The number of visits per year per 1,000 people aged 60 years and older was 6,296. The number of visits per client was 86. The vast majority of these visits, 97%, were planned, only 3 % were acute. Figure 2 indicates the activity (visits per hour) in an average evening and night.

Figure 2. Visits per hour in an average evening and night. Naestved 1982-83



Half the visits took less than 15 minutes, 40% took 15-30 minutes, and 10% more than 30 minutes. The main functions performed are shown in table 11.

Table 11. Main functions in planned and acute visits during the first year of the 24-hour home care service in Naestved (1983). Calculated in % of the total number of visits in evenings and nights

| | Planned visits | Acute visits |
|---|----------------|--------------|
| Observation | 32% | 20% |
| Medicine administration (incl. injection) | 38% | 12% |
| Changing clothes | 29% | 7% |
| Serve dinner | 20% | 1% |
| Helping into or out of bed | 23% | 8% |
| Colostomy and personal hygiene | 22% | 7% |
| Helping with visits to the lavatory | 13% | 7% |
| Conversation regarding illness | 4% | 7% |
| Care regarding ulcers and bedsores | 17% | 4% |
| N | 54,040 | 1,729 |

Evaluation

Evaluation regarding this type of home care service is in progress. The criteria for evaluation involved in the projects are the number of beds spared in institutions and other economic benefits. The evaluation, however, also includes measurements of the level of satisfaction among clients and staff members, and descriptions of resources and production. Some of the basic descriptive data has been presented earlier in this section.

The Viborg experiment was believed to have spared during the first year: 100 hospital admissions, 272 home visits by a physician at night, 85 nursing home beds, and 67 admissions to other institutions. The researchers evaluating the project, however, have expressed their scepticism over these calculations, claiming that the economizations are probably smaller. The final evidence is still

lacking (Anderson, 1980). The Viborg group also claims that a prerequisite for establishing such a system is a well-functioning home care organization.

The evaluation of the Naestved project is not yet complete. So far, however, the institute evaluating the programme claims that the fact that there has been an overwhelming increase in service provision, is an indication of a major need being fulfilled.

6. DISCUSSION

This paper discusses two extensions to the traditional Danish home care for the elderly:

1. an increased effort to detect acute illness/problems and introduce relevant individual intervention, and
2. a 24-hour home care service.

These services are not new. They can hardly be called innovations. The hospital system and the General Practitioner have for a long period of time, been dealing with acute and chronic problems in the health and care of the elderly. The innovative aspects are:

1. the new organizational setting for these services,
2. the direct association to the political objective of supporting old people in their own homes for as long as possible, and
3. the change of focus from diagnosis and illness, to functional capacity and well-being.

However, whether they may be called innovations or not, they fulfil an important uncovered need in strengthening the potentials of home-based care systems. The need for an acute community-nursing service has for some time been required by Danish physicians (Kirk and Dalgaard, 1980).

The main information gained from the project on intensified acute help for the elderly, can be summarized in four points:

1. Even in a community with a cost free and easily available, health care provision for the elderly, and even among the carefully monitored elderly, acute health problems are not necessarily dealt with in an adequate way.
2. A change in the approach of health services for the elderly, from risk groups to risk situations, may well result in a highly relevant and focused preventive action.
3. A significant proportion of the acute intervention can be organized in the primary health care system at a relatively low cost, compared to the total expenses for health care of the elderly. A prerequisite for this solution is a flexible and coordinated

collaboration between the various professional groups and authorities.

4. The data suggest that the services provided should be based on regularly repeated re-evaluation of needs.

The main information gained from the projects on 24-hour home care are:

1. A significant proportion of the elderly with an extended need for care, can be supported at home by a 24-hour home care service system. Nursing home beds can be spared but the magnitude of the economization is still unknown.
2. In communities with a 24-hour home care service, the bulk of the visits are carried out in the evening. The number of patients receiving personal help during the night is very small.

In an intermediate evaluation of this kind of service provision, the Danish National Board of Social Affairs concludes, on the basis of available experiences: that the reason for establishing night visits in small communities is limited. Home helpers on-call in the evening might prove to be sufficient. They also conclude that it is wise to start on a small scale and increase this service if necessary; it is important to organise this service provision in a very flexible manner in order to increase, as well as decrease, the number of visits as required.

The demonstration projects on 24-hour home care service show that it is possible to extend some nursing home and other institutional services into the homes of elderly at a relatively low cost. The need for such a service provision seems to be of a modest size, but if up-scaled, the number of visits with the function of 'observing' the patient, increases. Existing trials with this type of service indicate no major organizational or functional problems. This new service provision can easily be included in the primary health care sector. The practical organization of this function may vary significantly in several dimensions.

In the debate on elderly policy in Denmark, these services are now seen as natural components of a comprehensive system of health care services for the elderly. Given the specific health problems of the elderly, this emphasis on functional capacity, well-being and the importance of staying fit in old age seem to be an important supplement to medical treatment regimes. These innovations also challenge the local authorities and the professional groups providing health and social care. It is important that the results of this challenge

result in improved collaboration and flexibility.

However, it should be noted that we are still in need of solid empirical documentation on the benefits (and strains) of these forms of care. The data presented are far from being a sufficient basis for evaluation. Like most other demonstration projects these projects also seem to succeed in reaching their goals. Apart from this kind of documentation we need controlled studies, although it is often difficult to carry out studies for ethical reasons. Comparative studies involving communities with, and without, such services might act as a substitute for real controlled studies.

Also a number of more general questions need to be answered and elucidated. For instance we know almost nothing about the interaction between primary care, self care, and family care. We know very little about the ways in which these forms of care support or restrain each other, whether they compensate or are complementary to one another. One of the crucial problems is to determine the aggregate effect of simultaneous services. The effect of home care, plus family care, plus self care, plus medical treatment by the general practitioner, is not necessarily the sum of the effects of each of these services individually.

Another general question regards the societal prerequisites for successful extended home care, and the implications of these kinds of services. Are these services most efficient in affluent societies, with comprehensive health and social services available? Or are they even better suited to countries in which nursing homes and a comprehensive service system for the elderly are not yet developed? The implications for the professional providers of health care are not known, nor the consequences for the families and the elderly themselves.

It is very likely that extended home care is beneficial to some elderly but not to others. Which groups and which health problems should be dealt with in this way needs further clarification. Until these questions are answered the composition of services is partly based on trial and error.

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VIII. Family care of the impaired elderly: possibilities for innovations

Kees Knipscheer

1. INTRODUCTION

Important shifts in the care of the elderly are thought to be necessary in many European countries. These may be divided up into two categories of change: from intramural to extramural care, and from professional to informal care. For the Netherlands this means a fundamental change away from the policy of highly developed services for the elderly. This development entails an important increase in the number of tasks for the informal care support system of the elderly, especially in family care.

This chapter further deals with: modern changes in the nuclear and extended family, the most important recent research data concerning the problems associated with family care, new indications and trends, and finally, developments in the alternative forms of informal care. We will begin with a brief explanation of the Dutch situation regarding elderly people.

The Dutch situation

In some respects the Dutch situation differs strongly from that in other West European countries. One difference is the percentage of people of 65 years and older in the total population. This percentage is at present 11.8% (1983), whereas in most other European countries it is 1-3% higher. These differences are expected to be consistent until at least the year 2000. This special situation has been created by the high birth rate which showed a much earlier decrease in other countries. In the Netherlands this has only been the case since 1965. Consequently, not only is the percentage of people over 65 relatively low, but also the number of children (of the elderly) is higher than that of other countries. The latter facet would seem to offer great potential for family care of the elderly.

In the interpretation of this demographic situation it is especially striking that the percentage of elderly people living in intramural institutions in the Netherlands almost doubles that of the surrounding countries.

