Community Care for the Elderly in Lombardy
Needs, Resources and Outcomes

Thesis Submitted for Examination for the Degree of Doctor of Philosophy
By
Cristiano Gori

London School of Economics and Political Science
2002

ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

Table of contents

Part I - Policies, debate and methodology

Part II - Research findings

Appendices

Abstract

The thesis discusses the provision of community care for the elderly in Lombardy, a region of Northern Italy. The main part consists in an original analysis of the quantitative data gathered there, focusing on issues concerning services'utilisation, outcomes and costs.

The thesis is conducted using several tools and logics of the "Production of Welfare" approach, developed at the Personal Social Services Research Unit (PSSRU) since the '70s and used in a number of studies. It deals with three topics. The first topic concerns services' utilisation: the process through which care resources are allocated, their comparison with users and carers' needs and the geographical differentiations. The second topic regards outcomes: the aim is to to highlight the connections between inputs and outcomes (concerning hospitalisation, impact on users' health and on the dependency and other domains) and to understand the impact of the former on the latter. The third topic concerns costs: the thesis analyses different kind of costs (direct, indirect and intagible) borne by different stakeholders involved (users in different conditions, informal carers, public services and private professionals).

The thesis is divided into two parts. The first part discusses the policy towards the frail elderly in Italy and Lombardy and the debate on it; it then illustrates the methodology used in the empirical part of the work. The first part provides the background for the second one, concerning the original research findings. The latter, after presenting the research design, examines the overall context of community care in Lombardy and then focus on three major themes: the utilisation of the services, their outcomes and their costs.

Preface

The provision of publicly funded long-term care services is extremely low in Italy, and it is uneven across the country. Relatives have traditionally provided by far the great part of the care for the elderly, because family culture defines care to be a private issue. According to a recent OECD estimate, the share of the Italian population aged 65 and over receiving public formal help at home is 2.8 per cent and the percentage of those belonging to the same age group receiving long-term care in institutions is 3.9 per cent (Jacobzone, 1999). Privately paid services are increasingly emerging as a key source of care for dependent elderly, as 4.2 per cent of the families containing a person aged 65 and over accessed paid personal assistance for frail elderly (Istat, 2001). Against a background of scarcity of public services, the nineties witnessed a growth in their provision and an increased interest paid to them.

There are two publicly funded domiciliary services for the elderly in Italy: integrated domiciliary care and home help. The integrated domiciliary care (*assistenza domiciliare integrata, ADI*) is intended to become the main pillar of the Italian community care for the elderly. ADI is the subject of this thesis. In the *assistenza domiciliare integrata* both home help (social care), and health home care (home nursing and physiotherapy) are made available to the user at home. *ADI* encompasses a wide range of care inputs, and the packages of care provided can be substantially different from one another. The municipalities provide home help and the local health authorities provide home nursing and physiotherapy. The latter are also in charge of co-ordinating the overall provision of integrated domiciliary care. The delivery of home help inputs is both needs-tested and means-tested, whereas health care inputs are only needs-tested. Users receiving the former are often requested to pay a charge, health care inputs being free of charge. ADI is targeted towards users with multiple and complex needs, for whom a tailored package of care is designed. The *unità valutativa geriatrica* (UVG), an assessment and planning unit composed of social and health professionals initially assesses claimants' conditions, the team leader being an health professional. Depending on the users' needs, the unit sets up the most appropriate care plan (that is only domiciliary health services, only home help or both of these services) and monitors the elderly situation over time, modifying the plan if necessary. Along with the availability of different care inputs and the possibility of designing specific packages, the reassessment of users' conditions over-time (with the possibility of modifying the care plan) is at the core of the ADI logic. The UVG performs most of the core tasks of care management: assessment, care planning and monitoring of circumstances over time, modifying the package of care if necessary.

The thesis is based on an original study of the *assistenza domiciliare integrata* in three local health authorities of Lombardy, a region in Northern Italy. It is based on a primary analysis of a quantitative data set gathered as part of the research. The data were gathered by means of interviews with ADI users aged 65 and over, their principal informal caregivers (PICs) and the professionals involved at different points in time. Each new user and his or her principal informal carer were interviewed (alone) at the time of commencement of ADI provision, in order to map the formal and informal care inputs provided, and to investigate the conditions of PICs and other people (especially paid carers) involved in supporting the elderly. In the process of assessing the case and setting up the care plan, ADI professionals administered a questionnaire designed to gather general information on users and to assess their dependency, cognitive impairments and depression, to obtain information on the process from the referral to the setting up of the plan and on the plan itself, and finally to know the opinion of the UVG's members about the setting up process, the plan and its potential benefits. At the time users started to receive ADI, geriatricians or general practitioners involved in the service administered a questionnaire to evaluate their health conditions. Some three months after the users started to receive ADI, those still receiving it and their principal informal carers were again interviewed (alone) by IRS employees. The interviews gathered information about users' and carers' subjective experience of ADI, their satisfaction with it, their unmet needs and the perceived impact of ADI; and the (formal and informal) care inputs provided. Some six months after they began to receive ADI, a telephone follow-up with elderly and PICs was conducted to investigate the conditions of the elderly taking part in the project who were still alive. Interviews were conducted with both those still receiving the service and with those who were not. For the whole research period during which users received the service, the ADI professionals administered a questionnaire which tracked the resource inputs provided over time. It recorded the typology and the amount of care inputs provided.

The fieldwork created a huge dataset. This was analysed using a range of statistical techniques. The analyses applied the intellectual framework, logic and tools provided by the "Production of Welfare" (POW) approach, developed at the Personal Social Services Research Unit (PSSRU) from mid-1970s. The core idea of the approach is that system outputs are determined by resource inputs and non-resource inputs. It discusses and explains the relations between need-related circumstances of recipients and potential recipients, resources and outputs. It aims to research equity and efficiency, and the use of resources in community and long-term care related areas. The POW deals with a series of questions about who gets how much of what support and resources, at what costs to whom, and with what effects of evaluative significance. The approach looks at the relationships between components involved in the "Production of Welfare"; particularly inputs, including resource inputs (such as buildings and staff), and "non-resource inputs" (such as client characteristics and management procedures).

We chose this approach because it is particularly suitable for researching three main issues: service utilisation, outcomes and costs. These issues constitute the main research questions we aim to address in this thesis.

- The first question is "who gets what?". That requires the analysis of service utilisation. The subject will be approached from different perspectives. We are interested in the processes by which care resources are allocated, in their comparison with users and carers' needs and in geographical variations. We will, thus, deal with the following questions: "how to govern community care?", "what care inputs are most appropriate for what needs?" and "what are the geographical differences in the care provided?".
- The second research question is "with what effects?"; that is what are the outcomes of ADI care and how individual inputs affect them. The goal is to understand what are the effects of the services provided and what are their causes. We seek to detect the effects of variations in inputs on outcomes. In the outcome analysis, we will compare the views of the three main players involved in ADI: users, carers and professionals.
- The third research question is about the costs of ADI. The different kind of costs involved in community care are considered (direct, indirect and intangible costs), and the different stakeholders that bear them (users in different circumstances, informal carers, public services and private professionals). We shall compare the costs of ADI with those of alternative modes of delivery, hospital and residential care. We shall also discuss the costs of alternative allocative strategies.

The development and nature of the Italian debate on community care provide an important rationale for focusing on these research questions. The debate substantially improved in the nineties, but it concentrated on some topics (such as organisation and management) at the expense of others, such as services' utilisation, outcomes and costs. The latter are indubitably key policy issues, but they have been neglected by the Italian literature. Our understanding of the Italian community care system, and our capability to draw valid policy implications, would greatly benefit from a deeper investigation of these neglected issues. The over-arching rationale for the thesis is to cover policy issues of particular relevance for Italy that, until now, have not received the attention they deserve.

The thesis is divided into two parts. The first part discusses the policy towards the frail elderly in Italy and Lombardy and the debate on it; it then illustrates the methodology used in the empirical section of our work. Chapter 1 is devoted to an analysis of long-term care for the elderly in Italy and Lombardy. After presenting the main trends on age, disability and care needs, it discusses the public policies towards the frail elderly and the provision of private care. It then examines the situation in Lombardy and especially in the three local health authorities we studied. Chapter 2 presents and discusses the main issues concerning the Italian system of community care. Initially, it provides an overview on the Italian debate on community care so as to locate our effort in context. It then raises what we reckon to be the main policy issues about who receives ADI, the care process, outcomes and costs. Chapter 3 introduces the "Production of Welfare approach" (POW), which provides the theoretical framework and the methodology we used to conduct the project. The main concepts and analytical tools of the approach are introduced. The chapter also states some of the reasons why we believe that the approach can be successfully applied in the Italian context. Chapter 4 presents the research design. It describes the target groups of the project sampling, and the several steps of the fieldwork; finally, the chapter states the research questions.

The first part of the thesis provides the background for the second one, whose focus is the research findings. The discussion of our original results begins in Chapter 5. Its focus is users' characteristics and the formal and informal care inputs they receive. It analyses the needs-related circumstance of users and informal carers and the care inputs they provide, the circumstances and inputs of the privately paid assistants and of voluntary organisations, and the characteristics and quantity of ADI care inputs. Chapter 6 examines the utilisation of ADI, tackling it from different perspectives. It looks at the process through which resources are allocated, at their comparison with users and carers' needs, and at the decisions made about them. The overall aim is to examine how public resources should be allocated and how the allocation process works. Chapter 7 tackles several questions concerning ADI outcomes, from six domains: destinational outcomes, consumption of public resources, impact on health conditions and dependency, impact on psychological conditions, satisfaction with the service. It shows the results of ADI and illustrates what are the outcomes of variations in service inputs and users and carers circumstances. Chapter 8 analyses the costs of the *assistenza domiciliare integrata*. It looks at the different costs (direct, indirect, intangible) borne by the stakeholders, the stakeholders involved being users in different conditions, informal carers, public services and private professionals. It compares the costs of ADI with those of two alternative modes of delivery and compares different strategies in resources' allocation, their costs and outcomes. Chapters 6, 7 and 8 discuss respectively the three research questions presented above. The conclusions aim to exploit the findings of the empirical research in order to formulate policy implications and indications. The thesis also has three appendixes. Appendix 1 contains the questionnaires used in the fieldwork, appendix 2 a detailed description of the different steps of the PhD and appendix 3 some tables presenting additional evidence from our fieldwork.

The fieldwork was long, and comprised several steps. There were a number of difficulties and unexpected obstacles to overcome. A huge effort was required to complete it. The following words, used in the preface of a recent POW study on community care in Britain, are true for our own work as well: "By far the greater part of the effort of the project has been in design and collection, not the drafting of the final analyses and publications. It is one of the differences between the economics of this and of secondary analyses or most collections by consortia" (Davies, Fernandez, 2000, p *xxvii*). Furthermore, it is to be noticed that our project was placed in Italy, a country where it is particularly difficult to conduct social policy research based on the setting up of original and wide data sets. It is a country where it is extremely complex to conduct any kind of evidence-based research on social policy. We could conduct this project only because of the help obtained by several sources, mostly thanks to the support of the *Istituto per la Ricerca Sociale (IRS)* of Milan, an Italian leading Institution committed to the research of social and health policy the candidate has been working for years. Without the great support provided by the Institute, and the colleagues there, this project would have never been possible. The Director, Emanuele Ranci Ortigosa, persuaded the three local health authorities to take part in the project and to contribute to its funding. Each authority contributed to the project with 35.000.000 Lire (some £ 11.000). Also the National Research Council *(Consiglio Nazionale delle Ricerche)* provided 60.000.000 Lire (some £ 19.000). The overall funds obtained amounted to 165.000.000 (some £ 52.000). The funds were used to pay for interviewers, the work of IRS colleagues, the work of the candidate's research assistant, and secretarial and organisational costs borne by the Italian Institute. The PhD was, therefore, the result of a joint effort of the supervisors at the LSE, who led the project, and of the Italian Institute to whom the candidate belongs.

The work at the LSE took place in both the Department of Social Policy and the Personal Social Services Research Unit (PSSRU). The candidate was originally supervised by Howard Glennerster, who mostly followed the work in the first year and later on read the draft of several chapters and made comments on them. Since the end of the first year the lead of the PhD was taken by PSSRU, earlier Martin Knapp and for most of the time Bleddyn Davies. Both of them, especially the latter, supervised the work in the design process, the fieldwork and the data analysis. The candidate also obtained a lot of help from others scholars at PSSRU, especially Jose Fernandez.

In Italy the candidate obtained advices several times from Maria Chiara Setti Bassanini, senior research fellow at IRS and Emanuele Ranci Ortigosa. Their involvement in the project - as any other form of involvement from IRS - was previously agreed with the LSE supervisors. At different steps of the research process, the candidate received help from two consultants. Claudio Castegnaro, from IRS, helped the candidate in preparing the questionnaires and in setting up the instrumentation for inserting the data in the computer and analysing them. Clara Colombo, a geriatrician working in the Local Health Authority of Lecco, advised the candidate on how to use the scale for assessing the elderly conditions and helped the candidate in introducing the questionnaires to the professionals involved in the project. Giorgia Andreoli, an MA student, was the candidate's research assistant, who supported him in the organisation and management of the field collection. At some stages she was supported by Katia Avanzini.

The candidate has been a member of the IRS since 1995 and is now a senior research fellow there. The Institute provided him with a lot of organisational support through all the steps of the project, from finding the areas where to run it, to set it up and to manage it over time. IRS gave to the candidate a strong intellectual support as well, thanks to the advice provided, the number of discussions he had on the project with several colleagues and, more generally, its stimulating environment.

The interviews with users and principal informal caregivers were conducted – as stated above – by IRS employees specifically trained. The candidate was in charge of training the interviewers in two initial meetings and a number of meetings were held with them over time in order to monitor the development of the fieldwork. ADI professionals were strongly involved and did a considerable amount of work, as in the initial assessment and care planning phase they administered a complex questionnaire aimed to obtain information on the new users and for the whole length of the project they administered a questionnaire which tracked the typology and amount of care inputs provided.

General practitioners and geriatricians were involved as well, as they administered a questionnaire aimed to evaluate the health conditions of the new ADI users. ADI professionals, general practitioners and geriatricians were specifically trained to meet the project's requirements by Clara Colombo and the candidate. Each district appointed its own project's responsible, in charge of co-ordinating the local effort and acting as the liaison with the research team. Each authority involved appointed its own responsible for the project: they were the three managers in charge of ADI. Each of them appointed his/her deputy as the organisational liaison with the research team. The deputies were the persons we worked with in order to face the problems met throughout the project. We set up a working group composed by myself, the three managers and their deputies (and in the initial steps Emanuele Ranci Ortigosa as well), which met at the crucial stages of the project in order to discuss the main issues, both at the stage of the research design, of the fieldwork and of the data analysis.

Several human and economic resources were, thus, involved in the different stages of this project (a description of the different steps of the PhD process and of their timing is provided in appendix 2). Even with such a support, the burden on the candidate's shoulders was really high (and by far stronger than originally expected).

As it made clear above, the thesis is the outcome of an effort that saw several people and institutions involved. Without the contribution of each of them, it would have not been possible to complete it. I am deeply grateful to Bleddyn Davies, Martin Knapp and Howard Glennerster for the advices, suggestions and support they gave me at any step of the PhD. The support of the Instituto per la Ricerca Sociale, especially of its Director, Emanuele Ranci Ortigosa was invaluable as well. I am particularly thankful to the many professionals that contributed to the project, usually giving up urgent and more important tasks.

Part I

Policies, debate and methodology

Chapter 1

Long-term care for the elderly in Italy and Lombardy

1. Introduction

The ageing of the Italian population has been marked and rapid over recent years and the country is now one of the oldest in Europe. Along with the growth of the elderly, the support provided by family networks – which traditionally bear the burden of caring for the aged – has been decreasing. These two trends are far from ending, and the demand of public interventions for the frail elderly is likely to increase in the incoming years. Against this background, the Italian policies towards this group of people are underdeveloped by both quantitative and qualitative standards. The provision of domiciliary and residential care is scarce and extremely uneven throughout the country and, in the absence of clear evidence, there are also several doubts about the effectiveness and efficiency of the policies. Relatives have traditionally provided by far the greatest part of the care for the elderly, and Italy has been characterised by a family culture definitely considering care a private issue. But the family is now under stress, and does not support the elderly as much as it did in the past.

This chapter aims to discuss the provision of long-term care for the elderly in Italy. As a background, section two discusses elderly disability and care needs in the Mediterranean country. Section three examines the public policies towards older people, and section four concentrates on the private provision of paid care. Finally, we will discuss the situation in Lombardy, particularly in the three local health authorities involved in the project.

2. Ageing, disability and care needs in Italy

Italy has been experiencing a strong ageing process and this trend is going to strengthen in the next few decades. Such a trend is placing the Mediterranean country as one of the "greyest" in Europe. Table 1 presents the current situation of Italy and other European countries and some predicted trends for the coming decades. It emerges that Italy is currently the oldest country among those considered (they are representative of the different parts of Europe). Persons aged 65 and over are 18 per cent of the overall population, while the average of the countries considered was 16.4 per cent.

The percentage of elderly is higher in Italy than in any of the other countries and it is going to be the case in the future as well. The predictions concerning years 2010 and 2030 show that the pace of the ageing trend is going to be in the Mediterranean country quicker than elsewhere. What strikes in these data are the huge differences predicted between Italy and other European countries in the future. According to Table 1, in 2030 the percentage of persons aged 65 and over will be 4.4 points higher in Italy than in the UK and 8.4 points higher than in Denmark. The only country with a similar demographic profile will be Germany.

Table 1 – Persons aged 65 and over as percentage of the overall population, various countries, various years

	2000	2010	2030
Germany	16.1	19.9	26.7
UK	15.6	16.1	22.6
France	15.9	16.8	24.2
Italy	*18.0*	*20.4*	*27.0*
Spain	16.7	17.9	n.a.
Denmark	14.7	15.3	18.6
Finland	14.8	17.0	23.9
Sweden	17.3	19.2	23.9
Average	**16.4**	**18.3**	**24.9**

Source: *Eurostat.*

From a policy perspective, it is of great importance how the elderly population is divided into different age-bands. The presence of a tight association between age and disability is well known: the older a person, the higher the likelihood of being disabled. Italian data presented in Table 5 clearly shows it. The percentage of disabled people is 9.3 for those aged 65-74 and rises to 47.5 for those aged 80 and over. It is, thus, crucial to look at the size of the two groups and at the predictions concerning both of them. Those aged 65 and over are currently 18 per cent of the overall population and those aged 80 and over are 3.8 per cent: the ratio between the two groups is 22. That is to say that currently one out of five elderly is aged 80 and more. The latter group is going to grow at a faster pace than the other, expected to rise to 5.9 of the population in 2010 and to 9.7 in 2030. If we fix the 2000 percentage to 100, in fact, we note it raises to 155 in 2010 and 255 in 2030. Persons aged 65 and over, instead, rise to 113 in 2010 and 150 in 2030. The message for the policy debate is that the group of those with by far a higher likelihood to be disabled is expected to grow a lot, more and more than the overall elderly population. In absolute terms, it means a growth from 2.265.000 to 3.472.000 (year 2010) and to 5.775.000 (2030). The consequences with respect to the demand of long-term care cannot be underestimated.

Table 2 - Persons aged 65 and over and 80 and over as percentage of the overall population, Italy, various years

	2000	2010	2030
Persons aged 65 and over	18.0	20.4	27.0
Persons aged 80 and over	3.8	5.9	9.7
Number of persons aged 80 and over	2.265.000	3.472.000	5.775.000
Ratio 80+/65+	0.22	0.29	0.36

Source: *Author's elaboration on Istat, 1999.*

Italy is a country distinguished by deep differences between areas. These differences are not only cultural, social and economic but also demographic. Our picture of the Italian demographic characteristics cannot be complete if we take only data regarding the whole country into consideration, and we need to look at the different areas separately. In 1998, the percentage of people aged 65 and over was 17.4 per cent nationally but there were huge differences between the northern and central areas and the south. While the former was between 18.5-19.0 per cent, the latter was less than 15 per cent (Table 3). The percentage of elderly people is lower in the south than in the rest of the country.

Lombardy, the subject of our empirical research, belongs to the North West of the country but its percentage of elderly population is a bit smaller (17.5 per cent) and in line with the Italian average. Also the demographic predictions for the future of Lombardy are quite consistent with those concerning the whole country (Blangiardo, 2000).

The dependency ratio, the number of elderly (65 and over) per 100 children (0 to 14 years old), provides an appropriate indicator to analyse the differences between geographical areas. The national ratio was 46 in 1971 and 122 in 1998. This clearly indicates the "greying" trend that has characterised Italy over the decades. Analysing the dependency ratio, geographical differences appear clearly both in the past and at present. In 1971 there was already a sharp difference between North and Centre (whose ratios were 55 and 52 respectively) and the South (whose ratio was 35). Almost twenty years later, the difference has widened: the North and Centre ratios are 154 and 148 respectively, whereas the Southern one is 85. We infer that the entire country is facing a rapid ageing of population, but this process is at different stages depending on the region. It looks far more advanced in northern and central Italy compared with the southern part of the country (Table 4).

Table 3 - Persons aged 65 and over as percentage of the overall population by geographical area, Italy, 1998

North West	18.5
North East	19.3
Centre	19.0
South and Islands	14.8
Italy	**17.4**

Source: *Istat, 1999.*

Table 4 – Ratio of persons aged 65 and over to 100 children (aged under 14) by geographical area, Italy, 1971-1998

Area	1971	1998
North	55	154
Centre	52	148
South	35	85
Italy	**46**	**122**

Source: *Irer, 1999.*

The ageing process has increased the number of disabled people in the overall population. Disability is highly associated with age. The percentage of people aged 65 and over disabled[1] in Italy is 19.6. Within the elderly, the proportion of disabled grows dramatically with age. The disabled comprise 19.6 of those aged 65 and over, 33.5 of those aged 75 and over and 47.5 per cent of those aged 80 and over (Table 5). Data presented in Table 5 have to be considered along with those concerning demographic predictions presented in Table 2. Due to the increasing number of elderly (in particular the very oldest groups) and the association between age and disability, care needs of frail elderly have greatly increased in the past years and are likely to grow enormously in the near future.

---

[1] Istat defines as "disabled" people declaring to have a severe limitation in at least one activity of daily living such as personal care, walking, speaking, hearing and seeing;

Table 5 – Percentage of disabled elderly by class of age, Italy, 1999

Class of age	Disabled
65+	19.6
75+	33.4
80+	47.5

Source: *Author's elaboration on Istat, 1999.*

3. Public policies towards frail older people

3.1 The context

Long-term care is defined as "all the forms of continuing personal or nursing care and associated domestic services for people who are unable to look after themselves without some degree of support, whether provided in their own homes, at a day centre, or in an NHS or care home setting" (Laing, 1993, p. 18). Public long-term care for the frail elderly is delivered by health and personal social services. It comprises three main sources of care: community care, residential care and payments for care. After introducing the policy context, we will turn to the main features of each of the three sources.

The National Health Service (*Servizio Sanitario Nazionale*) was established in 1978. It was intended to be universalistic, to provide care to all citizens according to their needs, and to be primarily funded out of taxation. More than twenty years later, the health service is characterised by huge co-payments and a relevant part of its funds stems from social contributions. Both social contributions and taxes that fund the National Health Service used to be collected at the national level. In recent years a great part of the responsibility to fund the public service has been shifted to a regional level[2]. The private sector has a key role in the delivery of public services: there is a significant presence of private providers of publicly funded services. The planning and management of health care has over the years been substantially devolved from the centre to the local level. The national government enacts the fundamental legislation and sets overall aims and general rules, while the twenty regional authorities have a strong power in determining – through their own laws and regulation - the way in which the health services are actually provided. These services are managed by local health authorities, which either deliver them directly or purchase them from other (public or private) providers. During the nineties, the authorities have gained more and more autonomy in managing the services and in deciding how to allocate the resources. The local health authorities are in charge of home nursing, residential health care and other long-term care services for the elderly. The health community services are usually managed by the districts, sub-units of the local health authorities (a clear introduction to the *Servizio Sanitario Nazionale* is provided by Mapelli, 1999).

---

[2] Italy is divided in 20 Regions with their own government.

Personal social services have traditionally been the "Cinderella" of the Italian welfare state. A small amount of public resources is devoted to them, and there are huge differences among the areas of country in the quality and quantity of the services provided; there is a North-South divide, with the provision being greater in the former area than in the latter. As in other Mediterranean countries, according to the Italian culture the care of a person (child, disabled, elderly) is a family task and responsibility, and the state should intervene only as the last resort, when no other option is available (Saraceno, 1998). Personal social services have traditionally been both regulated and managed at a local level, as there was not any national legislation on whether, how and for what aims they should be provided. A framework national law was enacted in November 2000 (Bill 312/2000) and it was actually the first of this kind. The framework legislation it replaced was enacted in 1890. The bill comprises a number of aims and takes several issues into consideration. It declares the goal to be to set a minimum level of social care services to be provided over the entire country, but the tools (financial and normative) provided to pursue this goal are weak. It is widely believed that the new national law will not decrease territorial differences in the provision of personal social services. A more important aspect of the new law consists in the fact that it raises the amount of public resources devoted to personal social services. Despite this increase, provision remains low falls a long way short of meeting the needs of the Italian situation. The delivery of services is mostly regulated by regional legislation, but even within the same region provision tends to differ substantially among the municipalities. The latter are in charge of managing personal social services, either delivering them directly or - as is now more common - contracting them out to private (mostly non-profit) providers. The municipalities - no longer the key actors in providing personal social services – have the leading role in deciding what are the policy aims and how to allocate the public resources. The municipalities are in charge of home help, residential social care and other long-term services for the elderly. Personal social services are funded both from national and local taxation: while the former has been traditionally dominant, the latter has substantially increased over the nineties (a clear introduction to personal social services in Italy is provided by Ferrario, 2001).

3.2 Community care

There are two main publicly-funded domiciliary services for the elderly in Italy: integrated domiciliary care and home help. The integrated domiciliary care (*Assistenza Domiciliare Integrata, ADI*) is intended to become the main pillar of the Italian community care for the elderly. It is the subject of our empirical research. In this service both home help (social care), and health home care (home nursing and physiotherapy) are made available to the user at home. *ADI* encompasses in turn a wide range of care inputs and the packages of care provided can be substantially different from one another. Home help is provided by the municipalities, while home nursing and physiotherapy is provided by the local health authorities. The latter are also in charge of co-ordinating the overall provision of integrated domiciliary care. The delivery of home help inputs is both needs-tested and means-tested, whereas health care inputs are delivered only according to claimants' needs. Users receiving the former are often requested to pay a charge, but health care inputs are free. Even if we lack evidence at a national level, the findings of several projects are completely consistent in showing that the overall majority of ADI users receive only health care inputs (Presidenza del Consiglio dei Ministri – Dipartimento per gli Affari Sociali, 1999 and 2001; Censis, 1998; Abate, Bavazzano and Di Iorio, 1996).

The intention is that ADI should be targeted towards users with multiple and complex needs, for whom a tailored package of care is designed. Claimants' conditions are initially assessed by the *unità valutativa geriatrica (UVG)*, an assessment and planning unit composed of social and health professionals (the key person is one of the latter). Depending on the user's needs, the unit sets up the most appropriate care plan (i.e. only domiciliary health services, only home help or both of them) and monitors the situation over time, modifying the plan if necessary. Along with the availability of different care inputs and the possibility of designing specific packages, the reassessment of users' conditions over time (with the possibility to modify the care plan) lies at the centre of the ADI framework. The UVG performs several core tasks of care management: assessment, care planning and monitoring of circumstances over time, modifying the package of care if necessary. However it must be stressed that, in practice, the UVG focuses mostly on the initial assessment and care planning and its performance of monitoring and review is often weak and inconsistent. The main features of the *Assistenza Domiciliare Integrata* are summarised in Box 1.

Box 1 – ADI's main features

Services provided: packages of social and health services (mostly nursing and physiotherapy); often only health ones. Social care inputs are needs-tested and means-tested, and a charge can be required. Health inputs are only needs-tested and are free.

By whom: municipalities (social care) and local health authorities (health care). The organisation and delivery of ADI is lead by the health authorities.

Collaboration: the relationships between municipalities and local health authorities are extremely various both in the kind of formal arrangements and in the informal content.

Unit of assessment and planning: users' conditions are initially assessed by the UVG, which sets up the package of care, monitors the provision over time, and modifies the package if necessary. UVGs tend to focus mostly on assessment and care planning.

Integrated domiciliary care was introduced in Italy in the early nineties: at the national level, the key document was the project "Caring for the Frail Elderly", included in the 1992-1994 National Health Plan. This document had a huge impact in stimulating the development of ADI and designing the overall structure of the service. No other document of this kind has since been produced at national level. The 1992 Plan states that the *unità valutativa geriatrica (UVG)* should benefit from the contributions of different kinds of professionals, and should be composed of a geriatrician, a nurse and a social worker. The three professionals should compose the core group, assessing all the users. When the user's characteristics make it necessary, other professionals can be involved in the work of the unit, such as a neurologist, a physiotherapist and others. The idea is to set up the core group (geriatrician, nurse and social worker) and then to request the intervention of other professionals when necessary. According to the 1992 Plan, the general practitioners should keep on being the main reference for the health care provided to the elderly at home and he/she is responsible for the final approval of the care plan designed by the UVG (he/she can indicate the changes he/she reckons are necessary). The framework suggested by the plan relies upon a tight link between the UVG and the general practitioners and assigns to the latter the ultimate power to decide what is the best care for the elderly. The 1992 Plan states that ADI should ensure the following annual average standards for users: 140 hours of home help, 100 hours of home nursing, 50 hours of rehabilitation and 50 visits of the general practitioner. A target of the 2 per cent of the population aged 65 and over to receive ADI by 1997 was set (Department of Health, 1992).

The Plan was not always consistent (and its standards were not really clarified) but it had a huge impact in raising interest in ADI and it spurred the regional governments and the local health authorities to promote this new service. In some areas of the country ADI was – with different forms and names – already in place before 1992 but in most of the country it started after the plan's publication. In the 1990s, the service grew and the number of users' increased but – at the end of the decade – we can state that the development of the service was, in both quantitative and qualitative terms, smaller than expected. At the beginning of the new decade, in fact, its provision is still extremely underdeveloped and uneven. There are huge differences between regions and between Local Health Authorities regarding the amount of resources devoted to ADI, the number of users and how this service is actually organised and works; the composition of the UVG, for instance, is extremely variable. Nowadays, services that differ with respect to several traits are all grouped under the same name *Assistenza domiciliare Integrata.* Furthermore, the supply to the same household of home help and domiciliary health services is quite uncommon. This is due to two main causes: the traditional difficult relationship between health and social services and the fact that whereas the former are provided only according to users' needs (the financial situation of the elderly and his/her family is not considered) and without any charge, the latter are strictly means-tested and charged. In most cases, what is supposed to be integrated domiciliary care is actually just domiciliary health care.

In the absence of data for the whole of Italy, Table 6 presents the percentage of people aged 65 and over receiving ADI in some local health authorities located in different part of the country[3]. It shows the big differences in the percentage of elderly receiving ADI. In the provision of this service, there are two kinds of territorial inequalities: differences between the main regions and differences within these regions. There is greater provision of services in the North than in the South, and in each area the provision of services differs substantially among the municipalities and the local health authorities. It is really difficult to estimate a national average percentage of ADI users (or of community care users) as in Italy there is no information system to collect these data. According to a recent OECD project, the Italian share of the population aged 65 and over receiving formal help at home is 2.8 per cent; this datum comprises both ADI and home help (Jacobzone, 1999). It would not be appropriate to trust this datum too much but it is useful in providing a rough idea of the scarce provision of community care in Italy. The situation of this country is quite similar to the other Mediterranean countries: in Spain, for example, the share of population aged 65 and over receiving formal help at home is 1.6 per cent. In the rest of Europe, the coverage is far higher: 6.1 per cent in France, 9.6 per cent in Germany, 17 per cent in Norway, 5.5 per cent in the United Kingdom (Jacobzone, 1999). Of the Italian 2.8 per cent, it is reasonable to state that at least 1.5 per cent (maybe a bit more) gets ADI, and the others get home help.

Against this landscape, the provision of ADI is definitely going to increase over the next few years: both the Department of Health and the regional authorities are pushing in this direction. In recent years there has been a growth in the amount of resources devoted to ADI and it is expected to continue in the coming years as well.

Home help is the other main pillar of the Italian domiciliary care, and municipalities run it. It can be provided as part of the ADI package or autonomously, the latter being most common. It has a history longer than ADI, as the first services were set up in some northern cities in the early 1970s (but in the South it began to develop only in the late 1980s). As for ADI, the development of this service has been extremely uneven, and some municipalities still do not provide it (Kazepov, 1996). The last decade was characterised by a widespread introduction of charges and increasing use of means-testing of home help. Charging affects not only the applicants but also their relatives. The Civil Code states that if someone is not able to maintain himself or herself, his or her relatives (husband/wife, siblings, brothers/sisters, brothers/ sisters in law, parents and parents in law) must "provide him or her with alimonies" (art. 433). With reference to personal social services, this statement tends to be interpreted in the sense that relatives' financial situation must be taken into consideration in deciding both whether or not to charge a user and who is going to pay his/her charges; if the user cannot afford them, relatives are often forced to pay (if they are sufficiently well-off). The charging policy (and its consequences) has recently been one of the most hotly debated issues (Prospettive Assistenziali (editorial), 1999). Another main trend of the 1990s consisted of contracting out the delivery of personal social services to private (mostly non-profit) providers. Most

---

[3] These are some of the local health authorities included in the project conducted by Abate, Bavazzano and Di Iorio (Abate, Bavazzano and Di Iorio, 1997).

home help provision is currently contracted out, and this policy is increasingly common in domiciliary health care as well. The actual capability of the municipalities to regulate and control the publicly-funded provision of contracted out social care services is another main theme of the current debate (Gori, 2002).

The supply of home care is inadequate to meet population needs. It is extremely uneven across the country and – as is the case for ADI – the provision is higher in the North than in the South, and also within the two areas there are relevant differences. Data presented in Table 7, concerning some cities involved in a project led by the Istituto per la Ricerca Sociale, show these features (note that Naples was the only Southern city involved in the project and Rome the only city located in the central part of the country) (Table 7). We lack national reliable data on home help users. Relying upon the OECD datum introduced above, we can state that, of the 2.8 per cent share of population aged 65 and over receiving formal help at home, some 1.0-1.3 per cent receive home help (Jacobzone, 1999). In this context of a growing elderly population and scarce provision of public home care, the provision of home help by untrained assistants, often coming from countries outside the EU, paid by the elderly and their families is now very common. In most cases these assistants are paid in an informal and illegal way (see paragraph 4). As for ADI, nevertheless, it is reasonable to predict a growth of public economic resources devoted to home help. A part of the new resources introduced by the national framework law on personal social services (328/2000) will be probably be devoted to home help for the elderly.

Table 6 – Percentage person aged 65 and over receiving integrated domiciliary care, various local health authorities, 1997.

Health Authority/Region	%
Terni/Umbria	3.9
Asola/Lombardia	2.4
Chioggia/Veneto	2.4
Bologna/Emilia Romagna	1.7
Part of Rome/Lazio	1,6
Matera/Basilicata	1.2
Caserta/Campania	1.1
Lamezia/Calabria	1.1
Reggio Emilia/ Emilia Romagna	1.0
Torino/Piemonte	0.7
Savona/Liguria	0.4
Prato/Tuscany	0.3
Cosenza/Calabria	0.1

Source: *Department of Health, 1998.*

Table 7. Percentage of persons aged 65 and over receiving home help, various municipalities, 1997.

Municipality	%
Bologna	1.5
Venice	1.4
Milan	1.4
Truest	1.0
Genoa	0.5
Turin	0.5
Rome	0.4
Naples	0.3

Source: *Istituto per la Ricerca Sociale, 1997.*

3.2 Residential care

As we move from community care to residential care, we note a huge variety of institutions. Residential care institution typologies vary greatly between regions, both in their denominations and features. There are nevertheless two main types: nursing homes (*Residenze Sanitarie Assistenziali, RSA*) and residential homes (*Presidi Socio Assistenziali*). The former were introduced in the late 1980s and in the 1990s, and most of the public effort has been put into their development (Rebba, 2000). They should – at least in theory - provide a medium level of health care (medical care, nursing and rehabilitative) and a high level of social care; their users are dependent people who need health care as well. The *Presidi Socio Assistenziali*, on the other hand, provide only social care for dependent people with no relevant health needs; in practice their users are on average less dependent and needy than those of the *RSAs*. The *Presidi Socio Assistenziali* are funded by the municipalities and are subject to high copayments: middle-class people living in these institutions (or their families[4]) tending to pay most of their fees if not the whole cost. As has been happening with home help, residential home care in the recent years has been characterised by a stricter and stricter means-testing and growing use of charges. Nursing homes are instead considered to be both health and social care services. Therefore a part of the costs are covered for all the users by the National Health Service while the other costs ("the social costs") are divided between municipalities and users accordingly to the financial situation of the latter (Pesaresi and Simoncelli, 1999).

Residential care was developed earlier than domiciliary care in Italy, as it was in other countries. In Italy the two services share a common characteristic: scarcity of supply. According to a recent OECD estimate, the overall percentage of elderly receiving long-term care in institutions amounts to

---

[4] For both the *Presidi Socio-Assistenziali* and the social costs of the *RSA*, users' relative are often forced to pay for him/her. This stems from what the Civil Code states, as explained in the previous paragraph.

3.9 per cent of the population aged 65 and over (this datum is probably overestimated). In France the share of the population aged 65 and over in institutions is 6.5 per cent, in Germany it is 6.8 per cent, in UK 5.1 and in Norway 6.6. Both for domiciliary care and residential care Italy has one of the lowest users' percentages of Europe, along with the other Mediterranean countries (the share of Spanish population aged 65 and over in institutions is 2.9) (Jacobzone, 1999).

It must be stressed that – in Italy as in many other countries – there is a gap between rhetoric and reality in debate and policy. The public discussion is almost completely focused on domiciliary care and on its development, but it is actually really difficult to shift resources from residential care to the community.

3.3 Payments for care

Payment for social care became an increasingly common practise across much of Europe in the 1990s and has become a major issue in the long-term care debate. There are several definitions of these payments (e.g. Weekers and Pijl, 1998; Ungerson, 1997). By payments for care we mean here the cash provided to an elderly person or to his/her family in order to meet the additional expenses due to his/her disability (Gori, 2001a). According to this definition, there are in Italy two kinds of payments for care, one provided at national level and one provided at local level. The former is a care allowance named *indennità di accompagnamento*. It is a financed by the national government and addressed to all severely disabled people, no matter their age. It is neither linked to contribution nor means-tested: it is provided locally (by local health authorities) according to claimants' needs and financed out of the general taxation. The elderly who are totally (100 per cent) non self-sufficient (i.e. find themselves unable to walk without the permanent help of a companion or are not able to carry on the actions of every day life, need continuous assistance and are not in residential care) are entitled to the care allowance on the sole basis of their disability (independently of their financial situation). The *indennità di accompagnamento* is supplied to the disabled person for the purchase of commercial services or to pass on to caregiving relatives. In order to obtain the allowance, a claimant applies to a commission of this Local Health Authority which decides whether the level of disability and care needs meet the legal definition of disability. If the commission takes a positive decision, the claimant is referred to the Provincial committee of public assistance and benefits (CPABP), which has the final word. The level of the allowance is - in comparative terms - quite high (Weekers and Pijl, 1998) and higher than that of the basic pension: it is the same for all beneficiaries: around 800.000 Lire (400 Euros) a month (2001). With the cash provided a relevant number of hours of home care per month can be purchased. If we assume that an hour of private home care costs between 14.000 and 18.000 Lire (7 and 9 Euro), 45 to 60 hours of care work can be bought monthly (11 to 15 hours weekly). At the end of 1999, 1.02 million people were receiving the *indennità di accompagnamento*, 2.2 per cent of the Italian population. Among them, 45 per cent were aged 65 and over. Within young and adult population the occurrence of the allowance was 1.4 per cent of the group, while it was as high as 5.8 per cent among the elderly. We notice here a sharp difference between those aged 66-75 years and those aged 76 years and above: the *indennità* is received by 2.1 per cent of the former and 11 per cent of the latter.

The other main type of payments for care is provided to the family according to local arrangements. Italy does not have any national legislation concerning the delivery of payments for care to the families in order to support the care of their relatives. An increasing number of local health authorities and municipalities have nevertheless been introducing such a measure (it is considered in the former a social services and in the latter a health one) from the mid-1990s, and there is a growing expectation that it will become more and more widespread over the coming years. In most cases, the cash is provided to families caring for highly dependent elderly in order to avoid their institutionalisation. The findings of a survey conducted in a representative sample of Italian cities with more than 50.000 inhabitants show to what degree the new measure is spread in the country (Gori and Torri, 2001). Table 8 summaries its findings and provides an overall view on the geographical location of care allowances. It shows that 42 per cent of Italian cities with at least 50.000 inhabitants in either the Municipality or the Local Health Authority delivers the care allowance. Looking at the geographical differences, in the Centre-North it is provided in 64 per cent per cent of the cities whereas in the South the percentage does not rise higher than 12 per cent.

Table 8

Percentage of larger cities in which the municipality and/or the local health authority provide care allowances, Italy, 2000.

	Yes	No	Total
Centre-North	64	36	100
South	12	88	100
Total	42	58	100 (N= 43)

Source: *Gori and Torri, 2001.*

4. Private care

Access to private care has become a very important issue in recent years in Italy and it is expected to become more and more relevant in the future. Though informal care is still extremely important in the Italian welfare system, there are clear signs of change. In recent years, the number of families with at least one older person supported by informal networks has diminished, while there was increasing recourse to paid care work. In 1983, 14.8 per cent of the families with at least one elderly received informal help from outside (non co-habitant relatives, neighbours and volunteers). By 1998 the proportion was 11.7 per cent. During the same period, there was increased recourse to paid home help and care (Istat, 2000). It was estimated in the mid-nineties that 10 per cent of Italian families with at least one elderly bought private services such as personal care and domestic services (De Vincenti, 1999). In 2000, according to national surveys, 1.899.000 households (8.8 per cent of all households) used private paid services such as home help, childcare, elderly and disabled care. 317.000 of these families accessed paid personal assistance for frail elderly: 4.2 per cent of the families with one person aged 65 and over and 7.5 per cent of the families with one aged 75 and over (Istat, 2001). Elderly paid care is more expensive and more intensive in comparison with other kinds of services. For example, 11 per cent of all families buying home help are provided with more than 20 hours of work per week; this share goes up to 15 per cent among families with a personal assistant for frail elderly. Furthermore the total spending of families for personal care towards the elderly and disabled is on average 640.000 Lire (320 Euros), while it is much lower for the purchase of domestic help (around 350.000 Lire, 175 Euros) (Istat, 2001). The weight of paid care is, at this time, more significant than public supply of personal services. In addition to that, demographic and social changes are likely to continue to erode the family care potential – as occurred in the past few years - and to push towards the broadening of private care market.

Some local qualitative studies highlight the characteristics of private care supply system. Individual workers dominate this market, while organisations (both for profit and non-profit) mainly work for the public sector and tend not to offer services directly to families (Ranci et al, 2000). In fact, during the nineties a considerable development of private organisations supplying home care to frail elderly took place in relation to contracting-out of services undertaken by the public sector. Nevertheless, these organisations did not contribute to the development of a private market and paid care for the elderly, which is still strongly embedded with individual suppliers. This main feature of private care supply is associated with the low qualification of workers, the slight social recognition of these jobs, and the weak position of employees.

On the demand side, there is evidence that access to paid care is associated with the financial conditions of the family. Family income is recognised as one element that may encourage recourse to private care (Weinkopf, 2001). In fact, several surveys show that higher family revenues mean, on average, a significant growth in the recourse to private home and personal services (Ranci et al, 2000; Irer, 2000). As a result, low and medium income families are probably under great pressure when care needs emerge. Moreover, given the characteristics of the care market and its high degree of fragmentation, families in need of care have to search for employees through informal networks with no guarantee of reliability, continuity and quality of care.

As an activity that takes place in the household, private care tends to elude public regulation, at least in two ways. First of all, private paid care is usually totally disconnected from the provision of public personal services. They appear to be two unconnected domains both in policy making and implementation. Secondly, the grey market has a significant weight in this sector of activity. In the field of "domestic services for families and communities" 75 per cent of all workers are estimated to belong to the grey market in Italy[5]. According to these figures, 800.000 employees out of more

---

[5] Regular jobs are all activities regularly registered for tax, contribution, administrative and statistical purposes. Many different positions are considered to be in the grey market: not only persistent activities conducted outside laws and regulations of any kind, but also occasional activities carried out by people declared unemployed (such as students, housewives, pensioners), jobs undertaken by non resident foreigners, multiple jobs not declared for tax purposes.

than one million people working in domestic services operate in the grey market and only 250.000 of them are regularly employed (Istat, 2001). Certainly, in Italy as in other Mediterranean economies, the grey market is more relevant than in other European countries (Schneider, 2001; European Commission, 1998). Nevertheless, even in the Italian context, the share of underground activities is far higher in domestic services than in other service activities (Istat, 2001). Of course, available data do not refer only to care activities towards elderly people, as within these statistics elderly care is not distinguished from childcare and other household activities. As part of the latter, care work for the elderly is likely to be highly dominated by the shadow economy. In fact, if we assume that, as previously shown, 1.900.000 families buy private home and care services it is quite clear that the number of regularly employed domestic workers – around 250.000 (Istat, 2001) -- must be far below the actual number of all workers in this sector. A further remarkable feature of the care market is the incidence of non-Italian workers (nearly 50 per cent of the regular labour force) coming in particular from countries not belonging to the European Union (Asia, Africa, East Europe) (Inps, 2001). This fact requires a careful consideration of links between care market and migration processes, both legal and illegal.

5. Long-term care for the elderly in Lombardy

Lombardy is the most populated of the 20 regions into which Italy is divided. Some 9 out of the 58 million inhabitants of Italy live in this region placed in the North of the country. The elderly are 17.5 per cent of the overall population (10.2 per cent aged 65-74 and 7.3 aged 75 and over) (2000), lower than the national average (18.0 of the Italian population is aged 65 and over, see Table 1 and 2). During the last three decades, consistently with the national scenario, Lombardy has been experiencing a sharp ageing trend and it is predicted to continue for the incoming decades; the group of those aged 75 and over, in particular, being expected to grow dramatically (Blangiardo, 2000).

The overall supply of residential care consists of nursing homes (*Residenze Sanitarie Assistenziali, RSA*), that deliver a medium level of health care (medical care, nursing and rehabilitative) and a high level of social care. Lombardy is the only Italian region where the overall provision of residential care was converted into *Residenze Sanitarie Assistenziali*, a move consistent with changing characteristics of the elderly in residential care (increasing complexity of needs and growing health needs). That is to say that in Lombardy there are not proper residential homes (*Presidi Socio Assistenziali*) any more. In the year 2000, 2.8 per cent of the elderly were in RSAs, a percentage that varies a lot across the different areas of Lombardy[6]. The elderly in nursing homes are classified into three groups: totally dependent, partially dependent and needing particular treatment for Alzheimer's disease. In the year 2000, some 73 per cent of the users were totally dependent, 25 per

---

[6] This datum, provided by the regional government of Lombardy, is probably estimated using a methodology different than that used to obtain the OECD data presented in paragraph 3.3. It is, in fact, not realistic that the the provision of residential care is in Lombardy lower than the Italian average.

cent partially dependent and 3 per cent placed in the so-called "Alzheimer Unit"; the overall majority of the users were aged 80 and over and were female (Gagliardi, 2001). As we turn to community care, we have to distinguish between home help and ADI. In 1999, the former was provided to some 1,7 per cent of the elderly whereas the latter to some 3 per cent (Contegni and Ristori, 2001). As for the rest of the country, the provision of ADI is likely to increase in the coming years, as a growing volume of public resources is devoted to it. Over the years the regional government has produced some documents regarding how this service should be organised and delivered, and to whom it should be targeted, in order to increase the consistency among services across Lombardy. The directions set in the regional documents tended to resemble the indications of the national 1992 Plan Caring for the Frail Elderly (discussed in paragraph 3.2). This effort was not particularly effective and nowadays huge differences persist among the local health authorities and within each of them among the different districts.

With reference to the provision of cash, as well as the *indennità di accompagnamento*, which is provided in the whole country under the same criteria, several municipalities have recently introduced their own care allowances as an alternative to services in kind. In the year 2000, the Regional government introduced a new care allowance (*buono socio-sanitario*). All the Local Health Authorities provide it to the elderly aged 75 and over, totally dependent and whose family income is below a threshold. Users can choose to use it as a cash allowance or as voucher to buy services from accredited providers. In the year 2000 the *buono socio-sanitario* was provided to some 1.5 per cent of those aged 75 and over and the regional government is going in the near future to devote more resources to it, and is planning to make it the cornerstone of the Lombardy community care. Along with the provision of publicly funded services, there is in Lombardy a huge presence of care for the elderly delivered by privately paid persons. According to a recent survey, 6.8 per cent of the people aged 65 and over receive. The survey shows that the likelihood of receiving private care is strongly associated to age and income: the older the person the more likely they are to receive it, and the higher the income the more likely they are to receive it (IRER, 2000).

5.1 The local health authorities of Lecco, Milano and Monza

Lombardy is divided into 15 local health authorities, with an average population of 600.000 inhabitants. The empirical part of the thesis is focused on the provision of integrated domiciliary care in three of them, selected according to two criteria: our aim to involve Authorities with different features and their own interest in taking part in the project. The local health authorities involved cover the following areas: the city of Milan (population around 1.300.000), part of Milan neighbourhood (population 1.000.000) and the area of Lecco (a town in the north of Lombardy, population around 300.000). The areas involved are quite different. Milan is an urban area, the second biggest city in Italy and the financial and economic heart of the country; it is a peculiar urban context. The Milan neighbourhood is a heterogeneous area: 3 municipalities with 80.000-120.000 inhabitants (the biggest one is Monza, where there are the Authority headquarters) and sixty-two small municipalities. In this area there are both urban sides and countryside. The Lecco area, instead, is mostly countryside with several mountainous parts. It is really difficult to assess the performance of the three Authorities in community care for the elderly. The widespread feeling in Lombardy, confirmed by our own first-hand experience, is that Milan and Milan neighbourhood have an average performance while Lecco (especially the district of Merate, whose work is quite well-known outside Lombardy as well) is probably the most advanced and innovative in the region. In the year 2000 the percentage of elderly receiving ADI was 2.7 in Milan, 2.5 in Milan neighbourhood and 3.8 in Lecco, with a regional average of 3 per cent. In the same year, the places in RSAs were in 1.3 per cent Milan, 1.4 per cent in Milan neighbourhood and 3.5 per cent in Lecco, the regional average being 2.8 per cent[7].

Each Authority is divided into several districts: the city of Milan has six, Milan neighbourhood nine and Lecco three. The district is the level where services are organised and provided, the operative level; the actual delivery of services is entirely managed by districts. There are huge differences not only among the three local health authorities but also among the districts belonging to a single authority. These relate to the way they operate and how they deliver ADI. In order to understand these differences one has to understand that the districts have traditionally been quite autonomous in the Lombardy health care system and that till 1996 a lot of those now belonging to the same Authority belonged to a different one; in that year the number of Authorities was decreased and their boundaries re-drawn.

---

[7] The data concerning the three Local Health Authorities were provided by members of their staff involved in our project.

Table 9 – Local Health Authorities involved: summary profile

Local Health Authority (Population)	Main features	Number of Districts	Percentage of elderly receiving: - ADI - RSA
Milan (1.300.000)	Urban area (Milan is the second biggest city of the country)	6	2.7 (ADI) 1.3 (RSA)
Milan neighbourhood (1.000.000)	Heterogeneous area: 3 municipalities with 80.000-120.000 inhabitants and several small municipalities (total of 62 municipalities). In this area there are both urban sides and countryside.	9	2.5 (ADI) 1.4 (RSA)
Lecco (300.000)	It is mostly countryside with several mountainous parts.	3	3,8 (ADI) 3,5 (RSA)

Chapter 2

Policy issues in community care

1. Introduction

What are the main policy issues concerning the Italian system of community care, what are their features and why are they relevant? What are the issues currently mostly debated in Italy? This chapter aims to answer these questions, raising and discussing what – are currently the key policy issues. The goal is to not cover all the themes currently debated, but to focus on those most relevant to the thesis. The policy issues raised in this chapter will be the subjects of our empirical investigation presented later in the thesis. This chapter is complementary to the previous one, which discussed long-term care policies in Italy (with particular reference to Lombardy). These two chapters (along with chapter 3 on methodology) provide the baseline material necessary in order to be well equipped to read the chapters that follow, discussing the research design and the evidence gathered for this project.

We will begin the chapter with a review of the current Italian debate on community care, regarding its development over the years and its current situation (section 2). The review will show that the topics we are mostly interested in are often overlooked in the debate. In the following three sections we will therefore focus on the most important of these policy issues; who receives ADI (section 3), the care process (section 4), and outcomes and costs (section 5).

2. The Italian debate on community care

2.1 The uncertain growth of a field

Italian research on long-term care for the elderly has traditionally been scarce, scattered and fragmented. The last decade saw it grow, and the future looks promising. Research in this area, even if still weak, is improving. Within the long-term care debate, during the nineties *assistenza domiciliare integrata* was at the centre of the stage but the future prospects for the research on the topic are not clear.

The traditional scarcity and weakness of Italian research on long-term care can be attributed to several factors. Firstly, we have to look at the general underdevelopment of this sector in Italy. There has never been great attention (or much money) for the study of a sector that has been playing a marginal role in the Italian welfare state. Additional difficulties arise from the fact that social policy has never been an academic subject in Italy, and research on it has never obtained a prominent status. Most of the research on the topic has been conducted by a few independent institutions whose resources have been small in comparison with institutions committed to the study of community care in, for example, the UK or in Scandinavia (Ranci Ortigosa, 1990).

The Italian social sciences environment has, furthermore, not been very favourable to the study of long-term care because of the lack of an evidence-based orientation. Research on social policy is characterised by the prominence of a sociological approach that has not really been evidence-based in the study of social services and a lack of interest in studying characteristics and effects of different policy options. The weakness of an evidence-based approach is closely associated with the scarcity of data. Information systems have been extremely underdeveloped and the quality of available data has, therefore, been quite weak. There is no national information system on long-term care and the systems of the different regional governments are of varying quality. On the other hand, the kind of research conducted by geriatricians has been focused on users' conditions and on the instrumentation for their assessment, without taking the wider policy logic into consideration. In the context of these trends, it is not surprising that when in 1983 a scholar from PSSRU presented the "Production of Welfare" approach at a conference held in Italy, the reaction obtained was something between amazement and indifference (Bebbington, personal communication).

The improvements in the 1990s in research on long-term care, especially on ADI, can be explained by reasons that mirror those presented above. First of all, we have been experiencing the rise of public resources committed to the care of the frail elderly (and it is quite likely that in the near future they will grow further). There is nowadays a general consensus that we need to develop this sector and that our welfare state has to re-direct resources from benefits in cash to benefits in kind. Along with it, research on social policy has fundamentally changed its features and role in the 1990s (especially in the second part of the decade). Our field of social policy is widening its space, as an autonomous area that is really different from both sociology and gerontology as they are understood and practised in Italy. The role and status of social policy research have been growing and there is increasing acknowledgement of the necessity to develop this field. The number of people employed continues to grow and this trend is likely to continue for the next years. Consistent with the increasing importance acknowledged for it, the recent reform of the Italian University system introduced social policy as a new academic subject[1]. After decades of relegation, this change is going to be really important in terms of the status that social policy gains and the influence it is going to have.

Within these overall trends of development concerning research on long-term care, and social policy in general, ADI has gone through different phases. The history of research on the *assistenza*

---

[1] The author of this thesis teaches social policy at the University of Milan-Bicocca.

domiciliare integrata can be divided into three historical stages: before the 1992 National Health Plan, the five years after the Plan's publication and the most recent years. Before the 1992 Plan, ADI was not acknowledged at a national level and the actual experiences of this kind were quite scant. In just a few Local Health Authorities were there community care services providing a mix of different care inputs and aiming to follow the developments of the elderly conditions over time. These services comprised the two main features of the then ADI: the idea to initially assess the case and to arrange a care plan composed of a mix of care inputs most suitable to the user and the idea to follow the case over time, monitoring the developments of his/her conditions and changing the care plan when necessary. Some of these experiences became well known at a national level and were among the factors that encouraged the preparation of the Plan Caring for the Frail Elderly in the 1992 National Health Plan (discussed in the previous chapter).

The Plan introduced ADI in Italy and spurred the Local Health Authorities to promote the new service: the years following its publication were the most fruitful for the debate. Those years were the "golden age" of the ADI debate, from two points of view: the quality of the ideas developed and the quantity of projects and publications. In those years, several articles and books on ADI were published, focused on discussing the local experiences in setting up the new service and making suggestions on how to develop it. During those years, the *assistenza domiciliare integrata* gained a wide interest in the research environment.

The most recent period, in contrast, witnessed a different step in the debate as the interest in ADI is fading within the research on long-term care, and other themes are replacing it at the centre of the stage. Interest is increasingly shifting towards several other topics. The most relevant are payments for care, the huge debate on the introduction of freedom of choice, the discussion on "quasi-markets" and policies to support carers. The debate on ADI is decreasing its pace, fewer articles are published and there is less effort devoted to producing ideas to innovate the service. The current diminishing interest towards the service causes a major shortcoming as there was much more research on it in the years of its inception than there is now. In order to understand what are its strengths and weaknesses, instead, a service should be examined a few years after its inception, when it has come through its "honeymoon" period and is operating on an "ordinary" basis. To put it differently, the research community is decreasing its efforts in studying ADI at exactly the time when we could get a better understanding of it.

2.2 Mapping the debate

Research on ADI flourished in the 1990s but it focused on some topics more than on others. The development of research on the *assistenza domiciliare integrata*, to put it differently, was devoted to some approaches at the expense of others. Most efforts have been dedicated to the analysis of the organisational features of ADI and to the management of the service. Scant attention, instead, has been devoted to policy issues regarding resource allocation, outcomes and costs. Studies on the organisational issues have over the years dominated research on ADI and on community care more generally (e.g. Becchi and Bernini Carri, 1998; Scortegagna, 1996; Pavan, 1999). Their prominence is due to two main causes: one is that the organisational approach belongs to the field of sociology, which in Italy has had a leading influence on research in social policy. The other cause is that this kind of study has been able to attract financial resources as local health authorities and municipalities funded them in order to obtain suggestions and arrangements that could be used to improve their own organisation. This capacity to attract resources provided the concrete opportunity to develop the studies on the organisational features of ADI. The capacity to attract financial resources is a key reason to explain the development of another important stream in research on community care, linked to the organisational one, which comprises studies on the management of ADI and how to improve it (e.g. Lucchetti, 2001). The 1990s witnessed the flourishing of this kind of work in community care as part of a more general trend experienced by the overall social (and public) policy environment. During the last decade, in fact, the managerial approach – with its own tools and logics – entered the social policy environment loudly as many reckoned it was the "holy grail" that could rescue it from most of its chronic inefficiencies. As part of this trend, there was a huge rise in research projects and in consultancy activities examining community care from a managerial point of view. The rise in the managerial studies of community care has been strictly linked to the overall effort to introduce business-like tools and approaches in social policy. Despite the warnings of several scholars and commentators, worried by the widespread tendency to introduce business-like logic and tools without paying enough attention to the peculiarities of the public sector (Battistelli, 1998), there has been a strong and pervasive trend in this direction. Within the business-like framework, the user is conceptualised as a customer and all efforts are directed to increase his/her satisfaction. Not surprisingly, therefore, recent years have witnessed the development of surveys and other tools to measure customer satisfaction of ADI users (e.g. Ambroset, 1998; Longo and Baldino, 1996).

Research on community care has instead overlooked the policy features, its implementation strategies, inputs and outcomes. While the organisational and managerial streams flourished, the more typical social policy issues (by international criteria) did not receive that much attention. A first key theme that has not generated much interest till now is resource allocation- "who gets what", and its consequences. Apart from a few efforts (Di Iorio et alii, 1996; De Ambrogio and Gori, 1997) there has not been interest in understanding utilisation patterns, in finding out whether and to what degree the care provided matches users' needs.

A gap of not minor relevance in the research literature concerns outcomes. The study of community care effectiveness, its impact on users' and carers' conditions has to now been quite underdeveloped. This is an understandable gap as it is well known that huge stumbling blocks make the study of outcomes extremely complex, with reference to both the conditions of the dependent elderly (usually in a deteriorative trend that can be only slowed down) and to the difficulties of pinpointing what are the influences on outcomes. Reflecting on this issue in 1991, Bianchi noticed that "no studies or researches have been conducted to assess the effects of home help on the conditions, quality of life, and old-age lifestyle of users" (Bianchi, 1991, p 111). Since then there were in Italy two main studies concerning effectiveness. One was an experimental project – conducted in a town of Northern Italy - comparing a group of users receiving ADI with case management arrangements and a control group of users receiving community care under the usual arrangements. The results prove that case management arrangements lead to better outcomes (concerning health, physical functions, cognitive functions, institutionalisation rates and hospitalisation rates) and lower costs[2] (Bernabei et alii, 1998; Landi, 1996). The other project was a multisite (10 towns involved across the country) experimental study comparing users receiving ADI with a control group of elderly not receiving it. The results prove that ADI is cost-effective: better outcomes (also here concerning health, physical functions, cognitive functions, institutionalisation rates and hospitalisation rates) at lower cost (Ferrucci et alii, 1996). These two projects were really important in proving the cost-effectiveness of ADI and of case management but research on outcomes still has several gaps. In particular it is important to notice that we lack evidence concerning differences in outcomes among ADI users. We now know, in other words, that receiving ADI is "better" than not receiving it, but we do not know the impact of differences in care inputs on the outcomes for different users and carers. If we know it, we could draw important policy suggestions.

The costs of ADI and community care in general constitute another overlooked topic. Few papers on the subject were published, and those that were mostly reflected upon the comparison with the costs of residential care, (Hanau, 1987; Gori, 2000; Montanelli, 1999). There have also been some papers measuring the costs of community care in specific local health authorities (e. g. Hanau, 1994) and it is known that several authorities recently conducted exercises in order to estimate their own community care unit costs (the Lecco local health authority, involved in our project, for example, did it). The point to stress is that all the empirical effort led to measures of services' unit costs, while there was no effort aimed at measuring and comparing the costs of different policy strategies. The costs analysis was, thus, part of the managerial stream so successful in the 1990s. In such a stream, the work was intended as a tool to measure and understand how to reduce costs. There was no attempt to link costs to a policy debate on the outcomes and on costs of different strategies.

In this section we mapped the Italian debate of the 1990s on ADI and community care, stressing what topics got more attention and what got less. It turned out to be an unbalanced debate, with managerial and organisational issues gaining most of the interest, at the expense of the policy issues regarding resource allocation, inputs and outcomes. An additional shortcoming regards what kind of general view on community care we obtained. There are several discussions on specific issues and services but we lack an overall debate on community care taking the whole picture into consideration. There is not in Italy a comprehensive debate looking at the needs of the elderly in the community, the different foci of their care and their connections. This is a really important gap, for

---

[2] The definition of case management arrangements is, in this project, as follows. A community geriatriac evaluation unit, composed by a geriatrician, a general practitioner, a social worker and one or more nurses, followed the case through every step of the care process, from initial assessment to case closure. Within the members of the unit, one is the case manager (and is specifically trained). She/he represents the operational arm of the geriatric evaluation unit. She/performs the initial assessment at the referral and re-assess the case every two months thereafter. Also, she/he is constantly available to deal with problems, monitor the provision of services, and to guarantee extra help as requested by patients and general practitioners.

the very simple reason that the policy reality is made up of all these elements and of their interactions. This gap deeply hinders, thus, the possibility for research to have an impact on the decision-making process and to influence the key choices.

2.3 The place of our project in the Italian debate

This brief review helps to highlight the reasons for our project and its place in the Italian debate. Our analysis of original evidence gathered in Lombardy will discuss three main issues: service utilisation ("who gets what"), outcomes ("with what effects") and resources ("at what costs"), as illustrated in chapter four. The final aim is to locate the discussions of these different issues in a common picture, in order to provide a comprehensive analysis of community care policy, drawing implications and suggestions. Our project, to put it differently, will take into consideration the policy issues traditionally overlooked by the Italian literature and discourse, mostly interested in managerial and organisational issues. The ultimate goal is to provide a contribution in order to fill what we reckon to be crucial gaps in the Italian debate on community care. To do so we will use a methodology developed, in another country, to examine utilisation, outcomes and costs (the "Production of Welfare" approach, see chapter three).

The next sections of this chapter will be devoted to raising and discussing several themes concerning the three policy issues mentioned. As the latter have not received much attention in the Italian debate, it will be possible to build our discussion upon the existing literature only to small degree. The discussion will, instead, take the shape of an original essay.

3. Who receives ADI?

Service utilisation has traditionally been a neglected issue in the Italian debate. The absence of clear eligibility and targeting criteria has been one of the most striking features of the creation of modern community care systems in many countries. This has been a key problem for a long time but over the last one or two decades it has gained increasing attention in several countries, which have developed clearer and more explicit policies regarding "who gets what". This is the case, for example, in the United Kingdom (Davies et alii, 1990, Bebbington and Davies, 1993), Sweden (Bergmark, 1997), France (Martin, Math and Renadaut, 1998) and Australia (Gibson, 1996; Fine, 1998). In Italy, in contrast, the topic has not yet received attention but, in a scenario of growing demands and constrained public resources, it is predictable that in the future the public discussion will increasingly concentrate on how to allocate public services. Even if the Italian debate on community care and *assistenza domiciliare integrata* does not pay particular attention to this issue, its main traits are clearly identifiable. The discussion on services' utilisation is composed of two main themes: who receives ADI and what package of care inputs users get. We will look at the first theme in this section, whereas the second will be discussed in the next section (as part of the discussion concerning the care process).

3.1 Scarce supply, few information, local variations

Any discussion about who receives ADI has to move from the acknowledgement of the deep gap between needs and actual public supply. This is a key feature of the Italian landscape, stressed in the previous chapter: the delivery of publicly funded community care is utterly inadequate to meet the needs of the dependent elderly. According to an OECD estimation, only 2.8 percent of Italians aged 65 and over receive public community care, of whom at least 1.5 per cent (maybe a bit more) gets ADI and the others get home help (Jacobzone, 1999). The inadequacy of the Italian system of community care in meeting the needs of the dependent elderly is widely acknowledged and there is a unanimous consensus on it among scholars (e.g. Mengani, 1995; Gori, 2000). The stark gap between needs and supply has always sat at the centre of reflections on the Italian system of community care. The fact that most of the dependent elderly living in the community do not receive any form of public care has a number of consequences for current policies and for any attempt at reform.

Many of the dependent elderly not receiving public care, actually, do not know that *assistenza domiciliare integrata* exists, neither do their families. A number of surveys conducted in different areas of Italy revealed the same finding, that a huge group of frail elderly and their families do not know the presence of a public service of community care (for a review of these surveys see Cortesi, 2001). Several reasons explain the information gap. One concerns the taste of novelty that characterises ADI. It is a new service, established nationally in 1992, that began to spread only in the second part of the 1990s. The diffusion of home help started earlier, but it has been proceeding at a very slow pace. Nowadays, many people think that public policies for the frail elderly are constituted only by residential care, a service that has been provided, in different forms, over the centuries and that everyone knows. The scarce knowledge of ADI has to be considered along with the traditional Italian culture of care, still deeply rooted in the society. According to this culture, in fact, care is a private matter that a family must deal with autonomously (Taccani (ed.), 1994 and 1996). Families have, thus, really low expectations (if any) of a public service intervention to care for their dependent relatives.

In the last decade there has been widespread acknowledgement of the lack of information for citizens on community care (such as on many other social and long-term care services) within both the research community and the policy-makers (Rossi, 1995). The outcomes of the acknowledgement have been a growing rhetoric about the necessity to improve citizens' information and strategies experimented in some local authorities in order to pursue this goal (De Ambrogio and Setti Bassanini (eds.), 1996). The experimentations have, nevertheless, concerned a small number of authorities, usually the most innovative. Taking the whole country into consideration, in fact, we notice a wide gap between the rhetoric on improving citizens' information and the actual steps taken in this direction. With respect to ADI, there continues to be a big lack of information among potential users. The point to stress here, quite underestimated in the Italian debate, is that the situation partly depends on local health authorities' own policies. A number of authorities have embraced, in their declarations, the "information ethos" but their actual policies have followed a different route. Their managers know that in the community there is a widespread "silent" demand for ADI, that is many dependent elderly that would benefit from receiving the service do not claim it. If the authorities promote information strategies within the elderly and their families, (a part) of the "silent" demand will become "loud", as many people currently not getting ADI will request it. With the resources devoted to it, nevertheless, the *assistenza domiciliare integrata* is currently already under stress in matching the existing demand. It would not be possible to handle an additional demand. Any information strategy, to summarise, would raise in many citizens (and their families) currently not getting ADI the expectations to receive the service. As the local health authorities cannot satisfy more demand than the existing one, the outcome would be to disappoint some citizens (a situation able to create problems in political terms as well). It is not convenient for the Local Health Authorities to promote information strategies and this is the reason why the rhetoric on this issue, developed in the 1990s, has produced small results (Gori, 2002a).

The scarcity of supply of *assistenza domiciliare integrata* and the information gaps within the potential users have to be examined along with another key feature, that is the vague definition of the users' target. A clear indication of what should be the needs-related circumstances of the ADI users miss and the decisions on who receives the service and who does not lean on the shoulders of the "street-level bureaucrats" (Lipksy, 1980). Neither the national legislation nor the regional ones (in Lombardy, as in several other regions) clearly indicate what should be the need-related circumstances of the ADI users. Likewise, most of the local health authorities are reluctant to clearly define who should receive the service and who should not. In the absence of any clear indication or specific guideline, decisions on service allocation are left with the professionals working at a field level, often members of the *unità valutativa geriatrica* (described in chapter 1). The task is complex, especially as in several authorities the demand for ADI outstrips the supply and there are waiting lists. Neither politicians nor managers intend to explicitly tackle the issue of "who gets what". They reckon it is an issue politically too sensitive to face explicitly and delegate it to the lower levels of the organisation. The explicit definition of priority criteria about who should receive the service is difficult not only from a political point of view but also in technical terms, due to the nature of ADI. The latter in fact, is designed as a mix of care inputs (nursing, physio, home help) intended to meet a huge and heterogeneous range of needs. The lack of explicit criteria for resource allocation and the shift of the decisions about it to the "street-level bureaucrats" are not a peculiarity of ADI. It is, instead, a trait common to most social and long-term care services in Italy (Consoli, 2001).

In this section we have discussed the key issues to consider when reflecting upon who receives the *assistenza domiciliare integrata* in Italy. They are the gap between needs and supply, the scarcity of information among potential users and the lack of clear indications regarding service targets. There is an additional topic, which crosses all the others discussed here. It is the geographical differences. Even if the issues mentioned concern most of the country, in fact, how they actually take shape differs across it. The geographical differentiation was pinpointed in the previous chapter as a key feature of community care (and long-term care more generally) in Italy. It has a key impact on several determinants of demand. The expectations of support from public services in caring for the frail elderly vary across the country, being higher in the North than in the South. The delivery of private community care, another key determinant of demand, varies substantially across different areas of the country. Also the availability of hospital beds and hospital policies of discharging vary greatly across regions (they are decided at regional level), with a strong impact on the demand for ADI.

3.2 Policy issues about who receives ADI

As we intend to set the main policy issues concerning who receives the *assistenza domiciliare integrata*, according to the arguments presented above, we will lean on the concept of target efficiency. We mean by this concept "the efficiency with which resources are allocated to and among those for whom receipt of a service has been judged the most cost-effective method of intervention" (Bebbington and Davies, 1983, p 311). There are two kinds of target efficiency: horizontal target efficiency (the degree to which the target group receives the service) and vertical target efficiency (the degree to which those receiving the service belong to the target group) (Bebbington and Davies, 1983, 1993; Davies and Challis, 1986). The discussion of the policy issues on who receives ADI can be usefully developed in terms of horizontal target efficiency. The analysis of the Italian situation leads to a main point, which is quite paradoxical. We can state that in this Mediterranean country there is a huge deficiency in regard to horizontal target efficiency. We cannot, nevertheless, describe the features of such a gap and discuss it. Many elderly that would benefit from receiving ADI do not get it, the distance between needs and actual supply was pinpointed above. We cannot move further in the critique because the *assistenza domiciliare integrata* - in most of the Italian areas - does not clearly set its target. It would be particularly complex to set the target because it is a service comprised of several care inputs (of very different nature), that can be designed in order to meet a wide range of different needs. The current vagueness in the targets and the heterogeneity of needs it can meet therefore make it currently quite difficult to discuss the improvements needed to increase the horizontal target efficiency.

We notice, thus, two key policy issues – closely interrelated – concerning the amount of resources devoted to ADI and the definition of its target. The first one concerns the growth of public resources devoted to the service. It has occurred – in recent years – in most of the country and there is a widespread consensus, shared by both scholars and decision-makers, as to the necessity to continue to increase resources in the future. The question is whether, and to what degree, such a growth will actually take place. The amount of resources devoted to ADI has a crucial impact on service utilisation and the definition of a target. Especially due to the huge current gap between supply and needs, the amount of economic resources devoted to ADI is the first policy issue to take into consideration, and it must precede any other reflection on horizontal target efficiency. The second policy issue on horizontal target efficiency concerns the definition of the target groups of the assistenza domiciliare integrata. A relevant question for the future is whether, and how, further steps towards a clearer definition of the service's target will be taken. It is not possible to be too optimists that decision-makers will move in this direction. In a context like Italy, in fact, where need outstrips supply, public services do not have much incentive in clearly defining a target group. Such a definition, in fact, could only stem from an explicit debate on priority setting in community care. Most policy-makers want to avoid such a debate, as it is a sensitive issue in political terms and it can easily create problems in terms of consensus. The improvement of ADI, and of the overall Italian long-term care system, nevertheless, needs a clearer definition of the target. The reflection on horizontal target efficiency in ADI should look at three different kinds of needs-related circumstances simultaneously: health conditions, dependency and other sources of support (mostly family and private care). The discussion on the target of ADI cannot be conducted autonomously. It has to be inserted into a wider debate concerning responsibilities and aims of the other (public and private) sources of care for the dependent elderly. Which needs ADI is called to meet depends crucially, in fact, on the other services (domiciliary-based and residential) available and on their own target's definition.

3.3 Carers as co-users

We examine in this section the key issues concerning who receives ADI, and their policy implications. Our discussion on users has been focused on the elderly themselves. The question to raise now is whether they should be considered the only users of the *assistenza domiciliare integrata*. This is actually not the case, as their informal carers should also be considered users. Several commentators suggest to conceptualise informal carers not only as source of support for the elderly but also as co-users of community care, regarded as in need of help and being themselves a target of intervention by welfare agencies. There are several reasons to support this view, the most important being the huge and demanding care responsibilities they have to carry. This is particularly true in Italy, where relatives play an utterly dominant role in caring for dependent elderly and the provision of publicly-funded services is really low. It must also be noticed that carers are bound into family relationships, they cannot simply give up when the pressure becomes too heavy to be handled (Twigg, 1993, 1996).

Interest in informal carers and the problems they suffer as a result to their caring tasks has been steadily growing in recent years in Europe (Twigg, 1996; Tjadens and Pijl (eds.), 2000). It has led to increasing requests for services of various kinds designed to support informal carers of dependent elderly people (Pickard, 1999). The actual steps taken in this direction, nevertheless, are small and faltering. In an era of growing needs and cost-containment, policies tend to lean on the carers' shoulders more than relieving them. During the 1990s, in several countries the eligibility criteria to receive community care narrowed and it was provided only to elderly without a family or whose informal carers gave up (Rostggard and Friedberg, 1998). In this perspective, informal carers are not considered users but sources of care to exploit as much as possible, whose presence often leads the dependent elderly not to receive public care (Bergmark, 1997).

Italy resembles the rest of Europe from several points of view. In the 1990s, there has been increasing interest shown towards informal carers, a growing acknowledgement of their demanding and stressful responsibilities. The actual policies implemented to support informal carers, nevertheless, have been inadequate. The debate of the 1990s has been marked by the growth in awareness of families' problems and needs in caring for elderly people (Censis, 1999; Saraceno, 1998). Such acknowledgement has led to a call for more services to support caring relatives. Among the services to pursue this goal, attention has been focused on psychological support and counselling, self-help groups, financial support for carers and short-term spells in residential care for dependent elderly people (Bursi, Cavazza and Messora 1999). The actual delivery of services to support informal carers, nevertheless, is really scarce and fragmented and often only provided on an experimental basis. These services, furthermore, are usually provided without connections with the *assistenza domiciliare integrata*: they are usually perceived and implemented as interventions separate from the public provision of home care. The increasing awareness of family responsibilities, nevertheless, has also had an impact on the debate and practice concerning ADI. Several commentators have called for more attention to informal carers' views and needs in the different steps of the care process. With respect to the initial assessment and care planning, this means listening to the informal carers and taking account of their needs as much as possible when arranging the intervention. This principle has a number of practical applications, concerning the kind of care inputs provided, their amount, their way of delivery and others. To locate carers' support more appropriately among ADI goals often means also meeting their need for information and suggestions on several issues, such as other sources of available care and how to care for dependent elderly (Lucchetti, 1999; Pavan, 1999; Taccani, 2001).

Our discussion of the Italian situation highlights three policy issues, of great relevance now and in the future. One regards the possibility to shape the *assistenza domiciliare integrata* so that it is more oriented towards the informal carers. It concerns the degree to which the care process in ADI is tailored to users' needs. That is to say, to what degree professionals in charge of assessing the case, arranging the care plan and monitoring the situation over time are able to take carers' needs into consideration and to act accordingly. As previously mentioned, there can be several practical applications of this principle, regarding the typology and the amount of care inputs and the organisation of the service delivery. There is a lot of room for creative thinking aimed at improving the orientation towards carers' needs in ADI.

Another key policy issue regards the provision of additional services to support carers. There is in the Italian debate a widespread consensus on what are the most important among the many services that can be used to support carers (the general preference is for psychological support, self-help groups, financial support, short-term spell in residential care) and on the necessity to promote them (Gruppo di Lavoro – Fondazione Smith-Kline, 2000). As the delivery of such services is currently really limited, the question is to what degree they will spread in the future.

There is finally another issue, that does not relate to the characteristics of services but to their connections. The few local experiences in providing additional services to support carers have been promoted and conducted separately from the provision of *assistenza domiciliare integrata*. Both families and users would, however, probably benefit more from an integrated system of community care, where the provision of ADI and the delivery of services to support carers are co-ordinated and combined as the needs of the different stakeholders dictate. The different policy issues highlighted are part of a common, wider, picture, regarding the possibility to move the current community care system towards a more "carer-oriented" one. Such a move would need to comprise changes in ADI, introduction of new services and co-ordination of the former with the latter.

Box 1 - Who are the users? – Policy issues

Who are the users

- The amount of resources devoted to ADI and its consequences
- The definition of the ADI target groups (with respect to health, dependency and other sources of care)
- The ADI target within the overall long-term care system

Carers as co-users

- The degree to which the care process in ADI is tailored to carers' needs
- The provision of additional services to support carers (psychological support , self-help groups, financial support, short-term spell in residential care)
- The link between ADI and the additional services to support carers

4. The care process

4.1 ADI and the case management tasks

In the 1990s, the care process has received more attention than the topics covered in the previous section (who receives ADI) and in the next section (outcomes and costs). Such attention has been located in the stream of organisational studies on the *assistenza domiciliare integrata*. The organisational studies highlight several traits of the care process, but their contributions offer an incomplete understanding of it. They miss, in fact, the link between care process arrangements, policy choices and impacts on users. The Italian debate on the care process in ADI is quite similar to the English debate on case management. This is due to the fact that the design of the *assistenza domiciliare integrata* resembles, in many aspects, the design of English community care after the 1993 reform, with the introduction of "quasi-markets" and case management.

There are several definitions of case management. It is, in fact, an umbrella term used to define a bundle of policy ideas and logic that has been developing across the world since the 1970s and that has been translated into a number of practical applications in several countries. The different definitions of case management share common logic and policy principles (Davies and Challies, 1986; Bortoli, 2001). According to the UK Social Services Inspectorate, it is an "integrated process for identifying and addressing the needs of individuals within available resources, recognising that those needs are unique to the individuals concerned. For this reason, [it empathises] adapting services to needs rather than fitting people into existing services, and dealing with the needs separately for different services" (Social Services Inspectorate, 1991, a,b). The core tasks form the basis of case management. It constitutes "arrangements, techniques and commitments which focus on the 'better' performance of the core tasks necessary to match resources to the varying needs of individuals" (Davies, 1992, p 8). Generally speaking, the core tasks list includes: case finding, screening for eligibility and assessment, which is as purposive, skilled and comprehensive as is appropriate for the case; care planning and arranging, ongoing monitoring, review and the adjustment of care plans. The function is the co-ordination and linkage of care services provided to users with complex and long-term care needs. It pursues different goals: to provide continuity and integrated care, to increase opportunity for home-based care, to promote clients' wellbeing and to make better use of the resources (Challis et alii, 1995). Case management was introduced on a national scale in the British community care with 1990 NHS and Community Care Act, fully implemented since 1993. The reform made case management "the cornerstone of high quality care" (Department of Health, 1989).

The design of the *assistenza domiciliare integrata*, introduced in Italy at a national level in 1992, was presented in the previous chapter. It resembles the case management design in many aspects. ADI is targeted towards users with long-term multiple and complex needs. For these users a care package is arranged, tailored as far as possible to their needs. The core tasks consist in screening, assessment and care planning, monitoring and review. The similarities between ADI and case management do not only concern the care process logic, arrangements and techniques. As will be clear throughout this chapter, there are many similarities also in the problems encountered by ADI in the 1990s and the shortcomings experienced in the introduction of case management in the United Kingdom (Challis, 1999).

The similarities in both design and problems suggests that there might be advantage in analysing the policy issues concerning the ADI care process using the concepts developed with reference to case management. This is the task to pursue in this section, divided into different subsections according to the different tasks of case management.

4.2 Case finding and screening

By case finding we mean "the identification and recruitment of those who would most benefit from the case management provided by the agency or the team" (Davies, 1992, p14). We dealt with this step of the care process in the previous paragraph. We stressed the ADI deficiencies in terms of horizontal target efficiency and we suggested some reasons to explain them. These concern the gap between needs and supply, the scarcity of information among potential users and the lack of clear indications on the service's target. As the target it is not clearly defined, it is difficult to discuss vertical target efficiency (the degree to which those receiving the service belong to the target group). While we can maintain that there is a serious lack of horizontal target efficiency (the needs outstrip the supply), it is quite complex to take a stance with respect to vertical target efficiency. An issue to stress, in any case, is that the users' profile depends crucially on the availability of alternative community and residential long-term care services, and also on hospital discharge policies.

Case finding often leads to a process that selects the cases by whether the main needs are for simple information and referral only, simple continuing service input of some type, the skill mix of the case management team required, and the resource levels likely (Davies and Challis, 1986). Assessing the objectives achieved by case management since its introduction in the United Kingdom in 1993, Challis noted that "confusion existed as to whether eligibility concerned eligibility for assessment, service or care management" (Challis, 1999, p. 74). He stressed that the introduction of case management in the United Kingdom has been characterised by a widespread vagueness with respect to what should be the results of case finding and screening. It has led to inconsistent and confused behaviours that have produced negative consequences for the overall community care system. In a very similar tone, Guaita has recently pinpointed the confusion on which users should go through a comprehensive multidimensional assessment by the UVG (*Unità Valutativa Geriatrica*) as a key problem of ADI (Guaita, 2001). He has made the point that both the design and the policy implementation in Italy have failed to pay enough attention to the necessity to differentiate the kind of assessment and care planning to which users should be allotted. The common confusion on this issue, Guaita argues, has hindered the possibility to provide the most appropriate care process to different users.

4.3 Assessment and care planning

According to the logic of case management, assessment and care planning have to be conceptualised as two separate steps of the care planning process. Users' circumstances have to be examined in their own respect, and the actual availability of care inputs should not influence the assessment. The international experience shows, in fact, that quite often the assessment is conditioned by service available, hindering the understanding of users' circumstances (Davies, 1992). Care managers should assess the latter and then arrange the best care plan possible with the resources available. Care planning, among other things, negotiates and defines: "(i) the objectives, nature, quantities and sources of formal services; (ii) the support to and from family and other informal carers; (iii) the rights and obligations of informal carers and others...; (iv) the future role of the case manager; (v) and any financial arrangements demanded by agency policy" (Davies, 1992, p 16). The care plan should be able to look at several aspects of users' need-related circumstances (different dimensions of users' conditions, from dependency to morale, the informal support he/she can count on and other aspects). A key feature of case management is that the plan should set longer-term goals and a strategy to pursue them; the attainment of these goals will be monitored over time. The arrangement of a care plan should clearly define the responsibilities of professionals and clients involved in pursuing the goals. Comprehensive assessment, indications of goals and of a strategy to pursue them and the definition of clear responsibilities' constitute key features of case management (Davies and Challis, 1986).