Table 1. Per centage of people aged 65 and older currently living in communal accommodation (excl. hospitals), ca. 1980

| | |
|-----------------------------|------|
| Belgium | 5.0 |
| Denmark | 7.9 |
| France | 5.0 |
| Greece | 1.0 |
| Ireland | 3.6 |
| Luxemburg | 4.7 |
| Netherlands | 14.5 |
| Federal Republic of Germany | 4.5 |
| United Kingdom | 5.0 |

Source: Collot et.al., 1982

Table 1 represents a simplified comparison of a number of countries. An exact comparison would be more complicated because of the often widely differing definitions of the terms 'home for the aged' and 'nursing home'. Nevertheless the data clearly demonstrate that intramural care of the elderly in the Netherlands is much more extensive than elsewhere, despite its demographically advantageous position for family care. We do not intend to try to explain this paradox. However, knowledge of the Dutch situation is absolutely essential in the consideration of the possibilities and limitations of family care. In a society where despite demographically advantageous conditions the phenomenon of institutional care is so extensive, alteration in policy may prove to be even more difficult than in other societies.

2. FROM INTRAMURAL AND PROFESSIONAL CARE TO INFORMAL CARE OF THE IMPAIRED ELDERLY

The 'impaired elderly' are defined as those who, over a prolonged period of time, are seriously handicapped in their capacities of running an independent household. Three levels can be differentiated here.

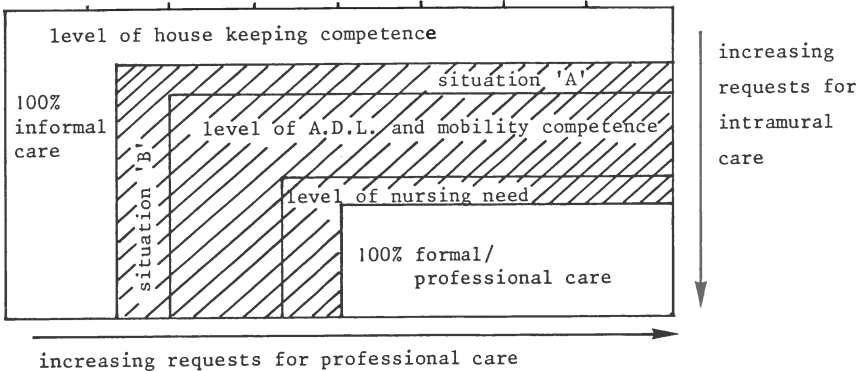
The first is housekeeping competence, i.e. to what extent is one still able to: prepare meals, clean the house, do the laundry, make beds, etc.

The second level is ADL and mobility characteristics, i.e. is the elderly person able to: dress and undress, wash him/herself, eat, use the lavatory, walk in and around the house, climb stairs?

The third level deals with nursing requirements. These may vary from proper washing/bathing, caring for wounds, giving injections, providing help in the use of aids for particular handicaps, to daily nursing, food and care.

There is usually some overlap in these levels of care requirements. As the housekeeping competence decreases, the chances of an impoverished ADL and mobility increases, resulting in the necessity for nursing care. These overlapping levels of impairment are represented in the block diagram in figure 1.

Figure 1. Scheme of decreasing competency and related request for professional and/or intramural care



In the definition of impairment most of the relevant aspects are included. Additional factors are: loneliness, isolation, uncomfortable living conditions, unavailability of informal care and serious mental problems. All these complicating factors will be omitted from our discussion.

In the definition of impairment a long period of time is involved. A convalescence of several weeks after hospitalization is not included. However, a situation in which the continuity of care must be guaranteed for at least several months is included.

After this clarification of the term 'impaired elderly', we can further analyse the shift in policies in the care of the elderly. As mentioned above, this change is twofold and involves a shift from intramural to extramural care, and from professional to informal care. In informal care, all nonprofessional care, i.e. family, voluntary or self help, are included. For the analysis of the change in policy we refer again to figure 1. An accumulation of the overlapping levels of impairment increases the need for care. In the diagram going from left to right, and from top to bottom, the likelihood of a request for intramural (professional) care increases. This would suggest that the request is solely dependent on the objective impairment of the elderly person in question. However, there are at least two other essential factors which co-determine the recourse to care establishments.

One factor is the subjective preference of the impaired elderly person himself. Quite a few show a strong preference for informal care, for as long as possible, while others prefer intramural care even at an early stage.

The second factor concerns the social situation of the person in question. Is he/she married; is the partner in good health? Are there any (un)married children living nearby; does their family situation allow intensive care provision and are they prepared to provide it? Are there any friends or neighbours who are willing to help out in acute situations? All these factors combined determine the moment that a request is made for intramural care.

The shaded area in figure 1 represents the circumstances in which some people turn to intramural care. The percentage of these people increases going from left to right. In the bottom right hand corner the level of impairment has risen to such an extent that there is an almost 100% request for intramural care. In the left and uppermost part of the figure one would only encounter informal care requirements (cfr. Coolen, 1984).

The aim of the new policy for the elderly is to achieve a change from intramural to extramural care, and from professional to informal care. This policy can be directed at each one of the three previously indicated factors, for example at the objective impairment, in order to sharpen the criteria of the grounds on which one becomes eligible for professional, namely intramural care. This would expand the upper and left part of the diagram and is best illustrated by the following examples:

Example A

The impaired person in situation 'A' (see figure 1) has scored badly on virtually all aspects of housekeeping competence, but is totally competent on the other levels.

Suppose this situation concerns the wife in a married couple where the husband is unable to compensate for the housekeeping.

Question: Should the criteria of the grounds on which this couple is eligible for a place in a residential home be changed in our future policy?

Example B

The impaired person in situation 'B' (see figure 1) has also only scored badly on housekeeping competence.

Suppose this situation concerns a widow living alone, with no children nearby and few social contacts.

Question: Is she eligible for home help, or should informal care be organized one way or the other?

Therefore the sharpening of the objective criteria of impairment may result in a heavier burden for the informal care systems (if present).

If the aim of the policy is directed at both the other factors, namely personal preference and social situation, then the shaded area in figure 1 will not decrease in size. Instead, one would be trying to increase the capacity of professional extramural care, and/or expand the scope of the informal care to suit more situations. The latter can only be achieved by active promotion of informal care. Many studies show that relatives, especially children, supply most of the informal care. In the next paragraph we will investigate the chances of success in the active promotion of family care.

3. IMPORTANT FACTORS IN FAMILY CARE FOR THE ELDERLY

Many aspects of the family and kinship systems have a bearing on the possibilities of family care for the elderly. Here we discuss the most important factors, focussing on the changes in recent decades. Firstly a general view of demographic and social trends in the household and the family; secondly a more detailed analysis of the relationships between old people and their children.

In practice, family care for the elderly is generally set up within this context, therefore, the nature of this relationship deserves closer study.

Structural changes in the family and kinship system

Below, we outline the main demographic trends, changes in financial relationships between generations, shifts in living patterns, changed attitudes towards marriage, women's changing role and finally, some research findings. We have largely consulted the following publications: Shanas et.al., 1968; Tews, 1974; Dooghe, 1970; Rosenmayr and Rosenmayr, 1978; Knipscheer, 1980.

From the demographic point of view one of the most important trends is the increase in life expectancy, i.e. more people reach old age. Although this trend began as early as the end of the last century, there has been a considerable increase since 1950. This phenomenon, combined with a decline in the birth rate, has led to a large increase in the percentage of elderly people (65+) in the general population. In most countries this percentage is expected to undergo further increase until the end of the century. The life expectancy of women has increased the most rapidly (in 1950 the difference was already 4 years). Statistics show that there are more old women than old men.

A further important demographic change is the family structure. Briefly, we can speak of intra-generational contraction combined with inter-generational expansion. In other words, the number of family members is decreasing per generation, but there are more generations alive at a given time. The reasons for this, apart from longer life expectancy, are: an increase in young marriages, fewer children per marriage and the fact that children are born to younger parents. This often means that the eldest generation becomes great-grandparents and that parents live for 30 to 40 years after their children have married. In the Netherlands the average duration of the 'postparental phase' is 25 years for women (Niphuis-Nell, 1978).