Boundaries between assessment and care planning and goal orientation constitute indubitably two shortcomings of the *assistenza domiciliare integrata.* They are of great importance but do not generate that much interest. Assessment and care planning are strictly interrelated, and are deeply conditioned by the availability of care inputs, both with respect to quantity and quality. The limited range and availability of services (home help and quite often physio) influence the care plan. These elements restrict the room available to the UVG (*Unità Valutativa Geriatrica*) in assessing and planning, and influence every step of the care process. The difficulty in setting goals to achieve through the care package is shared by most UVG and it is deeply rooted in the professionals' mentality and behaviours. The idea that community care is intended to pursue outcomes, that all the efforts should be finalised towards outcomes still has to take root among most professionals. Such a weak focus on goals and on how to pursue them hinders the capability to think about what would be the best allocation of care inputs between users. With such limited attention on outcomes, there is not that much reflection about who could benefit more (or less) from the care provided. The lack of orientation towards goals and the resistance to thinking and acting in terms of outcomes are problems shared by most long-term care and welfare services across the country. This is due to a phenomenon noticed also in the United Kingdom and named "developmental bias". "The bias is that increasing resources used for publicly-funded community and long-term care have been used to increase level of services; somewhat to increase their range; partly to raise their quality; partly to improve the pay and working conditions of employees....However, what the growth has not been used for is the development of effective mechanisms for matching a more varied range of resources to the complex variations in circumstances of persons which affect the most equitable and efficient ways of providing care and support" (Davies, 1992, pp. 4-5).

In the last decade, more attention was paid to the contents of care planning than to role of goals and outcomes. Interest in the contents of care planning has been mostly focused on two questions: which professionals should be involved in it and what topics should be covered. With respect to the latter, the national indication (1992 National Health Plan) stated that the UVG (*Unità Valutativa Geriatrica*) should be composed of a nurse, a geriatrician and a social worker (Department of Health, 1992); most of the regional guidelines follow this indication (AAVV, 1999). In practice, however, there is a high degree of variance concerning what actually occurs at field level, what professionals are involved and how responsibilities are split among them. Even if we lack evidence at national level, it is possible to state that quite often the social worker does not take part in the assessment and planning. These tasks are, to put it differently, quite often performed only by health professionals. With respect to the geriatrician, the situation is less clear but we can state that she/he is absent in several areas. There is a relevant debate on who should take part in assessment and planning, with several different points of view and proposals (Abate, Bavazzano and Di Iorio, 1996; AAVV 2001). An increasingly debated topic regards what issues should UVG deal with in care planning. As there is a widespread demand for information, suggestions and support by the families of dependent elderly, many professionals think that planning should take these needs into consideration. It means to use the planning process in order to provide information and suggestions to the families. If so, the process in itself is a source of support for families and leads to care plans better tailored to their needs.

The observation of the different degree of attention that is possible to pay to families introduces a more general issue, which is what stakeholders take into account in the care planning and how. There are several stakeholders involved in the care of elderly receiving the *assistenza domiciliare integrata*. They are the public services involved (home nursing, physio, home help), the users, the families, the voluntary services and the private services. There are several different alternatives regarding whether and how to involve any of these stakeholders in the process that have important consequences for the kind of care plan arranged. There is not a high level of agreement on this point among professionals and among scholars.

4.4 Monitoring and review

The continuity of responsibility distinguishes between a case management approach to long-term care and either an acute model of intervention or models in which assessment of eligibility and help with arranging service is followed by withdrawal until the agency is recontacted. Monitoring provides support, checks on the implementation and suitability of the care plan and allows the required adjustment to it, and provides information for the periodic reviews. The latter provide more systematic reappraisal of the care process, its actual implementation, its costs and outcomes (Davies, 1992).

The tasks of monitoring and review have a pivotal role in the design of the *assistenza domiciliare integrata.* Since its inception, in 1992, there has always been widespread consensus on the importance of these tasks. It is not clear, however, how and to what degree they are actually performed. The understanding of monitoring and review it is made complex by some additional factors: the heterogeneity across regions and across local health authorities, the lack of systematic evidence on the topic and the widespread rhetoric on it.

The policy issues regarding monitoring and review can be approached from two points of view, closely interrelated. One concerns the overall role of these functions in the care process, the other concerns their design and arrangements. With respect to the latter, the issue is whether to perform these tasks and what amount of resources to devote to them. Even if there is a widespread rhetoric on them, in fact, their actual presence is often at stake. It is possible to pinpoint a negative loop concerning the impact of the scarcity of resources on these tasks. Quite often, the demand for ADI outstrips the supply and/or it is hard for the service to meet users' needs. As they have to face this situation of scarcity, ADI managers tend to decreases the resources that are not devoted to the direct provision of services. That is to say that they decrease the resources dedicated to the case management functions in order to increase those devoted to the direct supply of services. Within those functions, they tend to protect the assessment and care planning, the initial step reckoned impossible to drop. What tend to be decreased, therefore, are the resources devoted to monitoring and review, a tendency facilitated by the fact that they have never been substantially developed in the *assistenza domiciliare integrata*. There is, thus, a key policy issue regarding the role assigned to these functions in a context of resource scarcity. A similar issue arises in the United Kingdom. Challis reports, in fact, "a lack of monitoring and review with care managers excessively focused upon assessment" (Challis, 1999, p 74).

Besides a general question about the role of these core tasks, there are several issues regarding how they should be arranged. Several of these issues are linked to those discussed with respect to assessment and care planning. A key bundle of policy issues, closely interrelated, concern goal orientation, continuity of functions and accountability. In the previous subsection we stressed the difficulties that UVGs (*Unità Valutative Geriatriche*) experience in finalising the care planning towards goals and in specifying strategies to achieve them. The lack of goal orientation hinders the development of the care process over time. As goals are not clearly set, it is difficult to monitor and review to what degree they are achieved, and to adjust the care plan in order to better achieve them. The virtuous circle to set goals, verify their achievement and consequently adjust the plan do not take place. The lack of the virtuous circle decreases the accountability of UVGs and professionals. As there are no goals or outcomes to measure their achievements, it is not clear to what criteria they are accountable. In such a situation, the overall case management process is in danger of being damaged, as the possibility for the care tasks to produce a relevant impact on the users' conditions is low.

Another set of policy issues deals with the shape of monitoring and review, as there are several different points of view about it (AAVV, 2001). Professionals are divided between those thinking that UVG should have a proactive role in the care process over time and those that prefer a more reactive approach. The former think that UVGs should autonomously check the users' situation from time to time, whereas the latter think that they should act only when conditions worsen, when there is a crisis and/or when users and families ask for it. This issue is interconnected with the one regarding whether UVGs should concentrate their efforts in the less structured monitoring task or in the more formalised review. The discussion whether to concentrate on monitoring or on review is one of the hottest among ADI professionals.

Which professionals to involve in monitoring and review and how to interact with the others stakeholders involved in these tasks are two issues of great relevance with respect to both assessment and care planning and to monitoring and review. The involvement of different professionals has a relevant impact on the attention paid to different users' needs-related circumstances in monitoring and review. The possibility of fine-tuning these core tasks to adjustments and improvements in the care provided depends crucially on the interaction with the many stakeholders involved (especially families and private care). The reflection on assessment and care planning and the reflection on monitoring and review share another policy feature that runs through all the others. It is the differentiation in the core task design and arrangement according to different users' need-related circumstances. It was previously stressed that the Italian debate and practice have overlooked this issue with respect to assessment and care planning. This is also the case with respect to monitoring and review. The debate on all the policy issues previously mentioned would benefit from more reflections on how to differentiate monitoring and review according to users' needs-related circumstances.

Box 2 – The care process – Policy issues

Assessment and care planning

- The role of care planning and its goal orientation
- The contents of the assessment
- The stakeholders to involve

Monitoring and review

- The position of monitoring and review in the care process
- Accountability and goal orientation
- Proactivity/reactivity, monitoring/review

5. Outcomes and costs

5.1 A complex bundle of outcomes

There is a wide range of outcomes regarding community care (Nocon and Qureshi, 1996) and several of them have been internationally used in empirical research (Davies, Fernandez, with Nomer, 2000; Weissert, Cready and Pawelak, 1988). They concern the impact that the provision of community care has on the utilisation of other services (mostly hospitals and residential care), user and carer well being, their satisfaction and several other domains. Among the wide range of outcomes, the Italian debate on the *assistenza domiciliare integrata* has concentrated mostly on two of them: decreases in the rate of hospitalisation rate and users' satisfaction. The predominant focus mainly on these two outcomes and the neglect of many others can be explained by general trends in Italian social policy. The aim to decrease the hospitalisation rate was a key reason for the introduction of ADI and it has many different causes. On one hand, there was for long time in Italy a huge problem of inappropriate hospitalisation, particularly of elderly people whose needs could be met by health care inputs provided by long-term care services (residential or domiciliary) but who do not receive them and are thus forced to enter the hospital. This issue continued to occupy a high-profile position in the political agenda till the mid-1990s, when the method of hospital-financing named DRG (Diagnoses Related Groups) was introduced. One of the main effects of introducing DRGs was to decrease length of stay in hospitals and to reduce "bed-blocking" by elderly in need of long-term care treatments (Fiorentini (ed.), 2000, 2001). On the other hand, much of the 1990s was marked by a strong cost-containment policy concerning health care and the welfare state more generally. The *assistenza domiciliare integrata* was thus conceived as a tool to decrease the health expenditure through the substitution of hospital with domiciliary care. Even if scholars and professionals like to think that the inception and diffusion of ADI is mostly due to the desire to avoid inappropriate hospitalisation, the cost-containment effort was (and still is) the strongest force driving it.

As mentioned above, there is evidence suggesting that ADI has a positive impact in decreasing hospitalisation rates (Ferrucci et alii, 1996; Bavazzano et alii, 1996) and also showing that case management arrangements are more effective (Bernabei et alii, 1998). Besides these specific studies, data gathered in Local Health Authorities with particularly advanced information systems confirm the effectiveness of ADI in decreasing hospitalisation rates. (This is the case with the data gathered in the Lecco Authority, involved in the project.) All the different sources of evidence show the same finding, that ADI has a positive impact in decreasing the hospitalisation rate. The impact of ADI on the institutionalisation[3] rate is, instead, overlooked in the debate. Of the two major studies mentioned, Bernabei et alii take it into consideration (proving that case management arrangements are more effective in avoiding it) while Ferucci et alii do not measure it. With the waiting lists for residential care growing in several areas of the country there are different reasons to pay more attention to understanding the possible link between ADI and institutional care (and, more generally, about policies that can avoid the former): concerns about the quality of life of the elderly and desire to control the costs due to residential care.

The impact of ADI in decreasing hospitalisation rates will continue to be a key policy issue in the future. Along with it, more attention should be paid to its impact on admission in residential care. There are three main determinants of admission to residential care in Italy: the health conditions of the frail elderly, the degree of the dependency and the problems (crises) of the informal carers in caring for her/him (Guaita, 2001). As ADI currently consists – in the overall majority of the cases - only in the provision of nursing and physiotherapy care inputs at home, it is able to deal with only one of the determinants of institutionalisation. This is the key reason why the debate does not pay much attention to the effectiveness of ADI in avoiding institutionalisation: in its current form, this service is not perceived as being capable of having a relevant impact on this outcome. It can increase its impact only by providing care packages that comprise different inputs, especially increasing the provision of home help and developing strategies to support the caring families. To increase the attention towards the role of ADI in avoiding institutionalisation means, therefore, to develop a wider discussion on what should be its main traits. The position of ADI with respect to

---

[3] By "institutionalisation" we mean here – consistently with the Italian usage of this word – only the admissions in residential care.

hospitalisation is, thus, ambivalent. As it is currently arranged in most cases, as just one health care input, it cannot have a relevant impact in avoiding institutionalisation. On the other hand, if the original idea of ADI, that is as a care package comprised of different inputs aimed at meeting different needs of users and families, is developed in practice, it could have a really positive impact in decreasing institutionalisation rates.

Along with the decrease in hospitalisation rates, the Italian debate on outcomes is particularly interested in user satisfaction. The growth of the attention paid to it is linked to wider trends currently experienced by the Italian social policy, previously mentioned. These trends include the introduction of a business-like ethos leading to the conceptualisation of users as "consumers" and to consider their satisfaction as the main result services have to pursue. There is a lot of interest in consumer satisfaction in social policy but its actual translation into practice suffers from several shortcomings. This is particularly true for a service like ADI, due to its own peculiarities that make it particularly problematic to place consumers satisfaction at the centre of the stage in *assistenza domiciliare integrata.* Two problems concern the conditions of the elderly and the definition of the ADI users. Those receiving ADI are frail elderly often in very deteriorated conditions and with cognitive impairments. That is to say, they are often not capable of expressing their satisfaction properly. Furthermore, there are several methodological and technical problems in the measurement of users' satisfaction, concerning the concept of "users' satisfaction" itself and the fact that, in most cases, consumer satisfaction is almost universally favourable among users. There are also complex matters regarding the tools used in order to measure satisfaction. The bulk of the issues raise several questions about the reliability of the data gathered (Ranci Ortigosa, (ed.), 2001). There is finally an additional problem, concerning the relationship between users' satisfaction and the objective outcomes, such as the impact on dependency, health, and hospitalisation. In the assessment of the British community care system of the 1980s, Davies et alii stated that "our findings have indicated that consumer satisfaction is not a good guide to whether some of the broader aims of social services provision are being achieved" (Davies et alii, 1990, p. 113) and this is quite often the case.

With respect to the definition of ADI users, in section 3 the importance of considering also informal carers as users of community care was stressed. Some arguments were presented to support this view that is increasingly embraced across Europe. The Italian discourse on users' satisfaction focuses, instead, entirely on those receiving care. In practice, however, quite often it is the families that complete satisfaction questionnaires on the behalf of frail elderly relatives who are not able to do so. It is very rare for different questionnaires to be circulated to measure both the satisfaction of the elderly and the satisfaction of the informal carers. This is a consequence of the traits of the Italian debate on satisfaction in welfare services, that focuses only on the users, without taking the point of view of other stakeholders into consideration.

The critical notes on how users' satisfaction is currently conceptualised and measured in the Italian system of community care have to be appreciated carefully. We do not mean, in fact, to question the necessity to ask users what they think about the services they receive, to pinpoint what they reckon are their main deficiencies and to underline their unmet needs. This is a crucial task and the changing service orientation towards the users in the 1990s was an important achievement (De Ambrogio and Bassanini (eds.), 1996). The measurement of users' satisfaction has to be conducted along with the analysis of the ADI impact on several other dimensions of the users' conditions. It is of particular relevance to mix the users' subjective assessment with objective indicators (ADL scores, health conditions, hospitalisation and institutionalisation and others). We should look at the ADI impact as a multidimensional item, made up of different dimensions, every one of which should be taken into consideration. That is to say we need to insert users' satisfaction into a wider framework. The key policy issue is, nowadays, to take several outcome domains into consideration and discuss all of them together. In such a discussion, we need to compare and contrast the different outcomes in order to get an articulate understanding of what we can gain from providing ADI.

To get such an articulate picture, we need to differentiate between the ADI impact on users and the impact on carers. Such a move is consistent with the definition of carers as co-users introduced in section 3. The latter, with respect to satisfaction as much as with other domains, has always been somewhat overlooked in Italy. One of the main reasons is that in this Mediterranean country we have traditionally missed a conceptualisation of users and informal carers as two different stakeholders involved in social policy. The concept of family lies at the centre of both Italian society and the welfare system. There is a common tendency to think about social policies to support families, without differentiating – within them – between those who receive the services and those who provide informal care. Also in the theoretical debate, there is usually reference to families as an organic unit, without looking inside them. It is not a suprise, therefore, that the impact of the service on the informal carers' stress and quality of life is overlooked both by the empirical research and the debate on community care. As an example, it is interesting to note that neither Ferrucci et alii nor Bernabei et alii (the two most important projects on ADI effectiveness conducted in Italy) include any effectiveness indicator concerning the impact on informal carers.

There is a need to differentiate not only between users and carers but also within the group of users. The main Italian projects on ADI effectiveness differentiate between elderly people receiving ADI or not, that is to say they differentiate only between users and non-users. The project led by Ferrucci is an experimental work, whose control group is people not receiving ADI (Ferrucci et alii, 1997). Bernabei et alii, instead, ran an experimental project comparing elderly people receiving ADI with case management arrangements with elderly people receiving the "traditional" fragmented and uncoordinated community care (Bernabei et alii, 1998). What we know from these projects is that it is more effective for users to receive ADI than to maintain the current situation and that it is more effective with case management arrangements. What we lack is evidence concerning what arrangements in terms of typology and quantity of inputs allocated are more effective and what are the features of the users that benefit mostly from it. The gap in the evidence available is consistent with the state of the Italian public debate on ADI. There is a widespread consensus on the effectiveness of ADI in decreasing hospitalisation rates and also with respect to several other domains of effectiveness (AAVV 1997, 2001). The debate has been entirely focused on differences in effectiveness between receiving or not receiving ADI. But almost no attention has so far been paid to the effectiveness among users in different needs-related circumstances and among different care packages. The Italian debate does not provide us with indications of the implications of different care packages and of different users' targets in terms of effectiveness. We know that ADI is better than the alternatives, but we do not know how to make the best of it in terms of effectiveness. These are, however, questions of great relevance in terms of resource allocation, closely linked to issues concerning horizontal and vertical target efficiency (discussed in the two previous two sections).

5.2 Beyond a narrow approach to costs

The analysis of the debate on ADI effectiveness in decreasing hospitalisation rates leads one to reflect on costs. The Italian debate on costs in community care is dominated by the fact that ADI has a positive impact in decreasing hospitalisation rates and its unit costs are far lower than the hospital ones. That "ADI is cheaper" has been for most of the 1909s an indisputable statement and the main force driving the development of this service across Italy. In more recent years, however, the voice of the critics has become louder and louder, challenging this statement. It is increasingly acknowledged that the debate on costs in the *assistenza domiciliare integrata* should be more articulated and should take several aspects into consideration. In the reality of community and long-term care policies there is a number of complex and interrelated issues about costs and the Italian debate should look at them (Gori, 2000; Netten and Beecham, (eds.), 1993).

A first policy issue regards the alternative modes of delivery to compare ADI costs with. ADI should be compared not only with the costs of hospital stay but also with the costs of residential care. The rationale to look at residential care is that it is the alternative to the provision of long-term care services in the community. Nevertheless, while the results of cost comparisons with hospitals are quite consistent and clear, it is not the case with residential care. It depends on users' needs-related circumstances, on the care package provided in the community that are alternatives to institutionalisation and on several other variables (Gori, 2000; Montanelli, 1999). The comments on the comparison between care in the community and in residential institutions raise a general point concerning cost analysis. It is necessary to differentiate among costs for users with different needs-related circumstances and who receive different packages of care (for different lengths of time) (Davies and Challis, 1986, chapter 4; Hanau, 1987). We face, in the cost analysis, the same shortcoming that marks the debate on outcomes: the focus has to now been on the comparison between elderly people receiving ADI and elderly people not receiving it. Really scarce has been a focus on the cost and outcome differences due to various needs-related circumstances and packages of care. When conducted, however, these analyses are of great interest. Di Iorio et alii, for example, highlight some statistically significant links between different users' traits and overall costs of the package of care. The costs are higher when: the CIRS (Comulative Ilness Rating Score) is higher, the ADL (Activities of Daily Living) score is worse, the age of the principal informal carer is higher and the user suffers from hard communicative problems (Di Iorio et alii, 1996). To examine how costs vary according to needs-related circumstances and care packages is useful not only for the comparison with alternative modes of care but also with respect to a wider range of issues. This kind of cost analysis can provide several suggestions in terms of both resource allocation within ADI users and of overall strategies of long-term care. The similarities with the debate on outcomes concern also the necessity to widen the debate in two directions: to take several stakeholders into consideration and to analyse different typologies of costs. The Italian debate on community care has been traditionally focused on the economic costs borne by public services. Other stakeholders to take into consideration, especially families and informal carers, will also bear costs. The main source of care for the elderly in Italy is families that have to face a range of costs to face this demanding test. These costs can be divided into three groups: economic costs for the additional expenditures due to the needs of the frail elderly (direct costs), costs of the lost salary of those who do not work in order to care for the elderly relative (indirect costs) and the huge costs – that cannot be translated in economic terms – concerning the stress of the carers, their decrease in their quality of life and so on (intangible costs) (Drummond, 1980). In the 1990s, the costs borne by families caring for dependent elderly have been increasingly acknowledged. It has been mostly due to the growing attention paid, in the public and academic debate, to families caring for elderly suffering from Alzheimer. Several projects that measured the different costs borne by these families have been conducted (Cresa, 1993, Bianchetti and Trabucchi, 1994; Cavallo and Fattore, 1997; Censis, 1999). In the academic debate, however, the link between the discussion of the different costs borne by families and the debate on the assistenza domiciliare integrata is quite weak. The consideration of different stakeholders and different costs is of great relevance for the reflection on the *assistenza domiciliare integrata*. In the comparison between ADI and residential care, for example, it makes a difference to consider only the economic costs borne by the public sector or to look also at the several costs borne by the families.

To summarise, the policy issues raised with respect to costs are quite similar to those concerning outcomes. They include the comparison between ADI and both hospital and residential care, the breadth of cost measurement , the consideration of different stakeholders and the analysis of cost variation due to users' needs-related circumstances and different packages of care. The Italian debate has, till now, ignored these policies issues. They are of great importance for policy-makers, but have been quite neglected because costs have been examined mostly with a managerial approach aimed exclusively to measure them, without placing them in a discussion concerning policy strategies and scenarios, and without linking them to outcomes or needs. To restrict the cost analysis to their measurement is not a satisfactory option as "narrow questions of cost comparison are shadows cast by assumptions about great policy issues, including assumptions about what are desirable social goals" (Davies and Challis, 1986, p 154)[4].

---

[4] A further discussion of the cost analysis is provided in section 2 of chapter 8.

Box 3 – Outcomes and costs – Policy issues

A complex bundle of outcomes

- The effectiveness in decreasing hospitalisation and institutionalisation rates
- The insertion of users' satisfaction into a wider framework of outcomes
- The different impact on users and on carers
- The various impact of different care packages on users with different needs-related circumstances

Beyond a narrow approach to costs

- The comparison of ADI costs with both hospital and residential care costs
- Not only the economic costs
- The different stakeholders bearing costs
- The various costs different care packages on users with different needs-related circumstances

6. Conclusions

The chapter discussed the history, current state and future perspective of the Italian research on community care. It was stressed that this field was traditionally scarce, scattered and fragmented but that in the nineties it experienced a relevant growth. A lot of attention was paid – throughout the last decade – to *assistenza domiciliare integrata* but it is not clear to which degree the interest towards ADI will continue in the current decade.

A main task of the chapter consisted in analysing the strengths and weaknesses of the research on *assistenza domiciliare integrata* conducted in the nineties. It was underlined that its development was quite unbalanced, making a huge effort in examining some topics and almost entirely overlooking other topics. Most efforts have been dedicated to the analysis of the organisational features of ADI and to the management of the service. Poor attention, instead, has been devoted to policy issues regarding resource allocation, outcomes and costs. Along with it, a more general shortcoming hindered the Italian debate on ADI and community care. It consisted in the lack of an overall debate on community care taking the whole picture into consideration. We have been missing, in Italy, a comprehensive debate discussing the needs of the elderly in the community, the different foci of their care and their connections.

While stressing the gaps of the Italian research, nevertheless, similarities with several other countries of the Western world should be noted. Even in countries with a by far more established tradition of research on community care, such as UK and US, the issues of resource allocation, outcomes and costs have traditionally been quite overlooked.

The aim of the thesis is to contribute to fill the gaps in the Italian debate and it is thus devoted to look at three main issues: service utilisation ("who gets what"), outcomes ("with what effects") and resources ("at what costs"). Most of this chapter discussed these issues, looking at them with reference to the Italian situation. The ultimate rationale to analyse these issues is to contribute to a better guidance of the policy on community care. The lack of analysis on service utilisation, outcomes and costs, in fact, increases the risk for this policy of being misdirected, inefficient or inequitable.

Chapter 3

Methodology

1. Introduction

Several different methodologies can be used in order to analyse community care. They differ in their conceptual frameworks and/or their analytical tools. It makes sense not to discuss the strengths and weaknesses of each methodology in general terms but in the context of specific subjects of analysis and specific research aims. In this chapter, I will present the "Production of Welfare" (POW) approach, and explain why it was chosen in order to examine community care in Italy. In discussing the reasons to apply the approach in Italy I will refer to the national policies and debate discussed in the previous two chapters. Section 2 will discuss the POW, focusing on the questions it aims to answer, its conceptual framework, its analytical tools and its relationship with policy-making. Section 3 will illustrate the reasons why I apply it to the Italian context; the effort here will be to pinpoint the gaps in the Italian debate on community care that the POW can help to fill. After arguing why POW can be fruitfully applied in Italy, I will focus on the adaptations it requires to do so. Section 4 will be, thus, devoted to discuss how to successfully use in Italy an approach developed in a country with several differences – with respect to both society and social policy – such as the UK.

2. The "Production of welfare" approach (POW)

2.1 Introduction

The empirical part of the thesis will be conducted using the "Production of Welfare" approach, developed at PSSRU since 1974 and used in a number of studies. The approach has been widely used in the UK in the last 25 years and its applications have had a strong influence on the policy-making. It is going to be briefly introduced in this section and discussed in more detail in the following one.

The core idea of the approach is that system outputs are determined by resource inputs and non-resource inputs. Therefore it discusses and explains the relations between need-related circumstances of recipients and potential recipients, resources and outputs. It aims to research equity and efficiency, and the use of resources in community and long-term care related areas. The POW deals with a series of questions about who gets how much of what support and resources, at what costs to whom, and with what effects of evaluative significance. The approach looks at the relationships among the different components in the "Production of Welfare". These consist of inputs, including resource inputs (such as buildings and staff) and "non-resource inputs" (such as client characteristics and management procedures). Inputs determine outputs, including "intermediate outputs" (such as services received by users and service quality) and "final outputs" such as improvements in health and quality of life. The approach is both an analytical framework and a collection of analytical tools. It relies on two kinds of understanding. One consists in the theories with the knowledge about the relationships involved in the production of welfare relations. The other consists in the development of the analytical tools for the measurements and analyses of the relationships thus derived. Because of its twofold nature, although POW "is essentially an evaluative technique" it is "one which builds explicitly and painstakingly on a body of received theory and empirical evidence, and so one which avoids the many pitfalls associated with many of the ad hoc evaluation which are all too common" (Knapp, 1984, p 27).

There is a substantial literature on the "Production of Welfare" approach. For an introduction to it see Davies (1985), Davies and Knapp, (1981), Davies and Challis, (1986), Knapp, (1984). To look at its application in community care for the elderly see Davies et alii (1990); and Davies and Fernandez[1] (2000). During the last 25 years, the approach has developed mostly with respect to community care for the elderly. Another field where it has been increasingly applied is mental health (e.g. Knapp et alii, 1992). Even if most of the POW exercises concern elderly and mental health, its logics and instrumentation can be successfully applied to several other users (for an application to child care see Knapp et alii, 1988). The POW was also developed in order to apply its logics and principles to research on informal care (Netten and Davies, 1991).

2.2 The main traits of the approach

2.2.1 Questions

In order to examine equity and efficiency in community and long-term care related areas, the POW addresses three main questions. They concern the *what*, *how* and *why* of the production of welfare. The *what* question is mainly a descriptive one. It asks "what are the costs of (or alternatively the mixes of resources inputs required to produce) the outputs which a hard-nosed citizen, beneficiary or taxpayer would consider important to the evaluation of spending on social care; and how are the

---

[1] These are just a few among the several books and papers produced by the Personal Social Services Research Unit. For a more comprehensive view see the Unit's website (www.ukc.ac.uk/PSSRU).

costs of these outputs affected by the characteristics of systems and the circumstances of users" (Davies, 1985, p. 1). This question asks to describe the costs (or the resources inputs required) of outputs, their connection with the system's characteristics and users' circumstances. Such a description, nevertheless, has to reflect causal processes if it is to provide a reliable basis for prediction in complex and changing situations of great variety. This is the reason why the "what" question leads to more complex questions. The understanding of what are the main factors in the production of welfare involves the determination of both which processes are affecting it (and in what way they do so) and the broader and more enduring, often system-wide, influences that over time have caused the patterns to be what they are. They are the "how" and the "why" questions respectively.

The *how* question can be summarised as "in what ways do each of the influential characteristics of social care systems or circumstances of recipients affect the production of outputs?" (Fernandez, 1998, p 19). In order to address this question, we look at different kinds of factors, both those other than services and the services themselves. The factors other than services comprise, for example, the social environment of the user (with whom does she/he live? what kind of informal support – if any – can she/he rely upon?), her/his health and dependency and the material environment (e.g. does the house have a lift or stairs?). The service factors comprise the nature and quantities of the care inputs actually provided and the way they are provided (e.g. different care management arrangements). In order to avoid misinterpretation, it is essential to distinguish the service factors from the other kind of factors. Answering the "how" question, we obtain information on two key issues: (i) the factors to take into account when examining the impact of services on the welfare of recipients and (ii) the way to describe the relationships between such factors and the outputs we are dealing with (Fernandez, 1998). To put it differently, the "how" question aims to explain the relations between inputs and outputs.

The *why* question is of a more general tone and deals with interpreting what we have learnt answering the *how* question. It can be summarised as "what are the reasons why each of the influential characteristics of social care systems or circumstances of recipients affect the production of outputs?". The aim is to interpret the links between (different kinds of) resources and outputs previously pinpointed. The importance of the third question is that a key (if not the main) goal of the POW is to formulate arguments that can at least contribute to prescription, to put forward ideas on the improvement of social policy. In order to do so, it is necessary to make sense of the links between inputs and outputs. Only a deep understanding of these links can lead us to appropriate and solid policy suggestions (Davies, 1985).

The three questions the POW aims to address are deeply interrelated. It is possible to look at the whole of them as a process aimed to understand means, ends and their links in social policy. The first step of the process describes the actors involved in the production of care, the inputs and the outputs (*what* questions). With the following step we move from description to explanation. We aim here to explain the relations between inputs and outputs ("how"). Once we understand the features of the relations between inputs and outputs, the final step consists in interpreting them, in order to get implications for care policy and practice ("why").

2.2.2 Conceptual boxes

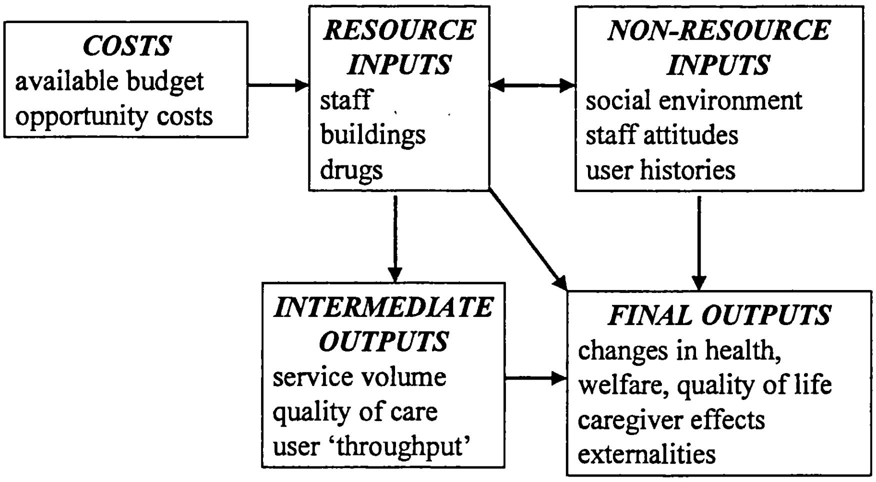
The approach focuses on five key elements in the provision of services. The analysis is concerned with the relationships between these elements (each with subcategories created as circumstances demand). They are:

- *Final output:* they are outputs for the beneficiaries of the production process of direct significance for evaluation. These are outputs of significance in their own right, not because they are thought merely to influence or be associated with less easily measured outputs which are of direct significance. Most final outputs correspond to the objectives of social services. However some are unintended and/or unanticipated effects.
- *Intermediate outputs*: units of service activity which are produced in order to achieve the final outputs. That is to say the volumes and qualities of service output, which are produced from the combinations of the resource and non-resource inputs. The service examined in this study is the *assistenza domiciliare integrata.*
- *Resource inputs:* physical units of resources, mainly staff, capital and consumables. They are characterized by having identifiable or measurable costs and are the focus of the analysis in studies of the relationship between individual resources and inputs.
- *Costs:* they measure the aggregate value of physical units of inputs in monetary terms, applying opportunity cost principles.
- *Non-resource inputs:* these are the non physical inputs or aspects of inputs affecting the levels and mixes of the final outputs obtained from the application of inputs (this is a "catch-all" category). They are the elements taking part in the production of welfare which do not have an identifiable price or which are not currently marketed. They are divided into two main groups: characteristics of systems (for example characteristics of the organization, such as care environment and staff attitudes; they are sometimes called "quasi-inputs") and recipients' characteristics[2] (of particular importance are clients' needs-related circumstances, such as health and disability) (Figure 1).

---

[2] The distinction between the two groups is based on whether they are to do with the nature of formal services, and so are in effect factors which affect the impacts of the service ("resource") inputs, or circumstances of users hypothesised to be likely to affect final outputs and, in particular, likely to influence the impact of resource inputs on final inputs.

Figure 1: The production of welfare



The approach assumes that final outputs of service interventions are influenced by the nature of the services provided, the types, levels and mixes of resources employed, the 'social environment' of the care-setting and other non-resource factors, that is to say by resource and non-resource inputs. This is the assumption underlying the POW, which makes it possible to link resource and non-resource inputs to intermediate and final outputs and to explain the relationships between the former and the latter. To understand what are the most important factors in the production of welfare we need to understand both what processes are affecting it (and in what way they do so) and the broader – often system-wide – influences that over time have caused the patterns to be what they are. In order to pursue this aim, one of the main difficulties to tackle concerns the different kind of inputs involved, how to understand the role and the contribution of each of them. "Much of the complexity which has to be unravelled in understanding the process of care in an intervention", in fact, "results from the interaction of resource and non-resource inputs" (Challis and Darton, 1990, p. 81).

Another key part of the POW analysis is the distinction between intermediate and final outputs. Intermediate outputs have traditionally got more attention in research on social care, but it is final outputs that measure aspects of welfare directly linked to the final objects of services. The question to answer is, thus, why to treat units of service as a measure of output? Several answers can be provided. First, it is easier and cheaper to collect data about intermediate outputs and they are easier to conceptualise. Secondly, the analysis of the intermediate outputs provides information about the links between inputs and final outputs. Even if the typical analysis of final outputs show what effects different inputs are having on what measures of outputs, it will not explicitly reveal the relationship between different groups of users and the levels of services provided to them. Thirdly, the analysis of intermediate outputs informs issues around resource planning (Fernandez, 1998). Even taking these arguments into account, it is crucial to distinguish intermediate and final outputs because the former are often only weakly correlated with the latter. It has to be noticed that in POW studies where the emphasis was on final outputs, service levels are actually often treated as resource inputs (Davies and Challis, 1986; Davies et alii, 1990; Davies and Fernandez, 2000). It can be generalised that "the more explicitly evaluatory is the argument, the greater is the importance of attempting to measure final outputs as well as intermediate outputs" (Davies, 1985, p. 8).

The reflection on final outputs lead us to look at the distinction between the weak and strong forms of the "Production of Welfare" approach. According to the strong form, increases in resource inputs are associated with one or more improved outcomes for some range of inputs. The focus is here on a causal relationship between changes in level of inputs (however defined) and levels of outcomes (final policy objectives of evaluative importance). The justification of the approach, however, lies in the weak form of the POW. According to this form, although other factors are the biggest influence on status and changes of outcomes of evaluative importance, increases in resource inputs are associated with one or more improved outcomes for some range of inputs. The essential difference between the two forms is the acknowledgement of the crucial effects that factors outside the control of the policy maker are likely to have on the outputs that we are trying to improve through the provision of services. It is well known that – in any kind of human service – variations in quantity and quality of the service provided have a smaller impact on the final outcomes of evaluative importance in their own right than the personal circumstances of the case (e.g. Verry and Davies, 1975). This is true for long-term care and community care as well. In order to obtain a good understanding of the ways to improve the welfare of social services users', it is essential to also understand the impact of external factors. It is thus necessary to pay attention to non-resource inputs and to take the overall context of a policy into consideration (Davies, 1985; Fernandez, 1998; Davies and Fernandez, 2000).

The focus of the POW analysis is, thus, the impact of resources on final outputs. It is concerned with the broad interpretation of equity and efficiency and they, rather than effectiveness, are the appropriate evaluative criteria in a POW study. This means that faced with a budget constraint it is not sufficient to demonstrate that resources can yield a benefit. What is required is that resources are distributed in relation to needs in ways that maximize the total potential for welfare gains given the weighting of equity and other objectives. In the POW studies, thus, it is essential to look at the difference between individuals. "POW studies are guided by the assumption that relationship between resources and outputs varies greatly between individuals. This implies that the type and mix of service inputs must reflect quite subtle differences in the need related circumstances of individuals in order to achieve an optimal level of equity and efficiency in social care" (Bauld et alii, 2000, p. 23).

2.2.3 Analytical tools

The approach consists of the framework presented above and a collection of analytical tools. The tools are exploited in order to measure and analyse the relationships suggested by the framework. There are two main groups of tools: utilisation functions and production functions. Utilisation functions consist of instruments for the analysis of the relationship between non-resource inputs and intermediate outputs. They aim to answer the question "who gets what" in social services, looking at the relationship between units of services provided and non-resource inputs (client circumstances and supply system characteristics). Estimating such relationships allows us to answer a wide range of questions, of which some of the most relevant are: which services are allocated to what kind of users? Is the pattern of resources' distribution primarily driven by users' circumstances or by other factors (if so, what are those factors)?

Production functions consist of instruments for the analysis of the impact of both non-resource inputs and resource inputs on final outputs. They are traditionally used in the theory of the firm to establish the technically efficient relationship linking any combination of factor inputs (labour and capital) and subsequent levels of whatever output (final goods, services and so on) produced by the firm (Koutsoyiannis, 1979). Even if quite clear at a theoretical level, production functions can be quite complex to be estimated empirically. On the one hand, the data required to estimate them are often difficult to collect, and on the other hand the successful estimation of a production function relies on its ability to account flexibly for the interactions involved in the production process. In the case of social care, the production function aims to establish the pattern of relationships between the amount and nature of care services (the resource inputs) and several measures of final outputs, given the different non-resource inputs of service users. It is possible to use different forms of production function, depending on the assumption we make and where we want our model to be most flexible. Production functions can help to answer crucial questions such as: are the services provided having an impact on the welfare of the recipients? If so, how do different services compare? What is the relative impact of the services on welfare as compared with impact on users' characteristics?

Utilisation and production functions share the use of statistical modelling techniques in order to fulfil their aims (Fernandez, 1998; Davies and Fernandez, 2000, chapter 3). There is a third group of functions, the cost functions, that are derived from the relationship implied by the production function (Koutsoyiannis, 1979). Instead of explaining the level of outputs through differences in non-resources inputs and level of services, they postulate that costs are a function of non resource inputs and final outputs. Due to their similarities, cost and production functions show some of the some features of production relations.

2.2.4 A comprehensive view

The above discussion of the "Production of Welfare" Approach focused on its potentialities and possible applications. We will begin the final section by summarising the key potentialities of the approach and will then focus on its main weaknesses.

The POW is an evidence-based approach, whose tools and logics aim to get the best possible understanding of reality. The approach develops policy thinking and practice that always relies on the evidence. A key strength of the POW is that it provides the analytical tools to make the most of the evidence analysed. Along with this, the approach provides a core of substantive theoretical arguments concerning the relationships involved in the production of welfare. It consists – to put it differently – of both a collection of analytical tools and a conceptual framework. Such an approach is able to lead to a better understanding of the links between means and ends in community care. By doing so, it becomes a useful tool for decision-makers seeking to understand the consequences of their choices. At the same time, it makes them more accountable for such consequences. To summarise, the POW can contribute to overcome the "developmental bias", a crucial shortcoming of many community and long-term care systems in Western countries. "The bias is that the increasing resources used for publicly-funded community and long-term care have been used to increase levels of services; somewhat to increase their range; partly to raise their quality; partly to improve the pay and working conditions of the employees...however, what the growth has not been used for is the development of effective mechanisms for matching a more varied range of resources to the complex variations in circumstances of persons which affect the most equitable and efficient ways of providing care and support" (Davies, 1992, pp 3-4).

The limitations of the approach stem both from its own design and its application over the years. With respect to the design, the "Production of Welfare" approach focuses on the differences within users of a service. It aims to pinpoint what are the differences in intermediate or final outputs explained by differences in resource and/or non-resource inputs. It is not intended, instead, to compare people receiving a service with people - in the same circumstances - not receiving it, that is to say that it does not run experimental work with control group. It does not allow, thus, to understand the strength and weaknesses of a service in comparison with other situations or services. It is, thus, quite a partial view.

Another key shortcoming due to the design of the approach is its data-hungry feature. Such a complex approach needs a collection of a huge amount of data, often gathered at different points of time. It relies upon complex, time consuming and expensive fieldwork. It can therefore be used only by research groups with big budgets and that can handle the bulk of problems the fieldwork is bound to raise. This trait of the approach is crucial in order to explain why, even if it is so promising, in the United Kingdom it has been hardly used by non-PSSRU scholars.

The possibility to look only within users' group and the data hungry nature are drawbacks stemming from the own design of the approach. Other two problems stem from the way POW has been developed over the years at the PSSRU. One concerns the complexity of PSSRU books and publications, most of them are quite demanding to read and ask the reader to make a huge effort (and to devote a lot of time) to understand them. It is quite a paradoxical feature for an approach intended to be useful for policy makers and to have an impact on their choice.

The other problem stemming from the actual development of the approach over the years regards the balance between data analysis and policy analysis. Most effort, in fact, has been devoted to develop the former at the expense of the latter. It means that the approach is nowadays really sophisticated in examining the data but it sometimes does not translate effectively those results into policy ideas.

3. Why POW in Italy?

The main traits of the Production of Welfare approach were introduced in this chapter. In the previous two chapters the state of community care policy and debate in Italy were discussed. If we look at the Italian situation bearing the features of the POW in mind, we can understand why the core task of the thesis was chosen as the application of this approach in the Mediterranean country. The main reasons are:

- *It is an evidence-based approach..........*The POW is conceived as an approach to analyse social policy evidence. Its tools and logics are applied in order to get the best possible understanding of the evidence and to make the most of it. Also when the aim of the work is not firstly to analyse evidence, the policy thinking is developed with the reference to it continuously in mind (e.g. Davies, 1992). Any idea is developed thinking about the evidence and has to be checked with it. In Italy, the evidence-based research in social policy is quite weak. More generally, the whole Italian research on public policy has traditionally been more inclined to engage with the discussion of principles and general theories than to confront them with evidence and the actual reality of the services. With respect to social policy, it means that the field has traditionally been not that much researched and – when it is the case – mostly with a sociological approach more interested in general concepts than in analysing evidence. The first reason why in this thesis we use the POW is that we think that it would be important in Italy to promote a more evidence-based social policy research. As we do not have a relevant tradition of it in our country, we looked abroad for useful tools and inputs.

-*....And it is also theoretically consistent and well-grounded.* One of the key POW strengths, as pointed out at the beginning of the chapter, consists in its twofold nature. It comprises both theories with the knowledge about the relationship involved in the production of welfare relations and analytical tools for the measurement and analysis of the relationships thus derived. It is an analytical framework and a collection of analytical tools. A main drawback of the scarce Italian research on social policy that is actually evidence-based is its lack of a theoretical framework, of theories and logics upon which to build the analysis of the data. The consequence is that when evidence is gathered, there are often deficiencies in how it is actually analysed, in the capability to draw policy implications. This trait is consistent with the really limited Italian tradition in evidence-based research in social policy. Due to the narrowness of this tradition, appropriate tools and logics to analyse the evidence and draw policy implications have not been developed. Another main reason why in the thesis we use the Production of Welfare approach is that, in Italy, there is a deficiency in logics, methods and tools convenient for an evidence-based social policy analysis. The POW approach can contribute to fill this gap.

- *It focuses on resources, outcomes and their links.* In the previous chapter we looked at the main subjects of the Italian research on community care. It was stressed that while the organisational and managerial streams flourish, the more typical social policy issues do not receive that much attention.

What we miss is a research stream looking at different policy alternatives, their implementation strategies, inputs and outcomes. We miss research on different resource allocation strategies (their costs and outcomes) and on what outcomes we can expect from different policy strategies (linking policy design and results). A key reason why we use the POW in the thesis is that it looks at these policy issues, focusing on the research questions that in Italy are overlooked but deserve more attention. The utilisation of the POW in Italy can help not only to develop a more sophisticated evidence-based tradition but also to arouse interest on issues of great importance but that have not received enough attention till now.

- *It provides policy suggestions*. To drawn from the research implications and suggestions for the decision-makers is another main trait of the POW. The conceptual framework and the analytical tools are designed so that the research effort leads to consideration of how to improve policies. The POW is based upon the idea that research and policy-making should be involved in a continuous, two-way, process of exchange and mutual learning. In Italy, instead, most of the social policy research does not aim to produce policy implications. This is consistent with its sociological approach and with its lack of focus on evidence. We think that it would be important to promote in Italy a closer link between policy-making and research in community care – as in social policy more generally - because both could greatly benefit. To move towards this aim, it is necessary to develop a research stream that aims to provide policy suggestions. Also from this point of view the utilisation of the POW in Italy can be useful.

4. Adapting the POW to the Italian context

There are good reasons, it was noticed in the previous paragraph, to apply the POW in Italy. It is an empirical approach built upon a consistent theoretical framework, devoted to the study of issues traditionally overlooked in Italy: resource allocation and outcomes. The approach was originally developed in order to analyse community care and related long-term care areas in the UK. There are deep differences between Italy and in the UK, from a social, economic and policy point of view. In order to be utilised in the Italian context, thus, the approach requires some adaptations.

With respect to the context, in Italy the family's role is more relevant and the provision of public services is smaller than in the UK. The informal support is of greater importance in the former and the public care is of greater importance in the latter. According to a recent OECD project, the Italian share of population aged 65 and over receiving formal help at home is 2.8 per cent, while in the UK it is 5.5 per cent (Jacobzone, 1999). Different indicators of informal support in care for the elderly, such as for children, show that in Italy families (and informal networks more generally) play a much bigger role (AAVV, 1998). The differences concern not only the countries considered but also the services examined. It must also be noticed that while in the UK the POW has traditionally been exploited in order to analyse personal social services, it is used in this project to study the *Assistenza*

Domiciliare Integrata (ADI), a community care service consisting mostly of health care inputs (home nursing and physiotherapy). There is a shift of the main focus from social to health care.

Both the differences in context and services analysed can be tackled successfully (at least we hope!). It was previously stressed that the POW is really flexible. The capacity to adapt its tools to different contexts – without losing its logic – is one of its key features and it is the main reason why we are quite confident about its utilisation in the analysis of ADI in Italy. With respect to the move from social to health care, furthermore, one has to notice that in this project we deal with community care for the elderly, the main subject of POW research in the UK.

With respect to the analytical tools deployed there are differences as well. The statistical instrumentation used in the thesis is less sophisticated than the instrumentation used in most of the POW projects run by the Personal Social Services Research Unit (PSSRU). This choice does not – in our opinion – decrease the inner POW nature of our own work. We follow the main indications of the approach (empirical work built upon a theoretical framework, links between means and ends, choice of topics), although we use only some of the analytical tools developed by those that have been using the POW over the years.

Chapter 4

Research design

1. Introduction

This chapter is a bridge between the first part of the thesis and the discussion of the findings that will start in the following chapter. We will present here the research design of our empirical project. We will present the target of our work and the sample (section 2), and then move to look at the different steps of the fieldwork (section 3). The final paragraph will illustrate the main research questions we aim to answer through such a research design, which will be dealt with in the following chapters (section 4). In the final section, a critical assessment of the research design will be conducted (section 5).

2. Target and Sample

2.1 Target

The focus is elderly people (that is, people aged 65 and over) receiving ADI who are new users of the service. Another eligibility criterion concerns the definition of the service: only people receiving ADI as strictly defined were selected for the project. Strictly defined, ADI is characterised by a full assessment of the user's condition conducted by the unit of assessment and planning (*Unità di Valutazione Geriatrica, UVG*) and the setting up of a care plan. This criterion was inserted because in Lombardy the same professionals providing ADI often also deliver short-term domiciliary health care inputs, without conducting a complete assessment and setting up a care plan; and in several cases these interventions are also named "ADI"; it was then necessary to specify what we meant by ADI. The third eligibility criterion concerns users' characteristics: we do not include the elderly terminally ill[1] (Box 1). We chose to exclude terminally ill people for two main reasons. First, the

---

[1] We used the definition of terminally illness adopted by the regional government of Lombardy and established by the Italian palliative care association. According to this definition, a person is judged terminally ill when she/he does not receive any kind of treatment aimed to improve her/his condition and the illness is evolving quickly with death diagnosed to occur in no more than three months, and has a score of 50 or lower on the Karnofsky scale.

focus of our project is on long-term care, not on palliative care and there are deep differences between them. Second, the Italian debate – as happens to be the case in several other countries – is increasingly considering the latter as an autonomous policy[2].

Box 1 – Users' eligibility criteria

- New user
- Aged 65 or over
- Receiving proper ADI (i.e. they are fully assessed by the unit of assessment and planning and a care plan is set up for them)
- Not terminally ill (according to the definition of the Italian Palliative care Association)

In order to understand who are the users and how ADI actually works it is also necessary to collect information about persons who started to receive the service during the recruitment period, met the eligibility criteria and chose not to participate in the project. Furthermore, while in some districts elderly terminally ill people are cared for by a unit of palliative care, in others ADI professionals are in charge of them. When this happens, even if these people do not enter the project it is necessary to gather some information about them, in order to paint the "whole picture" of provision of ADI in the recruitment period. To obtain some information on people belonging to these two groups (elderly meeting the eligibility criteria who refuse the project and those terminally ill receiving ADI) who started to receive ADI in the recruitment period, a short questionnaire gathering general information on their physical and social conditions was administered by the ADI professionals for each of them (Box 2). In the rest of the chapter we will focus on the elderly meeting the eligibility criteria and who agreed to take part in the project.

Box 2 – Users not included in the sample, for whom a short questionnaire was administered

- Those meeting the eligibility criteria but did not want to take part in the project, or
- Those meeting all the criteria except the one on terminal illness

Besides users, the principal informal carers (PICs) are the other main target of the project. They were interviewed – as described below – in both the first and in the second waves of the project. For each user we tried to identify his/her PIC, if they had one. We mean by principal informal carer the member of the user's informal network (relative, friend, neighbour, volunteer) who provides most help to him/her. The PIC is thus operationally defined as the person who each week dedicates more time than anyone else to care for the user without receiving any salary. The lack of any financial involvement is an important criterion because – as shown below – in Lombardy a relevant group of ADI users receive private paid care as well. To be considered the PIC, a person not living with the user has to visit the latter at least once a week. The definition of principal informal carer is summarised in Box 3. PICs were identified by ADI professionals asking the users, and in cases

---

[2] In 1999, the national government launched a plan aimed to set up several hospices throughout the country.

where their indication was considered insufficiently clear (e.g. the user had two main informal helpers or was cognitively impaired) it was the professional's responsibility to determine who was – if any – the principal informal caregiver in each case.

Box 3 – Principal informal carers' eligibility criteria

- The member of the user's informal network (relative, friend, neighbour, volunteer) who weekly dedicates more time than anyone else to care for him/her
- Not receiving any salary for the care provided
- If not living with the user, visiting him/her at least once a week

2.2 Sample

The initial aim was to obtain a sample of 400 new users, divided among the three local health authorities as follows: Milan 160 (20 for each of the 8 districts involved), Milan neighbourhood 120 (30 for each of the 4 districts involved) and Lecco 120 (60 for one of the districts and 30 for the other 2 districts involved). We targeted this number and spread of cases because it seemed to be an adequate balance between, on the one hand, each authority's interest to get a sample large enough to conduct some valid reflections on its own position and, on the other hand, the necessity to handle a really complex research process within an acceptable length of time. The number of cases actually included in the project amounted to 345 new users, divided among the three local health authorities as follows: 149 Milan, 119 Milan neighbourhood and 77 Lecco. The recruitment of 55 users fewer than the original aim was due to organisational problems in some districts and to the really low number of new users in others. For 292 of the new users the principal informal caregiver was identified, i.e. in 85 per cent of the cases we interviewed both user and caregiver.

As explained in the following pages, those still receiving the service after 12-15 weeks since provision started were interviewed again, in the second wave of the project. The number of users interviewed after 15 weeks amounted to 177, of whom 84 were in Milan, 60 in Milan neighbourhood and 33 in Lecco (Table 1).

Table 1 – Sample, first and second wave

	Sample – First wave	Sample – Second wave
Milan		
District 3	20 (20)	8
District 6	20 (20)	15
District 9	20 (20)	10
District 10	20 (20)	10
District 13	20 (17)	11
District 15	20 (20)	11
District 16	20 (12)	7
District 18	20 (20)	12
Total Milan	160 (149)	84
Milan neighbourhood		
District of Monza	30 (29)	11
District of Vimercate	30 (29)	20
District of Cinisello B.	30 (30)	15
District of Carate Brianza	30 (31)	14
Total Milan neighbourhood	120 (119)	60
Lecco		
District of Merate	60 (52)	22
District of Lecco	30 (8)	2
District of Bosisio	30 (17)	9
Total Lecco	120 (77)	33
Overall total	400 (345)	177

Case recruitment commenced in all fourteen districts between 20 September and 10 October, 1999. Since then, all the new users meeting the criteria presented in Table 7 of chapter 3 were asked to take part in the project and if they agreed, they entered the sample. The first district finished recruitment in February 2000, the last one in April of the same year. Between the commencement of recruitment and achievement of the sample target, for those new users meeting the eligibility criteria but refusing to take part in the project and for those meeting all the criteria except the one on terminal illness, professionals administered a short questionnaire with some general information on their conditions and the care they received. Those for whom the short questionnaire was administered amount to 223 elderly (Table 2). The data gathered through compiling the short questionnaire were initially looked at and – after a while – it was decided not to run a proper analysis of them. This decision was made for two main reasons. First, there were huge differences in the number of short questionnaires administered in each district and – after speaking with the professionals involved – we realised that in some of them the questionnaires were not administered for several of the elderly that needed it. Secondly, somewhat paradoxically, when we started to look at the data, we noticed that the main features of the elderly and the caregivers were actually quite similar to those of the research sample.

Table 2 – Number of elderly for whom a short questionnaire was administered

	Short questionnaires Administered
Milan	
District 3	9
District 6	14
District 9	16
District 10	7
District 13	14
District 15	25
District 16	41
District 18	0
Total Milan	126

Table 2 continues	Short questionnaires administered
Milan neighbourhood	
District of Monza	0
District of Vimercate	3
District of Cinisello B.	41
District of Carate Brianza	6
Total Milan neighbourhood	50
Lecco	
District of Merate	20
District of Lecco	22
District of Bosisio	5
Total Lecco	47
Overall total	223

3. The fieldwork in steps

3.1 Qualitative background

The bulk of the project consists of a quantitative analysis of users, carers, care inputs, costs and outcomes. In order to provide an appropriate background, we initially gathered some qualitative materials, conducting a series of semi-structured interviews with professionals at different levels. I personally interviewed (individually) the ADI managers of the 3 health authorities and then the UVG members in each of the 14 districts involved. The interviews aimed to understand how ADI is organised and works, what are the organisational structures and the daily practices. The main issues investigated were the institutional arrangements between local health authorities and municipalities, the financial arrangements (health and social services economic contribution to integrated domiciliary care, whether and how charges apply and with which consequences), the process of case management (how the unit of assessment and planning – *Unità valutativa geriatrica, UVG* – works, which professionals compose it and how they interact, if there is any devolved budget and so on). The aim was to understand how the unit acts through the steps of case finding, assessment, care planning, arranging support, monitoring and reviewing, the collaboration between social and health services in providing ADI (formal arrangements and practice), other organisational issues and recent evolution of the policies towards the frail elderly in the areas studied (with special reference to ADI). A crucial aim of the interviews was to understand both the formal arrangements of the organisations involved and the "informal reality", that is how they work in practice. These interviews were conducted before the beginning of the first wave interviews with users and carers, so that the information gathered could help in designing the latter. The qualitative interviews were helpful not only in designing the quantitative instruments. They were also helpful for the analysis of the quantitative evidence gathered and when drawing policy implications from our findings. We, thus, looked at the information collected in the qualitative interviews at several stages of the research process. In the initial phase, we also collected a number of papers, materials and data produced by the local health authorities (we kept on collecting this kind of material for the whole length of the project). In this round of initial interviews we set up several links with ADI professionals, which were useful for us through the whole length of the project. We summarise the first step of our work in Table 3. Further on in this chapter, the other steps of our work will be described through similar tables, presenting the research instruments, how they were administered and what were their aims.

Table 3 – Instruments and aims: period before the quantitative interviews

Instrument	Who administered it	Aims
- 3 semi-structured interviews with the managers of the Local Health Authorities involved	- Cristiano Gori	A) To obtain information on the service's organisation and on how it actually works
- 14 semi-structured interviews with the UVG's members/responsibles of the care plan of the districts involved	- Cristiano Gori	B) To obtain information on the relationships between the different actors involved in ADI
		C) To obtain information on particularly issues (informative policies, rationing and others)
- Collection of a number of papers, materials and data produced by the local health authorities	- Cristiano Gori	

3.2 First and second wave interviews

The first wave interviews were held between Autumn 1999 and Spring 2000, interviewing 345 new users and 292 principal informal carers. They started – as stated above - between 20 September and 10 October, 1999 and ended between February and April 2000.

Each new user and his/her principal informal carer (PIC) were interviewed within three weeks of commencement of ADI provision. Interviewers employed by IRS interviewed (individually) both of them, in order to map the formal and informal care inputs provided, to investigate the conditions of PICs and other people (especially paid carers) involved in supporting the elderly. In the process of assessing the case and setting up the care plan ADI professionals administered a questionnaire with a threefold goal. It aimed to gather general information on users and to assess their dependency, cognitive impairments and depression, to obtain information on the process from the referral to the setting up of the plan and on the plan itself and finally to obtain the opinion of the UVG members on the setting up process, the plan and its potential benefits. Within five weeks since users started to receive ADI, geriatricians or general practitioners involved in the service administered a questionnaire to evaluate their health conditions (Table 4 a, b and c). The content of these questionnaires and of all the other questionnaires used in the project is described in Appendix 1.

In the first month of fieldwork, the questionnaires to interview users and carers by IRS employees and the questionnaires to assess users and get information about them by ADI professionals were piloted. The pilot consisted of some 30 interviews with users, 30 interviews with carers (by IRS employees) and some 40 questionnaires compiled by ADI professionals. At the end of the first month of fieldwork, the IRS interviewers met with the candidate to discuss the questionnaires to interview users and carers. With reference to both questionnaires, it was agreed that they were too long and it was decided to drop some questions. At the end of the first month of fieldwork, the candidate met also the professionals that had piloted the questionnaire to assess users and to get information about them. Also in this case, the questionnaire was reckoned to be too long and some questions were dropped.

ADI professionals administered also the short questionnaire, aimed to get some general information on new ADI users who were in the target of the project but declined to take part in it or were terminally ill. These users were no longer considered in the project, and – as explained above – the data gathered through the short questionnaire were not fully analysed.

Table 4a – Instruments and aims: period within 5 weeks of the new ADI user's referral

Instrument	Who administered it	Aims
- Questionnaire aimed to get information on 400 ADI new users who are in the target of the project and accept to take part in it - Short version of the questionnaire, to compile for new ADI users who are in the target of the project but do not accept to take part in it or are terminally ill (these users are not further considered in the project)	- ADI professionals - ADI professionals	A) To obtain general social information on the users B) To assess users' dependency, cognitive impairment and depression C) To know how the service works in the process from the referral to the setting up of a care plan + to know the care-plan D) To know what the professionals reckon to be the potential benefits for the users and whether and how they would modify the service

Table 4b – Instruments and aims: period within 5 weeks of the new ADI user's referral

Instrument	Who administered it	Aims
- Questionnaire aimed to evaluate the health conditions of the new ADI users	- Geriatricians/Gps involved in ADI	A) To assess users' health conditions

Table 4c – Instruments and aims: period within 5 weeks of the new ADI user's referral

Instrument	Who administered it	Aims
- Questionnaire with structured interview (close answers) to new ADI users	- Interviewers from IRS	A) To map the care provided by family, friends, voluntary organisations and paid carers
- Questionnaire with structured interview (close answers) to their principal informal carers	- Interviewers from IRS	B) To investigate the relationship between users and principal informal carers C) To obtain general information on the informal carers and other people (especially paid carers) involved in supporting the elderly

Between 12 and 15 weeks after the users started to receive ADI, those of them - 177 (52% of the initial sample) – who were still receiving it and their carers were again interviewed by IRS employees. The interviews gathered information on users' and carers' subjective experiences of ADI and their satisfaction, their unmet needs, the perceived impact of ADI, and the (formal and informal) care inputs provided (Table 5).

Table 5 – Instruments and aims: period within 12 and 15 weeks since users started to receive ADI

Instrument	Who administered it	Aims
- Questionnaire with structured interview (close answers) to ADI users	- Interviewers from IRS	A) To record users and carers' subjective experience of ADI and their satisfaction
- Questionnaire with structured interview (close answers) to their principal informal carers	- Interviewers from IRS	B) To record users and carers' unmet needs C) To investigate the perceived impact of ADI D) To obtain general information on the (formal and informal) care inputs provided

3.3 Telephone follow-up

Some 6 months after they started to receive ADI, a telephone follow-up was conducted to investigate the conditions of the elderly taking part in the project who were still alive. Out of the original sample of 345 users, both those at the time still receiving the service (141) and those who were not (but were still alive and were possible to find) (74) were contacted. The interview was conducted by phone by IRS employees with both the principal informal caregivers and the users; most questions were asked to the former. These interviews aimed to map the hospitalisation and institutionalisation rate over the previous months, the other care inputs provided and the general conditions of users and PICs (Table 6).

Table 6 – Instruments and aims: period around six months since the users started to receive ADI

Instrument	Who administered it	Aims
- Telephone interview with elderly included in the initial sample and still alive - Telephone interview with their principal informal carers	- Interviewers from IRS - Interviewers from IRS	A) To map the hospitalisation and institutionalisation rate B) To map the care inputs provided C) To map the users' and carers' general conditions

3.4 Monitoring care inputs

For the whole research period in which users received the service, the ADI professionals administered a questionnaire which tracked the resource inputs provided over-time. It recorded the typology (home nursing, physiotherapy, home help) and the amount (number of visits) of care inputs provided.

Table 7 – Instruments and aims: the whole period in which users receive the service

Instrument	Who administered it	Aims
- Instrument to monitor the care inputs provided over-time	- ADI professionals and Cristiano Gori	- To track the consumption of ADI resources over time

4. Research questions

The evidence gathered will be presented and discussed in the next four chapters. The first one (chapter 5) will describe users' characteristics and will look at the formal and informal care inputs they receive. It will discuss the needs-related circumstances of users and their informal carers, and the care inputs provided by the latter. It will consider also the circumstances and the inputs of the privately paid assistants and the care inputs delivered by voluntary organisations and the *Assistenza domiciliare integrata (ADI)*. Chapter 5 will illustrate context, stakeholders and care inputs of community care in Lombardy. The following three chapters will tackle the main issues examined in the Production of Welfare approach: resource allocation, outcomes and costs. They are presented in turn.

4.1 Who gets what?

The question "who gets what?" lies at the centre of the social policy debate and the answers provided to it have several implications for community care. The analysis of service utilisation in community care is a cornerstone of the Production of Welfare approach and is conducted in several PSSRU studies (e.g. Davies et alii, 1990). Several data regarding the users' characteristics and the different care inputs they receive are gathered in this project. They will be exploited to run a detailed analysis of resource allocation, adapting the POW to the Italian context and to our own aims (chapter 6). This issue will be examined from different perspectives, as the chapter will pursue a threefold goal. We are interested in the process through which care resources are allocated, in their comparison with users' and carers' needs and in the geographical differentiations. In chapter 6, we will thus aim to answer three main research questions: "how to govern community care?", "which care inputs for which needs?" and "what are the geographical differences in the care provided"?".

With reference to the processes through which resources are allocated, we intend first to consider how the potential users reach ADI; in particular who suggested this service to them and their families. We will then examine how the initial and over-time assessment of users' conditions work. It means that we will follow the process from the moment when users and/or family are suggested to request ADI to the different steps of its delivery over-time. To widen the perspective, we will also look at the different actors with which UVG interacts in the community, and what it means for its role and tasks. We will furthermore analyse the need for information concerning users and carers, and the degree to which ADI professionals meet this need. The attention to information is due to the high relevance of this item in the allocation process.

The second main question concerns the matching issue; this is the examination of users' (and carers') needs and comparison with the inputs provided, of any kind. We intend to summarise users' needs (dependency, health conditions and behavioural disturbance) and then analyse the overall bundle of care inputs the users receive from informal carers, public services and private paid carers, focusing particularly on ADI inputs. This will be an objective comparison between needs and care inputs. It will be supplemented by the subjective assessment of users' and carers' unmet needs: to present both an objective and a subjective perspective helps to provide a more comprehensive view. The final matching issue considered concerns the boundaries between health and social care because they are of great importance in determining the degree to which needs are actually met.

The third main set of issues analysed concern geographical differentiations. These are transversal issues that concern most of the topics discussed. This final part of the chapter will look at the presence of geographical differences in the process of resource allocation.

4.2 With what effects?

The question "with what effects?" – that is what are the outcomes of community care - is of particular importance for the Production of Welfare approach. The main effort driving the POW consists, in fact, in understanding what are the effects of the services provided and what are their causes. It was previously shown that the issues concerning the outcomes of community care have not, till now, received enough attention in Italy. Chapter 7 will be devoted to it and will consider a number of outcome domains, mostly recorded after three months and - in a few cases - after six months. Our main goals in the chapter will be both to examine the outcomes themselves and to understand whether and how they are related to inputs. The task will, therefore, be to highlight the connections between inputs and outcomes, to understand the impact of the former on the latter. We want to detect what are the significant effects – if any – of changes in inputs on outcomes. It is not necessary to stress here the important policy implications and suggestions that it is possible to draw if one can understand these links. To pursue this aim, we will use different kinds of statistical tools, such as cross-tabulations (chi-square analysis) and multiple regressions.

In analysing the outcomes, we will compare the views of the three main players involved in ADI (users, carers and professionals). To do so, data concerning the subjective outcomes of the three of them were gathered in the fieldwork. In chapter 7 a particular interest will be placed upon similarities and differences in the perceptions on outcomes of the three main three players.

The outcomes to analyse are chosen according to two criteria: policy relevance and interest in the results. We will focus on those whose achievement is particularly important for ADI and whose analysis provides particularly interesting insights. We will consider four groups of outcome domains:

- destinational outcomes (impact of ADI on hospitalisation and institutionalisation and if users are still receiving ADI after three/six months);
- health conditions and dependency (the impact of ADI on health conditions and ADL functions according to users and carers);
- general and psychological well-being (to what degree does ADI have an impact in decreasing users' worries);
- satisfaction with the service (to what degree are users and carers satisfied with the service as a whole and with several specific elements of it).

In order to understand the causes of the ADI outcomes we will consider several inputs and quasi-inputs. We selected a number of them among the many possible items. The inputs and quasi-inputs to consider were chosen in the light of the issues we wish to discuss, the characteristics of the areas studied and the results and suggestions emerging from the literature. They can be divided into five groups:

- UVG and ADI features (regarding the process of resource allocation and the typology and amount of inputs provided),
- users' characteristics (such as gender, age, CIRS score and ADL score),
- principal informal carers' characteristics (such as stress and perceived health),
- private paid services (such as if private care is provided and what are its main traits),
- territorial differences (among local health authorities and among districts).

4.3 At what costs?

In the Italian context, it is nowadays particularly important to reflect on community care costs. Most of the arguments to support the development of community care in this Mediterranean country – as in many other states – assume that it is a way to save public money as it decreases the rates of institutionalisation and hospitalisation. It is not really clear, nevertheless, to what degree community care actually saves public money, how it does so, or under which circumstances. More generally, as stressed in previous chapters, cost analyses have previously been quite neglected in Italy. Chapter 8 will discuss the costs of community care. In doing so, we aim to consider the different kinds of costs involved in community care and to what degree the different stakeholders bear them. We will look, therefore, at direct costs (the consumption of financial resources to buy those goods and services that would not have been bought in the absence of disability or illness), indirect costs (the economic value of the time spent by persons caring for the elderly, time that could have otherwise been used in paid work or in other activities) and intangible costs (the costs of caring that cannot be translated into economic values, but that are of potentially high importance for the carers' quality of life). The stakeholders taken into consideration will be users in different conditions, informal carers, public services and private professionals.

Using this analytical framework, we deal with two main issues. One consists in comparing the costs of alternative modes of delivery. We will compare the costs of ADI with those of the two main alternative modes of delivery: hospital and residential care. We will focus particularly on the comparison between community care and residential care, and on the costs of substitution of the latter with the former. The issue of substitution with residential institutions or hospitals has always been at the centre of the debate on community care. Internationally one of the most important reasons that spurred the development of community care is that "ageing in place" is widely judged better than living in an institution (OECD, 1994). On the assumption that the quality of life of the dependent elderly is not adversely affected, another factor encouraging the development of community care has been expectations of lower costs borne by the public sector. Care in the community is reckoned to be cheaper than care provided in hospitals and residential homes, and the provision of the former is considered capable of decreasing the utilisation rate of the latter. We will conduct an empirical analysis of this topic for the Italian context.

The other main issue we will deal with is to reflect upon the costs of alternative allocative strategies. We will compare the current situation with two alternative strategies: "give less to more users" (the spreading strategy) and "give more to less users" (the targeting strategy). We will reflect upon the costs of alternative strategies under alternative scenarios (at the current budget or assuming a change in the public resources committed to community care). We will examine this issue because in Italy we have never had an explicit debate on the allocation of public resources in community care. We miss an open discussion on who should receive community care, who should be prioritised and why. The exercise that will be conducted in chapter 8 aims to contribute towards the development of such a discussion.

5. The research design: a critical assessment

The chapter discussed our research design, pinpointing the research questions it allows answering. As a final step, we will conduct a critical assessment of it in order to highlight its main shortcomings. As the rest of the chapter focused on what we could achieve through this design, we highlight here some of its key problems. The design is assessed in the light of the actual experience of the fieldwork and of the data analysis. This section should be read in conjunction with section 2 of the previous chapter, introducing and discussing the "Production of Welfare" Approach, and part 3 of the conclusions, presenting some general remarks on the PhD experience.

- **The size of the project**: The project was too big in both the number of issues analysed and the number of questionnaires compiled. It would have been wiser to focus only on one of the research questions presented in the previous section. Because the design was too big, the data gathered have been under-utilised. There are a number of variables gathered in the fieldwork that were not properly examined in the analysis. Too many energies and too much time of the candidate, furthermore, were used to manage the huge fieldwork at the expense of the time and energy devoted to the analysis (more remarks on the size of the project are in conclusions of the thesis).

- **The lack of a control group**: This is a key trait of our design. The lack of a control group is an inherent feature of observational studies. There was actually also a main practical argument that led us not to take the possibility of a control group into consideration: our budget could not bear the costs. It is a deficiency of the design because it decreases the significance of our findings in the outcome analysis. On the other hand, it is a strength because it allows us to concentrate on ADI users in order to understand differences between needs-related circumstances and packages of care (on the lack of a control group in "Production of Welfare" projects, its meaning and its consequences see also chapter 3, section 2).

- **The eligibility criteria**: We tried to define elderly ADI users as clearly as possible (not terminally ill, fully assessed by the unit of assessment and planning and with a care plan set for them). Nevertheless, we think that there were some problems of consistency within the users included in the sample. Under the label "ADI", in fact, there are community care services that are quite different (with respect to their organisations and care inputs delivered) one from the other. Also the users needs-related circumstances are extremely heterogeneous. Our eligibility criteria were not narrow and we could perhaps have used narrower one. To pinpoint the principal informal carers, instead, was easier and we had less problems about it. The criterion of "the member of the user's informal network who weekly dedicates most time to care for the user without receiving any salary" worked well and assured a high degree of consistency within the carers spotted.

Part II

Research findings

Chapter 5

Users' characteristics, formal and informal care inputs

1. Introduction

Who are the ADI users? What are their needs-related circumstances? What support do they receive from informal carers, paid carers and voluntary organisations? What care inputs does ADI provide to them? This chapter aims to answer these questions, presenting and discussing the users' characteristics and looking at the formal and informal care inputs they receive. The chapter is intended as the point of reference for the following three chapters, focused on such specific issues as resources allocation, outcomes and costs. We want to complete here the first step of a set of analyses that will then concentrate of specific issues.

The chapter will be divided into several sections, each dealing with different stakeholders and care inputs. We will start analysing the needs-related circumstance of users (section 2), and will then move to look at the needs-related circumstances of the informal carers and the care inputs they provide (section 3). The following section will examine the circumstances and inputs of the privately paid assistants (section 4). The analysis of the non-public sources of care will end with the voluntary organisations (section 5) and the following paragraph will be dedicated to the ADI care inputs (section 6). The final part will summarise the main findings of the chapter (section 7).

2. Need-related circumstances of users

In this project, the typical respondent has a well identified profile: she/he is a widow, aged 75 or over. This is what emerges from Table 1, where the frequencies concerning marital status, age category and gender of the users are shown and cross-tabulated. With reference to the age, ADI is a service mostly received by the "very old". Only 21 per cent of the users are aged between 65 and 74, whereas 40 per cent are between 75 and 84 and 39 per cent are 85 or over. The predominance of the "very old" among ADI users' is not a peculiarity of this service but is a trait shared by most of the long-term care services across Italy. Several projects show that now most of the publicly funded long-term care services are delivered to people aged 75 or over. Most of the users are aged at least

80) both in Lombardy (Facchini, ed , 2001) and in Italy (Presidenza del Consiglio dei Ministri - Dipartimento per gli Affari Sociali, 2000). The current situation is the outcome of the shift, occurred in the last decade, from "younger" to older users of services for the frail elderly, due mostly to the huge ageing process experienced.

Two users in every three are female, a trait similar to the overall elderly population of Lombardy. In the region, in fact, 62 per cent of the people aged 65 or over are female and 38 per cent are male (Irer, 2000). The widowed predominate, constituting 57 per cent of the users. There is also a huge group of married people, 38 per cent, whereas lower proportions are single, separated or divorced. Looking at the overall elderly population of Lombardy, the widowed are 40 per cent of the total and married 49 per cent (the data at national level are quite similar) (Irer, 2000).

Cross-tabulations highlight the user profiles. Most of people receiving ADI are female, but the gender patterns vary across the different age groups. In the 65-74 group there are more men than women, while the opposite is the case within the users aged 75 or over. Consistent with the pattern within the overall elderly population, the female percentage grows as the increases. In Lombardy, females are 57 per cent of the population aged 65-74, 66 per cent of the population aged 75-84 and 77 per cent of those aged 85 or over (Irer, 2000). The female majority within the users is due not only to the women's predominance in the elderly population (especially the very old) but also to the well know fact that – at an equivalent age – there is a higher disability ratio within the female elderly than within the male elderly (e.g. Mengani, 1995). According to recent estimations about Italy, in the group of those aged 65-69, the proportion of persons who are disabled is 8.1 per cent among male and 9.8 per cent among female, in the 75-79 group the percentage is 21.2 and 25.1 respectively, and in the group of those aged 80 or over, it rises to 38.7 and 51.7 respectively (Presidenza del Consiglio dei Ministri – Dipartimento per gli Affari Sociali, 2001). Also marital status varies with the age structure. Within the 65-74 group the majority are married, while in the other groups, the widowed are the biggest category. Within the overall population of Lombardy there are – as previously mentioned – more married and less widowed elderly: in the age group 65-74 the former are more than the latter whereas among those aged 75 or over it is the opposite (Irer, 2000).

A third feature, obviously linked to the other two, concerns the relationship between marital status and gender. Most of the men, 26 per cent of the overall sample, are married and most of the women, 46 per cent of the overall sample, are widowed. Re-aggregating the data, the sample is mostly composed by two groups: unmarried women (52 per cent) and married people (38 per cent). As is the case in relation to the link between age and gender, the patterns of the marital status-age and gender-marital status connections within the users are also consistent with those of the overall elderly population in Lombardia and Italy (Irer, 2000; Facchini (ed.), 2001;ISTAT, 2000).

Table 1

Proportions of ADI users in age and gender groups by marital status, per cent

	65-74		75-84		85+		Total	
Marital status	**M.**	**F.**	**M.**	**F.**	**M.**	**F.**	**M.**	**F.**
Married	83	32	79	22	39	13	*26*	*12*
Single/separated/Divorced	7	7	8	8	0	7	*1*	*6*
Widowed	10	61	13	70	61	80	*9*	*46*
Total	100	100	100	100	100	100		
	(N=38)	(N=29)	(N=45)	(N=83)	(N=32)	(N=93)		
Total	*12*	*9*	*14*	*26*	*10*	*29*	*100* *(N=320)*	

The basic profile of the ADI users is completed by data on their children and their households. Table 2 shows whether the respondents have children and, if so, how many. The majority, 84 per cent, have children and 6 out of 10 have two or more. With reference to the living conditions, Table 3 shows that only 16 per cent of the users live alone. The evidence on users' children is quite similar to the data concerning the overall elderly population of Lombardy: in the region, in fact, 15 per cent of those aged 65 or over do not have children (Facchini, 2001). There are, instead, huge differences in the living conditions: 16 per cent of the users live alone whereas those in these circumstances grow to 35 per cent among the overall elderly population (Irer, 2000). This illustrates what will, later on, emerge as a key feature of elderly persons receiving ADI: the service is targeted towards people who can rely upon a substantial family network. For people who cannot draw support from this network, it is more likely that deterioration in physical and/or cognitive ability leads to institutionalisation.

Table 2

Distribution of users by number of children, per cent

	Per cent
None	16
One	25
Two	31
Three+	28
Total	100 (N=347)

Table 3

Proportions of users by living conditions, per cent

	Per cent
Alone	16
With others	84
Total	100 (N=351)

After looking at the basic users' characteristics, we move now to analyse their degree of dependency and their health conditions. The ability to carry out the tasks to live independently can be measured by several indexes. The most commonly used (and one of the simplest) is the index of the activities of daily living (ADLs), created by Katz (Katz et alii, 1963, 1970). The index defines the degree of personal autonomy in the basic activities of everyday life and considers the individual ability to perform six basic tasks of everyday life: bathing, dressing, toileting, transfer, continence and feeding. The way in which the six variables are scaled is not by chance but intentionally constructed as in most of the people the progressive loss of autonomy follows that order. The ADL index is usually complemented by the index of the instrumental activities of daily living (IADLs), created by Lawton and Brody (Lawton and Brody, 1969). This index considers eight more complex household activities (using the telephone, shopping, meal preparation, heavy housework, light housework, transfer outside the home, handling own medications and handling own money). It is conceived as an extension of the ADL index, aimed to measure the autonomy in more complex activities that are more difficult to perform. The score in these two indexes is one of the most reliable indicators of the amount and type of care needed by the person. Table 4 presents the ADL score, with the respondents classified according to the number of functions deteriorated. On average, users are deteriorated in 4 out of the 6 functions considered. The mean value reflects the scores of two main groups, placed at the extremes of the scale. The biggest one includes those who are severely dependent (with four or more functions deteriorated): 67 per cent of the users. On the other extreme, there are those with none or one function deteriorated (25 per cent). For the latter group, the delivery of ADI cannot be motivated by the presence of disability and its reasons have, thus, to be found in other causes, such as health problems.

The presence of cognitive impairment has a strong impact both on the conditions and the behaviour of the elderly, and on their need for care. Therefore, it is important to assess the presence of cognitive impairment. To do so, we use the Short Portable Mental Status Questionnaire (SPSMQ), elaborated by Pfeiffer and used all over the world (Pfeiffer, 1975). This instrument measures both the presence and the intensity of cognitive impairments in the elderly. The data presented in Table 5 highlight the presence of cognitive impairment in more than half of the users (57 per cent). The cross-tabulation with the ADL score aims to "map" the care needs along two key dimensions. It appears that the overall majority of the users with four or fewer functions deteriorated are cognitively impaired, whereas the opposite is the case in the group with the greatest dependency[1]. It is particularly important to stress the presence of one third of users that are both highly dependent and suffering from cognitive impairments: this is a group with considerable need for care.

To complete the dependency profile of the respondent, we look at the IADL score. The mean shows the presence of dependency in 6 out of 8 functions. Almost all of the users have at least 5 functions deteriorated: 37 per cent between 5 and 6, 50 per cent between 7 and 8. To cross this score with that recorded in the ADL allows us to present the dependency characteristics of the users. Table 7 shows that those with the highest ADL dependency are mostly severely dependent also in the IADL, those in middle ADL group are mostly in the middle IADL and those with lower ADL score have the lower IADL ones.

Table 4

Distribution of users by ADL score, per cent

Functions deteriorated	Per cent
0	15
1	9
2	6
3	3
4	10
5	10
6	47
Mean Score	4,0
Total	100 (N=348)

---

[1] The presence of disturbance behaviour was mapped as well. Professionals were asked whether the users suffer from them and 9% answered affirmatively.

Table 5

Proportions of users in ADL score groups by cognitive impairment[2], per cent

Functions deteriorated	C.I.	No C. I.	Total
0-1	2	22	24
2-4	5	14	19
5-6	35	22	57
Total	42 (N= 171)	58 (N= 194)	100 (N=295)

Table 6

Distribution of users byIADL score, per cent

Functions deteriorated	Per cent
1-2	4
3-4	9
5-6	37
7-8	50
Mean Score	6,0
Total	100 (N= 322)

---

[2] The presence of cognitive impairment was defined as a number of errors of five or more (out of a total of ten).

Table 7

Proportions of users in ADL score groups by IADL score, per cent

Functions – deteriorated IADL **Functions – deteriorated ADL**	**1-4**	**5-6**	**7-8**	**Total**
0-1	13	9	2	24
2-4	-	15	4	19
5-6	-	13	44	57
Total	13 (N= 42)	37 (N= 119)	50 (N= 161)	100 (N= 322)

The *Assistenza Domiciliare Integrata (ADI)* consists mostly of health care inputs. It provides nursing, physiotherapy and home help inputs, but the overwhelming proportion of the care provision consists of the nursing element. The assessment of the physical health is thus essential in order to understand both the users' conditions and their need of care. This assessment is performed through the Cumulative Illness Rating Scale (CIRS) (Linn et alii, 1969). We chose this instrument because it is one of the most universally used, it is quite reliable and it is not particularly complex. It is an indicator of multiple pathology. We need this kind of indicator in our analysis because the effects of combinations of health/disease problems are different from the sum of the separate effects suggested by indicators of each problem. The scale considers 14 groups of diseases and examines whether a person suffers from each of them. Table 8 shows the scores recorded for the users. The mean indicates the presence of 4.1 diagnoses. 43 per cent of the users have fewer disease diagnoses than the mean, while 57 per cent have more. Box 1 lists, among the CIRS groups of diseases, those that are most prevalent. The health problems found most frequently are those concerning the muscle-skeleton system – skin (65 per cent), followed by heart (53 per cent) and nervous system (52 per cent).

One of the most challenging tasks ADI has to deal with regards how dependency and physical health interrelate: these are two very important features, and their mix is a key characteristic of the users. The ability to conduct a proper multidimensional assessment of a user's condition, to understand both each single dimension and the whole picture, often makes the difference between the success or failure of *assistenza domiciliare integrata.* In such a perspective, the connection between dependency and physical health is of great importance. Table 9 cross-classifies the functions deteriorated (ADL) and the disease diagnoses (CIRS), the latter with a cut-off of 4. The percentage of those suffering from 4 pathologies or more grows as the ADLs lost increases. In the first group (0-1 ADL lost), they comprise 45 per cent, in the second 58 per cent and in the third 64 per cent.

Table 8

Distribution of users by CIRS score, per cent

Disease diagnoses	Per cent
0-1	12
2-3	31
4-5	31
6-7	19
8+	7
Mean Score	4,1
Total	100 (N=270)

Box 1 – Prevalence of disease types among ADI users, per cent

Muscle – skeleton system, skin	65
Heart	53
Nervous system	52
Vascular diseases	45
Hypertension	42

N = 270

Table 9

Proportions of users in ADL score groups by CIRS score, per cent

Disease diagnoses (CIRS) **Functions deteriorated (ADL)**	**1-3**	**4+**	**Total**
0-1	55	45	*24*
2-4	42	58	*19*
5-6	36	64	*57*
Total	42 (N= 113)	58 (N= 155)	100 (N=268)

This project collected data in 3 out of the 14 local health authorities in Lombardy: in that is Milan, Milan neighbourhood and Lecco. In the last Table of this paragraph, the main characteristics of the elderly receiving ADI in these areas are compared with those of the elderly receiving ADI in Lombardy and Italy. We compare, in fact, the data gathered in our project with those from other pieces of research conducted in Lombardy and in other areas of Italy. The data concerning Lombardy are those gathered in the "VEAD" project in 1995. These data were gathered in 16 of the 21 local health authorities that Lombardy was, at that time, divided into (the sample amounted to 509 cases) (Nobili, Perilli and Focarile, 1997; Nobili and Tettamanti, 1997). The data for Italy were gathered in 14 sites throughout the country for the "ReteArgento" project[3] in 1997-1999 (there was a sample of 3361 cases) (AAVV, 1999). The comparison of the main baseline data indicates the presence of a common profile of ADI users with reference to gender, age, marital status, dependency and physical conditions. The percentage of female users is really similar among the three samples, approximately 60 per cent. Most of the users are aged 75 or over (the mean value is around 80), one third are married and more than half widowed; more than 80 per cent live with others. With reference to dependency and physical conditions, there is an average of some 4 ADL functions[4] and 6 ADL functions deteriorated and a mean of 3,5-4 disease diagnoses. The consistency of the users' profile among different areas of Lombardy and Italy is quite striking.