Many parents continue to work for a number of years after the children have left home. In most cases retirement no longer leads directly to financial dependence upon the children. Thanks to the general old-age pension schemes, combined with the build-up of private entitlements, most parents, health permitting, can manage their own household for at least a number of years without recourse on their children. The fact that the older generation remains (financially) independent of their children for many years, is a great triumph compared to the past (cf. Anderson, 1977). The relationship between the generations would have been subjected to great pressure if the earlier situation had persisted.

Partly as a result of the above trends, we have witnessed major shifts in the living patterns of old people in recent years. Table 2 shows that the number of one-person (single) households in the over 64 age group has increased enormously in the Netherlands during the last decades.

It is far less common for children, married or otherwise, to live under the same roof as their parents. More or less the same trends would seem to exist in other countries. Indeed the fact of managing one's own household is an important verification of one's independence.

Also, as far as the attitude towards the marital relationship is concerned, a number of notable and relevant changes have occurred. These attitudes have important consequences on the kinship structure. Marriage has increasingly become an equal rights relationship between man and woman, with a high priority over any considerations of companionship. We have witnessed a shift away from marriage as an 'institution', i.e. a guarantee of family continuity in tradition and behaviour, towards marriage as a relationship between two people who have founded their own family/social unit on the basis of mutual attraction (Burgess and Locke, 1953; Stone, 1981). This weakens the integration of the kinship system. There is no doubt that this shift has affected the marital attitudes of the children of the oldest generation living today.

Finally on the strength of this study, we must keep in mind the altered position of women. From approximately 1920 to 1930 the change in marital attitudes (referred to above) went hand in hand with an increase in the number of marriages, a trend which has become even more pronounced since the Second World War. The number of unmarried women has decreased steadily, which means that fewer and fewer elderly people can depend on having an unmarried daughter

Table 2. Percentages of people running a one person household, living alone in a house, or sharing it with others, in age groups in 1960 and 1970 (household as defined in 1974)

| Age | 1960 | | 1970 | |
|---------|--------|--------|--------|--------|
| | single | shared | single | shared |
| 40-49 | 46.4 | 53.6 | 83.7 | 16.3 |
| 50-64 | 56.1 | 43.9 | 81.6 | 18.4 |
| 65-69 | 59.0 | 41.0 | 85.2 | 14.8 |
| 70-74 | 59.4 | 40.6 | 86.0 | 14.0 |
| 75 > | 60.7 | 39.3 | 82.2 | 17.2 |
| Average | 57.2 | 42.8 | 83.5 | 16.5 |

Source: Remmerswaal (1978)

to care for them. Women today are having fewer children, over a shorter period. This allows them far more freedom to return to work after their children are born. This tendency has been reinforced by the second wave of women's emancipation.

The mutual interaction of these trends and changes has had far reaching consequences for the position of the oldest generation within the kinship system. A large number of studies have been carried out in the past 25 years on various aspects in the relationship between old people and their children. On the basis of the conscious or unconscious assumption that the oldest generation has become isolated, studies have been made on the frequency of contact and the role of mutual assistance.

Generally the results of the studies have been very reassuring. Most elderly parents seem to have regular to frequent contact with their children, and mutual assistance is a normal feature; if anything, the willingness to provide assistance is greater than the actual assistance provided. There were indeed fewer multigenerational households with the head of the family of over 65, but the inter-relationships between the generations were maintained. Although the results of the studies were reassuring, a number of questions still remain unanswered, which to some extent undermine these optimistic conclusions:

- Almost all the studies are unilateral, i.e. only the parents were interrogated. Consequently, there is a great risk towards positive bias. In most cases, parents were only asked about their relationship with their children. Difficulties with one or the other of the children were generally overlooked. Thus, the resulting parental disappointment is all too readily soft-peddled.

- The studies generally focus on the somewhat 'primitive' aspects of the relationships between old people and their children. No thorough analysis has been made of the character of the relationships between elderly parents and their children. There is a fundamental asymmetry in these relationships which overshadows the positive features. The perspective of future dependence colours the existing relationship.

Regular contacts, occasional help and a widespread concern for each other's welfare are of great value in this relationship. However, we feel that it is necessary to go one step further in order to assess the potential of this relationship in the context of a study on the possibilities of family care for the elderly.

Analysis of the relationship between elderly people and their children

As Laslett (1967, 1972) and Mitteraur (1973) have pointed out, nostalgic references to the three generation family of former times are largely based on friction, especially when it is assumed that such living arrangements were free from conflicts and tension. Already in 1963, Tartler had warned against excessive idealization of this former family community.

Cohabitation imposed by economic circumstances is not conducive to a relaxed atmosphere. Naturally in such a situation there was much talk of intensive cooperation and mutual solidarity, but it is more than likely that relationships were strongly influenced by various forms of dependence, mutual or otherwise (cfr. Anderson, 1977).

To illustrate this, we will briefly examine inheritance arrangements. A thorough analysis of these arrangements would suggest that it was in the interest of the oldest generation to retain control over their property for as long as possible. Not only were inheritance arrangements recorded by a notary, but in some cases, also agreements for lifelong maintenance. In some parts of the Netherlands, where the three generation household still exists to this day, the child destined to inherit the property must also take on

the responsibility of looking after his/her parents in their old age (Rijpma, 1981).

We have chosen this example, not so much for its informative value, but in order to point out that even in three generation households old people wanted the firm guarantee that they would be looked after in the event of their infirmity. More or less voluntary benevolence on the part of the children was obviously not considered to be sufficient. This situation is rarely encountered today. However, it underlines the fact that in the past family relationships between successive generations were to a large extent dominated by economic considerations.

Much has changed in this respect. The leverage which the old people have to ensure their children's benevolence is steadily decreasing. Material inheritance plays a far less important role. However, the investment which the parents make in their children's education and subsequent career have a far greater bearing on the children's economic situation. Parents have to rely on feelings of gratitude, as inheritance is of merely symbolic value. At the same time, parent's dependancy on their children has diminished with the growth of social welfare. Thus, the customary principle that one must look after one's parents has lost much of its impact (see note 1).

We may conclude that for all parties in the inter-generational relationship, both customary pressures and economic/material sanctions have lost much of their significance (Bengtson and Treas, 1980).

Numerous studies over the past 20 years have shown that elderly people like to live independently for as long as possible, preferably with at least one of their children living in the neighbourhood (Shanas et.al., 1968; Shanas, 1979; Rosenmayr, 1965; Houben, 1980). Obviously parents feel a great need to live independently. The extent to which this wish can be realized depends on the available resources and is determined by the social-economic development of society.

One may ask why this need for independence is so great among old people. Have they assimilated to so great an extent the general cultural trend towards individualization and privacy, or are the causes rather to be sought in the nature and character of the relationship between adult children and their elderly parents?

It seems that both hypotheses are interconnected.

Let us examine some of the evidence. Now that the social-economic

aspect of the relationship between old people and their children no longer predominates, the qualitative and emotional features of this relationship have become more important. Studies in the United States and elsewhere indicate that the emotional involvement of both parties in the relationship is substantial, but that the involvement is greater for the oldest generation compared to the second-oldest generation (Bengtson and Black, 1973; Hill, 1970; Pitrou, 1976; Teeland, 1978; Bevers, 1982). This finding tallies with the 'developmental stake' theory (Bengtson and Kuypers, 1971; Bengtson and Cutler, 1976). According to this theory, parents and children have different interests in the relationship. The importance which each of the parties attaches to the relationship depends on the extent to which each can realize his or her objectives within the relationship. Assuming that elderly parents stand to gain more from the relationship with their children than vice versa, it is understandable that their emotional involvement is greater.

In a discussion on the expression 'Intimitaet auf Distanz', intended as a brief definition of the relationship between old people and their children, Anthes (1978) speaks of an asymmetry in the relationship which Rosenmayr's terms do not express. According to Anthes, this asymmetry lies in the fact that older people are more interested in intensifying mutual contacts than their children are. A study carried out by the author (Knipscheer and Bevers, 1981; Bevers, 1982) shows that elderly parents and their children have different opinions on a number of points which affect their relationship (e.g. preference with regard to visits, the expression of differences of opinion, how both generations feel about mutual understanding, knowing what the other person is doing, etc.). Likewise it has become clear that in many cases parents and children did not know where their opinions differed. Moreover, it turned out that the children expressed differences of opinion in 20% of the cases and parents in 11.9% of the cases. Parents also reported that they were unaware of their children's opinions more often than vice versa. The authors consider these data as an indication of the asymmetry we have referred to.

A number of studies suggest that there is a correlation between the old people's general attitude towards life (morale) and the extent to which they feel dependent on their children. Kerckhoff (1966) notes that positive morale is often associated with the relative independence of both generations. Seelbach and Sauer (1977) have reached the same conclusion, namely that there seems to be a correlation between negative morale and the extent to which old people

consider their children as responsible for them. Thus, the more parents expect of their children in the line of filial responsibilities, the less likelihood there is of a positive morale.

Ultimately, these trends in relationships may be traced back to a general law of personal relationships which was first formulated by Ross in 1921. Ross states: 'In any sentimental relation the one who cares less can exploit the one who cares more. In the man-woman relation and the mother-child relation we see this plainly'. This general law was later reformulated by Waller and Hill as 'the principle of least interest' (1951).

In the relationship between old people and their children it is generally the parents who are more interested in maintaining a good relationship. There are two possible reasons for this inclination by old people:

1. their relationships with people of their own age group decrease steadily,
 2. their risk of dependency (on their children) increases steadily.
- Bevers (1982) concludes that it is usually the children who define the boundaries of the relationship.

The analysis of the above relationship between old people and their adult children leads us to the conclusion that the care capacity of the kinship network is limited. The net result of the structural changes discussed, is that (especially) elderly people lose all their freedom when becoming dependent. The social-cultural developments have strengthened the asymmetry of the relationship between the elderly and their children. This certainly does not form a healthy basis for an extensive shift from professional to family care.

4. PROBLEMS WITH INFORMAL CARE OF THE IMPAIRED ELDERLY

In recent literature on informal care of the impaired elderly within family relationships, two opposite hypotheses are put forward. Shanas (1979) states that family care is dominated by the principle of substitution, i.e. there is a self-evident order of family members eligible to act as care providers. The order is as follows: firstly the partner, secondly one of the children (usually a daughter), thirdly a brother/sister and fourthly uncles, aunts and grandchildren. The principle of substitution implies that family members are available in serial order, so that if one individual is not available to help, another will step in. In contrast, Litwak (1980) proposes the principle of the shared function kinship system where the

specific needs of the older person are matched to the most appropriate primary relationship, as determined by long-term commitment, proximity and degree of intimacy.

An inventory of recent research data clearly emphasizes the principle of substitution. There usually appears to be a central care provider, i.e. somebody providing the main contribution of the care and also coordinating the care provided. The order of the family members eligible to fulfil this role is the same as above. For the central care providers this usually means a heavy mental and physical burden.

Many publications deal extensively with this burden. An inventory of the problems causing the most stress has been drawn from these publications (see overview 1). But firstly, in order to understand informal care situations, we must take the following points into consideration:

1. Every central care provider uses his/her own criteria when discussing the burden in the care of an impaired elderly person. Regularly the question arises as to how much of the care can still be coped with and for how long. Sometimes one draws distinct lines here. When these care capabilities are surpassed, a request is made for professional and/or intramural care. However, these lines are subject to a wide degree of interpretation, depending on the particular care provider. Barnes et.al. (1981) speak of 'prisoners of love' in this respect, as this happens specifically when the central care provider is the partner. Varying subjective limitations (of the burden of the care which is imposed on the central care provider) largely explain the width of the shaded area in figure 1.

2. The central care provider sometimes persists with the task to such an extent, either aware or unaware of the fact that (s)he obstructs others who would otherwise be prepared to assist. The persistence in the caring area is not usually understood by relatives, neighbours and other involved parties, although they often accept it as it legitimizes the unequal division of the care to their advantage. This persistence is partly explained by the belief, of the central care provider, that the other people do not know the impaired person as well as they do, they do not fully appreciate his specific need of care and that their care will not be adequate. In practice, the person receiving the care also shares a role in this. It is very much to his/her advantage to be sure about who to appeal to and what can be expected of this person. In a good care relation-

ship each person needs to know exactly what can be expected of the other.

3. It appears to make quite a difference whether it is the partner or one of the children who fulfils the role of central care provider.

Overview 1 presents the problems which form the greatest burden for the care provider, i.e. partner or children. The most striking aspect with one of the children as central care provider is the high risk to the quality of the relationship. Perhaps this is due to the nature of the relationship.

The situation is paradoxical because various studies show that children are generally prepared to contribute to the care of their parents (cfr. Bevers, 1982). Cicirelli (1981) found that children feel more obliged to help their parents than their parents expected. The children's willingness is also shown in the studies reported in overview 1. Johnson (1983) however, remarks: 'At the same time, the obligatory and internally motivated nature of the parent-child dyad is taken for granted, but the expectations of specific functions are often diffuse and ill-defined in terms of the extent of the sacrifice which should be made'. This situation has been analysed elsewhere by means of the concept 'anomy' (Knipscheer, 1984). It could explain the variability in the extent to which children are prepared to accept the care provision. The indistinctness of norms and expectations thus allows room for one to state one's limitations.

In Hamburg research was carried out on adult married children who had taken in one of their dependent parents. Their motivation for this act was expressed as gratitude and a feeling of obligation. Most striking however, was that the motivation was preceded by a kind of underlying evidence of acceptance of the role of central care provider (Klusman et.al., 1981). This underlying evidence was also noticeable in 20 intensive open interviews with the central care providers of seriously impaired elderly in Nijmegen (Janssen, 1984). Here the feasibility of a family culture arises and one is also aware of an exceptional situation. People regularly indicate that they go too far with their caring activities and that this will become detrimental to their own health. It seems as if there is hardly any limit to the burden of care willingly accepted in this situation.

Overview 1. The most stressful problems in the informal care of impaired elderly

| | Johnson Bursk 1977 | Robinson Thurner 1979 | Zarit 1980 | Parody 1981 | Lindsey Hughes 1981 | Barnes e.a. 1981 | Rabins 1982 | Horl Rosemayr 1982 | Johnson 1983 | Braun 1983 |
|--|--------------------|-----------------------|------------|-------------|---------------------|------------------|-------------|--------------------|--------------|------------|
| A. Mental burden resulting in anxiety, confusion, depression, denial, because of: | | | | | | | | | | |
| 1. experience of increasing deterioration, increasing dependency, no prospect of improvement | x | x | x | | x | x | x | x | x | x |
| 2. confrontation with generational differences (2) | x | | | | | | | | | |
| 3. compromising between one's own family, work and dependent elder (2) | x | x | | x | | | | x | x | x |
| 4. lack of space/privacy | x | | | | | | x | | | |
| 5. deterioration of quality of the relationship between care provider and dependent person (2) | | | | | | | | | | |
| 6. lack of appreciation from dependent person | | | | | | | | | | x |
| 7. lack of mental support from the environment | | | | | | | | | | x |
| 8. threat to own health (1) | | | x | x | x | x | x | | | |
| 9. lack of insight into dependent person's disease | | | | | | | | | | |
| B. Physical burden resulting in exhaustion, tiredness, overburdening because of: | | | | | | | | | | |
| 1. physical burden of care provision activities | | | | x | x | x | x | | | x |
| 2. the time-consuming nature of care provision activities | | x | | | | | | x | | x |
| 3. lack of night's rest | | | | | | | | | | |
| 4. lack of assistance from environment | | | | x | | | | | | |
| 5. threat to own physical health (1) | | | x | x | x | x | | | | x |
| 6. no time for personal activities/relaxation | | | x | | | | | | x | |

(1) especially problematic in partner relationships
 (2) especially problematic in parent-child relationships

Horl and Rosenmayr (1983) have in a sense concluded exactly the opposite. A microcensus in Austria shows that over one third of the children (14,000) providing support for one of their parents, finds this a heavy burden. In 2% of these cases community nursing is provided. Of the children assisted by professional care it appears that a higher percentage finds care provision a heavy burden compared to those who do it by themselves. One of the suggestions made by the researchers to explain this is: 'The subjective yield capacity is lower among those who are supported in their nursing activities by social service organizations, ... low yield capacity leads to efforts to get some external aid for the relative needing care' (p. 89). The subjective limitations to the burden of care are very low in this case.