---

[3] The "Reteargento" project set up a wide database assessing the users in different areas with the "VAOR-ADI" instrument. It is the version for the *assistenza domiciliare integrata* of the well-known "MDS/RAI" (Minimum Data Set / Resident Assessment Instrument) compiled in residential care (Challis, Carpenter and Traske, 1996). Even if sample was not gathered following any criterion to be representative of the whole country, it provides useful information.

[4] The IRS and VEAD data present important similarities also concerning the percentage of users with 0-1 and 6 functions deteriorated.

Table 10

Users characteristics compared, per cent

	Gender	Age	Marital status	Living alone
3 Local Health Authorities in Lombardy[5]	Female = 64	65-74 = 22 75-84 = 40 85+ = 38 Mean = 82	Married = 37 Single/separated/ Divorced = 8 Widowed = 55	16
Lombardy[6]	Female = 65	65-74 = 28 75-84 = 39 85+ = 33	Married = 37 Single/separated/ Divorced = 9 Widowed = 54	-
Italy[7]	Female = 59	Mean = 79	-	17

Users characteristics compared (second part), per cent

	ADL	IADL	CIRS
3 Local Health Authorities in Lombardy	0-1 Functions deteriorated = 29 6 Functions deteriorated = 47 Mean score = 4,0	Mean score = 6,0	Mean score = 4,1
Lombardy	0-1 Functions deteriorated = 21 6 Functions deteriorated = 42 Mean score = 4,1	-	-
Italy	Mean score = 4,5	Mean score = 5,8	Mean score = 3,4

---

[5] It is the IRS project, including Milan, Milan neighbourhood and Lecco. The sample amounts to 351 cases and the data were gathered in 1999-2000.

[6] It is the Vead Project, including 16 Lombard Local Health Authorities (out of the then 21). The sample amounts to 509 cases and the data were gathered in 1995.

[7] It is the Reteargento project, including 14 sites throughout Italy. The sample amounts to 3361 cases and the data were gathered in 1997-1999.

3. Need-related circumstances of the informal carers and their care inputs

The Italian welfare state is built upon the family and its caring role. In comparative terms, this a main trait of our own country and a characteristic of the so-called "Southern model" of the European welfare states (Ferrera, 1996; Gori (ed), 2001). Overwhelmingly, the main source of assistance to the frail elderly is the family, while publicly funded delivery of services in kind is extremely scarce, with the level of provision being among the lowest in Europe (Gori, 2000). As in the other Southern countries, there is a huge imbalance between the public provision of services in cash and in kind. The most recent national survey on this topic confirms these characteristics and shows the growth of the population providing informal care over the last 15 years. The survey – based on data gathered in 1998 – looks at those providing informal care to someone living in another household at least once a month: they represent 22.5 per cent of the population aged 14 and over (ISTAT, 2000). A recent survey conducted in Lombardy, furthermore, clearly shows the wide and huge tasks performed by informal carers looking after the frail elderly. It also proves that there is a clear correlation between the dependency of the elderly and the amount of time informal carers devote to their care: the latter grows as the former does (Irer, 2000). In the international experience it is well known, furthermore, that the frail elderly requiring assistance on a regular basis have often a main helper, who provides most of the care (Twigg, 1996; Chappell, 1990). A recent project concerning the carers of elderly people suffering from Alzheimer's disease proves the presence of this trait in Italy as well (Censis, 1999).

The people providing informal care on a regular basis, the "principal informal carers", are the topic of this paragraph. In this project, by "principal informal carer" we mean the person mostly involved in caring for the frail elderly without receiving any payment (we will deal with the privately paid carers in the next paragraph). We identified a "principal informal carer" in 83 per cent of the cases (N= 289). Table 11 shows the age of the carers: half of them are aged between 34 and 59 years old, whereas the other half are aged 60 or over. Particular attention has to be dedicated to the latter group of carers. The caring activities are often highly demanding from both a physical and a psychological point of view and to carry them out can be particularly stressful for people aged 70 or over (24 per cent of the respondents), especially for those providing assistance to an elderly person with ADLs deteriorated in 2 or more functions (19 per cent of the overall respondents). An indicator of the burden associated with helping a frail elderly could be the length of time that the carer has been caring for the user. Table 12 indicates the presence of two main groups: those who have been caring for a long time (at least 2 years), who are the majority (56 per cent), and those who have – more or less – recently started to care, who comprise a third of the sample (31 per cent). The conditions of the 30 per cent of carers providing assistance for more than 2 years to an elderly person with 5-6 ADL functions deteriorated seem particularly important to examine.

With reference to gender, three carers out of four are women. Most of the carers do not have a paid job: 49 are pensioners and 26 are housewives or unemployed[8]. Cross-tabulating the two variables, we see that the majority of the carers are women who do not have a paid job (60 per cent) (Table

---

[8] The percentage of unemployed amounts to 2 per cent of the sample.

13). The last variable to examine in order to define the carers' profile concerns their relationship to the users: 56 per cent are siblings, 29 per cent husband or wife, and 15 per cent have another kind of relationship. Looking at their overall profile, the main traits are that half of them are aged 60 or over (and 24 per cent are 70 or over), some 6 of out of 10 have been providing care for more than 2 years, 3 out of 4 are women, 3 out of 4 are not in a paid job, some 6 out of 10 are users' siblings (and 3 out of 10 are their husband or wife).

Since the second half of the 1990s there has been in Italy a growing interest by the research community in the conditions and the problems of informal carers looking after dependent elderly. Different projects on this topic, with a quantitative approach, have been conducted in recent years and they have reached common conclusions with reference to both carers' profile and their difficulties. These conclusions can be usefully compared with the findings concerning our own sample. The principal informal carers considered in this project share some characteristics with their "colleagues" across Italy. The common traits are the tripartition according to age (a huge group among 30 and 60-65, a group of young old and a group of very old) and the predominance of women (always at least 7 out of 10). Another common finding is that most of the carers are pensioners and the second biggest group is composed of housewives, even if in Lombardy – probably due partly to the features of the labour market there - there is a higher percentage of working carers than elsewhere. This evidence could be also linked to the huge presence of paid carers in the region, see below. Finally, also in the other parts of Italy, at least half of the carers are children and the second biggest group are spouses. In our own sample 24 per cent of the carers are aged 70 or over, 57 of the carers look after elderly dependent in 5 or 6 ADL functions and 56 per cent of the carers have been looking after the dependent elderly for more than two years. The other Italian projects – through different methodologies and different indicators – come to similar conclusions: they agree that carers' age, elderly dependency and length of time that the carers have been caring for them are three predictors of carers stress and low quality of life (Mastriforti et alii, 2000; Censis, 1999; Tarabelli et alli, 2001; Zanetti et alii, 1997).

Along with aiming to understand "who" are the carers, we want also to know "what" they do in order to support and help the users, what are the features of the tasks they carry out. We know that 64 per cent of the carers live with the users, but this variable does not seem to be the key. The wide presence in Italy of the "intimacy at a distance" - elderly people and carers living in a different households but being in constant contact and spending a lot of time together (Saraceno, 1998) - makes us focus on the traits of the user-carer relationship, whatever the living arrangements. Table 15 shows that the overall majority of carers (85 per cent) meet users everyday. The carers were also asked how many (on average) of the 12 hours included between 8 in the morning and 8 in the evening they spend with the users every day they meet. Only 28 per cent of them spend less than 5 hours with the users, 16 per cent spend between 5 and 9 hours and 54 per cent spend between 10 and 12 of the 12 hours with the frail elderly. The data on days and hours the carers spent with the users highlight their tight and continuous commitment to the frail elderly. It is well known that actual arduous caring tasks can take a small amount of time. On the other hand, it is difficult to think that such a tight and continuous commitment does not turn out to be highly demanding and stressful for the carers. Such a commitment drives our attention towards the compelling necessity to promote services designed to support the carers and provide them with respite: we will come back to this issue in later chapters.

Table 11

Proportions of users in age groups by ADLs functions deteriorated, per cent

Functions deteriorated ADL Age of carers	**0-1**	**2-4**	**5-6**	**Total**
34-49	4	4	10	18
50-59	8	5	20	33
60-69	5	6	14	25
70+	5	6	13	24
Total	23 (N= 65)	20 (N= 58)	57 (N= 165)	100 (N= 289)

Table 12

Proportions of users grouped by length of time that carers have been caring for them by ADLs functions deteriorated, per cent

Functions deteriorated ADL Length of time	**0-1**	**2-4**	**5-6**	**Total**
Less than 1 year	6	6	19	31
1-2 years	3	2	8	13
More than 2 years	14	12	30	56
Total	23 (N= 65)	20 (N= 58)	57 (N= 165)	100 (N= 285)

Table 13

Proportions of users in gender groups by employment status of carers, per cent

Employment status **Gender**	**Pensioner**	**Working**	**Housewife/ Unemployed**	**Total**
Female	35	16	25	76
Male	14	9	1	24
Total	49 (N= 140)	25 (N= 72)	26 (N= 75)	100 (N= 287)

Table 14

Distribution of users by propinquity of the carers to them, per cent

	Per cent
Children	56
Husband/wife	29
Other (brother/sister, son-in-law, brother-in-law ecc)	15
Total	100 (N= 283)

To understand the characteristics of the caring tasks, “what” the carers do in the several hours they spent with the frail elderly, we have to turn to Table 16. The carers were asked, for each task presented in the Table, whether or not they carry it out on average at least weekly. Almost all of the respondents provide company and general surveillance and three out of four provide housework and personal care. The lower percentages are recorded for health/nursing care (which requires more technical skills and is provided by ADI), 59 per cent, and help going outside the home (most of the users are not able to do it), 36 per cent. We record, thus, the following tendency: the more the care task is complex (from company to personal care to health/nursing care) the lower the percentage of informal carers providing it.

Table 15

Proportions of users grouped by how often they meet carers by average number of hours spent together every day they meet between 8.00 am and 8.00 pm, per cent

Hours spent together **How often they meet**	**12**	**10-11**	**5-9**	**1-4**	**Total**
Every day	40	13	13	19	85
4-6 days a week	1	-	-	5	6
No more than 3 days a week	-	-	3	4	7
Total	41 (N= 118)	13 (N= 37)	16 (N= 46)	28 (N= 80)	100 (N= 287)

Table 16

Tasks performed weekly by the carers for the users, per cent

	Per cent	Number of cases
Company	95	284
General surveillance	94	284
Housework	79	280
Personal care	75	280
Health/ nursing care	59	281
Help in going outside the home	36	276

4. Need-related circumstances of the privately paid carers and their care inputs

The privately paid provision of social care to older people, disabled people and children is a particular feature of the Italian context, as in other Mediterranean countries (Antonnen and Sipila, 1996). According to some estimates, more money is spent on privately than on publicly funded care. (Rinaldi, 1998). As stated in chapter 1, 8.8 per cent of all Italian households used private paid services such as home help, childcare, elderly and disabled care in 2000. 4.2 per cent of families with a member aged 65 or over and 7.5 per cent of families with a member aged 75 or over accessed paid personal assistance for frail elderly (Istat, 2001). The percentage is higher in Lombardy, where 6.8 per cent of families with a member aged 65 or over received, in 2000, private care (Irer, 2001). In chapter 1 it was also stressed that elderly paid care is more expensive and more intensive in comparison with other kinds of services. In fact, 11 per cent of all families buying home help is provided with more than 20 hours of work per week. This share increases to 15 per cent among families with a personal assistant for frail elderly. The topic, however, has been scarcely researched until recently (among the few studies are Cerfe, 2000 and Ranci et alii, 2000). The features of the privately paid provision of care makes it difficult to study. It is, in fact, well known that most of this care is provided illegally (without paying taxes/contributions) in the "grey market" outside any public regulation or control.

Users (and their principal informal carers) were asked whether they receive privately paid care: 45 per cent of the respondents answered that they did. That high percentage has to be interpreted with a caveat in mind. In fact, it is probably reasonable to assert that the real percentage of users receiving this kind of care could be higher because of under-reporting. This could be due to two reasons: the care was provided illegally, and some may have feared that to admit to receiving private care would cause the provision of the public one to be interrupted.

Several questions were addressed to the users in order to highlight the private carers' profile and to understand the tasks they carry out. Attention was focused on the carers providing most of the private care. In 81 per cent of cases there was only one carer, but in 19 per cent there is also a second private carer. Table 18 shows their features with reference to age and gender: the overwhelming majority are women (87 per cent), a half are in the central age group (30-49), 20 per cent are aged under30 and 30 per cent are aged over 50[9]. A matter of particular interest concerns the carers' country of origin, which in only half of the cases is Italy. 5 per cent come from other European countries and 42 per cent come from non-European countries (Table 19). The group of foreigners providing care privately has increased rapidly over the last decade (ISMU, 1999). The overall profile of the private carers thus consists of a huge majority of females, a majority in the middle spell of life (but with relevant percentage for those below 30 and above 50), half Italian and half foreigner (with a predominance of non-Europeans among them). The data on the private carers' nationality lead our attention to the impossibility to look at them only from the perspective of the long-term care policies. The perspective has to be threefold, taking into consideration long-term care policies, labour market policies and immigration policies. If one compares the profile of the

---

[9] Only 5 per cent of the privately paid carers are aged 60 or more.

private carers with that of the principal informal carers – apart from the obvious differences concerning the nationality – it appears that the former have a percentage of females higher than the latter. What strikes one more, nevertheless, are the differences regarding the age: 70 per cent of the private carers are younger than 50 whereas for the principal informal carers the percentage decreases to 18 per cent.

Table 17

Distribution of users receiving privately paid care, per cent

	Per cent
Yes	45
No	55
Total	100 (N= 303)

Table 18

Proportions of privately paid carers in age group by gender, per cent

	Female	Male	Total
Less than 30	18	2	20
30-49	42	8	50
50+	27	3	30
Total	87 (N= 118)	13 (N= 18)	100 (N= 136)

Table 19

Distribution of privately paid carers by country of origins, per cent

	Per cent
Italy	53
Other European country	5
Non European country	42
Total	100 (N= 136)

As we did with informal carers, after looking at the profile of the paid private care providers we turn to the amount and typologies of activities they carry out to support frail elderly people. Those living with the elderly constitute 29 per cent of the sample. Once again, however, specifying the frequency and length of their meetings sheds more light than simply looking at living arrangements. With reference to the frequency with which users and carers see each other, Table 20 shows the presence of two main groups: 58 per cent meeting (almost) every day and 30 per cent meeting no more than 3 days a week. The length of the meetings is between 1 and 3 hours for 45 per cent of the respondents, between 4 and 19 hours for 28 per cent and between 20 and 24 hours for 27 per cent. Comparing the principal informal carers with privately paid ones, clear differences emerge: the former meet the users more often than the latter and spend more time with them each time they meet. The data presented in Table 21 show that differences are found also in the tasks performed for the users. We asked, for each task presented in the Table, whether the privately paid carers carry it out weekly. The percentage of those providing company and general surveillance is far lower (from 94 per cent to 64 per cent) and these two tasks are here not the most frequently performed. Similarly, there is a substantial decrease in the percentage of those providing health/nursing care (from 59 per cent to 34 per cent) and help in going outside the home (from 36 per cent to 15 per cent). There is, instead, a smaller decrease in the percentage of those providing housework (from 79 per cent to 70 per cent) and personal care (from 75 per cent to 70 per cent). So it is a general feature that private carers perform fewer tasks than informal carers, and they are more focused on specific tasks. They provide more housework and personal care than company and general surveillance, and provide health/nursing care only to one user out of three.

Table 20

Proportions of privately paid carers grouped by frequency of meetings with users by average number of hours spent together every day they meet, per cent

Hours spent together **How often they meet**	**20-24**	**4-19**	**1-3**	**Total**
6-7 days	25	11	12	58
4-5 days	2	10	10	22
Less than 4 days	-	7	23	30
Total	27 (N= 33)	28 (N= 34)	45 (N= 55)	100 (N= 122)

Table 21

Distribution of tasks performed weekly by the privately paid carers for the users, per cent

	Per cent	Numbers
Housework	70	128
Personal care	70	128
Company	64	122
General surveillance	64	121
Health/ nursing care	34	122
Help in going outside the home	15	119

5. Care inputs from voluntary organisations

The voluntary sector is the third source of non-public care. By "voluntary organisations" we refer here to groups of people (participating freely without any restriction and mostly unpaid), whose action is in some way (more or less formalised) connected and that can get some financial contributions from the public sector but do not rely mostly on it. These organisations can be quite formalised and structured (such as CARITAS) or more informal (such as people attending the same parish church who decide to set up a group to support frail elderly people). Voluntary organisations play a key role in the Italian system of social protection, and because the provision of publicly funded services is quite restricted, their activities are very important in meeting the needs of many people (Barbetta, 2000).

Table 22 shows that only a small proportion of users receive help from the voluntary organisations, amounting to 5 per cent of the sample of respondents. Users belonging to this group share a particular trait: we know, from the interviews conducted with ADI managers, that the contribution from the voluntary sector tends often to concentrate on supporting the users involved in hospital discharges. The evidence on the rather small contribution from the voluntary sector to the care of ADI users must be considered in the context of the low percentage of elderly receiving publicly funded community care in Lombardia (and Italy) (see chapter 3). In this project we did not gather data on the overall contribution of the voluntary sector in the areas studied, but our evidence seems to suggest the presence of a "division of labour" between the former and the public sector. It seems, in fact, that the voluntary sector concentrates its effort on the elderly who do not receive public assistance. This suggestion is supported by the experiences of several people involved in the voluntary sector in Lombardy with whom we spoke.

Table 22

Distribution of users receiving help from voluntary organisations, per cent

	Per cent
Yes	5
No	95
Total	100 (N= 303)

Both users who do not receive help from voluntary organisations and their principal informal carers were asked about their desire to receive it, in order to compare their wishes. Among users, the overwhelming majority do not desire help from voluntary organisations: 69 per cent do not and 31 per cent do (see Table 23). The carers' answers point in the opposite direction: 53 per cent desire help from voluntary organisations and 47 per cent do not (see Table 24). The data show that users' and carers' wishes therefore strongly diverge. The former do not want other people to be involved in their care, a stance linked to feelings of embarrassment and distrust toward unknown people. The fact that the majority of informal carers desire an intervention from a voluntary organisation is to be connected with the heavy care burden they to have to bear (see section 5.3). Having to face such hard tasks, they would welcome some support from the intervention of the voluntary sector. We can also state that their positive answer to the question "do you desire help from voluntary organisations in caring for the dependent elderly?" can be interpreted in a wider sense. It can be read, in fact, as a general request for support in their caring role, consistent with the evidence on the demands of their daily responsibilities, as presented in a previous chapter. The necessity of services designed to support the carers comes again to the surface.

Table 23

Distribution of users desiring help from voluntary organisations, per cent

	Per cent
Yes	31
No	69
Total	100 (N= 168)

Table 24

Distribution of carers desiring voluntary organisations to help their dependent users , per cent

Yes	53
No	47
Total	100 (N= 270)

6. ADI inputs

In ADI, the integrated domiciliary care, both home help (social care) and domiciliary health care (home nursing and physiotherapy) are made available to the user at home. *ADI* encompasses in turn a wide range of care inputs and the packages of care provided can be substantially different. Municipalities provide home help, while local health authorities provide home nursing and physiotherapy. The latter are also in charge of co-ordinating the overall provision of integrated domiciliary care. The health care inputs are free of charge, whereas there is normally a fee to pay for the social care inputs. Claimants' conditions are initially assessed by an assessment and planning unit consisting of social and health care professionals (*Unità di Valutazione Geriatrica, UVG*). The unit sets up what is believed to be the most appropriate care plan, using whatever health and social resources are available.

Table 25 presents the percentages of users receiving the three ADI care inputs: 72 per cent receive home nursing, 33 per cent receive physiotherapy and 9 per cent receive home help. The data indicate a considerable predominance of nursing inputs, a third of the users receiving physiotherapy and a very small contribution from home help. With reference to the latter point, it is important to bear in mind that ADI encompasses only the social care inputs provided to the elderly needing domiciliary health care, whereas the home help provided autonomously is a different service. The following Table is the most relevant in order to understand what the users actually get from ADI: 60 per cent receive home nursing only, 17 per cent physiotherapy only, 19 per cent a combination of two care inputs and 4 per cent a combination of all the three inputs (see Table 26). It therefore emerges that the widespread official documents, acts and guidelines describing ADI as a service providing a package of care composed of different inputs do not have a relevant impact on the actual reality of community care in Lombardy. Only a minority of users (23 per cent) receive multiple inputs whereas the overall majority of them (77 per cent) gets one service.

Table 25

Distribution of users receiving ADI care inputs, per cent

	Per cent	Numbers
Home nursing	72	319
Physiotherapy	33	319
Home help	9	319

Table 26

Distribution of users receiving ADI care packages, per cent

	Per cent
Home nursing only	60
Physiotherapy only	17
Home nursing and physiotherapy	13
Home nursing and home help	4
Physiotherapy and home help	2
Home nursing and physiotherapy and home help	4
Total	100 (N= 283)

Tables 27 and 28 examine the number of weekly visits undertaken for the two major ADI input of nursing care and physiotherapy. With reference to the former, the mean of 3.64 visits a week encompasses very different situations. It seems important to notice, in fact, that 32 per cent of the users receive 1-2 visits a week, whereas 40 per cent receive 5-7 visits (see Table 27). The mean of physiotherapy weekly visits is 2.9, lower than for nursing. The overall majority of those obtaining this input, 63 per cent, receive 3-4 visits a week, whereas a group amounting to 29 per cent receives 1-2 (see Table 28).

Table 27

Distribution of users by number of weekly home nursing visits, per cent

	Per cent
1-2	32
3-4	28
5-7	40
Mean	3.64
Total	100 (N=231)

Table 28

Distribution of users by number of weekly physiotherapy visits, per cent

	Per cent
1-2	29
3-4	63
5-7	8
Mean	2.9
Total	100 (N=104)

The concept of the *Assistenza Domiciliare Integrata* is mainly the co-ordinated interventions of several (health and social) care professionals. Among them, particular emphasis is placed upon the contribution expected from the general practitioners, as stressed in chapter 1. They are supposed to contribute mostly at two points: at the initial stage (assessment of the case and setting up of the care-package) and in monitoring the user's conditions over time. In many cases, as the users cannot leave the home, to monitor the case means to visit them there. General practitioners have a specific incentive to do so: for each visit a user's home they obtain an extra financial reward. Table 29 indicates in how many cases the initial care plan includes at least a visit to the user's home in the first 4 weeks of the ADI delivery: they amount to some half of the respondents, 51 per cent. The following Table looks at the contribution of the consultants (geriatricians, cardiologists, neurologists, and urologists) at the users' home. It shows that in 42 per cent of the cases the initial care-plan includes at least a visit there in the first 4 weeks (see Table 30).

Table 29

Distribution of users receiving GPs' visits at home at least once a month, per cent

	Per cent
Yes	51
No	49
Total	100 (N=319)

Table 30

Distribution of users receiving consultants' visits at home at least once a month, per cent

	Per cent
Yes	42
No	58
Total	100 (N=319)

7. Conclusions

This chapter provides a first look at the original evidence gathered for this study. It pursues two aims: to describe the users' profile and to highlight the main features of the (formal and informal) care inputs provided. The main need-related characteristics of the elderly receiving ADI are now quite clear. With reference to marital status and age, they are mostly widowed (there is also a smaller but relevant group of married people) and 8 out of 10 are aged 75 or over. There is a link between age and gender structure. The proportion of women, in fact, increases with age. Taking living conditions into consideration, ADI users usually live with someone else. The data gathered allow us to describe the users' characteristics concerning dependency and health conditions as well. The average number of ADL functions deteriorated is 4.0 and the users can be divided into two main groups: those dependent in 0 or 1 function (24 per cent) and those dependent in 5 or 6 functions (57 per cent). The average number of IADL functions deteriorated is 6.0, but the biggest group comprises by those dependent in 7 or 8 of them (50 per cent); the average number of disease diagnoses (measured by the CIRS score) is 4.1. The users' profile presented in this chapter matches, to a high degree (more than expected), the descriptions produced in other projects conducted in Lombardia and Italy (see Table 10). The considerable degree of congruence (concerning gender, age, marital status, dependency and health conditions) across these different projects is striking: it would seem that there is a sort of "Italian model" of ADI user.

The other main contribution provided by this chapter has been to introduce the main features of the different care inputs involved in supporting the ADI users. These features raise several issues that are crucial to an understanding of community care in Lombardy (and in Italy) and that will be at the centre of the analyses conducted in the following chapters:

- *The " real" characteristics of the ADI*: Introducing the *assistenza domiciliare integrata* in the 1990s, a lot of emphasis was placed on the fact that this service would lead to the design of care packages constituted by different inputs. This is how ADI was designed in official documents such as the national *Progetto Obiettivo Anziani 1992*, that had a key role in promoting the new service across Italy. In line with it, the debate of the 1990s paid a lot of attention to the delivery of a care package composed of different kinds of inputs. The main idea was that the multiple needs of many elderly could be met only through the co-ordinated provision of different care inputs. The evidence gathered shows that the reality is, instead, quite different. The overall majority of users (77 per cent) receive just one service and in most cases this is home nursing. In the following chapters, we will thus deal with what are in the reality three different services: home nursing only (60 per cent of the users), a mix of 2 or 3 care inputs (23 per cent) and physiotherapy only (17 per cent). The reflections on the matching between needs and resources, how to reach ADI and the process of initial assessment/care planning/re-assessment will be deeply affected by this tripartition. The argument about the distance between rhetoric and reality in community care works with reference to the collaboration between social and health care services as well. This is another supposed feature of ADI, widely stressed since its inception, that the real world evidence does not support. It is only 1 user out of 10 who receives a care package composed by both these care inputs. In most of the cases there is a "division of labour" between public services and families (the latter also often with the contribution of private carers): the former concentrate their activities on health/nursing care and the latter on personal care. In the qualitative interviews, conducted at the beginning of the fieldwork, several managers of the districts and authorities involved in the project stressed the lack of provision of physiotherapy and of social care. With respect to physiotherapy, there is a common view that its provision is really inadequate and that the health authorities should increase it. This deficiency comes from the past: the provision of physiotherapy in Lombardy has always been very low and, in fact, in the recent years it was increased in several health authorities of the region. The scarcity of physiotherapy is actually a problem shared by many Italian regions (Presidenza del Consiglio dei Ministri – Dipartimento affari sociali, 2001). With reference to the very low proportion of ADI users receiving home help, the managers think this is due to two main reasons:

home help (a social care services) is strictly means-tested while home nursing and physiotherapy are only needs-tested, and many home help users do not need health care inputs.

- *The dominant role of informal care*: Most of the care burden sits on the shoulders of the informal carers (predominantly the family). The principal informal carers meet the users on a daily basis in 85 per cent of the cases, spend a huge number of hours with them (the majority at least 10 out of the12 hours between 8am and 8pm) and perform several tasks to support them. Asked about the role and impact of informal carers, in the qualitative interviews, the managers of the districts and authorities involved in the project shared a common view: they think it is informal care rather than public care services which are pivotal in the successful care of the frail elderly in the community. Even if in Italy we lack ultimate evidence on this issue, this is a view shared by most of the commentators as well. Quite often, dependent elderly people without strong informal support cannot continue to live at home, no matter whether ADI is provided or not. This apparently key role of the informal networks should encourage the public services to reflect on which are the best ways to interact and co-operate with them. On the one hand, it requires thought about the ways ADI professionals and managers interact with the informal networks in order to build effective arrangements concerning respective roles and functions. On the other hand, such a situation requires thought about how to develop the range of possible interventions aimed at supporting the carers (respite care, self-help groups and so on). In contrast to what happens with informal networks, the data show that the voluntary organisations play a marginal role in caring for the elderly receiving ADI. It seems they target their efforts towards other types of need.

- *The huge role of privately paid care:* According to the data gathered some half of the users receive privately paid care and it is reasonable to think that this proportion is underestimated. Half of the private carers are foreigners (in several cases without permission to stay or work in Italy). In most of the cases, the private care is provided in the "grey market", outside any public regulation. Therefore, there must be concerns regarding the quality of the care provided and the working conditions of the workers (more generally, their overall situation). Both the research and the policy debate have, until recently, paid little attention to this topic but its seemingly rapid spread should make us reflect more about it. Our result shows that the collaboration we have mostly to deal with is not between home health inputs and home help but between ADI (i.e. mostly health inputs) and private care. There is a need for policies to promote regular employment in this kind of service to households. These policies have to be designed at regional and national level (not by single local health authorities) and have to deal simultaneously with issues concerning care, immigration and labour market. In fact, they have been really underdeveloped until now (to put it better, they do not exist). It is, therefore, reasonable to state that it will take quite a long time before we can see relevant improvements.

Chapter 6

Who gets what?

1. Introduction

How do the elderly become ADI users? What kind of assessment and re-assessment do they go through? To what degree do the service inputs provided match their needs? Why do they receive different amounts and types of service? Are there local differences in the care provided? This chapter will deal with these questions, looking at the several issues concerning resource allocation: the "who gets what" questions.

Resource allocation is examined from different perspectives. We look at the process through which resources are allocated, at their matching with users' and carers' needs, and at the decisions made about them. The overall aim is to examine how public resources should be allocated and how the process of doing this should be shaped. That begs the question whether (and to what degree) ADI should have a role of governance of community care in a wider sense. An issue running through the whole chapter is the local differences in the process and/or in the resources provided. The process foci are how the potential users reach ADI and the assessment and re-assessment of their conditions over-time. In a wider perspective, we look at the different actors UVG has to interact with in the community and what this means for its roles and tasks. We furthermore analyse the need for information by users and carers, and the degree to which ADI professionals meet this need (see Box A). These issues are mostly analysed in section 2. To examine users' (and carers) needs and the inputs provided to meet them, we start to analyse the overall bundle of care inputs that ADI users receive. The following step consists of focusing on the ADI inputs. The discussion then moves on to look at the boundaries between health and social care. The last questions of this part of the chapter concern the unmet needs of both users and carers (see Box B). These issues are mostly analysed in sections 3 and 4. This chapter deals with another set of issues, regarding geographical differentiation. These are pervasive issues, because they concern most of the topics discussed in the chapter. This final set of issues looks at the presence of geographical differences in the process and resource allocation and the level at which decisions are made (see Box C). Section 4 is devoted to the investigation of the reasons for different patterns of service utilisation in the *assistenza* *domiciliare integrata.* It presents the results of four models of logistic regression exploring influences on different types and amounts of care inputs for users. Several independent variables are tested to detect those with a statistically significant link with these dependent variables. The independent variables considered include users' needs-related circumstances, how services are organised and delivered, and territorial differences. Taking such a complex bundle of independent variable into consideration, the models concern most of the research questions asked in Boxes A, B and C.

RESEARCH QUESTIONS

A. How to govern community care?

- How to reach ADI: are Gps the best way through?
- The UVG assessment and care-planning role over time: how is it? Why?
- A public service in a complex community: which actors deliver care in the community?
- Needs extended beyond care: is there a need for ADI professionals to provide information/suggestions for users and family?

B. Which care inputs for which needs?

- The bundle of care: how do the different care inputs mix together?
- The public intervention: which are the ADI inputs?
- Highlighting the "grey area": where is the boundary between health and social care?
- Caring for the users: which are their unmet needs?
- Caring for the carers: what do they need?

C. What geographical differences?

- The geographical fragmentation: are there local differences in the process and/or in the resources provided? To what degree?
- Deciding for community care: at which level of government are policy choices made?

2. The process

2.1 Becoming an ADI user

Our analysis of the process through which frail elderly people get in touch with ADI, become users and are cared for over time begins with an examination of their location before starting to receive the service. Table 1 shows where users were to be found before starting to receive ADI. According to their answers, they can be divided into three main groups: those who were at home (the overall majority, 71 per cent), in hospital (21 per cent) and in institutions for short-term care (IDR, homes for rehabilitation) and long-term care (nursing homes) (the total for this group is 8 per cent). In the light of the changes that affected the Italian health care system in the 1990s, particular attention must be devoted to those who start to receive ADI as they leave hospital. In chapter 2 it was argued that the introduction of a new method of hospital reimbursement, based on DRGs (Diagnostic Related Groups), led to a decrease in the average number of in-patient days increasing the pressure on the community care system. The frail elderly are a group for whom DRGs are particularly inadequate and since their introduction there has been fierce opposition to them in Italy by most scholars and practitioners (Salvioli and Cucinotta, 1996). In such a changing scenario, we would have expected a bigger group of users coming from hospital wards. These findings raise some questions about the destination of elderly after receiving hospital treatment. Are there many of them who would need ADI but are not receiving it? To find an answer to this question goes beyond the scope of our work, but it would deserve attention in further pieces of research. It could be that several elderly leaving hospitals look for private nursing support (which is, nevertheless, more difficult to find than the less specialised home help support). Other hypotheses to be tested in future research would concern the possibility that some elderly (and their families) are not aware of the possibility to get ADI and that they request but not receive it.

The professionals in the sample involved in caring for the users discharged by hospitals were asked whether or not it was a planned discharge (i.e. if when the person was still in hospital the ADI professionals gathered at least some basic information on his/her condition and it was agreed to provide the service). This happened in 62 per cent of the cases, while in 38 per cent the elderly were discharged to their home and then they (or their families) requested ADI, with all the assessment and care planning process starting once they had returned in the community. The interpretation of these results could be equivocal[1]. It is certainly true that 38 is a high percentage (and the definition of planned discharge used was not demanding). On the other hand, it must be remembered that over the 1990s the Lombardy health care system went through several changes, quite deep and still to be fully implemented. A major change consisted in the introduction of the split between providers and purchasers of acute care. The latter, i.e. the Local Health Authorities, are also in charge of the provision of community care (and more generally of long-term care). The outcome of the change is, thus, that there is a division between the providers of acute care and the providers of long-term care (each of them with their own agenda and their own budget). The interaction between this separation

---

[1] A note of caution is also due to the number of those who were in hospital before receiving ADI: 71 people.

and the utilisation of the DRGs has been producing negative consequences for the care of the frail elderly (we miss scientific evidence on this issue but there is a widespread consensus about it within professionals, users and scholars). If one considers the changes introduced in the 1990s, and their inconsistencies, 62 per cent of planned discharge can be rated a positive result.

Table 1

Users by location prior to receive ADI, per cent

Home	71
Hospital	21
Istituto di Riabilitazione (IDR)	8
Nursing home	1
Total	100 (N= 348)

Who suggested that the users (and/or their families) required ADI? This was investigated as well. Such a question aims to find out the link between potential users and the service, which person or agency suggested to them to request ADI in order to meet their care needs. In table[2] 2, the respondents were divided into four main groups: those who were suggested by the GP (55 per cent), by other public services (Local Health Authority, Municipality, Hospital, 28 per cent), by the informal network (friends/neighbours or others, 16 per cent) and by no one (i.e. he/she was already aware of ADI, 2 per cent). The findings highlight important features of the process through which the elderly become ADI users. In almost all cases, they (and their family) were not aware of ADI before looking for care. When they actually started to look, in the overwhelmingly majority of cases they turned to a welfare professional/agency, mostly GPs (the professionals they are more used to). The elderly and their families do not immediately reach ADI, when they start looking for community care. Instead they reach another welfare service which suggests the former. It is only a small group that get the suggestion to request ADI from other sources. It is a two-step process: they first ask another welfare agency and then reach the *assistenza domiciliare integrata*.

These data pinpoint the necessity to develop informative policies concerning both the existence of the service and how to obtain it. These policies have to be focused towards a double target: the overall population and the different welfare professionals. It is, in fact, important to spread information about ADI so that, when an elderly person and his/her family start to look for community care it is much likely as possible for them to become aware of the service (and how to obtain it). Informative policies were put in the public policy agenda in the 1990s, and were the subject of increasing debate and interest. A number of projects prove that the population asks for

---

[2] In this table, in the following box and the following table, only users who were located at home before beginning to receive ADI are considered, as the others – hosted in hospital or institutions – were already in touch with a welfare agency.

more information concerning what public welfare services are available and how to get them (e.g. Rossi. 1995). The new national framework legislation on personal social services enacted in 2000 (law 328/200, see chapter 1) inserted informative interventions within the basic level of services that has to be provided all over the country. The actual implementation of the informative policies, nevertheless, is still in its early stages and further and stronger developments are needed, both in Lombardy and in Italy (but it is not clear to what degree the framework legislation on personal social services will be able to contribute to pursue this aim). Our qualitative evidence, gathered by interviewing UVGs and managers, shows that it is the case in the sample Authorities as well. In Italy the debate on informing the population about public services (and the policies pursuing this aim) hides an underlying contradiction. On one hand there is widespread rhetoric (shared by professionals, managers and scholars) on the importance of information and on the necessity to spread it among the population. On the other hand, the provision of long-term care services in Italy is extremely scarce, by far outstripped by the needs for care. The actual demand for public services is really lower that the need: one of the main reasons is that many families are not aware of the possibilities to receive some services or – if they are – they do not have the information necessary on the process to get them. If families were more informed, there would be higher and higher demand for long-term care services, a demand the public welfare cannot meet. This is probably a reason why the translation into policies of the rhetoric on the necessity to spread information is faltering.

The second part of the information issue concerns the public welfare professionals and agencies: they should all be well aware of ADI, its features, its target and how to approach it. They should be both ready to pinpoint a need that ADI could satisfy and well aware of all the information that elderly people (and their families) need to fulfil it. They also, or at least the GPs, should have a direct connection with the UVG, in order to direct prospective users to them. There are, thus, two issues concerning welfare professionals and agencies: one is that they should be well informed, the other that they should have a direct link to the *Unità Valutativa Geriatrica*. We do not have quantitative evidence on these two issues in the region, but our own knowledge of the Lombardy welfare system leads us to think that there is an high degree of variability on this matter. The qualitative evidence collected for this project supports this view.

Table 2 - Who suggested to request ADI? Per cent

GP	55
Local Health Authorities services	7
Municipality services	10
Hospital	10
Friend/Neighbours/Others	16
None	2
Total	100 (N= 248)

Table 2 illustrates how the general practitioners are the main gateway to ADI. They have, thus, a crucial role in governing the access to the community care public services. A further investigation throws more light on it. Users can be divided into those suggested to request ADI by their GPs and those suggested or referred by others (the sum of the other possible answers in table 3, i.e. both other public agencies and informal network). The mean of the CIRS score (cumulative illness rating score, indicating the number of diagnosticated diseases) is lower for the first group than for the second. The analysis of variance (Mann-Whitney Test) showed that the difference was statistically significant ($p < 0.05$) (see box 1). It means that the elderly referred to ADI by their GPs were in better health than those referred by others, with a significant connection between the two variables.

That elderly referred to ADI by GPs have better health is consistent with the role of the latter as the welfare professionals best known and most often met by people belonging to this group. It is a particularly important finding because in Italy people tend usually to turn to public community care when their conditions deteriorate to a serious degree and there is little room fpr improvement, a trait consistent with the scarce provision of these services. It is possible to draw two suggestions from this evidence. One is to strengthen the GPs' role in referring elderly to ADI: to make more and more clear to them the importance to refer elderly people to UVG at an appropriate time (with a direct contact between them and the UVG) and to ensure that GPs have all the information on ADI that can be useful to prospective users. This evidence supports the view of the general practitioners that was initially suggested by the *Progetto obiettivo anziani* in 1992. That document produced by the national government, and that had a huge echo in the 1990s, stated that the general practitioner should be a cornerstone of the *assistenza domiciliare integrata*, "the main reference for the different kind of health services provided at home to the dependent elderly" (Department of Health, 1992, p 45). Over the 1990s, a number of publications stressed the importance to have GPs actually playing this role, underscoring the benefits it is possible to get in this way (e.g., AAVV, 1997; Peduzzi, 1995). The experience has actually not always been of this kind and there is a huge degree of variety in the role played by GPs in ADI.

On the other hand, this evidence highlights the necessity to develop policies on information described above in order to make the other frail elderly (and the professionals and agencies they refer to) more aware of ADI and of how to access it.

Box 1

Who suggested to request ADI by CIRS score, Mann-Whitney Test[3]

```
Mean Rank   Cases   Mean        Variable


   88.21      95    3.7         GP suggested ADI
  107.30     100    4.4         Others suggested ADI
             195    4.1         Total

Corrected for ties
      U           W            Z      2-Tailed P
   3020.0      8380.0     -2.3837      0.0171
```

Table 3

Local Health Authority by source of referral to ADI, per cent[4]

	GP	Others	
Lecco	80	20	100 (N= 56)
Monza	39	61	100 (N= 69)
Milano	52	48	100 (N= 116)
Total	55 (N= 133)	45 (N= 108)	100 (N= 241)

Chi-Square (Pearson): Value 0.2204744, DF 2, Significance $p < 0.001$

The actual role of GPs differs substantially between the three Authorities studied. There are relevant differences at local level among the Authorities (and the Districts) with reference to all the factors analysed, as will emerge later in this thesis when we return to this topic. In Lecco they initially suggested ADI in 80 per cent of the cases, in Monza in 39 per cent and in Milan in 52 per cent. Being in one Authority or another clearly makes a difference, as the statistically significant chi-square test suggests (see table 3).

---

[3] This box takes into consideration only the users who were located at home before receiving ADI.

[4] This table takes into consideration only the users who were located at home before receiving ADI.

The data presented in the appendix to this chapter show that, within the trends concerning the three Authorities, there are statistically significant differences between the districts (2 belonging to Lecco, 4 to Monza and 8 to Milan). It must, however, be emphasised that there is quite a good degree of consistency within each Authority, which is not the case for other issues examined later in the chapter.

2.3 Care plan and re-assessment

After getting in touch with ADI, elderly people go through a process leading to a decision[5] on the eligibility and – if it is affirmative – to the delivery of the service. This process varies markedly between the three Authorities and often also within them, among their districts. It takes different shapes and is composed of different steps. Differences concern screening, assessment, care planning and monitoring. The qualitative interviews conducted with managers and the literature review show that there are two main options to arrange a care plan. One is to have a formal meeting intended for this purpose (usually one meeting is held to arrange several plans). In this meeting, professionals in charge of the assessment of the users' conditions and/or of the different professions involved (nursing, physiotherapy, and social care) gather and work together to set the most appropriate plan. The alternative is not to have a formal meeting and to define the plan through an informal process. It is for a professional in charge of the care planning (usually a nurse) to arrange it after considering the assessment (that he/she and/or others have completed) and consulting with the person responsible among the different professions involved. The most detailed study on how ADI is actually organised and works in different sites across Italy, conducted in the mid-1990s, showed that these are the two main alternatives and that all the local services are placed in different points of the continuum between them (Abate, Bavazzano e Di Iorio, 1995). In 53 per cent of the cases a formal meeting was held while in 47 per cent it was not. This overall result hides important differences between the 3 Local Health Authorities. In Lecco a meeting takes place in 22 per cent of cases, in Monza in 43 per cent and in Milan in 75 per cent. The difference between the Local Health Authorities matters, as the chi-square of their cross-tabulation with the formal meeting is statistically significant ($p < 0.0001$) (see table 4).

Why are there such huge differences in the process leading to arrange the care plan? Are they due to different users' conditions or to choices made by each Authority? After describing the options chosen, the next step is to understand the causes behind the different scenarios, particularly to look at the impact of the users' need-related circumstances on them. The findings shown in box 2 aim to address this issue. We look at the variance of the formal meeting variable with the three main needs indicators: CIRS score, SPMS score (Short Portable Mental Status questionnaire, to measure the cognitive impairment) and ADL score (Activities of Daily Living, to measure the functions deteriorated). The variance of the formal meeting variable is not significantly related to the CIRS

---

[5] I refer here to a "decision" here because at this stage a complete assessment does not take place. It was illustrated in chapter 2 that usually the decision is based on a preliminary and partial assessment.

score and it is not significantly related to the SPMS score. It is actually significantly related to the ADL score, but in the direction opposite to that expected: the more ADL functions are lost the lower is the percentage of users assessed in a formal meeting (see Box 2). The overall conclusion from the findings presented in table 4 and box 2 is that the only significant variance in the formal meeting variable is linked to different Local Health Authorities. In order to throw more light on the reasons why a formal meeting to arrange a care plan is or is not held, we analysed the variance of this variable by the three main needs indicators (CIRS, ADL, SPMS) in each of the three Authorities separately. None of the cross-tabulation conducted reveals a statistically significant difference. Therefore it seems that the only variable significantly related to the choice of formal meetings to arrange care plans regards the Authorities. The appendix to this chapter shows the cross-tabulation with the 14 districts considered in this project (the chi-square is statistically significant, $p < 0.01$). Looking at the single districts, it emerges that in 3 out of 14 one option is chosen in at least 80 per cent of the cases[6].

We can conclude, therefore, that whether or not to conduct a formal meeting to arrange a care plan depends on local choice. The decision is not made according to users' needs but in response to different local policies. Lecco had a consistent policy, the two districts following the same line. In Monza, the districts make different choices, following different directions[7]; it is their choices that matter. In Milan as well, there is no consistency across the districts: 6 out of the 8 analysed have a formal meeting to arrange the care-plan in almost all cases, whereas in 2 it is the opposite[8]. While discussing the evidence concerning the formal meeting to arrange the care plan, one has to look at Italian debate on whether or not it is necessary to conduct it. There is no consensus on this matter as some commentators and professionals stress the importance of it and others support an opposite view, stating that there are more appropriate informal ways to arrange the care plan (Andreoni (ed), 2000). The current state of the research on ADI and community care cannot provide an answer to the question regarding the real importance of the formal meeting to arrange the care- plan (and the consequences of having it or not). There is, instead, a huge consensus on the necessity to re-assess users' circumstances over time.

---

[6] In Lecco 1 the answer is no for 70 per cent of the cases and in Monza 1 for 77 per cent. In Monza 3 it is yes for 63 per cent of the cases.

[7] Districts 1, 2 and 4 follow a clear strategy whereas the situation of district 3 is more unclear, see the appendix

[8] Number 4 and 7, see the appendix.

Box 2

The formal meeting to arrange the care plan, other relevant Chi-Squares

- CIRS score by formal assessment meeting:	$p > 0.05$ (N= 283, Value= 15.63078, DF= 10)
- SPMS by formal assessment meeting:	$p > 0.05$ (N= 297, Value= 12.50999, DF= 10)
- ADL (functions deteriorated) by formal assessment meeting:	$p < 0.05$ (N= 343, Value= 15.35081, DF= 6)[9]

Table 4

Local Health Authority by formal meeting to arrange care plan, per cent

	Yes	No	Total
Lecco	22	78	100
Monza	43	57	100
Milano	75	25	100
Total	53 (N= 183)	47 (N= 162)	100 (N= 345)

Chi-Square (Pearson): Value 0.10294, DF 1, Significance $p < 0.0001$

After setting the care plan up, users start to receive ADI (in an emergency they start receiving it before the plan is arranged). According to (national and regional) legislation and guidelines (since the *Progetto obiettivo anziani 1992* onwards), the users' conditions and the appropriateness of the care packages arranged will be monitored over time. Both the official documents and most of the professionals (and scholars) agree on the importance to promote a process of initial assessment, arrangement of the care plan, monitoring and re-assessment over time (with the possible change of the care plan). The rhetoric and the reality are, once more, quite different. In practice, the features (and intensity) of the follow up and the monitoring of the users' conditions over time are extremely variable between Local Health Authorities and between districts. This is a trait that Lombardy shares with the rest of Italy.

We asked professionals in charge of arranging the care plan if, at the end of the process leading to it, a date was decided a date for re-assessing the user's condition (it may look a rough indicator but

---

[9] Please not that themore ADL functions are lost the lower is the percentage of users assessed in a formal meeting.

considered along with the question concerning the reasons for the different choices on this issue, see below, can provide quite a comprehensive view). The sample is, again, almost equally divided: for 49 per cent of the cases a re-assessment was arranged, for 51 per cent it was not. We find, once more, sharp differences between the three Authorities[10]. The data concerning Lecco are consistent with the overall findings (and there are not huge differences between the two districts), whereas in Monza in 93 per cent of the cases the re-assessment was not arranged (with a great consistency between the 4 districts involved). The re-assessment was arranged for 79 per cent of the cases in Milan (where there is a bit more variance between the district and district number 7 is an outlier, as in questions on the care-plan) (see table 5).

Table 5

Local Health Authority by arranged re-assessment, per cent

	Yes	No	Total
Lecco	47	53	100
Monza	7	93	100
Milano	79	21	100
Total	49 (N= 164)	51 (N= 170)	100 (N= 334)

Chi-Square (Pearson): Value 128.76056, DF 2, Significance $p < 0.0001$

Both the characteristics and impact of the re-assessment were strongly influenced by the frequency. Professionals who arranged the re-assessment were asked when it was scheduled. In 75 per cent of the cases it was planned for 2 months after the user started to receive ADI, with an average length of 1.9 months (see table 6). The short period by which the users are to be re-assessed is due to their main need-related circumstances, highlighted in the previous chapter: their conditions are in most of the cases severely deteriorated, they have multiple problems, and they often suffer from health problems. In a nutshell, they are in severe and quite volatile conditions, reasons why the re-assessment cannot be scheduled too far into the future. The findings on when to conduct the re-assessment are also consistent with those concerning the length of time over which elderly people receive ADI, presented further on in the thesis.

---

[10] The data on the single districts are presented in the appendix to this chapter.

Table 6

(If the re-assessment is arranged) When is it scheduled? Per cent

In 1 month	49
In 2 months	26
In 3 months	21
In 4 months or more	4
Mean	1.9
Total	100 (N= 165)

The UVGs that did not arrange the re-assessment were asked why. They could choose one among the answers suggested. The three most frequent answers actually chosen are “we are in touch with the professionals providing care to the user” (33 per cent), “if problems emerge, the professionals will let us know” (24 per cent), “we are in touch with the user and/or the caregiver” (17 per cent) (see table 7). Only 12 per cent chose the unpredictability of the users’ conditions as the answer. These findings lead to different interpretation. The fact that in only 12 per cent of the cases the re-assessment was not arranged because of the unpredictability of the users’ conditions means that this is - 9 times out of 10 – a choice concerning how to organise the service, not the needs of those receiving it. This evidence supports the view – widely shared among the commentators – that the idea to re-assess the users’ conditions over time is still quite rarely embedded in Italian community care. 39 per cent chose the two answers “if a problem emerges….”, presenting a reactive idea of the re-assessment. It was not considered as a device to maximise the users’ well-being over time but as a way to intervene when problems arise. Such a choice restrained the scope and the impact of the re-assessment and of the professionals involved. We miss here a core idea of how ADI is designed (quite consistent with all the literature on case management, see Davies and Challis, 1986), that the monitoring and reassessment is not a way to control if problems suddenly arise (intervening when necessary) but to make the best of the care package provided, tailoring it to the changing needs of the users. 51 per cent stated they did not arrange a re-assessment as they were in touch either with the professionals or the family. They imply they are in day-to-day contact with people caring for the elderly and they are thus – in practice – providing continuos supervision. This can be true, but – as argued further on – a proper re-assessment could provide benefits which are different from such “continuous supervision”.

Table 7

(If the re-assessment is not arranged) Why? Per cent

We are in touch with the professionals providing care to the user	33
If problems emerge, the professionals will let us know	24
We are in touch with the user and/or the caregiver	17
If problems emerge, the family will let us know	15
The development of the user's conditions is not predictable	12
Others	1
Total	100 (N= 148)

As with the formal meeting to arrange the care-plan, it is necessary to understand whether the fact of arranging a re-assessment was significantly related to users' needs. The analysis of variance shows this is not the case: none of the cross-tabulations of CIRS, SPMS and ADL scores by the arranged re-assessment was statistically significant (see box 3). We additionally conducted these analyses with the three main need indicators separately for the three Local Health Authorities studied and the results obtained (not presented here) are not statistically significant. These findings are similar to those concerning the connection between formal meeting to arrange the care plan and indicators of users' needs.

Having proved that both the formal meeting and the re-assessment are not significantly related to the indicators of users' needs, we turn to the look at the link between them. Table 8 shows that the arrangement of the re-assessment is not related to the users' needs but to the presence of a formal meeting to define the care plan. When a formal meeting is hold there are more probabilities that a re-assessment is arranged. We also conducted the cross-tabulation of table 8 for the 3 Local Health Authorities separately: it turns out that the chi-square is not statistically significant in Lecco and Monza, while it is in Milan.

Box 3 – The arranged re-assessment, some relevant Chi-Squares

- CIRS score by arranged re-assessment:	p > 0.05 (N= 273, Value= 15.63078, DF= 10)
- SPMS by formal assessment meeting:	p > 0.05 (N= 285, Value= 12.13704, DF= 10)
- ADL (functions deteriorated) by arranged re-assessment:	p > 0.05 (N= 333, Value= 2.02890, DF= 2)

Table 8

Formal meeting to arrange care-plan by arranged re-assessment, per cent

	Arranged re-assessment	No arranged reassessment	Total
Formal meeting to arrange care-plan	64	36	100
No formal meeting to arrange care plan	32	68	100
Total	49 (N= 164)	51 (N= 169)	100 (N= 333)

Chi-Square (Pearson): Value 33.56645, DF 1, Significance p < 0.001

This paragraph sheds more light on the processes of initial and over-time assessment that users go through. The choices on how to run these processes are not led by the users' needs but by decisions made by the Authorities, quite often also by the districts they are divided into. We identify two main options: the "formal" (formal meeting to arrange care-plan and a reassessment arranged) and the "informal" (no formal meeting to arrange care-plan and no reassessment arranged). The choice of one option or the other is made at the level of the Authority (sometimes district) and applies to the majority of the users of the area concerned, no matter what their needs.

2.3 Providing suggestions and information

This section looks at the overall process beginning when an elderly person gets in touch with ADI and ending at the case closure. Most of it is devoted to examine what are (and what should be) the tasks conducted by UVG throughout this process, initial arrangements and re-assessment over time. The UVG's role and functions are analysed as part of the wider debate concerning the public services' role in governing care in the community. Other issues have to be considered in this debate. It is particularly necessary to look at the information and suggestions provided by the ADI professionals on the other services available. In Lombardy (and in Italy generally) there are, in fact, several actors (public and private, formal and informal) delivering care in the community to the frail elderly, but the former (and their family) often miss the necessary information about them. The Italian community care is characterised by two main traits: the multiplicity of the actors involved, and the difficulties elderly and their families face to get in touch with them. The lack of information has to be overcome in order to arrange the articulated bundle of care inputs that the elderly, especially the frailest elderly, need. The information is needed at two different levels: about what services are actually available and about how to reach them. In the 1990s the informative problems gained more and more attention in the debate, also thanks to the many projects that demonstrated the gaps in information among the population and the requests of so many citizens to know more (e.g. Rossi, 1995).

Users still receiving the service after 3 months are asked if – over that length of time – the ADI professionals provided them and/or their carers with information or suggestions on other services. It happens really seldom, with the partial exception of the information on how to receive other public services, provided to 31 per cent of the users (see table 9). The data on information and suggestions provided themselves do not matter that much. Their relevance depends on the suggestions users and carers would actually like to receive. Over the 3 months considered, 64 per cent of them would have liked to get suggestions by ADI professionals on how to receive other public services, 42 per cent on how to receive support from other public organisations, 36 per cent on how to use care allowances and 23 per cent on to receive privately paid care (see table 10). These findings show a widespread need for more information by users and carers. This need is currently satisfied by ADI professionals only to a partial degree.

Table 9

Over 3 months did ADI professionals provided users and/or carers with suggestions on..? Yes, per cent

How to receive other public services	31
How to use care allowance	14
How to receive support from the voluntary organisations	12
How to receive private paid care	7
Total	100 (N= 172)

Table 10

(For each subject) If you didn't get suggestions, would you and/or your carer have liked to receive them? Yes, per cent

How to receive other public services	64 (N= 118)
How to receive support from the voluntary organisations	42 (N= 149)
How to use the care allowance	36 (N= 143)
How to receive privately paid care	23 (N=150)
Total	100 (N= 172)

3. Users' needs and care inputs

3.1 A Map

The main outcome of the process of referral, assessment and care planning is the indication of the package of ADI care inputs to be provided to the users. In this paragraph we analyse the ADI provision in the light of the users' needs-related circumstances and of the care inputs delivered by other sources (family, privately paid care). The data presented in the previous chapter show that it would not make sense to look at the ADI inputs without considering the broader context of actors involved and care provided in the community. We intend, therefore, to contrast users' needs with the overall bundle of care inputs stemming from different sources (see tables 11.1,11.2 and 11.3).

Table 11.1 draws a profile of the users according to degree of dependency and health conditions. Users are divided into three main groups: those dependent in 0 or 1 ADL functions (24 per cent), in 2 to 5 functions (29 per cent) and in 6 functions (47 per cent). To divide a population of frail elderly people into the groups of those with light dependency, medium dependency and high dependency is quite a common strategy in the literature on community care (e.g. Davies et alii, 1990; Spector and Kemper, 1994). It highlights the main differences between users in a simple but meaningful way. Apart from the influence of the international literature, we chose to do so in the light of some Italian work. The data gathered for a national project on ADI users (conducted in 1996 in ten sites across the country) were analysed in this way, providing the only analysis we know on the targeting of this service. The authors used there the eight function version of the scale and therefore divided the users into those dependent in 0-1 functions, 2-5 function, 6-8 functions. Their assumption was that elderly people in the second group (when supported enough by the informal network) are those who can benefit from ADI, whereas for the other two groups the delivery of this service is not appropriate. Those dependent in 0-1 functions should probably receive home help (i e social care without health inputs) and those dependent in 6-8 functions should probably enter a residential institution. They found that 39.8 per cent of users belong to the first group, 38.1 per cent to the second and 22.0 to the third (Dentizzi et alii, 1996; Mengani et alii, 1996).

In our sample, 24 per cent of users are dependent in 0-1 functions (out of 6), 29 per cent in 2-5 functions and 47 per cent in all the six functions. That is to say that almost one in two users is entirely dependent. The examination of cognitive impairment sheds further light on the users' conditions. 42 per cent of the population suffers from this problem, of which 31 per cent belong to the group of those entirely dependent. It means that one in three users is both dependent in all the ADL functions and cognitively impaired. It must also be noticed that the big majority of the 9 per cent of users suffering from behavioural disturbance are concentrated in the group of those completely dependent. The presence of the disturbance among the latter is 16 per cent (among those suffering from cognitive impairment it rises to 23 per cent). The overall point to underline concerns the overlap between dependency in all the ADLs functions and cognitive impairment, and, to a smaller degree, with behavioural disturbance.

When we turn to the health conditions we find a relevant degree of consistency with dependency. This applies to both the objective and subjective health conditions. The mean CIRS score of the overall sample is 4.1 pathologies and it shows meaningful differences among the three dependency categories. It rises from 3.3 within the least dependent to 3.8 in the intermediate group and to 4.8 within the most dependent. The perceived health conditions are - to a high degree – consistent with the objective ones. Users are also asked how they rate their health conditions - with the possibility to select among four answers from very good to very bad[11] - and the answers are gathered in two groups: "good" and "bad". While within both those least and middle dependent the sample is almost equally split among good and bad, within the most dependent those that reckon to have negative health conditions increase to two-thirds of the sample (see table 11.1).

Consistent with the aim to examine the overall bundle of inputs provided in the community, table 11.2 reports the main traits of both informal and privately paid care. The former is unambiguously acknowledged as the (by far) main source of care for the elderly but the latter also has an important role. The data presented in the previous chapter clearly show the relevance of informal support: 85 per cent of the principal informal carers meet the users on a daily basis and the average number of hours they spent together is 8.2 (out of the 12 hours between 8 a.m. and 8 p.m.). According to the frequency of the user-carer meetings, the sample can be divided into two groups: those dependent in 0 or 1 functions and the others. The former have a light level of dependency (or none) and this presumably widens their chances of living a more "ordinary" life, with less need for support. In fact, they meet their carers less often and a third of them live on their own (which is not the case for those who are more dependent). The link between degree of dependency and care inputs is particularly strong with reference to privately paid care. 29 per cent of those with light dependency, 41 per cent with intermediate dependency and 58 per cent receives this support for those entirely dependent (see table 11.2). (It must be noticed that also the number of days a week the two meet and average number of hours they spend together each time grows along with the dependency.) The needs of those dependent in all the ADLs functions are huge to meet and in many situations the help provided by privately paid care is essential. Otherwise some families can also rely on the home help input. Families that cannot rely upon either private care or public home help are left alone coping with a totally dependent relative.

To complete the complex picture of care in the community, the next table looks at the ADI inputs received by different groups of users. As a whole, two-thirds of them receive one input (54 per cent nursing and 17 per cent physiotherapy). Those with 0-1 and 6 ADLs lost receive, in most cases, only home nursing (62 and 64 per cent) whereas in the intermediate group (2-5 ADLs lost) this is the case for 37 per cent. The distribution of physiotherapy follows the reverse direction: (as the single input) those dependent in 2-5 functions are more likely to receive it (29 per cent versus 14 and 11 per cent). It must be noticed that, considering also the users receiving mixed packages of care, 57 per cent of those in the intermediate group get physiotherapy, a far higher percentage than that of other two groups (26 per cent in the first one and 28 per cent in the third one). The social

---

[11] The four possible choices are very good, quite good, quite bad, very bad.

care inputs (home help) have, instead, an utterly minor role. It must be remembered that ADI consists of health input(s), home nursing and/or physiotherapy, plus home help when the latter is needed and the eligibility criteria are met. The need for only home help is dealt with by a different service, run by municipalities. Nevertheless, it is remarkable that in spite of the wide social needs revealed by the data, only 15 per cent of users receive home help. The provision of ADI input is considered along with the UVG's assessment of (whether or not) ADI is the most appropriate service for the users. UVG members were asked what service would be the most appropriate – among all the different alternatives[12] - for the users. As a whole, 62 per cent answered ADI. Among those who chose another service the preferred option is home help (18 per cent) followed by respite care and day care (8 and 7 per cent). Looking the different single groups, ADI is considered the most appropriate for 70 per cent of the cases in the first group, 68 per cent in the second group and 55 per cent in the third group: the higher the dependency the lower the judgement of appropriateness by UVG members (see table 11.3).

---

[12] The answer could be one among ADI, home help, respite care, day care, nursing home, hospital.

Table 11.1

Users' needs related circumstances[13]

Number of ADLs with which difficulties (per cent, of whom without C.I. with C.I.)[14]	*Cirs Score (mean)*	*Perceived health, per cent (a= very/quite good b= very/quite bad)*	*Behavioural disturbance (yes, per cent)*
0-1 **(24 per cent, of whom:** **22 no C.I.** **2 yes C.I.)**	3,3	A= 52 B= 48	1
2-5 **(29 per cent, of whom:** **20 no C.I.** **9 yes C.I.)**	3,8	A= 52 B= 48	3
6 **(47 per cent, of whom** **16 no C.I.** **31 yes C.I.)**	4,8	A= 36 B= 64	16 (no C.I.= 7 yes C.I.= 23)
Total **(100 per cent, of whom:** **58 no C.I.** **42 yes C.I.)**	4,1 (N= 317)	A= 47 B= 53 (N= 317)	9 (N= 317)

---

[13] Two Milan districts (number 6 and 7) are not considered in this paragraph, because they are included in the project only the users receiving home nursing.

[14] The presence of cognitive impairment was defined as a number of errors in the SPMS of five ore more (out of a total of ten).

Table 11.2

Users needs-related circumstances by informal and privately paid support

Number of ADLs with which difficulties (per cent, of whom without C.I. with C.I.)[15]	*Per cent of users living alone (no, per cent)*	*Per cent of users meeting carers daily* *Mean hours together (/12)*	*Per cent of users receiving privately paid care* *Mean days a week* *Mean hours (/24)*
0-1 **(24 per cent, of whom:** **22 no C.I.** **2 yes C.I.)**	67	74 7,6	29 (mean days: 3,4 mean hours: 4,7)
2-5 **(29 per cent, of whom:** **20 no C.I.** **9 yes C.I.)**	81	90 8,3	41 (mean days: 4,4 mean hours: 7,2)
6 **(47 per cent, of whom** **16 no C.I.** **31 yes C.I.)**	94	87 8,2	58 (mean days: 5,3 mean hours: 11,5)
Total **(100 per cent, of whom:** **58 no C.I.** **42 yes C.I.)**	84 (N= 317)	85 8,2 (N= 317)	46 (mean days: 4,8 mean hours: 9,4) (N= 317)

---

[15] The presence of cognitive impairment was defined as a number of errors in the SPMS of five ore more (out of a total of ten).

Table 11.3
Users needs-related circumstances by ADI support

Number of ADLs with which difficulties (per cent, of whom without C.I. with C.I.)[16]	*Per cent of users receiving only home nursing Mean weekly visits*	*Per cent of users receiving only physiotherapy Mean weekly visits*	*Per cent of users receiving a mixed package*	*Per cent of users for whom receiving ADI is appropriate (UVG's judgement)*
0-1 **(24 per cent, of whom:** **22 no C.I.** **2 yes C.I.)**	64 (mean weekly access: 3,9)	14 (mean weekly access: 3,1)	22, of whom: inf & fisio= 5 inf & socio= 5 socio & fisio= 5 inf & fisio & socio= 7	70
2-5 **(29 per cent, of whom:** **20 no C.I.** **9 yes C.I.)**	37 (mean weekly access: 3,5)	29 (mean weekly access: 2,8)	34, of whom: inf & fisio= 15 inf & socio= 6 socio & fisio= 0 inf & fisio & socio= 13	68
6 **(47 per cent, of whom** **16 no C.I.** **31 yes C.I.)**	62 (mean weekly access: 3,6)	11 (mean weekly access: 2,9)	27 of whom: inf & fisio= 14 inf & socio= 6 socio & fisio= 4 inf & fisio & socio= 3	55
Total **(100 per cent, of whom:** **58 no C.I.** **42 yes C.I.)**	54 (mean weekly access: 3,6) (N= 317)	17 (mean weekly access: 2,9) (N= 317)	29, of whom: inf & fisio= 14 inf & socio= 6 socio & fisio= 2 inf & fisio & socio= 7 (N= 317)	62 (N= 317)

---

[16] The presence of cognitive impairment was defined as a number of errors in the SPMS of five ore more (out of a total of ten).

3.2 Users and carers' unmet needs

3.2.1 Users

Three months after they started to get it, the elderly still receiving ADI and their carers are asked about their unmet needs. Their subjective judgement is intended to complete the objective data on needs and resources provided elsewhere in the chapter and the professionals' judgement on ADI appropriateness. Such a mix of data aims to offer a comprehensive view on needs and the resources provided to meet them, based on subjective and objective indicators and on the assessments of the main actors involved (users, carers and professionals).

For each of the main needs-related tasks, users are asked whether they need additional help. The highest affirmative percentage is for health care, needed by one user in three, followed closely by company. Two other tasks getting quite a relevant amount of affirmative answers are needs for help with housework (23 per cent) and personal care (18 per cent). In order to pinpoint what are considered the most urgent needs, those that should perhaps be prioritised on the policy agenda, users were asked to state which is the most important tasks to them. Health care takes again the lead (27 per cent), followed by housework (24 per cent) (see table 12).

Questions on users' needs were also asked of carers. They were initially asked whether they think users should get more help, whatever the source (public/private, formal/informal). 58 per cent of the carers think that it is so (table 13). When then asked in which areas should the users be supported more, those answering affirmatively to the previous question pinpointed health care (28 per cent) and hygiene (22 per cent) (see table 14).

Looking at the overall picture, users and carers state there are important needs gap to fill, but to a degree which is not to be overestimated. When one takes users' conditions into consideration, it is reasonable to state that we could have expected higher percentages of reported unmet needs in tables 12 and 13. Along with this, a crucial finding to stress regards the consistency between users and carers and what is their main unmet need: health care.

Analyses not shown here prove that the higher the number of ADLs functions lost the bigger the users' unmet needs, according to both their own judgement and the carers' judgement. In a wider perspective, the users with higher dependency (especially those dependent in all 6 ADLs functions) have more unmet needs with reference to several issues. They, in fact, have more needs for hygiene that are not satisfied and desire more to receive information from ADI professionals on other public services, private services and voluntary agencies (calculations not shown).

Table 12

(After 3 months of ADI) ***In which tasks do users want more help? Which is the most important? Per cent***

	Need additional help	Most important
Health care	35	27
Housework	23	24
Company	33	17
Personal care (Hygiene)	18	16
Total	100	100
	(N=74)	(N=74)

Table 13

(After 3 months of ADI) ***Should the user receive more help (carer's assessment)? per cent***

Yes	58
No	42
Total	100
	(N=167)

Table 14

(If the user need more help) ***In which tasks should him/her be mostly supported (carer's assessment)? per cent***

Health care	28
Personal care (Hygiene)	22
Company	16
Housework	13
Total	100
	(N= 82)

3.2.2 Carers

In our work, carers are considered both sources of help and people needing help themselves. This is consistent with the pivotal role they have in the Italian community care and social care more generally, as previously described. This is also consistent with the really frail conditions of most ADI users, calling for a lot of effort from their informal networks.

Carers of elderly people still receiving ADI after three months were asked whether they desire other services to support them. Table 15 shows that one out of three desires other services. The profile of those requiring services to support them is consistent with both their own subjective stress and the care burden they have to carry. With reference to the former, relevant stress indicators are significantly linked to the desire to get other support: the more one is stressed, the higher the probability he/she desires further support[17]. With reference to the objective burden, table 15 shows that people caring for the most dependent elderly were keener to receive other services to support them. Those requiring more additional support were asked which services they would like and two options emerge as stated desires: short-term periods in institutions for the elderly (29 per cent) and to meet a psychologist (17 per cent).

These findings indicate the presence of a big group of carers who request support. The request is to be taken particularly seriously, as the people identifying these desires tend to be those most stressed and having the highest care burden on their shoulders.

Table 15

(After 3 months of ADI)*Would the carer desire other services to support her/him? Per cent*

	Yes	No	Total
User dependent in 0-1 ADLs	28	72	100
User dependent in 2-5 ADLs	31	69	100
User dependent in 6 ADLs	43	57	100
Total	36 (N= 60)	64 (N= 107)	100 (N= 167)

---

[17] These data, not shown here, are the results of a crosstabulation between "would the carer desire other services to support him/her" and two stress indicators treated in phase one ("In the last month how often did you feel you need help in caring for the use?" and "In the last month how often did you think you cannot cope with the elderly?")

3.3 The boundaries between health and social care

The remit of community health care and its boundaries with social care have always been a controversial topic among policy-makers, politicians and users themselves. Whether the former receive health care (needs-tested and free) or social care (means-tested and charged) has important consequences for both them and the welfare agencies. The official legislation and documents do not help to make more sense of such a contentions issue. Neither the national nor the regional government, in fact, provides guidelines on the health/social boundaries. The Authorities (and districts) make their own choices. The "grey area" between health and social care concerns the tasks labelled under the name of hygiene (mostly related to bathing). To investigate it, UVG professionals were asked two questions. The first one concerns whether the users need hygiene. UVGs answered affirmatively in 69 per cent of the cases, indicating the huge presence of this need (table. 16). For users needing it, members of the UVG in charge of health care inputs were asked whether ADI health professionals (those providing nursing and physio, i.e. all of them apart from the tiny group delivering home help) provide hygiene: it happens only in 26 per cent of the cases (see table 17). The data thus shows the predominance of a definition of the health care remit which is quite sharp and focuses on the pure health inputs. According to such a dominant definition, the mission of the Local Health Authority is to concentrate their effort on the core health tasks, without meeting the needs at the boundary between health and social care. These needs have, in turn, to be met by social care services (depending on availability and whether the elderly meet the strict eligibility criteria) or, more likely, by families and privately paid care.

It is not a surprise to find wide differences between the three Authorities in relation to how they respond to such a controversial issue. In Monza these intermediate inputs are not provided at all in any district, indicating the presence of a strong policy direction at the Authority level. The situation is less clear in other two Authorities. There is a big difference between the two Lecco districts (one providing it in 57 per cent of the cases and the other in 22 per cent) and the situation is utterly fragmented in Milan. Here two districts clearly provide it (numbers 2 and 7) and three don't (numbers 3, 4 and 8) while the situation is not clear in the other three (numbers 1, 5, and 6) (the table concerning districts is presented in the appendix to this chapter).

Table 16

Do the users need hygiene (UVG's assessment)?, per cent

Yes	69
No	31
Total	100 (N=352)

Table 17

(If the users need hygiene) Local Health Authority by do the ADI health professionals provide it? per cent

	Yes	No	
Lecco	33	67	100 (N= 49)
Monza	0	100	100 (N= 84)
Milano	44	56	100 (N= 103)
Total	26 (N= 62)	74 (N= 164)	100 (N= 236)

Chi-Square (Pearson): Value 77,497, DF 1, Significance $p < 0.001$

4. Explaining service utilisation

This section is devoted to the investigation of the reasons explaining different patterns of service utilisation in the *assistenza domiciliare integrata*. It is consistent with the previous two sections and supplements them. We have already looked at the process through which resources are allocated and then at what are the care inputs provided, contrasting them with users' needs-related circumstances. The analysis of reasons explaining different utilisation patterns is conceived as the final step of the route we followed in this chapter.

We aim here to understand the reason why some users receive some types of care inputs and others do not, and why some users receive more visits than others do. We take a number of independent variables into consideration and explore their links with the dependent variables, so as to highlight the impact of the former on the latter – a standard regression model approach. In the previous chapters it was shown that explaining differences in service utilisation constitutes a core task of the "Production of Welfare" Approach. In the PSSRU work, the analysis of the link between means and ends in community care is usually conducted using sophisticated statistical tools (for instance, Davies, Fernandez, Nomer, 2000; Davies et alii, 1990). We will concentrate here on logistic multiple regressions. These regressions seem particularly suitable for our tasks, as illustrated below.

The dependent variables discussed in this paragraph are chosen in order to address the two main questions on service utilisation conceived in the "Production of Welfare" approach: what care inputs users receive and what amount of them:

Type of care inputs: the two main care inputs delivered in ADI are home nursing and physiotherapy. We aim to investigate the reasons why users receive home nursing or not and the reasons why users receive physiotherapy or not. It is the qualitative section of our analysis ("what inputs").

Amount of care inputs: most of the users (74 per cent) receive home nursing. We aim to investigate why some users receive more weekly visits than others do. We try to answer this question also with respect to the overall number of weekly visits. It is the quantitative section of our analysis ("how many inputs").

The tables on the next pages illustrate the domain indicators we consider and their frequencies. Among the many possible items we gathered data about (see appendix 1 for the list of all the variables considered in the project) we select a number of them as independent variables. For each of the outcomes analysed in this chapter, the impact of any of these inputs on the outcome was tested, focusing then (and presenting to the reader) only on those we believe to be more important. The inputs considered are presented below and are chosen as they seem suitable to investigate the three main research question tackled in the chapter: how to govern community care? which care inputs for which needs? what territorial differences? They are divided into five groups, regarding UVG and ADI features, users' characteristics, carers' characteristics, informal care and privately paid services and territorial differences.

SERVICES' UTILISATION (DEPENDENT VARIABLES)

Type of care inputs

Variable	Values
- User receives home nursing	*1= yes (74 per cent)* *0= no (26 per cent)*
- User receives physiotherapy	*1= yes (30 per cent)* *0= no (70 per cent)*

Amount of care inputs

Variable	Values
- (If user receives home nursing) How many home nursing visits a week?	*0= 1-2 visits (31%)* *1= 3+ (69%)*
- Overall number of weekly visits	*0= 1-2 visits (28 %),* *1= 3+ (72%))*

INDEPENDENT VARIABLES

UVG and ADI

Variable	Values
- A meeting was hold to arrange the care-plan	*1= yes (53 per cent)* *0= no (47 per cent)*
- A re-assessment was arranged	*1= yes (48 per cent)* *0= no (52 per cent)*
- Overall number of weekly visits (squared)	*Range 1 to 100*
- How many months the user has been receiving the service for (1 to 6 months)	*Range 1 to 4*
- How many months the user has been receiving the service for (1 to 6 months) (squared)	*Range 1 to 16*
- How many months the user has been receiving the service for (1to 4 months)	*Range 1 to 6*
- How many months the user has been receiving the service for (1 to 4 months) (squared)	*Range 1 to 36*

UVG and ADI (continues)

Variable	Values
- Care plan could have been better (UVG assessment)	1 = yes 0 = no
- ADI's predicted positive impact (by UVG) on users' dependency	0 = not at all/a bit (20 per cent) 1 = quite/ a lot (80 per cent)
- ADI's predicted positive impact (by UVG) on users' health	0 = not at all/a bit (47 per cent) 1 = quite/ a lot (53 per cent)

User's characteristics

Variable	Values
- Age	*Range 61 to 103, mean 81*
- Age (squared)	*Range 3721 to 10609*
- Gender	*1= male (33 per cent)* *0 = female (67 per cent)*
- ADL score	*Number of ADL functions lost (range 1 to 6, mean 4.0)*
- ADL score (squared)	*Range 0 to 36*
- CIRS score	*Number of disease diagnoses (range 0 to 10, mean 4.1)*
- CIRS score (squared)	*Range o to 100*
- SPMS score	*Range 1 to 10, mean 4,3*
- SPMS score (squared)	*Range 1 to 100*
Whether the user was in hospital in the six months before starting to receive ADI	*1= yes (51 per cent)* *0= no (49 per cent)*
- User is discharged from hospital	0 = no (79 per cent) *1 = yes (21 per cent)*

Carer's characteristics

Variables	Values
- Carer's age	*Range 34 to 90 (mean 60)*
- Carer's age (squared)	*Range 1156 to 8100*
- Carer's gender	*0= female (23 per cent)* *1= male (77 per cent)*

Carer's characteristics (continued)

Variables	Values
- Is the carer the daughter/son of the user?	*0= no (44 per cent)* *1= yes (56 per cent)*
- Is the carer the husband/wife of the user?	*0= no (71 per cent)* *1= yes (29 per cent)*
- Stress 1	- How often in the month before the interview you thought you need rest from caring for the elderly person? *1= always-often (47 per cent) cent)* *0= sometimes-never (53 per cent)*
- Stress 2	*- How often in the month before the interview you thought you cannot cope with caring for the elderly person?* *1= always-often (24 per cent)* *0= sometimes-never (76 per cent)*
- Perceived health	*1= very-quite good (77 per cent)* *0= quite-very bad (23 per cent)*

Informal care and privately paid services

Variable	Values
- Users live with others	*0= no (84 per cent)* *1= yes (16 per cent)*
- User-PIC relationship	*It is the pic's assessment:* *1= very good (50 per cent)* *0= very good/very- quite bad (50 per cent)*
- PIC performs housework for the user	*1= yes (80 per cent)* *0=no (20 per cent)*
- PIC performs personal care for the user	*1= yes (75 per cent)* *0=no (25 per cent)*

Informal care and private paid services (continues)

Variable	Values
- PIC performs health/nursing care for the user	*1= yes (59 per cent)* *0=no (41 per cent)*
- User receives private paid care	*1= yes (45 per cent)* *0= no (55 per cent)*
- Paid carer performs housework for the user	*1= yes (70 per cent)* *0=no (30 per cent)*
- Paid carer performs personal care for the user	*1= yes (69 per cent)* *0=no (31 per cent)*
- Paid carer performs health/nursing care for the user	*1= yes (34 per cent)* *0=no (66 per cent)*

Territorial differences

Variable	Values
- Local Health Authority Milan	*0= No (56 per cent)* *1= Yes (44 per cent)*
- Local Health Authority Milan Neighbourhood	*0= No (66 per cent)* *1= Yes (34 per cent)*
- Local Health Authority Lecco	*0= No (78 per cent)* *1= Yes (22 per cent)*

4.1 The type of care inputs received

The statistical technique utilised in this chapter – as in the next one – is logistic regression. It is used in order to analyse nominal/ordinal dependent variables with only two categories and independent variables may be any scale of measurement; to do so, we transformed all the dependent variables into dummy variable. Logistic analysis deals with odds ratio. When the probability of an event happening is greater than the probability of an event not happening, then the odds ratio will be greater than 1. When the probability of an event happening is less than the probability of an event not happening, then the odd ratio will be less than 1. The R^2 measure is not really applicable to logistic regression, so the so-called pseudo-R^2 measures have been developed. We will use the Nagelkerke Pseudo R^2 Square throughout all our analyses.

We used the statistical package SPSS 10.1 for Windows. For each model presented, in the preliminary stages of our analysis we investigated the effects of any independent variable listed on the outcomes studied. In the preliminary stages we also used techniques that can help the statistical analysis, such as backward and forward stepwise; they were useful in order to shape our thoughts concerning causal connections between dependent and independent variables in community care. In the final models, those presented in the chapter, we do not use any of these techniques and we do include variables without significant effects on the dependent variable.

The fact that the latter are not found to be significant means that we cannot reject the hypothesis that their effect is equal to zero (and therefore that the variable should be out of the model). Including non-significant effects in the model in other circumstances would be appropriate if what we did was more 'hypothesis-testing' rather than 'exploratory' modelling. If we were to have in mind a very clear picture of which variables ought to be in the model and how they should interact with our dependent variable then showing whether they are significant or not helps prove/disprove our postulated theories. In our project, one could make a case for including all the variables we have (and many more that we want to have) in the model. Including just a few may give the impression that they are 'helping' us to find significant effects on others. Including all the variables in the model, given the high collinearity between them, would make the resulting model extremely difficult to interpret. Additionally, given that we do not have many cases, including only the significant effects in our model will help increase the number of degrees of freedom. Of course, noting that when tested some variables are not found to have a significant effect is very important.

The first model presented is intended to highlight the reasons why users receive home nursing. ADI users receive at least one of home nursing and physiotherapy. The former is provided to 74 per cent of the users and is by far the most commonly delivered input of those available with ADI. Table 18 presents the results of the logistic regression modelling exploring influences on users receiving home nursing. The model explains some 45 per cent of variation in home nursing receipt and in fact is the best fitting model in the thesis.

Several independent variables have a statistically significant link with the dependent variable. Three of them concern needs-related circumstances: users' gender, cognitive impairment and principal informal carers' stress. With respect to gender, females have much higher probabilities of receiving home nursing than males. This finding is consistent with the well-known fact that among the elderly the health conditions of the former are worse than those of the latter. Within the sample, as cognitive impairment grows (SPMS score increases) the probability to receive home nursing increases. Cognitive impairment is one of the best predictors both of service utilisation (see the other models presented in this chapter) and of service outcomes (see the models presented in chapter 7). It is a result common to many other pieces of research on community care (e.g. Diwan et alii, 1997; Spector and Kemper, 1994). The other variable regarding users' needs-related circumstances concerns carers' stress (how often in the month before the interview the PIC thought they needed respite from caring for the elderly person). The direction of the link is here opposite to what might be expected, as the greater is carers' stress the lower the probability to receive home nursing. The result, nevertheless, is quite consistent with the rationale of home nursing. The latter is, in fact, provided to meet specific nursing/health needs: it is provided neither to relieve the carers nor to meet needs such as dependency, strictly linked to carers' stress. To summarize, as we are dealing with specific nursing/health inputs and not social care inputs, this finding should not be surprising.

Two independent variables concerning the organisation and delivery of ADI are linked in a statistically significant way to the probability to receive home nursing. One is the delivery of physiotherapy: if users receive it, their probability of getting home nursing decreases greatly. This result confirms a finding presented in several other parts of the thesis: what we call *assistenza domiciliare integrata* is first and foremost the autonomous delivery of either home nursing or physiotherapy. It is one or the other, as they meet quite different needs. Looking at the other variable of this kind included in the model, we notice that as the unit of assessment and planning (UVG) predicts - at the end of the initial assessment - a positive impact on users' health, the probability of receiving ADI increases. This result indicates consistency in the UVG behaviour, as home nursing is intended to meet users' health needs. The Unit arranges the delivery of this input when it reckons it is going to have a positive impact on users' health condition.

The last two variables in the model concern territorial differences. They will appear in several other models presented both in this chapter and in the next one. If the users belong to the local health authority of Milan or of Milan Neighbourhood, the probability of receiving home nursing decreases. This finding is consistent with a general impression we have had in studying the three local health authorities over time: being in one or in another is the crucial reason to explain several features of the service provided. It is a trait that characterises the overall Italian situation and not only Lombardy. The relevance of territorial differences cannot be underestimated and it is important to prove it empirically. This result is also quite complex to interpret. The territorial variable can, in our view, be interpreted in different ways, regarding both users' circumstances and service organisation. It could be a proxy for the differences in users' circumstances across the three authorities that are not captured elsewhere in the model. It could concern differences in how the service is organised and delivered among authorities that are not captured elsewhere in the model. The variations could relate to the professionals involved, outreach procedures, assessment and care planning procedures, monitoring over-time, office hours, availability of other services and several other traits not captured elsewhere in the model. And they could concern differences in the availability of care inputs, of particular relevance in a context where the delivery of community care is scarce and outstripped by demand. From our own knowledge of the authorities investigated and from the different kinds of evidence gathered we tend to think that differences in services organisation and strategies play an important role in explaining the significance of the territorial variable. We also think that different availability of inputs at local level is crucial in order to explain it.