Points 1 to 3 above, clearly point out that overview 1 must be interpreted with caution and that important differences exist between the situations in which the partner or the children are the central care provider.

Nevertheless overview 1 presents a good insight into the aspects causing most stress in the informal care of the elderly. It also forms the basis for finding ways of lowering the stress.

5. PROSPECTS FOR PROMOTING INFORMAL CARE

In section 2 we described the proposed change of policy from professional and/or intramural care to informal care. Three aspects were mentioned, namely the sharpening of objective criteria, personal preference and social situation. Here we will expand on these aspects and explore some alternatives.

Restricting criteria

The simplest way of extending informal care in the care of impaired elderly is to sharpen the objective criteria of eligibility for professional, namely intramural, care (Min. C.R.M., 1982). The size of the shaded area in figure 1 would then be reduced and the least urgent impairment would be left to informal care. Although this seems to be a logical and plausible solution and also one which is easy to carry out for administrative agencies, there are important disadvantages associated with it. The most important disadvantage is the decrease in the capacity to deal with specific care requirements. The influence and responsibility of the care provider over

the work premises are also limited.

Stimulating existing informal care

A second possible way of expanding informal care is to stimulate people into taking on the care of their impaired relative for a period of time. This is thus an expansion of the most frequently occurring informal care, i.e. the family system.

The substitution model, as mentioned before, suggests the existence of a substitution hierarchy based on the eligibility of primary relatives. A second not explicitly stated aspect of this model is that the further one descends down the hierarchy the more inconsistent the duration of the care becomes, i.e. it is unusual if an impaired elderly person is taken care of for a long period of time by distant relatives, friends or neighbours. When speaking in terms of the stimulation of the existing informal care, it is not our intention to produce a shift in the substitution hierarchy in order to make an appeal to categories further down the list.

Here we discuss three other methods of approach in the stimulation of informal care. Each is followed by a short prediction of the effects it would have on the extension of informal care.

A. Family consultation

The discussion on this form of stimulation of family care is especially stimulated by the 'Family Support Cycle' model of Kuypers and Bengtson (1983). This model is based on a system's analysis of the 'older family' (see note 3) and the way in which it is confronted with the aging of the parents. The analysis of the problems which arise leads to some directives which enable the older family to cope with the care of an impaired elderly person.

The most important directives are:

1. Discussing the situation of the impaired and explaining it if necessary.
2. Investigating the extent of the care which the family members can provide.
3. Discussing the possible feelings of obligation and guilt which may exist towards an impaired parent.
4. Determining, in consultation with others, just how far reasonable care can go and laying down feasible limits.
5. Investigating how much care can be provided by professional institutions.

In Kuypers' and Bengtson's opinion these directives should be applied under the supervision of a social worker and a process should be started in which the care of an impaired elderly person is defined as a family affair. The coordinating role of the central care provider could be maintained and as soon as other family members are involved in the care the central care provider is no longer alone in facing the problems. A mutual arrangement over the care which can be provided assigns the care providers to their tasks, but also leaves every person who is involved regularly the opportunity to leave the care to others.

If we succeed in modelling family care in this way, the number of problems of the central care provider (overview 1) will diminish, i.e. the moral support from the people in the environment is greater, the deterioration of the relationship between the care provider and the impaired is less probable, the continuous compromising between the care of the impaired and one's own family diminishes. Therefore, the physical and mental strain would decrease considerably in various ways.

This model is based on the assumption that the informal care situation is less easily strained when the care becomes the responsibility of all involved. It implies a change away from the substitution principle to the above mentioned 'shared functioning' principle. When such a change succeeds, the impaired person can probably continue to live independently.

B. Payment for informal care

The question regularly arises as to whether or not informal care should be paid for. Two aspects are relevant: does payment for informal care lead to an expansion and does such a change present financial savings? We can only respond to these questions in a speculative manner.

However, one point should be made. When a system of payment is put into operation this should be managed for as long as possible by the impaired person him/herself. They should be entitled to extra financial means in order to be able to afford the care. This care may be provided by family members, private help or possibly professional extramural care providers, or it could be divided among them. In this way an elderly person could still maintain the feeling of being independent of family care. It also leaves the family care providers with less of a feeling of being exploited, in comparison to similar situations in which professional and/or intramural care is provided.

C. Design of respite care

The list of problems associated with caring for an impaired parent (overview 1) shows the enormous burden on the care provider. In view of these problems it is strange that up until now many countries have virtually no systematic policy designed to create respite care as a temporary relief to informal care, in order to prolong the independence of the impaired person.

In the Netherlands centres for day care/nursing located in nursing homes were set up gradually starting in the 1970's. The intention was to provide supplementary medical care by means of this day nursing, so that after treatment the impaired person could return to full care in the home environment. In our experience this goal is rarely achieved. In most cases we can only speak of a creche function.

However, in our opinion the creation of structural possibilities to enable temporary care of an impaired person by professional and/or intramural care provisions forms a crucial facet in a policy which is intended to stimulate informal care. Examples of these structural possibilities are: day nursing, day care, holiday relief, community function in a residential home and 24-hour on-call care service in case of emergencies.

We have discussed three possible ways of stimulating the existing forms of informal care. These three alternatives could lead to a decrease in requests for professional and/or formal care by elderly people. It also appears that the informal care systems and the provisions policy must both change. Further development of these changes will have to be carried out in accordance with the local situation. The extent to which these changes will lead to the desired effect, i.e. to a considerable shift towards informal care, will depend on the interaction between the informal care and the formal care.

Alternative forms of informal care for the elderly

In addition to the usual forms of informal care for the elderly, new initiatives have come to our attention. These initiatives have developed almost completely outside family networks and can be seen partly as a reaction to strongly individualized life styles and partly as an effort to compensate for the disadvantages in existing professional care systems. Usually the elderly unite forces in these initiatives, although sometimes voluntary organizations are to some

extent involved. In the long run these developments could contribute to the shift from formal to informal care. We have called them alternative forms of informal care. We do not intend to discuss all the widely varying forms individually, and restrict ourselves to an indication of the most important varieties in order to estimate how they might be able to ease the burden on professional and/or intramural care. We have divided the various forms into three categories.

A. Group living arrangements and informal care

Various forms of group living for the elderly have recently been developed in the Netherlands. A limited number of projects on communal living have already been accomplished in the past few years and an even greater number are in preparation. At the moment however, we must note that these forms of arrangements are not alternatives for the problems dealt with here. These projects do not usually aim to take on the care of impaired fellow residents. Naturally, incidental mutual care is included under the general goals, but does not provide an alternative for the prolonged care of impaired elderly people at present.

However, we do not exclude possible useful future developments derived from this. In time such groups would be confronted with the problem of impairment. In addition to these groups, there is an experiment in progress in which five or six psychogeriatric patients live in a normal house with the support and guidance of a nursing staff. Although the first results from this form of group living (for this category of the elderly) are encouraging (Genormaliseerd wonen, 1984) it is too soon to draw far reaching conclusions concerning (the cost of) this form of informal care. Nevertheless this form of guided living deserves further development and evaluation.

In addition to these forms of group living, the possibility for the elderly person to live alone supported by means of communicatory alarm systems, telephone circles, delivery services, meals, cleaning, transport and visits, are being expanded. These services stimulate independent living for as long as possible, while combining a maximum of privacy with a minimum of burden to others. The supporting services needed for this can be arranged either by voluntary help services or by professional services. In the former situation some professionalization is necessary. In any case these forms of care, which link a maximum of privacy to independent living, deserve stimulation and if possible further development. Other forms of group living limit the amount of privacy too much for many of the elderly people.