Table 18

Results of the logistic regression modelling exploring influences on users receiving home nursing

Independent variables	B	S.E.	Wald	df	Sig.	Exp(B)
Users' gender (Male= 33 per cent; Female= 67 per cent)	.763	.399	3.662	1	.056	2.145
SPMS score (Range 1 to 10, mean 4.3)	.214	.064	11.048	1	.001	1.238
How often in the month before the interview pic thought to need rest from caring for the elderly person (Sometimes-Never= 53 per cent; Always-Often= 47 per cent)	-.826	.389	4.500	1	.034	.438
Users receive physiotherapy (No= 70 per cent; Yes= 30 per cent)	1.664	.395	17.730	1	.000	.189
ADI's predicted positive impact (by UVG) on users' health (Not at all/A bit= 47 per cent; Quite/A lot= 53 per cent)	1.285	.429	8.960	1	.003	3.614
Local Health Authority Milan (No= 56 per cent; Yes= 44 per cent)	2.988	1.064	7.880	1	.005	.050
Local Health Authority Milan Neighbourhood (No= 66 per cent; Yes= 34 per cent)	-3.449	1.089	10.031	1	.002	.032
Constant	2.695	1.138	5.603	1	.018	14.805

Nagelkerke Pseudo R Square .450 No. of cases 210

Table 19 presents the of the logistic regression modelling exploring influences on users receiving physiotherapy. The model explains some 30 per cent of the observed variation in physiotherapy receipt [yes / no] and looks particularly interesting with respect to the independent variables included. The three main indicators of users' needs-related circumstances considered in our work are included in the model: SPMS, ADL and CIRS scores. At higher levels of cognitive impairment (SPMS) the probability of receiving physiotherapy is lower, a finding opposite to the result obtained when home nursing is the dependent variable. Of great relevance is the different direction of the links the dependent variable has with ADL and CIRS score. At the higher levels of dependency the likelihood of receiving physiotherapy is higher, but people with a poorer health status have a lower likelihood of physiotherapy receipt. This finding is consistent with the rehabilitative aims of physiotherapy, targeted towards elderly whose key problems regard dependency. On the other hand, physiotherapy is not intended to meet health/nursing needs.

The model includes also two independent variables concerning different sources of care in the community. Users who receive private paid care are less likely to receive physiotherapy. We detect here a substitution effect between private and public care: if the former grows the latter diminishes. The other variable of this group concerns carers' stress. The probability of receiving physiotherapy is lower when their principal informal carers are more stressed (measured by how often in the month before the interview PIC thought she/he cannot cope with caring for the elderly person).

Among the variables concerning the organisation and delivery of ADI, two have statistically significant links with the dependent variable. One regards whether a meeting among professionals was held in the setting-up phase to arrange the care-plan. When it is, there are higher probabilities of receiving physiotherapy. This finding could be due to two different reasons. On one hand, it could be that cases with physiotherapy needs are more complex and professionals need a formal meeting to discuss their situation. On the other hand, as physiotherapy is not the "typical" ADI care input (that is home nursing) before delivering it a more articulated procedure is requested. We tend to think the latter explanation is of particular relevance as ADI is in most cases a service led by home nursing professionals. The other variable of this group with a statistically significant link to the dependent variable is the prediction of a positive impact on dependency by the Unit of assessment and planning (UVG). When there is such a prediction, the probability to receive physiotherapy is higher. This finding is consistent with the main aim of physiotherapy, that is to decrease dependency. The Unit arranges the delivery of this input when it reckons it could produce a positive impact its main aim. Similarly, as the main aim of home nursing is to meet health/nursing needs in the previous model the prediction of a positive impact on this domain is associated with the delivery of the input.

Table 19

Results of the logistic regression modelling exploring influences on users receiving physiotherapy

Independent variables	B	S.E.	Wald	df	Sig.	Exp(B)
SPMS score (Range 1 to 10, mean 4,3)	-.168	.064	6.867	1	.009	.846
ADL Score (Range 1 to 6, mean 4.0)	.446	.108	17.089	1	.000	1.562
CIRS Score (Range 0 to 10, mean 4.1)	-.237	.093	6.426	1	.011	.789
How often in the month before the interview pic thought you cannot cope with caring for the elderly person?(Always-Often= 24 per cent; Sometimes-never= 76 per cent)	-.880	.450	3.828	1	.050	.415
User receives private paid care (No= 55 per cent; Yes= 45 per cent;)	-.918	.392	5.478	1	.019	.399
A meeting was hold to arrange the care-plan (No= 47 per cent; Yes= 53 per cent)	.955	.391	5.976	1	.015	2.599
ADI's predicted positive impact (by UVG) on users dependency (Not at all/a bit= 20 per cent; Quite/ A lot 80 per cent)	1.118	.381	8.614	1	.003	3.059
Constant	-1.358	.621	4.789	1	.029	.257

Nagelkerke Pseudo R Square .301   No. of cases 202

Table 20

Results of the logistic regression modelling exploring influences on users receiving 3+ visits of home nursing per week

Independent variables	B	S.E.	Wald	df	Sig.	Exp(B)
User's Age (Range 61 to 103, mean 81)	-1059	.309	11.762	1	.001	.347
User is discharged from hospital (No= 79 per cent; Yes= 21 per cent)	1.071	.400	7.182	1	.007	2.920
A meeting was hold to arrange the care-plan (Yes= 53 per cent; No= 47 per cent)	.949	.332	8.190	1	.004	2.584
Local Health Authority Lecco (No= 78 per cent; Yes= 22 per cent)	1.892	.436	18.832	1	.000	6.630
Constant	.135	.288	.220	1	.639	1.145

Nagelkerke Pseudo R Square .213   No. of cases 17

4.2 The amount of care inputs provided

In the previous two models we tackled the questions regarding "what type of care inputs" users receive. We turn here to the second main question to address in order to model service utilisation: "how many care inputs" users receive. We will address this question in two regression models, one concerning the amount of weekly home nursing visits and the other the overall number of ADI weekly visits (home nursing, physiotherapy and social care).

Table 20 presents the results of the logistic regression modelling exploring influences on users receiving 3 or more visits of home nursing per week. Only users receiving this service (74 per cent of the total) are included in the model. The number of weekly visits is a continuous variable (range 1 to 7) but as we deal with logistic regression models, it has to be reduced to a binary variable. We divide the users receiving home nursing between those getting 1 or 2 visits (31 per cent) and those receiving 3 visits or more (69 per cent). The separation between two and three visits represents – in our view – the boundary between a mild and a strong amount of home nursing provided. The model explains some 21 per cent in variations of impact on users receiving 3 or more visits of home nursing per week. The user's age has a statistically significant link with the probability to receive 3 or more visits. The older the user the lower the probability. The other variable concerning needs-related circumstances included in the model regards hospital discharge. Users discharged from hospital have a much higher probability to get 3 or more visits per week. They need more visits as part of the rehabilitation from the acute intervention they went through.

As in the previous model there is a statistically significant link with the variable concerning if a meeting was hold to arrange the care-plan. When this was the case, it is more likely that users receive 3 or more visits of home nursing per week. This result can be due to two different explanations. On one hand, it could be that before delivering a high amount of care the professionals involved want or have to hold a formal discussion. On the other hand, it could be that users getting a higher number of visits are the most problematic and professionals need a formal discussion about them. We think that both the suggested explanation have relevance. It is to stress that in a context of particularly scarce public resources – such as the Italian community care – it is quite likely that professionals want and/or have to hold a formal meeting before delivering a high number of visits.

The final variable included in the model is the territorial one: users in the local health authority of Lecco have a higher probability to receive 3 or more visits of home nursing. As previously stated, the presence of a territorial variable in a model can be interpreted in different ways. It could be a proxy for the differences in users' circumstances across the three authorities that are not captured elsewhere in the model. It could concern differences in how the service is organised and delivered among authorities that are not captured elsewhere in the model. And it could concern differences in the availability of care inputs. From our own knowledge of the authorities investigated, we tend to think that both differences in service organisation and in the availability of inputs play an important role in explaining the significance of the territorial variable. We also reckon that the different availability of inputs among authorities is of particular relevance. From our qualitative interviews and analysis of other documentation, in fact, we know that Lecco has a budget devoted to ADI that is bigger than in the other authorities involved (considering the number of elderly inhabitants) and pursues an explicit policy aim to provide users with an adequate number of weekly visits.

Table 21 presents the results of the logistic regression modelling exploring influences on users receiving 3 or more overall ADI visits (including home nursing, physiotherapy and home help) per week. Users are divided between those receiving 1 or 2 visits a week (28 per cent) and those receiving 3 visits or more (72 per cent). As with the previous dependent variable we think that the separation between two and three visits is the boundary between a strong and mild intervention.

Four variables concerning users' needs-related circumstances have a statistically significant link with the overall number of visits per week. As the cognitive impairment increases the probability to receive 3 or more visits per week decreases. As the dependency increases, in contrast, the probability grows. Those in hospital in the six months before starting to receive ADI have a higher probability to get 3 visits or more, whereas for those with the principal informal carer more stressed it is opposite (how often in the month before the interview the PIC thought she/he cannot cope with caring for the elderly person). We find a higher consumption of public resources for users who are less dependent, less cognitively impaired, in hospital in the six months before ADI and with carers less stressed. The inverse relation to dependency is explained by the fact that the great majority of inputs provided are health and not social care ones. The growth of dependency usually leads to a growth of social care provision but not of domiciliary health care provision. Also with respect to PIC stress, it is usually related to dependency and not to health needs and so the link we found does not suprise us.

This is the only model presented in this chapter where the tasks performed by the principal informal carers have a statistically significant link with the dependent variable. If the carer performs health/nursing care for the user it is less likely that he/she receives 3 or more visits effects. This probably means that demanding elderly people can live in the community only if they have a strong provision of home nursing inputs from both public and informal sources. On the other hand, when the carer performs housework for the user, the probability to receive three or more visits decreases. We are not dealing here with a substitution effect, for it is more likely that this result is due to the fact that the performing of housework by carers is linked to users' dependency whereas the delivery of ADI is mostly linked to health-related needs. The last variable in the model is a territorial one, as users in the local health authority of Milan neighbourhood have a lower probability to receive 3 or more visits per week.

Table 21

Results of the logistic regression modelling exploring influences on users receiving 3+ ADI visits per week

Independent variables	B	S.E.	Wald	df	Sig.	Exp(B)
SPMS score (Range 1 to 10, mean 4,3)	128	.064	3.961	1	.047	1.137
ADL score (Range 1 to 6, mean 4.0)	-.231	.100	5.369	1	.021	.794
Whether the user was in hospital in the six months before starting to receive ADI (Yes= 51 per cent; No= 49 per cent)	.797	.375	4.512	1	.034	2.218
How often in the month before the interview the pic thought she/he cannot cope with caring for the elderly person?(Always-Often= 24 per cent; Sometimes-never= 76 per cent)	-1.075	.407	6.979	1	.008	.341
Pic performs health/nursing care for the user yes (Yes= 59 per cent; No= 41 per cent)	.768	.382	4.030	1	.045	2.155
Pic performs housework for the user (Yes= 70 per cent; No= 30 per cent)	-1.005	.551	3.331	1	.068	.366
Local Health Authority Milan Neighborhood (No= 66 per cent; Yes= 34 per cent)	-1.107	.398	7.738	1	.005	.331
Constant	*1.895*	*.667*	*8.057*	*1*	*.005*	*6.650*

Nagelkerke Pseudo R Square .258 No. of cases 95

4. Conclusions

In this chapter we looked at resource allocation, analysing several features of this important dimension. We examined the processes through which resources are allocated, their matching with users' and carers' needs and the decisions made about them. The overall goal was to consider how public resources should be allocated and how the process of doing this should be shaped. In the introduction we summarised the research questions to be addresses in this chapter. In this final section we go through these questions again, summarising the evidence gathered and drawing some policy implications. We look first at the issue of how to govern community care, then at relationships between needs and inputs and then at the geographical differences.

4.1 How to govern community care

- How to reach ADI: are GPs the best way through?

The evidence indicates that GPs are the most common sources of referral to ADI. When the need for care emerges, elderly people and their families ask for information and advice from a public welfare professional/agency, and it is usually that suggested that they approach the *assistenza domiciliare integrata*. Among the different alternatives, most users are referred to ADI by GPs. There is a (statistically significant) difference between those who reach ADI through the general practitioners' suggestion and the others: the former are in better health conditions than the latter. The importance of this finding is due to the widespread Italian habit of turning to public community care only when the claimants' conditions are deteriorated to a serious degree and it is really difficult to improve them. People suggested by GPs reach ADI in better health conditions, increasing the probability for this service to be actually effective. We can say that the general practitioners are actually the best way through. Our evidence suggests, thus, to promote the GPs' role in ADI in two ways: to strengthen their presence and role among the prospective ADI users, and to strengthen the link between the practitioners and the UVGs. Along with it, the evidence suggests to develop consistent informative policies on ADI (its existence and how to reach it) aimed at different targets: the prospective users (and their families) and all the public welfare professionals/agencies.

- The UVG assessment and care-planning role over time: how is it? Why?

We examined in this chapter two key variables concerning the care process: the initial assessment (looking at whether a formal meeting to arrange the care plan is held) and the re-assessment over time (examining whether such a re-assessment is arranged). With respect to both variables there is a high degree of differentiation among the three Authorities and, within them, among their districts. We examined the possibility of links between the choices made at local level on these two variables and the needs of the elderly and discovered that there is nothing of any significance. The two variables are, instead, (statistically significant) related to each other: when a formal meeting is held there is a higher probability that a re-assessment is arranged. There are, thus, two main options: the "formal" (a formal meeting to arrange the care-plan and a reassessment arranged) and the "informal" (no formal meeting to arrange care-plan and no reassessment arranged). These findings suggest that the choices on how to organise the care process are not led by users' needs but by the Authorities' own choices, often by the districts' own choices. The results of the modelling exercise seem to support this view. They show, in fact, that in specific circumstances the decision to hold a meeting is statistically significantly linked to the delivery of less physiotherapy and to the delivery of more home nursing. That is to say that before making less routine choices in resource allocation, professionals tend to hold a formal meeting. Another main finding of the modelling concerning UVG is the consistency between its assessment and the care package it arranges: the UVG delivers home nursing to users for whom it predicts a positive ADI impact on health and it delivers physiotherapy to users for whom predicts a positive ADI impact on dependency.

There is no shared consensus in the debate on the opportunity to hold a formal meeting to arrange the care plan whereas the importance of re-assessment is widely acknowledged. In half of the cases in our sample the re-assessment is not arranged, on the grounds that either it will be arranged if problems arise or that the continuous contact between UVG and professionals or users/carers makes it unnecessary. This evidence suggests that there is a widespread concept of reassessment as a reactive tool to control the situation if problems suddenly arise (intervening when necessary) while it is not considered a device to maximise users' well-being over time, to make the best of the care package provided.

- A public service in a complex community: which actors deliver care in the community?

The data on the different actors delivering care in the community are presented mostly in the previous chapter (the main ones are presented also in section 3.1). We want to refer to them here as they are crucial in thinking about how to govern community care. The care in the community is composed of several different kind of inputs, especially in a country like Italy. In order to manage it effectively all these inputs have to be taken into consideration and, to different degrees, connected; they are, in fact, different inputs provided to care for one elderly person. ADI users have the support of a principal informal carer and it tends to be a full-time commitment. In some half of the cases in our sample a privately paid carer is involved as well. The elderly often visit GPs (sometimes consultants) and may receive other public services as well. There are thus several different actors in the community caring for frail elderly people. Such a situation raises an issue about how to co-ordinate the efforts of the different actors and which agency should take overall charge. The UVG is definitely a candidate to widen its role so as to develop its functions to govern community care in a wide sense.

- Needs extended beyond care: is there a need for ADI professionals to provide information/ suggestions for users and family?

The lack of information on what services are available and how to get them has been increasingly acknowledged in the last decade as a main deficiency of Italian community care (and in Lombardy).

In order to obtain a complete view of community care and of the kind of services that can be provided we paid particular attention to it in our project. We found out both the scarce current provision of suggestions and information on other services and the users/carers' needs for them. Very few among the users still getting ADI after 3 months had received – over that period of time – information/suggestions about voluntary services, private care and care allowances from ADI professionals; the partial exception concerns information on other public services, provided to 31 per cent of the users. Asked whether they and/or their carers would have liked information/suggestions (among those that did not receive them) 64 per cent answered affirmatively with reference to other public services, 42 per cent with reference to voluntary organisations and 36 per cent on how to use care allowances. This evidence suggests a need to promote a wider role for ADI professionals, encouraging them to provide of information and suggestions on other welfare services. The *Unità Valutativa Geriatrica* could play a leading role in providing information and suggestions: its work of assessment and care planning would put it in the best position to do so. Such a growth of the UVG's tasks would be consistent with the development of a bigger role in governing community care, suggested above.

4.2 Which care inputs for which needs

- The bundle of care: how do the different care inputs mix together?

The data presented illustrate the complex mix of care inputs received by ADI users. From the previous chapter we know that voluntary organisations are not that much involved in caring for ADI users, whereas private carers are. The involvement of the latter is concentrated towards the elderly dependent in all the ADL functions. The percentage of elderly receiving private care grows, in fact, from 29 per cent among those dependent in 0-1 ADL function to 58 per cent among those dependent in 6 functions. For those in such a situation private care is a source of continuous help. The principal informal carer is by far the main source of support and in most cases he/she meets the elderly person on a daily basis and spends most of the day with him/her. Only among those dependent in 0-1 functions is there a lower percentage of the carers meeting the elderly on a daily basis.

- The public intervention: which are the ADI inputs?

In this chapter we looked at the provision of ADI inputs for different groups of users, examining how the care provided differs between them. The main input of ADI consists of home nursing, received (alone or together with other inputs) by 81% of the users. Another main finding is that two-thirds of the users receive one care input (54% nursing and 17% physiotherapy) and that as a user receives physiotherapy the probability of also receiving home nursing is much lower. As one turns to the different packages of care provided to the three groups of users, some similarities appear between those with 0-1 and with 6 ADLs lost. In both groups some 6 out of ten users receive only home nursing, one out of ten only physiotherapy and the rest get a mixed package. The delivery of physiotherapy is instead concentrated in the group of those with 2-5 ADLs lost: in this group 29 per cent of the users receive only this service and 28 per cent receive it in a mixed package. The provision of the social care input (home help) is, instead, really scarce for all the groups. It must finally be noticed that there are huge differences in the provision of care inputs between the three Authorities.

The modelling exercises highlight needs-related circumstances that are predictors of care provision. The most important links are: as the dependency increases the probability to receive physiotherapy and the probability to receive 3 or more overall ADI visits per week grows, as the cognitive impairment increases the probability to receive physiotherapy diminishes and the probability to receive home nursing and the probability to get 3 or more overall ADI visits per week grow, as the CIRS score increases the probability to receive physiotherapy diminishes, as the users are discharged from hospital the probability to receive 3 or more home nursing visits per week increases and if users were in hospital in the six months before starting to receive ADI the probability to get 3 or more overall ADI visits per week increases.

- Highlighting the "grey area": where is the boundary between health and social care?

Our project also looked at the controversial issue of what is the remit of community health care and where are the boundaries with social care. We tried to understand which needs are met by health community care (an input free of charge and only needs-tested) and which have to be met by home help (an input charged and also means-tested). To do so we looked at the need for hygiene (mostly related to bathing), that constitutes the core of the disputed space between health and social care. Our data show that the need for hygiene is quite widespread within the ADI users but that in most of the cases (74%) the health professionals do not meet it. It is thus left to the home help or, mostly, to family and privately paid care. There are, once more, huge differences among Authorities and districts in this respect.

- Caring for the users: which are their unmet needs?

The objective data on needs and care inputs provided are completed with the subjective assessment of users and carers on their unmet needs. With reference to the former, those still receiving ADI after three months were asked about their unmet needs. Carers were asked about users' unmet needs as well. Considering the bad conditions of most of the users, the degree to which they and their carers state that there are needs to fill must not be overestimated. It is, instead, important to notice that carers and users agree on the main unmet need of the latter: health care. According to both of them, furthermore, the more ADL functions lost the bigger the users' unmet needs. Users with a higher dependency (especially those dependent in all the 6 ADLs functions) have more unmet needs with reference to several other issues: more needs for hygiene that are not satisfied and more desire to receive information from ADI professionals on other public services, private services and voluntary agencies.

- Caring for the carers: what do they need?

The data presented in this chapter, as those introduced in the previous chapter, stress the huge burden that carers have to bear. They usually meet the elderly on a daily basis and spend together most of the day with them. In most cases, carers support elderly people who are very frail and demanding. The delivery of ADI is not intended to support carers, it is (mostly) intended to meet users' health-related needs. The signs of the statistically significant links between PIC stress and provision of ADI in the modelling are really clear in this respect. The key is the result showing that as the carers' stress grows the probability of receiving 3 or more ADI visits a week decreases. Our findings indicate that one carer out of three would like additional services to support him/her. The requests coming from this group of carers have to be taken very seriously as they tend to be from those who are most stressed and carrying the highest care burden on their shoulders.

4.3 What geographical differences?

- The geographical fragmentation: are there local differences in the process and/or in the resources provided? To what degree?

There are very important differences among the Health Authorities with respect both to process and resource allocation. Concerning process, a wide range of indicators shows the presence of deep differences: examples are who suggested ADI, the formal meeting to arrange the care-plan and the re-assessment. Our analyses on the formal meeting and the arrangement of the care plan show that the differences in how the process of resource allocation is shaped are due not to diversities in users' needs but to different choices made at local level.

Relevant differences appear in the resources actually allocated as well (the data on the ADI resources by Authorities are not shown here). An apparent difference concerns physiotherapy, not provided in the Lecco sample, while the (scarce) provision of home help tends to be quite similar among the three Authorities. This is not the case for the nursing input, where there are not in fact huge differences concerning both the percentage of users receiving it and the number of weekly visits. The results of the modelling exercise highlight the importance of territorial differences as independent variables to explain the type and amount of care inputs received. Differences in how the resources are actually allocated depend to a certain degree on the different users' needs and to a certain degree on the choices and constraints of each Authority and each District.

- Deciding for community care: at which level of government are policy choices made?

The findings presented in this chapter lead to the conclusion that, first of all, policy choices are not made by the Regional Authority. The policy choices are made by Local Health Authorities and by districts. In Lecco there is quite marked consistency between the two Districts (a fact that seems to indicate the presence of policy of the Authority) whereas in Milan and Monza there are relevant differences among districts.

Chapter 7

With what effects?

1. Introduction

How and to what degree are the inputs related to outcomes in ADI? What is the impact of the service on users' conditions? To what degree are they (and the carers) satisfied with ADI? What is the impact of the service on the hospitalisation rate of elderly people? This chapter covers these and several other questions concerning ADI outcomes. For most of the variables analysed, outcomes are studied with reference to the users' situation after three months whereas in a few cases we consider outcomes after six months. The domains considered are: destinational outcomes, consumption of public resources, impact on health conditions and dependency, impact on psychological conditions, satisfaction with the service. What really matters, however, are not just the outcomes but whether and how they are related to inputs. The main task consists, thus, in highlighting the connections between inputs (concerning UVG and ADI, users' characteristics, carers' characteristics, informal care and privately financed services and territorial differences) and outcomes. To discover and discuss this link is the key goal of the chapter. The understanding of such a link can be really useful in drawing policy implications and designing better public interventions.

The chapter will be divided into nine sections, each dealing with a different kind of outcomes (and their links to inputs). Before looking at any of these outcomes, there will be two introductory sections. Section 2 will introduce the outcomes and inputs examined further on in the chapter, and section 3 will present the findings of a qualitative analysis conducted simultaneously with our quantitative work. In sections 4 to 8, we will deal with each group of outcomes in turn: destinational outcomes, consumption of public resources, impact on health and dependency, impact on psychological conditions and satisfaction with the service. Section 9 will summarise the main findings of the chapter and the policy implications we can draw from them.

2. Outcomes and inputs

The chapter is devoted to the analysis of outcomes recorded (mostly) three months after the users have been receiving ADI. We analyse several outcomes and for each of them we present the frequencies. For some of them we try to detect links between inputs and outcomes as well, so to highlight the impact of the former on the latter. It is, thus, a two-step effort: first to describe the outcomes and then to understand (some of) their causes. As illustrated in previous chapters, explaining the differences in outcomes linking them to the impact of inputs ("linking means and ends") constitutes a core task of the "Production of Welfare" Approach. In previous PSSRU work, the analysis of the link between means and ends in community care has usually been conducted using sophisticated statistical tools (for instance, Davies, Fernandez, Nomer, 2000). We will concentrate on logistic multiple regressions. These regressions seem particularly suitable for our tasks, as will be illustrated below.

The outcomes modelled are chosen by two criteria: policy relevance and interest of the results. We focus on those whose achievement is particularly important for ADI, and whose analysis provides interesting insights. In the preliminary work to prepare this chapter the exercise to link means and ends was conducted for several outcomes, through the utilisation of different statistical techniques. In the text we present only those for which we found particularly interesting results and that can provide a value-added in terms of policy thinking. Another feature of this chapter – consistent with a key direction set by the "Production of Welfare" Approach – is to compare the view of the three main players involved in ADI: users, principal informal carers (PICs) and professionals. Several questions on ADI's impact were asked of both users and carers and UVG members in the first wave of interviews. In the chapter we will reflect on the main similarities and differences between the three players.

We are interested in four groups of outcomes, presented here. For each of them, the tables presented in the next pages will illustrate the domain indicators we consider and their frequencies.

Destinational outcomes: we are here interested in whether users are still receiving ADI after three and six months. If they are not, we want to look at their conditions: are they living at home but not receiving ADI, living in institutions or dead? In the follow-up after three months, for those not still receiving the service, we investigate the reasons for closing the case. The analysis of destinational outcomes is particularly helpful in order to draw users' actual profiles.

Consumption of public resources: the impact of ADI on the probabilities of hospitalisation and institutionalisation are widely seen as key outcomes of the service. Our evidence does not allow us to look at institutionalisation whereas we can analyse the impact on hospitalisation. Both users and carers were interviewed again 6 months after the users started to receive ADI. This follow-up, the third interview for most of them, was conducted by telephone and was intended to gather data about whether they were in hospital during this period. As we initially asked whether the users were in hospital during the six months before starting to receive ADI, our data cover a period of twelve months. The comparison between the hospitalisation rates six months before and six months after starting receiving the service allows us to understand its impact with reference to this outcome.

Impact on health conditions and dependency: the impact of ADI on health conditions and ADL functions is one of the most important domains looked at in our project. It is here investigated through a subjective approach consistent with the choice made in several PSSRU studies (for instance, Davies, Fernandez and Nomer, 2000). Users are asked what is – in their opinion – the impact of ADI on their health conditions and on ADL functions. Carers are also asked to assess the impact of the service on the users' conditions and they are additionally questioned on the impact that ADI has on the likelihood of institutionalisation.

General and psychological well-being: services provided in the community are assumed – and required – to care not only for health conditions and dependency of the elderly but also for the broader well-being of users. Services are intended to have an impact on the their quality of life, to increase their satisfaction with life and decrease problems such as depression and worries. In our project we take general and psychological well being of the users into consideration, asking them to what degree ADI reduced their worries.

Satisfaction with the service: in several countries the debates of the 1990s stressed the importance attached to user satisfaction. This is particularly true for Italy, where it has been probably the main issue of the last decade. Users and carers are asked several questions about their own satisfaction. They are asked to what degree they are satisfied with the information received, to what degree they are satisfied with the timetable of ADI visits, whether professionals take what they say into consideration, and to what degree they are satisfied with the number of weekly visits. They are also asked a question on their overall satisfaction with the service.

In order to understand the causes of the ADI outcomes we take several inputs and "quasi-inputs" into consideration. Among the many possible items we gathered data about (see appendix 1 for the list of all the variables considered in the project) we select a number of them here. For each of the outcomes analysed in this chapter, the impact of any of these inputs on the outcome was tested, focusing then (and presenting to the reader) only on those we reckon to be more important. The choice of the inputs to consider in this chapter was made using three criteria: the issues we want to discuss, the characteristics of the areas studied and the results and suggestions emerging from the literature. Pondering on their value, we come to the inputs listed below.
They are divided into five groups, presented here. For each of them, the tables presented in the next pages will illustrate the variables considered and their frequencies.

UVG and ADI features: we consider here mostly two groups of inputs, those relating to the package of care provided by ADI and the process through which it is allocated and monitored. We consider the different typologies and amounts of inputs provided and whether the meetings to set up the care plan and a re-assessment are arranged. We look also at the UVG's assessment on the appropriateness of the care plan and on the expected outcomes of ADI.

Users' characteristics: the characteristics of the elderly receiving ADI are considered from several points of view. We consider their age and gender, their dependency and health (objective and perceived), life events in the six months before entering ADI, and whether they are discharged from hospital.

Carers' characteristics: with reference to the principal informal carers, we focus on some inputs rather than others, just on those our literature review suggests are likely to be of particular importance. We look at their age, perceived health, relation of propinquity with the user and indicators of stress.

Informal care and private paid services: we include here the variables describing the typologies and amounts of informal and private care received. We consider whether the user lives alone, how often he/she meets the principal informal carer (PIC) (and how many hours they spend on average together) and the quality of their relationship (PICs own judgement). We look also at whether the user receives private paid care and (if she/he does) how often and on average for how many hours. Finally, we consider what kind of tasks principal informal carers and private carers perform for the users.

Territorial differences: we take into consideration the main indicator of geographical differentiation, that is to which of the three Local Health Authorities users belong.

OUTCOMES

Destinational outcomes

Domain	Values
- Whether the user was still receiving ADI after three months	*1= yes (59 per cent)* *0= no (41 per cent*
- Whether the user was still receiving ADI after six months	*1= yes (41 per cent)* *0= no (59 per cent)*

Consumption of public resources

Variable	Values
- Whether the user was in hospital in the six months after starting to receive ADI	*1= yes (21 per cent)* *0= no (79 per cent)*

Impact on health conditions and dependency of the user

Variable	Values
	"To what degree has ADI improved......
- User's own assessment of ADI's impact on his/her health after three months	*User's health (own assessment)* *1= A lot/enough (60 per cent)* *0= A little/not at all (40 per cent)*
- User's own assessment of ADI's impact on his/her ADL functions after three months	*User's ADLs (own assessment)* *1= A lot/enough (33 per cent)* *0= A little/not at all (67 per cent)*
- PIC's assessment of ADI's impact on the user's health after three months	*User's health (PIC's assessment)* *1= A lot/enough (56 per cent)* *0= A little/not at all (44 per cent)*
- PIC's assessment of ADI's impact on the users' ADL functions after three months	*User's ADLs (PIC's assessment)* *1= A lot/enough (23 per cent)* *0= A little/not at all (77 per cent)*

Impact on psychological conditions

Variable	Values
- To which degree has ADI decreased users' worries on their own health conditions and dependency	*1= A lot/enough (62 per cent)* *0= A little/not at all (38 per cent)*

Satisfaction with the service

Variable	Values
- User's overall satisfaction with ADI	*To what degree are satisfied with ADI?* *1= A lot (56 per cent)* *0= Enough/A little/not at all (44 per cent)*
- PIC's overall satisfaction with ADI	*To what degree is ADI a support in caring for the elderly person?* *1= A lot (49 per cent)* *0= Enough/A little/not at all (51 per cent)*

INPUTS and "QUASI-INPUTS"

UVG's and ADI

Variable	Values
- A meeting was hold to arrange the care plan	*1= yes (53 per cent)* *0= no (47 per cent)*
- A re-assessment was arranged	*1= yes (48 per cent)* *0= no (52 per cent)*
- User receives home nursing	*1= yes (74 per cent)* *0= no (26 per cent)*
- User receives physiotherapy	*1= yes (30 per cent)* *0= no (70 per cent)*
- User receives home help	*1= yes (9 per cent)* *0= no (91 per cent)*
- Overall number of weekly visits	*range 1 to 10, mean 3.6*
- Overall number of weekly visits (squared)	*Range 1 to 100*
- How many months the user has been receiving the service for (1 to 6 months)	*Range 1 to 4*
- How many months the user has been receiving the service for (1 to 6 months) (squared)	*Range 1 to 16*
- How many months the user has been receiving the service for (1 to 4 months)	*Range 1 to 6*
- How many months the user has been receiving the service for (1 to 4 months) (squared)	*Range 1 to 36*
- Care plan could have been better (UVG's assessment)	*1 = yes* *0 = no*
- ADI's predicted positive impact (by UVG) on users' dependency	*0 = not at all/a bit (20 per cent)* *1 = quite/ a lot (80 per cent)*
- ADI's predicted positive impact (by UVG) on users' health	*0 = not at all/a bit (47 per cent)* *1 = quite/ a lot (53 per cent)*

User' characteristics

Variable	Values
- Age	*Range 61 to 103, mean 81*
- Age (squared)	*Range 3721 to 10609*
- Gender	*1= male (33 per cent)* *0 = female (67 per cent)*
- ADL score	*Number of ADL functions lost (range 1 to 6, mean 4.0)*
- ADL score (squared)	*Range 0 to 36*
- CIRS score	*Number of disease diagnoses (range 0 to 10, mean 4.1)*
- CIRS score (squared)	*Range o to 100*
- SPMS score	*Range 1 to 10, mean 4,3*
- SPMS score (squared)	*Range 1 to 100*
- Whether the user was in hospital in the six months before starting to receive ADI	*1= yes (51 per cent)* *0= no (49 per cent)*
- User is discharged from hospital	*0 = no (79 per cent)* *1 = yes (21 per cent)*

Carer's characteristics

Variables	Values
- Carer's age	*Range 34 to 90 (mean 60)*
- Carer's age (squared)	*Range 1156 to 8100*
- Carer's gender (Female= 77 per cent, Male= 23 per cent)	*0= female (77 per cent)* *1= male (23 per cent)*
- Is the carer the daughter/son of the user?	*0= no (44 per cent)* *1= yes (56 per cent)*
- Is the carer the husband/wife of the user?	*0= no (71 per cent)* *1= yes (29 per cent)*
- Stress 1	*- How often in the month before the interview you thought you need rest from caring for the elderly person?* *1= always-often (47 per cent) cent)* *0= sometimes-never (53 per cent)*

Carer's characteristics (continues)

Variables	Values
Stress 2	*- How often in the month before the interview you thought you cannot cope with caring for the elderly person?* *1= always-often (24 per cent)* *0= sometimes-never (76 per cent)*
- Perceived health	*1= very-quite good (77 per cent)* *0= quite-very bad (23 per cent)*

Informal care and private paid services

.Variable	Values
- Users live with others	*0= no (84 per cent)* *1= yes (16 per cent)*
- User-Pic relationship as reported by PIC	*It is the PIC's assessment:* *1= very good (50 per cent)* *0= good/very bad/quite bad (50 per cent)*
- PIC performs housework for the user	*1= yes (80 per cent)* *0=no (20 per cent)*
- PIC performs personal care for the user	*1= yes (75 per cent)* *0=no (25 per cent)*
- PIC performs health/nursing care for the user	*1= yes (59 per cent)* *0=no (41 per cent)*
- User receives private paid care	*1= yes (45 per cent)* *0= no (55 per cent)*
- Paid carer performs housework for the user	*1= yes (70 per cent)* *0=no (30 per cent)*
- Paid carer performs personal care for the user	*1= yes (69 per cent)* *0=no (31 per cent)*
- Paid carer performs health/nursing care for the user	*1= yes (34 per cent)* *0=no (66 per cent)*

Territorial differences

Variable	Values
- Local Health Authority Milan	*0= No (56 per cent)* *1= Yes (44 per cent)*
- Local Health Authority Milan Neighbourhood	*0= No (66 per cent)* *1= Yes (34 per cent)*
- Local Health Authority Lecco	*0= No (78 per cent)* *1= Yes (22 per cent)*

3. A qualitative view

The primary approach taken in this project is the quantitative analysis of data using statistical tools[1]. However, as has already been seen in the previous chapter, we use some other data and approaches to assist in the interpretation of results. The only exception consists in the two open questions included in the questionnaires for the users still receiving the service after three months. Users were asked to express their thoughts about the main strengths and weaknesses of the service. Such a request was intended to complement the quantitative data on outcomes and satisfaction presented below. The views on services expressed by the users were written down by interviewers and then analysed. We are struck by the consistency of the views among different users. From their statements, some issues clearly emerge to be the most important. With regard to the positive features most appreciated in the service, the overwhelming majority of the users identified these to be the kindness, courtesy and good manners in general of the professionals. The second positive features – much less frequently mentioned – are the skills and ability of the professionals. Thirdly, users stress the appropriate schedule of the service that several judge to be tailored to their needs. Turning to the negative features, most of them are directed towards the same issue: the amount of care provided. Several users state, in fact, that the number of ADI visits is inadequate. No other negative features were indicated by many users, but the number of visits clearly matters to them greatly. These qualitative data highlight what users reckon to be the main causes of the users' satisfaction or dissatisfaction. Our findings are here really consistent with what has been suggested by other research undertaken in Italy on this issue. The importance of the factors emerging (courtesy, professional skills, schedule and amount of care) has, in fact, been recognised in several other studies concerning both health and social care in Italy (e g Trabucchi (ed.), 1996; Ranci Ortigosa (ed.), 2000; De Ambrogio, Setti Bassanini (eds.), 1996; Ambroset, 1998).

Box 1

Users' qualitative judgement on ADI

Positive features (rank)

1. Kindness, courtesy and good manners in general of the professionals
2. Skills and ability of the professionals
3. Appropriate schedule of the service, tailored to users' needs

Negative features

- Number of visits not adequate

---

[1] In the preliminary stage, however, qualitative interviews were conducted with ADI responsible and UVG members.

4. Destinational outcomes

Our analysis begins by looking at the destinational outcomes: is the user still using ADI three months after the first receipt? If not, what is the main reason why he or she ceased to receive ADI? Table 1 summarises the data on users' destinations after three months of receipt: 59 per cent are still getting ADI, 25 per cent are not receiving it and living at home, 13 per cent are dead and 3 per cent are in residential care. Here, as in all the chapter's table showing frequencies, we present the data concerning the overall sample. In appendix 3 we show frequencies for each of the three Local Health Authorities studied. Six months after they started to receive the service, 41 per cent of the users are still getting ADI. This means that a large group of the users need support by the domiciliary service for a long period. The patterns of destinational outcomes after 3 and 6 months show the great heterogeneity of the elderly receiving this service. They can be divided among those receiving it for no more than 3 months (41 per cent), those receiving it for 4 or 5 months (18 per cent) and those receiving it for at least 6 months (41 per cent). For several reasons – particularly the difficulties in tracking users for such a period of time – the data concerning the users' situation after six months should be viewed with extreme caution (see table 1). Apart from the organisational problems in running the fieldwork, one has to bear in mind the selection criteria for the recruitment, discussed in chapter 3. In the highly heterogeneous universe of users getting this service we take into consideration only new ones, aged 65 or more, receiving proper ADI (i e they are fully assessed by the assessment and planning unit and a care plan is set up for them). The terminally ill (as defined by the Italian Department of Health) were excluded.

The conditions of those who after three months are not receiving the service anymore are further described in table 2, which reports why – according to the UVG members - users ceased to receive ADI. Respondents can choose only within a range of suggested answers. One third of those belonging to this group are now dead whereas in one half of the cases the interruption is due to a change in the users' conditions. In 33 per cent of cases, professionals state that the service is not necessary anymore because of improvements in users' conditions, whereas in 14 per cent it is affirmed that the service does not produce significant outcomes any longer. In 16 per cent of the cases, instead, the family is now self sufficient in caring for the user. This last group is mostly composed of cases for which professionals spend time training the family and other informal or paid caregivers in techniques to care for the elderly. When the carers learn these techniques and can apply them themselves, the elderly do not need to be ADI users anymore. In almost 50 per cent of the cases for which the family is self-sufficient in caring for the user or the service is no longer necessary after three months because of improvements in users' conditions. That is, in some half the sample the *assistenza domiciliare integrata* ceases to be provided because of an improvement in either elderly conditions or carers' skills. This is an important positive outcome.

We do not separately report the reasons for case closure after six months as they closely resemble, indeed are identical to, those recorded after three months.

Table 1

Users after 3 and 6 months, per cent

	3 months	6 months
Still receiving ADI	59	41
Living at home, not receiving ADI	25	34
Dead	13	19
Living in residential institutions	3	5
Total	100 (N= 348)	100 (N= 348)

Table 2

Main reason for the case closure after three months, per cent

	Total
ADI is no longer necessary because of the improvement in the user's conditions	33
Dead	32
The family is now self-sufficient in caring for the user	16
ADI does not produce significant outcomes for the user anymore	14
Institutionalisation	3
There are not the resources to provide ADI anymore	2
Total	100 (N= 94)

5. Consumption of public resources

Among ADI outcomes, the impact on hospitalisation attracts a lot of interest. Several commentators reckon the possibility to decrease the hospitalisation rate to be the most important outcome of the *assistenza domiciliare integrata,* and many managers and decision-makers share this view. The great importance assigned to this outcome is mostly due to the cost-containment ethos that deeply influences the debate on long-term care and on the Italian welfare state in general. The two main experimental projects on ADI effectiveness conducted in Italy prove that to receive this service decreases the rate of hospital admission (Ferrucci et alii, 1996; Bernabei et alii, 1998).

Our project is a before-after design without comparison group and it is not possible to compare the outcomes for ADI users and for a control group. Therefore, we follow the most common strategy used in Italy to examine the effectiveness of the service in decreasing the hospitalisation rate when there is not a control group: to compare the six months before users started to receive ADI and the six months after in order to understand whether and how the pattern of hospitalisation changes (Bavazzano et alii, 1996). Such a design, nevertheless, is able to produce results that are less significative than those produced by experiments with a comparison group. The findings suggest a positive impact of ADI on decreasing hospitalisation: 59 per cent of the users were admitted to hospital during the six months before and only 21 per cent in the six months after. The crosstabulation of these two variables suggests even more clearly a positive impact of ADI: almost one user out of two (45 per cent) was hospitalised during the six months before, but was not later (see table 3). This evidence suggests a strong ADI impact on hospitalisation rates and it is consistent with the results of previous experimental studies run in Italy (Bavazzano et alii, 1996 Ferrucci et alii, 1996; Bernabei et alii, 1998).

Table 3

Users stayed in hospital in the 6 months before starting ADI by usersstayed in hospital in the 6 months after starting ADI, per cent

	Was admitted into hospital during the 6 months after starting ADI	Was not admitted into hospital during the 6 months after starting ADI	Total
Was admitted to hospital in the 6 months before starting ADI	13	45	59
Was not admitted to hospital in the 6 months before starting ADI	8	33	41
Total	21 (N= 45)	79 (N= 170)	100 (N= 215)

5.1 Explaining the consumption of public resources

In this chapter, we aim both to describe outcomes, through descriptive statistics, and to explain them, through regression analysis. To pursue our explanatory goal we use logistic regression. This technique is used in order to analyse nominal/ordinal dependent variables with only two categories and independent variables may be any scale of measurement; to do so, we transformed all the dependent variables into dummy variable. Logistic analysis deals with odds ratios. When the probability of an event happening is greater than the probability of an event not happening, then the odds ratio will be greater than 1. When the probability of an event happening is less than the probability of an event not happening, then the odd ratio will be less than 1. The standard measure of goodness-of-fit (R^2) is not really applicable to logistic regression, and so the so-called pseudo-R^2 measures have been developed. We will use the Nagelkerke Pseudo R^2 Square throughout all our empirical exercises.