B. Geographical proximity and informal care

For care activities which must be provided daily or at least weekly, it is necessary that the care provider lives within close proximity. Frequently care can no longer be provided due to isolation problems. Community help services are organized to compensate in this particular situation. Usually voluntary care organizations cover a wide range of supporting activities.

However, this support provision often has two disadvantages for the seriously impaired, i.e. there is not an adequate guarantee of continuity and regularity in care and there is usually a frequent change of care providers. Thus an autonomous structural contribution to the care provision of the seriously impaired elderly can not very often be guaranteed by these voluntary care organizations. For these elderly, without relatives or at least not living nearby, such a situation leads to a rather early request for professional care.

Challis and Davies (1980) give an interesting description of an experiment in which community-directed care of the elderly is combined with voluntary care work. In their opinion, proximity is not the only criterium when choosing a care provider (in this case voluntary worker), for the impaired person. They also consider it important to match client and helper on the basis of factors such as interests, compatibility and skills.

The experiment also showed that good coordination of care is only feasible on district level. A good organizational structure and regular communication between supervisor and care provider is essential in order to facilitate the continuously changing care requirements, the shifting care consumer population and the associated priorities. At district level sufficient opportunity exists for flexibility in the utilization of both formal and informal care providers. They will of course both belong to the same organizational structure.

It is only recently that the (many) residential homes in the Netherlands have been given the task of setting up care assistance schemes for the impaired elderly living in their vicinity. This situation provides the opportunity of coordinating extramural care in cooperation with voluntary organizations. Thus the interaction of intramural, extramural professional care and informal voluntary organizations creates new scope in keeping the elderly independent for as long as possible, yet with adequate care.

C. Elderly for elderly, mutual solidarity and informal care

It has sometimes been suggested that new solidarity schemes for mutual care could be developed within the extensive group of the elderly (Braam, 1983). The compatibility of the elderly as well as the existing religious organizations could form an important basis for this. It can not be denied that the degree of organization for the elderly has greatly increased during the last decades along with the development of a growing solidarity.

However, it remains to be seen whether this solidarity also includes the impaired elderly! Is this solidarity not rather more directed towards the mutual achievement of the interests of the elderly and politicians?

Various recent studies (Knipscheer, 1980; Cantor, 1980; Jerrome, 1981; Bankoff, 1983) confirm earlier findings that relationships with friends and neighbours of approximately the same age can be very important for the well-being of elderly people. The support functions which are supplied by them usually lie more in the emotional and affective level than in an instrumental level. As the level of impairment increases, so does the tendency to seek help from close family members (Lehr, 1982). A longitudinal analysis of data on the social relationships of the elderly showed that many friend/neighbour relationships, fulfilling an important role in the area of help and intimacy, disappeared over a period of five years (Janssen and Knipscheer, 1983). Research indicates that the elderly show little tendency of appealing to friends of the same age in the case of impairment. This is probably because of the difficulty of combining different support functions when one of the partners is impaired. The stress aspect of care provision threatens the quality of a relationship.

Especially the prospects of a balanced exchange relationship disappear in the long run. Therefore, expectations of solidarity among the elderly regarding the care of the impaired elderly, should not be too high. Policies attempting to realize a shift from intramural and/or professional care to informal care do so at the risk of failure in this respect. But this does not mean that experimentation in this area should not be attempted. In the closer cooperation of professional care and mutual care for each other a suitable task division should be developed.

We have discussed three different trends which might provide alternatives in the informal care of the impaired elderly. Our conclusion

is that the perspectives of short term arrangements are not promising. The social mechanisms governing the process of informal care for the elderly evoke only modest expectations. It is not our intention to imply that these alternative trends are irrelevant. They may be covert starting points which later prove to be fruitful. In this area long term experiments are absolutely essential.

One study on living alternatives for the elderly (Houben, 1984) is of especial interest in this respect. The researchers planned to discuss living/housing wishes with the elderly people themselves starting from scratch, i.e. without taking the present housing provisions in to consideration. After some time they arrived at the conclusion that this was virtually impossible. The discussion returned all too often to problems concerning the existing housing situations. The elderly were unable to consider new ideas about living conditions and new operational forms. Hence, prolonged experiments where the possibilities are demonstrated might lead to a more productive participation from the elderly.

6. CONCLUSIONS

Our analysis on the possibilities of a change of policy (concerning provisions for the elderly towards more informal care) does not justify any optimism concerning the possibilities of extending 'family care', or expectations for alternative methods of informal care.

However, some conclusions may be drawn regarding stimulation of the desired policies. In the first place it has been proved repeatedly that an intensive interaction of formal and informal care areas is necessary. As an elaboration on this general conclusion professional care will have to adapt itself more to the conditions of a well functioning informal care system.

Moreover, formal and informal care demand more coordination than perhaps could be accomplished within a professional framework. Formal care provisions must create ample opportunities for the temporary relief of care providers. In our opinion these elaborations require that care and care coordination should be provided in close connection with each other, i.e. at district level.

Although the short term expectations for the contributions of the alternatives towards the care of the impaired elderly must be modest, these forms still deserve encouragement and continuous evaluation. We can not preclude the possibility that in the long run useful alternatives may develop from them.

Notes

1. There are still great differences in this respect among various countries. In Belgium and Germany the income and assets of the children may be taken into consideration when deciding whether the parents are entitled to financial assistance. This also applies to institutional care. In the Netherlands the situation is reversed. Stays in residential homes must be paid for by the elderly person for as long as possible from his/her own resources. The children are not required to maintain their parents.

2. Braam (1983) distinguishes two functions of primary relationships: instrumental support and support providing a 'sense of security'. According to him the latter function could not be sufficiently provided for by professional care providers. For this reason he encourages the care of the elderly by the elderly. However this form of assistance for the seriously dependent elderly appears to offer only limited possibilities according to our analysis.

3. For the purpose of this discussion the term 'older family' refers to the nuclear family where parents and children are all adults.

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IX. Innovations in health services for the elderly: some characteristics

M. Boekholdt, G. Schrijvers

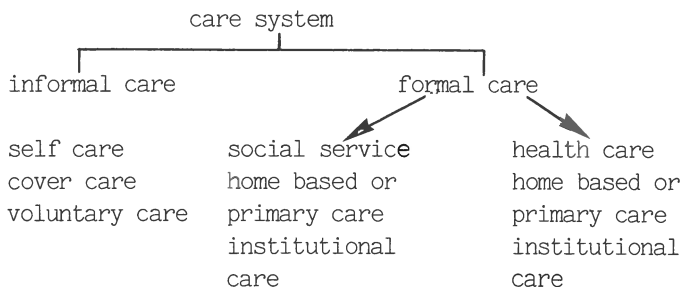
1. INTRODUCTION

The preceding chapters describe some innovative projects in care systems for the elderly and how these innovations are supported by scientific research. Firstly, this chapter tries to present some general characteristics of care innovations and to compare these against a background of general developments in the care of the elderly. The contents, strategies and conditions for special innovative projects are also discussed. The chapter ends with some conclusions.

2. CARE SYSTEMS AND INNOVATION

Caring for the elderly is a comprehensive and complex social institution. Within this institution a distinction may be made between two interdependent care systems: the informal and the formal care system (see figure 1 and the following analytical distinctions).

Figure 1. Care systems distinguished by some characteristics



The first system comprises of self care, cover care and voluntary care. People, including elderly people, permanently care for themselves. Mostly they do this implicitly.

Actually the self care system is the most voluminous of all the systems. Informal care is also provided within primary social networks; this is the cover care. Partners, family, neighbours and friends belong to these social networks. The care they provide may be implicit or explicit; explicit means that the care is organized or structured. Volunteers who do not belong to the primary social network are the third kind of providers of informal care. Mostly they do their work within an organizational structure.

The formal care systems incorporate all care from professional providers. Sometimes formal care may be referred to as professional care. This care is formally organized and mostly financed by public or (social) insurance funds. Social services and health care are two components of the formal care system. Both are organized on two levels: primary or home based care and institutional care. Care systems for the elderly may, as illustrated in figure 1, be split up into different blocks: informal and formal care, and the latter again into primary and institutional care. In practice these blocks interact and interdepend. The preceding chapters show examples of these interactions, c.g. Knipscheer. Our differentiation is based on analytical reasoning rather than on organizational principles.

Care systems change continuously: they grow and develop implicitly. Sometimes however, conscious and structured modifications are introduced into the functioning of the care systems. If such a change is regarded by patients and care providers as an improvement, in comparison to the previous situation, then we call it an **innovation**. Which criteria make a conscious and structured modification and improvement depends on the existing situation and differs from place to place and from time to time. Innovation is a subjective concept not an objective one. It is defined by norms and values, and by the consideration of the elderly and the care they need. Often a change is mentioned after an innovation. Innovations of care are based on prevailing ideas or realistic opinions about future care for the elderly. Some examples are briefly laid out below; the reader may also refer to preceding chapters. The first and foremost prevailing idea for care systems will be an emphasis on the meaning of 'being elderly'.

Every age has its own charms, including old age. Being old does not mean being out of date. It has its own specific expectations on the quality of life and its own needs and problems. Knipscheer, for

instance, describes some of the expectations which the elderly have about their children and family (see also Daatland).

A second prevailing idea concerns the effect of the individual approach on the elderly person by the person who is responsible for the care. Biography, life expectations, housing and living environment are central in this approach, and one tries to continue and maintain these three aspects in a harmonious way without sudden changes. The question is how to put the existing capabilities of the elderly people to as much use as possible.

A third prevailing idea relates to the necessity of emphasizing the multidisciplinary of the problems of the elderly and the role of the social network around him or her. The approach of the formal care provider must become a comprehensive one, in which the older person himself is given as much responsibility as possible in the caring process. The Swedish project discussed in this book, shows some examples of this multidisciplinary approach and the personal responsibility of the older person (see also Holstein and Almind).

A fourth prevailing idea implicates that informal care systems (see figure 1) become increasingly important and must be supported and not replaced by formal systems. This means for the latter systems that the home based social services and the primary health care should be promoted in order that elderly people can live at home for as long as possible.

Institutional care supports the home based care on this point of view: if an admission to hospital is inevitable, then also the continuity of the social network and the role of the primary care workers ought to be guaranteed. Moving the elderly person from one institute to another should be avoided as much as possible. Formal care both supports and is supplementary to informal care.

Innovation based upon prevailing ideas is a continuous evaluation process of an existing situation, by means of an innovative project towards an aimed situation (see figure 2).

Innovative projects have two interdependent characteristics: the content and the strategy of the innovation. The content relates to the change in the care. The strategy relates to the way in which the activities are planned at the start and the further implementation of an innovation. We discuss both in paragraph 3.

How care systems function in reality, how they interrelate, which prevailing ideas exist and which innovative projects are introduced,

Figure 2. Innovation as a process

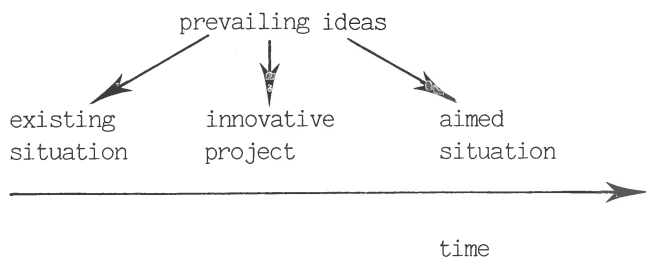
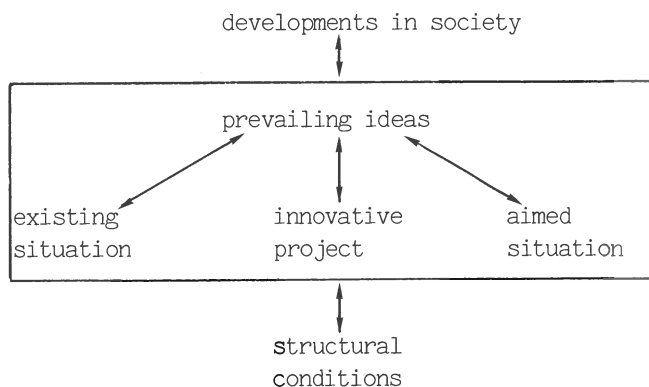


Figure 3. An innovative process on the context of developments in society and structural conditions



depends on developments in society and on structural conditions (see figure 3).

Structural conditions are factors from outside the care system which promote or obstruct an innovative project.

Structural conditions for innovative care systems for the elderly are for example: the financial level of the pensions of retired persons, the quality of the housing facilities for elderly people and the planning and financing systems of the formal care system. We define a conscious and structured change in a structural condition as an '**indirect innovation**'. An indirect innovation may stimulate innovation of the care system itself (primary innovation).

Developments in society are not specifically linked to the care system as the previously mentioned prevailing ideas are. Nowadays

developments give rise to questions concerning the present formal system and puts pressure on them. Here we mention three developments in society.

The first development is demographic change. The number of elderly people increases and especially the number of very old people.

The second development is the economic recession, which sometimes leads to a reduction in the formal care systems and also influences the financial level of the pensions of retired persons.

The third development is the change in the care requirements. The number of senile elderly people will increase because of the increase in the number of very old people. However, more physical handicaps and less social capabilities will be combined in really complex, multidisciplinary i.e. somatic, psychological and social, care requirements.

3. INNOVATIONS IN CARE SYSTEMS

In this paragraph the content of the direct innovations and their strategies will be discussed with some remarks on the innovation of conditions influencing the care system (indirect innovation) in conclusion.

Content of innovations

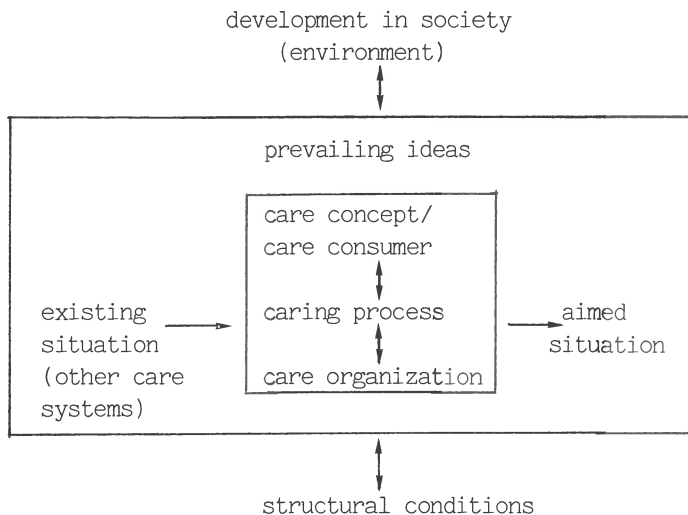
Within a care system four elements must be differentiated which interact with each other. They are: the care consumer (patient/client), the care concept, the care organization and the caring process (see figure 4).

The care consumers (patients or clients) have care requirements. As we have already mentioned, the needs of elderly people are often very individualized and have a multidisciplinary character. Needs can be more or less stimulated by the care organization and the care provider. Both elements are able to hospitalize patients or to appeal to their responsibilities and self care capabilities.

The second element is the care concept: the implicitly or explicitly guiding principle of the care system. What are the dominant factors within the system: medical treatment or other types of care? Is nursing technically or more socially orientated?

These questions are answered by, for instance the care concept. The system is most greatly influenced by the views of the care providers

Figure 4. Four elements within an innovative project



on treatment and care. These views are based on: perception of people, social and cultural values, and last but not least professional education. The care consumer and his or her social network may also influence the care concept.

Care organization is the third element of this system. Important here is the number and variety of care providers. Also relevant are their skills and knowledge, task division and the way in which they communicate and cooperate.

The last element is the caring process. This is related to the direct caring activities which the patients experience.

The four elements interact with each other in a care system which is open, i.e. takes into consideration the relationships within its own environment and that of other care systems.

Direct innovation relates to one of the four above mentioned elements within a care system, or to a combination of them. The innovation of one of these elements may change the innovations of other elements. In other words the functioning of each element must be consistent with and adapted to the other elements and relationships. Figure 5 compares 'traditional' and 'innovative' care systems according to the four elements.

Possibly figure 5 overaccentuates the differences between traditional and innovative projects, however, this figure could be useful as an analytical tool. In each of the projects described in previous chapters, innovation through one of the elements is involved. Holstein shows a new care concept by identifying risk situations.

Van der Plaats et.al. brought forward the needs of the clients in a day hospital by inviting them to ask questions and by taking heed of the answers. She also emphasized the necessary changes in the attitudes of the care providers. In all projects new categories of patients change from institutional care to home care: for instance in Sweden in the hospital based home care experiment, and in Denmark in the acute nursing and 24-hour home nursing experiments.

Organizational changes are necessary for the day care facility discussed by Cantley.

Figure 5. Traditional and innovative care systems, compared according to the four elements

| | INNOVATIVE PROJECTS | | |
|----------------|---|--|---|
| | Traditional | Primary care projects | Self care projects |
| care consumer | case | client | colleague |
| care concept | somatical recovery | plus physical wellbeing; holistic | plus consciousness: emancipating |
| caring process | treatment and nursing care; care provider is technical expert | care plus companionship: care providers patient orientated | formal and informal care interact; care provider is family orientated |
| organization | hierarchical, discipline orientated | multi-disciplinary teamwork | cooperation with social network |

Strategies of innovation

There is more than one way to achieve innovation. A strategy may be compulsory. It may also be an implementation of a new, elsewhere developed, element in a care system by for instance: the appointment of a new group of care providers in a care system. We will not discuss these strategies, because in our opinion they are only supplementary to another strategy; the so-called 'developmental approach' (D.A.).

The D.A.-strategy is based on the idea that for an innovation changes must be made in norms, attitudes and the behaviour of people, i.e. patients, social networkers and care providers. Innovations will be real and lasting if these changes do occur. Individual people in a D.A.-strategy must become aware of the necessity to change their norms and conduct and secondly they must learn the new way of functioning of the care system through experience. By active participation in the innovative process it is possible to adapt the new care concept and the organization to the real situation.

A care system is comprehensive and complex and can only function with mutually consistent elements. Innovation, according to the prevailing ideas described in paragraph 3, demands an improvement in: the social processes between patients and care providers, the solving of individual problems, teamwork and communication. For professional workers these are fundamental factors of their functioning. It takes time for them to become conscious of the benefits of the innovation and to learn their new conduct through experience. A developmental approach provides these opportunities for both care providers and patients.

A D.A.-strategy requires the participation of all workers in designing and implementing the innovation and in adapting the existing situation. Through their participation the feeling may grow that the innovative project is their own. Also they learn new skills by taking part in the process, through communication, teamwork and management. It is important to realize that care systems mostly have more than one centre of power. Professional power is centred in teams of workers; bureaucratic power is centred in management teams. Two or more of these centres create the need for negotiation within the care system. An innovation understands and recognizes these power relationships and manipulates them. A D.A.-strategy provides the opportunity, although the way is long, tiring and complicated. However, it is a first priority to achieve an innovation without too

much stress and conflict. If nevertheless stress and conflicts do arise, one of the supplementary strategies may be used, such as: compulsory decision making or the replacement of care providers. If these strategies are not realizable, the innovative project must be stopped.

Looking at the strategy used for the innovative projects discussed in the earlier chapters, we do not see much emphasis on strategy.

Innovations, which are started because of waiting-lists (Van der Plaats) or because of a new building (Cantley), are dangerous ones. What at first might seem to be highly successful, might prove to be disappointing when the waiting-lists disappear or the building is a few years old. Therefore, for this type of conditional change innovation a developmental approach is absolutely essential, in order to make sure that the change is permanent when the original reason has been resolved.

Unexpected effects leading to a shift in the goals of the project can never be completely avoided. An evaluation of the existing situation must be made in order to reduce the chance of unexpected experiences. The following evaluation tools should be taken into consideration: simulation games, literature study and stocktaking of the existing patient flows, perceptions of patients and care providers, protocol of decision making structures and of informal networks.

Although it is understandable that innovators wish to start as soon as possible with the execution of prevailing ideas, one should beware of the failure of an innovative project due to a bad organizational start which may give rise to a delay of many years for future innovation!

Indirect innovations

In paragraph 2 structural conditions were defined as factors from outside the care system which promote or obstruct an innovative project. Innovation of these structural conditions was defined as indirect innovation. Here we will discuss the political, planning and financing systems.

In several countries the social and health services are planned and financed by different public authorities. This impedes integrated care provision for the elderly as desired according to the prevailing ideas. Another problem is often the lack of interest shown in new prevailing ideas by planners (local authorities, politicians). Frequently the planning is structured according to financial

resources and/or number of beds, jobs, or other quantitative units. On the other hand however, there are conditions conceivable which promote the direct innovation of care systems for the elderly in accordance with the prevailing ideas. We will mention three of them.

Firstly, planning processes should be explicitly based on the type of care which is required. Informal care should be included. Also the effects which political decisions in other areas of governmental policy making have on the well-being of old people should be taken into consideration.

Secondly, responsibilities for the care of the elderly should be split into those categories where authorities are in direct contact with the elderly and with the services providing care.

Thirdly, the innovation of a structural condition in the integration of governmental departments which are developing policies for the care of the elderly. Care of the elderly as an integrated field of policy making, should also find its origin in governmental organization.

Innovation of the existing structural conditions, along the lines of the three conditions formulated above, demands a political strategy. This is because changes in conditions are mostly achieved with the help of the (local) government. There is also a developmental approach necessary here, in which politicians become aware of the problems, learn new ideas and attitudes. Some comment may be made on the relationships between the direct and indirect innovations in care systems for the elderly. Direct innovation is possible without indirect innovation.

In fact innovative projects may cause a change in conditions after their introduction. It depends on the opinion of the role of the state in society, whether this is considered a correct or incorrect sequence. Etatism supporters will emphasize the necessary changes in conditions to promote direct innovations. Followers of the adage 'structure follows strategy', will accentuate the bringing forward of concrete innovative projects in order to change the minds of politicians and bureaucrats. The examples in the previous chapters were all bottom-up instead of top-down innovations. Maybe bottom-up projects are more common among innovators.

If conditions put pressure on a care system, the answer is not necessarily a change. Perhaps the innovator is a chaotic pioneer, who will never adjust to any form of regulation. If that is the case, the answer is to replace him after a couple of years, by a

diplomat who safeguards the continuity of the project within existing rules. If there are no problems with the pioneer, then deregulation could be the answer instead of new regulation. Just how necessary are: special rules, an organization structure, or financing arrangements for an innovative project?

New conditions may impede future innovations. That is why each new condition should be tested on its capability of inciting human creativity and the freedom to act in further innovations.

When however, new conditions are indeed desirable, a coalition between innovators and politicians is necessary. Such coalitions form a potential danger to the care systems for the elderly. Politicians may stimulate the re-allocation of money from institutional care to home based care or informal care, without really having the intention to create the conditions necessary to strengthen home based care or informal care. Their political aims may be a reduction in the cost of care and not an innovation of care. If this happens, innovators, but especially the elderly, are left out in the cold. Responsibilities on local levels and the planning of care in the ways mentioned above, are the best guarantee that this will not happen.

4. CONCLUDING REMARKS

Direct and indirect innovations are necessary to create actual change in the care systems of the elderly. Both are very time consuming, and may prove to be even more so than innovators, politicians and bureaucrats expect. The former may wish to apply the prevailing ideas as soon as possible in caring for the elderly, whereas the latter may be anxious to create new conditions.

For the innovator a real danger of disillusionment exists, followed by apathy if changes in the elements of the care system do not appear fast enough. The same disappointment follows for politicians and bureaucrats when the indirect innovation of conditions is over-emphasized: 'you may take a horse to the water, but you can not make him drink', i.e. some circumstances are beyond one's control. That is why an innovative strategy based on a developmental approach is desirable.