We used the statistical package SPSS 10.1 for Windows. For each model presented, in the preliminary stages of our analysis we investigated the effects of any independent variable listed on the outcomes studied. In the preliminary stages we also used techniques that can help the statistical analysis, such as backward and forward stepwise; they were useful in order to shape our thoughts concerning causal connections between dependent and independent variables in community care. In the final models, those actually presented in the chapter, we do not use any of these techniques and we do include variables without significant effects on the dependent variable.

The fact that the latter are not found to be significant means that we cannot reject the hypothesis that their effect is equal to zero (and therefore that the variable should be out of the model). Including non-significant effects in the model in other circumstances would be appropriate if what we did was more 'hypothesis-testing' rather than 'exploratory' modelling. If we were to have in mind a very clear picture of which variables ought to be in the model and how they should interact with our dependent variable then showing whether they are significant or not helps in proving/disproving our postulated theories. In our project, one could make a case for including all the variables we have (and many more that we want to have) in the model. Including just a few may give the impression that they are 'helping' us to find significant effects on others. Including all the variables in the model, given the high collinearity between them, would make the resulting model extremely difficult to interpret. Additionally, given that we do not have many cases, including only the significant effects in our model will help increase the number of degrees of freedom. Of course, noting that some variables are not found to have a significant effect when tested is very important.

The first model presented aims to illuminate why some users were admitted to acute hospital beds since they started to receive ADI. As our dependent variable, we chose admission into residential care for those still receiving ADI five and six months after beginning to receive it. They are 50 per cent of our initial sample. We made this choice because we cannot assume that the decrease in the rate of hospitalisation that comes through in the descriptive analysis is due (entirely) to ADI. ADI is likely to target a huge part of its intervention on users following their discharge from hospital and/or following an acute health crisis. Even if services were not to be effective in reducing hospitalisation, one would expect the rate of hospitalisation to fall during the subsequent six months. The decline in hospitalisation is more likely to occur in the months just after the beginning of ADI intervention, that is soon after the crisis that led the user to claim ADI. To concentrate on users still receiving ADI after five or six months allows us to better pinpoint the "net" effect of the service.

Table 3.1

Probability of hospitals' utilisation in the fifth and sixth months since first receipt of ADI

Independent variables	B	S.E.	Sig.	Exp(B)
Overall number of weekly visits (range 1 to 10, mean 3.6)	.239	.087	.006	1.270
Local Health Authority Milan Neighbourhood (No= 66 per cent, Yes= 34 per cent)	.856	.429	.046	2.355
High Cognitive Impairment (No= 63 per cent; Yes= 37 per cent	-.943	.383	.014	.389
Constant	-.424	.411	.303	.655

Nagelkerke Pseudo R Square .145 No. of cases 166

The model explains some 14 per of variation in hospitalisation. It shows that the overall number of weekly visits, the local health authority inhabited and the presence of a high cognitive impairment have a statistically significant link with the hospitalisation rates five and six months since starting to receive ADI. The direction of these links, however, is not as one would expect. The likelihood of being hospitalised grows as the overall number of weekly visits increases. The policy message, of course, is not to decrease the amount of care inputs in order to decrease hospitalisation ratios. A possible interpretation is that users who are in the worse conditions (in terms of health) receive the higher number of weekly visits and for them it is then not possible to avoid hospitalisation. The number of weekly visits – from this point of view – is to be interpreted not as a resource input but as a risk factor. The higher number of visits would indicate worse health conditions, leading to higher hospital ratios. Another possible interpretation is that the amount of care inputs provided does not matter that much. It is not the quantity but, the quality that makes the difference. It is what are those inputs, their quality and appropriateness, how the care package is arranged and what kind of care process is organised that matter in order to have a positive impact on users' well-being and hospitalisation rates.

The only users' needs-related circumstance with a statistically significant effect on hospitalisation is the presence of a high degree of cognitive impairment. Users with high cognitive impairment have lower probabilities of being hospitalised. There is, therefore, a productivity effect concerning this group of users. It is a finding consistent with the results of projects conducted in other countries, showing that community care users with marked cognitive impairment have a higher probability not of being hospitalised but of being institutionalised in residential care (Davies and Fernandez, 2000).

The third variable is a territorial one. Compared to other people in the study sample, the inhabitants of the local health authority of Milan neighbourhood have 135 per cent higher probabilities of being hospitalised during the fifth and sixth month after the commencement of ADI. These findings confirm a feeling we have had in studying the three local health authorities over time: being in one or in another is the crucial reason to explain different hospitalisation rates. It is a trait that characterises the overall Italian situation and not only Lombardy. The territorial differences are of great relevance but are quite complex to interpret, as we do not distinguish risk factors from supply factors and types of influence of each kind. The territorial variable can, in our view, be interpreted in different ways, regarding both users' circumstances and service organisation. It could be a proxy for the differences among users' circumstances in the three authorities that are not captured elsewhere in the model. It could concern differences in how the service is organised and delivered among authorities that are captured elsewhere in the model. The variations could concern professionals involved, outreach procedures, assessment and care planning procedures, monitoring over-time, office hours, availability of other services (such as day care) and several others traits not captured elsewhere in the model. On the other hand, territorial differences could be explained by differences concerning hospitals. We refer to different hospitals' policies concerning admissions of frail elderly and differences in bed availability. From our own knowledge of the authorities investigated, we tend to think that both differences in services organisation and delivery and in differences hospital characteristics play an important role in explaining the significance of the territorial variable.

6. Impact on health conditions and dependency

What are the consequences of ADI for the conditions of the elderly? The impact on users' health conditions and dependency is one of the most important groups of ADI outcomes. This impact is quite difficult to measure and there are several ways to do it. The main choice is between the objective assessment (the utilisation of an assessment tool by professional or trained interviewers, that evaluate the conditions of the elderly) and the subjective assessment (the elderly assess the change, if any, in their condition). In this project we choose the latter, asking the users to what degree has ADI improved their health and their capabilities in ADL functions. We complete the users' assessment with that of the principal informal carers and of the professionals belonging to the UVGs. The choice for a subjective approach is due to reasons of an entirely different kind. First, this is the research strategy adopted by the most important PSSRU projects on community care, explained by the difficulties of detecting objective improvements in the dependent elderly and by the importance assigned to the users's own view (Davies, Fernandez and Numer, 2000). Secondly, it must be considered that three months is too short a spell to detect objective changes (that are usually measured after six months). Thirdly, from an organisational point of view, in our budget there were not enough financial resources to conduct an objective assessment (that has to be conducted by professionals whereas interviews are usually conducted by students).

The utilisation of the subjective assessment has to be accompanied by some caveats about how to interpret the data. Users tend to overestimate the impact of the services, they attribute to the services benefits additional to those actually there. The overestimation can be due to different reasons. First and foremost, the simple fact of receiving domiciliary care makes users really satisfied and so they tend to like it, whatever the care inputs provided and whatever their actual impact. There is not a tradition of community care in Italy and ADI was introduced only in the early 1990s. Frail elderly living in the community are not used to receiving any kind of public care (most of them actually do not). The simple fact of getting something makes them really happy and creates a bias in assessing the actual impact of the service. In a similar vein, users are not really inclined to criticise ADI as they fear it might poison the atmosphere or – worse still - it could reduce the amount or quality of the care they receive (Ranci Ortigosa (ed.), 2000). Finally, one has to consider the indirect effect of support and the end of the pre-ADI crisis on mood, resulting in a more up-beat perception of everything. Taking these caveats into consideration, we should be really careful in analysing the single satisfaction items on their own and – in doing so - we should look at the trend they suggest and not at the precise percentage. We will work quite a lot on the comparison among different items.

While users and carers are interviewed three months after they have been receiving the service, for the professionals we consider their predictions at the time of referral (i.e. some three months before). All the questions allow the interviewees to choose among four possible answers that – for the sake of clarity – have been regrouped in two: the positive (those that reckon the service improved their conditions "a lot/enough" and the negative ones (those that reckon the service improved their conditions "a little/not at all").

In relation to users' health conditions, ADI had a positive impact according to 60 per cent of them and to 57 per cent of their PICs; the UVGs predicted this outcome for 80 per cent of the cases. On the ADL functions, the service had a positive impact according to 33 per cent of the users, 22 per cent of the Pics and 50 per cent of the users. We look at a third indicator as well: the impact of the service on the likelihood of users' institutionalisation[2]. It is positive according to 32 per cent of the PICs and predicted so by 81 per cent of the UVGs. The data show a clear-cut difference between the health and social impact of ADI: the former is by far the bigger of the two (for any of the three actors interviewed). The positive impact on health concerns the majority of the users, whereas the opposite is the case for the impact on dependency. The predominance of the health outcomes is consistent with the fact that ADI is mostly a health service whereas it provides just a few social care inputs, as discussed in the previous two chapters. We also note a high degree of consistency in the assessment of users and carers, which is confirmed by the crosstabulations on health and dependency, not shown here. For both of them, they reach similar judgements for some 75 per cent of the cases. There is less consistency with the predictions of the UVGs: in both health and social care – in fact – the professionals predicted more positive outcomes than those stated by users and carers. The divergence is greatest when institutionalisation is faced: the UVGs at the referral

---

[2] We miss the users' own judgement on this issue.

predicted a positive outcome in decreasing its likelihood for 81 per cent of the cases whereas after three months the carers stating that this is the case are only 32 per cent. This is the only indicator of this group with the carers' and UVGs answers pointing at two different directions. As a whole, we notice that those providing care have a more positive view on it than those receiving care (see table 4).

Table 4

To which degree has ADI improved user's health and capabilities in ADL functions and decreased the likelihood of institutionalisation by users, PICs, UVGs, per cent

	Users	Pics	UVG[3]s (prediction at the referral)
On user's health	A lot/enough= 60 A little/Not at all= 40	57 43	80 20
On user's ADL	33 67	22 78	50 50
On likelihood of institutionalisation	-	32 68	81 19
	(N= 100)	(N= 148)	(N= 168)

6.1 Explaining the impact on health conditions and dependency

After presenting the views of the different stakeholders on the impact of ADI on users' ADL functions and health, we try now to explain the differences in outcomes. We look at health and dependency reported by both users and carers, beginning with the latter. Table 4.1 presents the regression of ADI impact on users' health according to PICs. The model explains 19 per cent of variation in the impact on users' health. Three needs-related circumstances have a statistically significant impact on outcomes, gender, dependency and whether they were discharged from hospital as they started to receive ADI. With respect to gender, carers report that ADI has a far higher positive impact on the female than on male. This finding can probably be explained by the differences in health conditions and dependency between the two genders, the former being on

---

[3] For the UVGs, the table considers the cases for which the carers answered after three months the questions on the impact.

average in better conditions than the latter. Concerning dependency, as the ADL score increases the impact on users' health decreases. The findings suggest that the *assistenza domiciliare integrata* produces a better impact when users are in less deteriorated conditions. A similar finding will be presented with respect to other outcome domains. The impact on the health of those discharged from hospital is reported as almost four times higher than on the other users, a result due to the peculiar characteristics of the former. Elderly people discharged from hospital, in fact, have usually more and more room to improve than other users. There is also an independent variable regarding care inputs with a statistically significant impact on the reported health: the delivery of home nursing inputs, received by three users out of four. Those receiving these inputs have a higher positive impact on health than the others. It is a result consistent with the goals of the home nursing intervention, which is aimed at health problems and pathologies, whereas physiotherapy has a rehabilitative goal. The next table shows that physiotherapy has a positive impact on ADL functions.

Table 4.1
Probability of ADI impact on users' health according to PICs

Independent variables	B	S.E.	Sig.	Exp(B)
ADL Score (number of ADL functions lost, range 1 to 6, mean 4.0)	-.176	.080	0.28	.839
User is discharged from hospital (No= 79 per cent,Yes= 21 per cent)	1.218	.529	0.21	3.381
User Gender (Male= 33 per cent, Female= 67 per cent)	-.935	.367	.011	.392
Whether user receives home nursing (Yes= 74 per cent, No= 26 per cent)	.159	.083	.055	1.172
Constant	.770	.458	.093	2.160

Nagelkerke Pseudo R Square .190 No. of cases 566

Table 4.2 presents the probability of ADI impact on users' ADL functions according to principal informal carers. The model explains some 28 per cent of variation in the impact on ADL functions. Those in hospital in the six months before starting to receive ADI are reported to experience an improvement that is much bigger than the others. Also with respect to needs-related circumstances, users dependent in more ADLs are reported to benefit less. As in the previous model, the higher is user dependency, the smaller is the positive impact of ADI on users' conditions. This is due to the fact that less deteriorated conditions allow the service more room to produce a positive impact. With reference to the care inputs provided, the users receiving physiotherapy, some 30 per cent of the total, are reported to experience a better impact on ADL functions. This is a finding consistent with the nature and goal of physiotherapy, that is to rehabilitate the elderly and to improve their autonomy.

Taking both tables 4.1 and 4.2 into consideration, it is possible to make some comments on the impact of ADI as reported by principal informal carers. In both the models, the greater the dependency the smaller the positive impact produced by ADI. That is to say that if services are targeted towards users with less dependency, their productivity is higher. The two models share also the presence of a variable concerning a previous stay in hospital. Both users discharged from hospital and in hospital in the previous six months get a better impact from ADI. Dependency and previous stay in hospital emerge, therefore, as the two key needs-related variables with respect to productivity as reported by users. In the analysis of this result, it is important to bear in mind that we deal with reported outcomes and that, by definition, perceptions have an important role in defining them. Previous stay in hospital (and discharge) can therefore positively mediate the users' perception as they lead to overestimate the impact of ADI. Bearing this caveat in mind, nevertheless, the findings of our modelling look of great interest. The two models presented here share also the presence of a variable regarding care inputs. Users receiving home nursing experience a better impact on health and users receiving physiotherapy experience a better impact on dependency. The two different productivity effects are consistent with the fact that the former input is intended to meet needs concerning health disease and pathologies and the latter input is intended to pursue rehabilitative goals.

Table 4.2
Probability of ADI impact on users' ADL functions according to PICs

Independent variables	B	S.E.	Sig.	Exp(B)
Whether the user was in hospital in the six months before starting to receive ADI (Yes= 51 per cent, No= 49 per cent)	1.739	.540	.001	5.689
User receives physiotherapy (Yes= 30 per cent, No= 80 per cent)	.254	.136	,062	1.289
ADL Score (number of ADL functions lost, range 1 to 6, mean 4.0)	-.293	.089	.001	.746
Constant	-1.584	.566	.005	.205

Nagelkerke Pseudo R Square .284 No. of cases 150

After considering the impact of the *assistenza domiciliare integrata* as perceived by carers, we turn to the impact reported by users themselves. We consider the probability of ADI impact on users' health according to users (Table 4.3). This model has a better fit than any other does in this chapter explaining 59 per cent of the variation. Five independent variables have a statistically significant link with the dependent variable. Users living in the local health authority of Milan experience a worse impact than the others. We find a territorial variable, that does not distinguish risk factors from supply factors and types of influence of each kind. The territorial variable could be a proxy for the differences among users' circumstances in the three authorities that are not captured elsewhere in the model or it could reflect differences in how the service is organised and delivered among authorities that are captured elsewhere in the model. The variations could concern professionals involved, outreach procedures, assessment and care planning procedures, monitoring over-time, office hours, availability of other services (such as day care) and several others traits not captured elsewhere in the model. On the other hand, territorial differences could be explained by differences concerning hospitals. We refer to different hospitals' policies concerning admissions of frail elderly and differences in bed availability. As previously stated, we reckon that both differences in services organisation and delivery and in hospital's characteristics contribute to help explain the significance of the territorial variable.

The two most important indicators of health and dependency, ADL and CIRS scores, have a statistically significant link with users' health. As the ADL score grows, the positive impact on users' health decreases. As the CIRS score increases, the positive impact on users' health diminishes. In both cases, when the health/dependency conditions worsen the *assistenza domiciliare integrata* produces a smaller impact. Users discharged from hospital report a better impact of the service on their health conditions. This is probably due to the fact that elderly people discharged from hospital have usually more room to improve. The last variable included in the model is the gender of the carers. Users whose principal informal carers are male report a far worse impact on their health conditions, a difference probably due to the (on average) better health and dependency conditions of the women.

The comparison between the impact on users' health as reported by users' themselves and as reported by principal informal carers allows a deeper understanding of outcomes. Both in table 4.1 and 4.3, there is a statistically significant link (in the same direction) between ADL score, users discharged from hospital and ADI impact on users' health. In the model based on PICs perceptions the kind of care inputs provided (home nursing or not) has a role, while this is not the case in the model based on users' perceptions. Modelling the latter shows that there is an additional key needs-related variable (CIRS score) and a territorial variable (whether users belong to Milan local health authorities) has a significant role.

Table 4.3

Probability of ADI impact on users' health according to users

Independent variables	B	S.E.	Sig.	Exp(B)
Local Health Authority Milan (No= 56 per cent, Yes 44 per cent)	-2.140	.895	.017	.118
ADL Score (number of ADL functions lost, range 1 to 6, mean 4.0)	-.682	.184	.000	.506
CIRS score (Number of disease diagnoses, range 0 to 10, mean 4.1)	-.654	.236	.006	.520
User is discharged from hospital (No= 79 per cent;Yes= 21 per cent)	3.503	1.365	.010	3.219
Carer's gender (Female= 77 per cent, Male= 23 per cent)	-1.917	.843	.023	.147
Constant	6.311	1.675	.000	550.745

Nagelkerke Pseudo R Square .590 No. of cases 74

7. Impact on psychological conditions

The psychological conditions of the elderly are another domain of ADI outcomes to analyse. In the Italian debate on community care, it is generally considered less important than health conditions and dependency, but from the users' perspective this is less likely to be the case. There is evidence suggesting that the frail elderly request from the public community care services a kind of support that goes beyond caring for health conditions and dependency. There is a need for a service that actually supports the users to improve their overall quality of life and to decrease problems such as depression or worries (Taccani (ed.), 1996). The need for services whose impact goes beyond the physical and health conditions also appears quite clearly to everyone involved with frail elderly people and with community care.

In the project, elderly people still receiving ADI after three months were asked to what degree ADI has decreased their worries on their own health conditions and dependency. Some two-thirds of the users stated that the service actually had a relevant impact in decreasing their own worries (the answers are grouped, as previously, in two groups: the "positive" (a lot/enough) and the "negative" (a little/not at all) ones).

Table 5

To what degree has ADI decreased users' worries about their own health conditions and dependency, per cent

	On user worries
A lot/enough	62
A little/Not at all	38
Total	100 (N= 100)

7.1 Explaining the impact on psychological conditions

As we did with other outcome domains, after describing to what degree – according to users - ADI has decreased their worries (about?) their health conditions and dependency, we aim to explain the impact. The model presented in Table 5.1 explains some 33 per cent of variation of ADI impact in decreasing users' worries. The only explanatory variables concern needs-related circumstances of the users. As the degree of dependency increases, according to ADL score, the impact on decreasing users' worries decreases. In order to get better productivities in terms of users' psychological conditions, the intervention should be targeted towards elderly people with a lower degree of dependency.

The overall age effect – of both age and its square - is negative: as age increases the probability of ADI impact on decreasing users' worries decreases. Besides ADL score and age, there is another independent variable that has a statistically significant link with the impact on decreasing users' worries, which is the quality of relationship between user and PIC, as reported by the latter. Users whose relationship with principal informal carers is reported "very good" experience a better impact of ADI on decreasing users' worries. This is the only model presented in this chapter where the quality of the user-PIC relationship has a statistically significant link with the outcome. The connection between this relationship and the ADI capability to decrease users' worries is of particular relevance because of its policy implication. As long as the goal of the *assistenza domiciliare integrata* is not only to improve users' health and dependency but also to improve their well being as well as the well-being of those most involved in their care, the determinants included in this model are of particular importance.

Table 5.1
Probability of ADI impact on decreasing users' worries

Independent variables	B	S.E.	Sig.	Exp(B)
ADL Score (number of ADL functions lost, range 1 to 6, mean 4.0)	-.389	.122	.001	.678
User-PIC relationship (PIC's assessment, Very good= 50 per cent, Others= 50 per cent)	1.650	.602	.006	5.207
Age (Range 61 to 103, mean 81)	.009	.005	.057	1.009
Age (squared) (Range 3721 to 10609)	-1.448	.747	.052	.235
Constant	58.797	29.435	.046	3.4E + 25

Nagelkerke Pseudo R Square .327 No. of cases 78

8. Satisfaction with the service

The importance assigned to "customer satisfaction" in the Italian health and social care during the last decade was stressed in chapter 2. According to many commentators and professionals, users' satisfaction must be the main outcome of social and health care services, though others take a more cautious view (Trabucchi (ed.), 1996). The tendency to emphasise this issue has been evident in many European countries as well as in Italy. Our view is that the satisfaction of users is an important outcome which has been overlooked in Italy. The cursory attention which this outcome has received in Italy as in many other countries closely reflected the shortcoming these services suffered in their orientation to the users. The increased relevance assigned to user satisfaction is, therefore, to be welcomed but should also be seen in a broader context. The outcome domain of user satisfaction should be considered together with other domains, as we do in this thesis, in order to pursue a multi-dimensional analysis of the service impact on the users' conditions. This is consistent with the Production of Welfare approach as well. While looking at the satisfaction, the elderly point of view should be complemented with that of carers and professionals, as we do in our work.

The project examines several aspects of the satisfaction of users still receiving the service after three months and the satisfaction of their carers. Both of them are asked the same questions; it should be noticed that the questions to PICs concern their own satisfaction with ADI, i.e. the degree to which the service meets the needs they have because of their caring tasks. There is a difference with the issues previously considered: while with reference to health and dependency carers are questioned about users' situation, here they are asked about their own satisfaction. The items inserted look at four specific issues: the information received about the service[4], to what degree "professionals take what you say into consideration", the timetable of the ADI's visits and their frequency. They are completed by a final question investigating the overall satisfaction with ADI. The answers available – originally four as in many of the items discussed in the chapter – are gathered here in three groups: "a lot", "enough", and "a little/not at all". The first answer signals the presence of satisfaction, and the third the presence of dissatisfaction. The intermediate group ("enough") stands in a sort of neutral position, where there is room for improvement.

Analysing the four questions specific to the needs of PICs, the one on information stands out as by far the worst. The degree of dissatisfaction is very great and shows the need for improvement. On the other hand, the item both users and carers are most satisfied with is the consideration they receive from professionals. Satisfaction with timetable and frequency is at an intermediate level: the percentage of great satisfaction "a lot" does not reach here the majority of users, nor of carers, signalling the presence of room to improve. Moving to the overall judgement, some half of users and carers in the sample are strongly satisfied with the service. It means that there is another half whose satisfaction can be improved. The group of strongly dissatisfied users (about one fifth of the sample) deserves particular attention. UVGs also predicted the impact of ADI on supporting the carers at the referral. Comparing their views with the PICs' views, they tend to disagree: the former predicted an impact smaller than the one actually recorded by the latter. Between users and carers there is instead a high degree of consistency in all the answers, as proved by some crosstabulations conducted between them (not shown here).

---

[4] The question to users asks the degree of information obtained on ADI before starting to receive the service, while the question to carers asks to what degree they reckon to be informed about the service and its features. The questions on consideration, timetable and frequency are the same for users and carers, asking to what degree they are satisfied with these features. The questions on overall satisfaction are expressed a bit differently: users are asked their degree of overall satisfaction with the service and carers are asked to what degree is ADI a support in caring for the user.

Table 6

To which degree are users and carers satisfied with the following items, per cent

	Information received	Take what you say into consideration	Visit timetable	Visit Frequency	Overall satisfaction with ADI
Users	A lot = 6	62	47	47	56
	Enough = 30	34	45	35	40
	A little/Not at all= 64	4	8	18	4
	(N= 97)	(N= 97)	(N= 97)	(N= 97)	(N= 97)
PICs	A lot= 13	60	42	40	49
	Enough= 42	35	50	47	31
	A little/Not at all= 45	5	8	13	20
	(N= 152)	(N= 152)	(N= 152)	(N= 152)	(N= 152)
UVG[5]s (prediction at the referral[6])	-	-	-	-	24
					65
					11
					(N= 149)

---

[5] For the UVGs, the table considers the cases for whom the carers answered after three months the questions on the impact.

[6] The question is "To which degree do you think ADI will turn out to be a support for the carers?".

8.1 Explaining user satisfaction with the service

Table 6.1 presents a regression of users' overall satisfaction with ADI. The model explains some 39 per cent of variation in users satisfaction. Once more, the degree of dependency, recorded by ADL score has a statistically significant link with the outcome. Users with higher dependency have lower satisfaction. A lower degree of dependency is significantly connected to several positive impacts. Another independent variable that is present in several models in this chapter is what local health authority users belong to. In this model, users in Milan signal a far lower degree of satisfaction. This could be due to a variety of reasons, of objective or subjective nature. From an objective point of view, the provision of community care in Milan might suffer from more shortcomings than in the other two authorities. From a subjective point of view, people living in a Milan may have higher expectations than people elsewhere. The other independent variable included in the model is user gender, showing that males are more satisfied than females.

Table 6.1
Probability of users' overall satisfaction with ADI

Independent variables	B	S.E.	Sig.	Exp(B)
ADL Score (number of ADL functions lost, range 1 to 6, mean 4.0)	-.332	.103	.001	.717
Local Health Authority Milan (N0= 56 per cent, Yes 44 per cent)	-2.183	.536	.000	.113
User Gender (Male= 33 per cent, Female= 67 per cent)	-.932	.486	.055	.394
Constant	2.478	.553	.000	11.919

Nagelkerke Pseudo R Square .394 No. of cases 106

9. Conclusions: main findings and policy implications

Abundant evidence was introduced throughout the chapter as we looked at several inputs and outcomes and at a number of possible links between them. In this final section we summarise the main findings and highlight their possible policy implications. The following are the most important issues that come to the surface:

- Among the *needs-related circumstances* of the users, two turn out to be of particular relevance. ADL score has significant connections to outcome in several models. The significant link between degree of dependency and positive outcomes of ADI pinpoint an important effect of this risk factor. As the ADL score grows, the reported positive impact on health, dependency and users' worries, such as the overall users' satisfaction decrease. We highlight here a clear consequence of such an important risk factor: the smaller the number of ADL functions deteriorated the better the ADI reported impact. The positive link between lower dependency and better outcomes of the *assistenza domiciliare integrata* leads us to draw a policy implication of major interest that concerns the targeting of ADI. It is an implication consistent with the results shown in the previous chapter. The modelling implies that when service delivery is started when users' conditions are not yet too deteriorated, there is a reported positive impact in a number of outcome domains.
The other main needs-related circumstance that has several statistically significant links with the outcomes concerns the previous stays in hospital. Users who were in hospital in the six months before the commencement of ADI experience a really positive impact on ADL functions (according to PICs). What is of particular interest is that the ADI impact on users' health (according to both users themselves and PICs) is far better for those that were discharged from hospital. As stated above, this finding is quite consistent with the needs-related characteristics of the users discharged from hospitals. There is a relevant productivity effect as the users discharged from hospitals are quite often elderly with a relevant potential to improve their conditions.

- The delivery of ADI has a strong impact on the *hospitalisation rate*. Almost one user in two (45 per cent) was hospitalised in the six months before starting to receive ADI and was not in the same length of time after it. It is a very important positive outcome and it is consistent with the findings of several projects conducted in other parts of our own country (Bernabei et al, 1998; Ferrucci et al, 1996; Bavazzano et al, 1996). The impact on the hospitalisation rate is an outcome many commentators and decision-makers look at with particular interest because of its implications in terms of containing public expenditure, although of course we should not overlook the positive consequences this outcome has in terms of quality of life. This finding supports the growth and the development of ADI and, among all the evidence presented, is probably going to be the most effective in this direction. It was therefore of no surprise when, at the final presentations of the research findings to the three Local Health Authorities involved, the impact of ADI on the hospitalisation rate was the point that attracted most attention. We will come back to the hospitalisation rate in the next chapter, where we examine the institutionalisation rate as well.

- With respect to the *care inputs provided*, our models present some relevant findings concerning the two inputs most commonly delivered. Users who receive physiotherapy experience a better impact of ADI on their dependency. Users who receive home nursing, on the other hand, experience a better impact on their health conditions (both outcomes reported by PICs). These results are quite consistent with the features of the two inputs and with what we could expect as their key outcomes. Home nursing aims, in fact, to meet needs due to health problems and pathologies and to improve the health conditions of the users. Physiotherapy, on the other hand, pursues a rehabilitative goal that is more concerned with the overall capabilities of the elderly.

- There are important *territorial differences* in the outcomes recorded. Being in one Authority or another is significantly related to several outcomes. It is a finding consistent with what emerges throughout the thesis, that there are deep differences among the three authorities with respect to several variables. In the models regarding outcomes, it is the local health authority of Milan that matters. Users in this authority experience a higher hospitalisation rate in the five-six months since the commencement of ADI, a worse impact on users' health (according to PICs) and lower user satisfaction. However, the findings on territorial differentiation have to be considered with extreme caution because they can be explained by several causes. It is particularly important to distinguish between two possible causes of territorial differences in outcomes, one concerning public services and the other concerning users' (and PICs) expectations. On the one hand, they can be due to different quality in the delivery of ADI (hospitalisation rates can be due to different hospitals' policies). On the other hand, differences in satisfaction and reported outcomes can be due to different expectations of users and carers.

- The quality of the *relationship between users and principal informal carers* is significantly linked to the impact of ADI on the psychological conditions of the former. The better the relationship the better this outcome. The evidence shows that the capability that ADI has to improve the well being of users depends crucially on the quality of their relationship. As long as the aim of the service is not only to improve users' health and dependency but also to improve their well being, these results deserve attention. They show the need to provide services intended to support this relationship, i. e. to complement the delivery of the main care inputs (home nursing, physiotherapy and home help) with other inputs. We refer mostly to services intended to provide carers with some respite and psychological support. It must be noticed that respite care and counselling with a psychologist are two services requested by carers themselves (see the previous chapter);

– In several domains there is a strong consistency between *outcomes predicted by UVGs at referral* and those reported by users and carers after three months. This in itself is a proof of the values of the work of the *Unità di Valutazione Geriatrica* in assessing the cases and of their skills in understanding who will mostly benefit from ADI. This finding backs the claim of those who want to maintain and strengthen the UVGs' role of governance in both ADI and community care as a whole. To prove that UVGs are particularly good in understanding who will benefit from ADI leads, in fact, to think that to maintain and strengthen their role in deciding "who gets what" could improve the appropriateness of the resource allocation.

- Users and carers agree on the *outcome domains* in which older people benefit most. Carers and users state that the service produces the most positive effect on the health and on the worries of the latter. The impact on ADL capabilities and in preventing entry to residential care is far smaller. While for most of users an improvement is recorded with reference to health and worries, the opposite occurs for dependency and institutionalisation. Our evidence provides, thus, a quite clear picture of what can be expected from ADI and what cannot. The views expressed by the professionals involved (UVG views at the referral) are, however, different from those of users and carers. They are, in general, more positive than the former on the effectiveness of the service. They state that ADI has a more a positive impact on health conditions, in half of the cases produces a positive impact on ADL functions and is even effective in preventing institutionalisation.

Chapter 8

At what costs?

1. Introduction

What are the costs of ADI? How do the different stakeholders involved bear them? How do costs change for different groups of users and different policy strategies? How do they relate to outcomes? What about the comparisons between the costs of ADI, residential care and hospital? There are several intriguing questions concerning the costs of community care and this chapter intends to tackle some of them. It is particularly important to reflect on community care costs for two main reasons. First, most arguments to support the development of community care lean on the assumption that it is a way to save public money as it decreases the rates of institutionalisation and hospitalisation. On the other hand, it is not so clear to what extent community care actually saves public money, how it happens and under what circumstances. This chapter will try to disentangle such complex issues, taking the perspective of the several stakeholders involved and looking at different kinds of costs. To pursue this aim we will compare the costs of ADI with those of the two alternative modes of delivery (residential and hospital care) and reflect upon the costs of different allocative strategies. We will draw some policy implications from the findings.

The chapter is divided into six sections. The next one will present the analytical framework upon which our work on costs is built and the research questions we are going to address (section 2). The following two sections will compare the costs of the *assistenza domiciliare integrata* with those of two alternative modes of delivery (section 3 and section 4). We will then compare different strategies in resource allocation, their costs and outcomes (section 5). The final part will summarise the main findings and draw some policy implications (section 6).

2. Costs, stakeholders, outcomes

2.1 The framework

Our effort in this chapter consists in dealing with the different kinds of costs associated with the *assistenza domiciliare integrata*. Before beginning our analysis, we want to present the analytical framework we are going to use. It is the framework developed by PSSRU in a number of projects over three decades of work on the Production of Welfare approach. We do not intend to present it here in detail and we do not look at the several technical issues about how to cost long-term care services. The reader can find this discussions developed in some detail elsewhere (see Davies and Challis, 1986; Knapp, 1984; Netten and Beecham (eds.), 1993; the arguments presented in the rest of the paragraph stem from these books and from the PSSRU work more generally). In this section, we are going to introduce the key elements that will lead our own work, the overall framework that will shape our analysis. The elements that are of particular relevance for our work concern the typologies of costs taken into account, the stakeholders we look at and the links between costs and outcomes.

We shall apply a wide definition of costs, taking both the private and social ones into consideration. It is intended to include a comprehensive list of costs borne by the government, users, family and others, that is to say all the costs of the long-term care policy borne by individuals and agencies. The list has to include economic costs and intangibles ones, i e costs that is not possible to measure in economic terms.

We will look at the economic costs borne by the public sector, stressing the differences between the different agencies involved: between social and health services, between acute and long-term care and between community and residential care. Exploiting the differences between different public agencies with respect to the costs they bear will be particularly helpful in order to discuss several policy issues. It is, in fact, well known that their actions and their interactions are – to a relevant degree – influenced by the costs they have to bear.

We will also look at the economic costs borne by users and families, analysing the direct and the indirect ones. By the former we mean the costs representing the consumption of financial resources to buy those goods and services that would not have been bought in absence of disability or illness, the out-of-pocket expenses incurred in caring for a frail elderly. Among the direct costs, those borne to pay for the private care will be examined with particular interest. By indirect costs we mean the economic value of the time spent by persons caring for the elderly, time that could have otherwise deployed in paid work or in other activities, the opportunity costs to family of forgoing work or leisure. The huge care tasks requested by most of the ADI users (also with respect to the number of hours) make the indirect costs particularly important. We will not limit our interests to the economic costs but will consider also other kind of costs borne by the principal informal carers, the so-called "intangible costs". These are costs of caring that cannot be translated into economic values, but are of high importance for the carers' quality of life. Examples are stress, illness, time available for other activities and so on (Drummond, 1980; see also Netten, 1993). The analysis of the different stakeholders' perspectives constitutes a cornerstone of the Production of Welfare Approach and is of particular importance in the Italian context. The Mediterranean countries are characterised by the low supply of public services, the prominence of the family and the growing role of the paid carers. In this context, not to take different stakeholders into consideration would seriously hinder the consistency of our view. The benefits of such an approach are summarised by Davies "so a variety of perspectives leads to variety in the formal methods of handling evidence, and to different answers to empirical questions. That is not to argue that some answers are correct and others wrong" (Davies, 1993, p 199).

The PSSRU framework in the cost analysis is a mix of comprehensiveness and differences. On the one hand, it aims to be inclusive of the service elements taken into account, to provide a comprehensive measurement of costs. On the other hand, it aims to explore the cost variations – between users, services and so on - that inevitably emerge in every empirical analysis in order to understand the policies analysed, their strength and their weaknesses. A key PSSRU message is that we have to be aware of the cost differences among users and carers and make the most of them in order to understand the long-term care policies.

The cost analysis is in itself of great importance and can provide several insights. This is particularly true in a country like Italy, where the issues concerning costs have traditionally been overlooked by the social policy research. Nevertheless, to get a better understanding of community care policy, data on costs should be examined in connection with those regarding outcomes. Cost analysis should always be linked to outcomes and outcome analysis should always be linked to costs, this is one of the key messages of the Production of Welfare approach. As one looks at the ultimate goal of this approach, the reasons for the attention paid to this link are quite clear: it would not be possible to draw policy implications from the evidence gathered without taking costs and outcomes simultaneously into account. The importance of the link between costs and outcomes to get a complete - and "real" – policy analysis is well summarised by Knapp, as he states that the Production of welfare approach pursues a "premeditated and purposive integration of costs with other dimensions in the policy or practice debates, and this means the examination of hypotheses which are not 'cost questions' nor, say, 'outcome questions' but are the types of questions faced by the policy-maker who has to balance resources against achievements, efficiency against equity, irate social work managers against persistent accountants" (Knapp, 1993, p 62).

2.2 The research questions

As in the rest of the thesis, the Production of Welfare instrumentation will be adapted to our own aims. We intend here to conduct two kinds of comparisons, between modes of delivery (ADI or residential/hospital care) and between resource allocation ("give more to less" or "give less to more"). In comparing policy alternatives, we are going to analyse different kinds of costs (social and private, direct, indirect and intangible) and to assume the point of view of several stakeholders (users, families, and public services).

The first group of comparisons will concern *assistenza domiciliare integrata*, residential care and hospital care. We will compare the care in community with the two main alternatives, institution and hospital, looking into their costs and the different stakeholders that bear them. The answers to the questions on modes of delivery, stakeholders and cost will be examined to draw policy suggestions (see Box A). The second group of comparisons will regard the different strategies of resource allocation. After having identified the two most important strategies, "targeting" (give more to less users) and "spreading" (give less to more users), we will contrast their respective costs and outcomes, and we finally draw policy implications (see Box B).

RESEARCH QUESTIONS

A. What are the cost differences among alternative modes of delivery? ***(mostly sections 3 and 4)***

- What are the cost differences between ADI and Residential care? With respect to what costs and to what stakeholders?
- What are the cost differences between ADI and Hospital care?
- What are the policy implications?

B. What are the differences among different strategies of resources allocation? ***(mostly section 5)***

- What are the differences between the "targeting" and the "spreading" strategy with respect to outcomes and costs?
- What are the policy implications?

3. Costs of outcomes in domiciliary and residential care

The issue of the substitution for residential institutions or hospitals has always been at the centre of the debate on community care. One of the most important reasons that spurred the development of community care at international level is that "ageing in place" is unanimously judged to be better than living in an institution (OECD, 1994). Strictly linked to the argument concerning the quality of life of the dependent elderly has traditionally been another, regarding the costs borne by the public sector. Care in the community is reckoned to be cheaper than that provided in hospitals and residential homes and the provision of the former is considered capable of decreasing the utilisation rate of the latter.

Substitution lies at the heart of the community care development in Italy during the nineties. In chapter 2 it was stated that such a service has always been underprovided in Italy, as it is in the other Mediterranean countries of Europe (Greece, Spain, Portugal and to a smaller degree France). In order to increase the public money devoted to it and to support its growth, both the argument of ageing in place and that of the financial savings for the public sector have been loudly expressed. Different stakeholders have looked at one or the other argument with different degrees of interest. Among scholars and among practitioners it is the opportunity to let dependent elderly live in their own environment that is the most often stressed. On the other hand, among decision-makers, it is the potential to save public money that appeals more. In this respect, it must be noticed that during much of the nineties there were severe cost-containment policies in health and social care. More generally, in a context of growing needs and restrained supply the promise or potential for community care to save public money and to improve citizens' welfare has been attractive to decision-makers. So this was probably really the leading cause – beyond the rhetoric on "ageing in place" - for the development of the *assistenza domiciliare integrata.*

The first part of the decade was featured by an overall consensus – at all levels – about community care's positive impact on the quality of life of the elderly and its capabilities to save public money by avoiding institutionalisation and hospitalisation. As the provision of health inputs is much greater than that of social care inputs, efforts have been more focused on avoiding hospitalisation. Nevertheless, over the years the debate has progressively become less consensual, as different stances emerged. Several questions are nowadays asked about the actual capabilities of community care in saving public money, its effectiveness in improving users' quality of life and the economic and social costs borne by the families when the dependent elderly are cared for in the community. A growing call to go beyond the general consensus on community care in order to distinguish among positive outcomes and costs borne by different stakeholders involved (users in different conditions, informal caregivers, public and private professionals) is coming to the surface (for instance Gori, 2000). This is the approach followed in the first two sections of the chapter, that look at the substitution between care provided in the community or in different settings. This section takes residential care into consideration, whereas the next one analyses the substitution between community care and hospitals.

3.1 Elderly persons of intermediate dependency

The first step of the analysis on community and residential care consists of cost comparisons. In this exercise we will use the framework presented above, taking several stakeholders and several typologies of costs into consideration. With respect to the former, we will look at public services, principal informal carers and privately paid carers. With respect to the costs, we will examine several dimensions (economic, social and psychological) involved in long-term care. We will look at direct, indirect and intangible costs, previously defined. Direct costs are of great importance, especially for the dependent elderly with a high need for care, auxiliaries and drugs. Examples of direct costs are those borne to buy drugs and auxiliaries. Another kind of direct costs really important in economic terms concerns the private carers paid by users and their families. The widespread presence of these care providers in Italy was stressed in chapter 1 and the data presented in chapter 5 are consistent with it as they show that 45 per cent of ADI users receive private paid care. The choice of the direct costs to use in our comparison is made for two reasons: to keep the exercise simple and to focus on the most important issues. According to these criteria, looking at community care we consider one group of direct costs that have a major impact but are underestimated in the debate: those borne by elderly and families to pay private carers. With reference to residential care we look at the charges paid by users and/or their families (with municipalities paying only if they cannot afford them).

The importance of the indirect costs depends on the features of the principal informal carers. Our data about the latter show that only a small proportion of them are currently employed (26 per cent). About half is pensioners (49 per cent) and others consist of housewives (23 per cent); the remaining 2 per cent are unemployed. What particularly matters for our purposes is the low proportion of those that quit working since they began to take care of the frail elderly (8 per cent). It is also to notice that a quarter of those currently employed (some 7 per cent of the overall sample) work fewer hours now than they did before starting taking care for the frail elderly. To summarise: the care burden may have pushed as many as 15 per cent of the sample to reduce their effort in the labour market. What these data do not show is whether (if so, how many) there are principal informal carers that would like to enter the labour market but do not because of their commitments with the elderly. In our exercise we will consider the time that principal informal carers use to care for the elderly as it is a key proxy and summarising variable of several indirect costs.

In this exercise, what we are particularly going to take into consideration are the intangible costs. The Italian debate has traditionally been inclined to underestimate them because the family has been considered the proper place to care for the frail elderly. This is consistent with the overall profile of the Italian welfare state, characterised by a low provision of in-kind services. As caring for the elderly relative is judged a "natural" responsibility of other family members, little attention is paid to the intangible costs they have to bear. In recent years, however, the Italian culture has been changing and family duties have weakened. Family responsibilities are still quite widely recognised by relatives, but it is increasingly not taken for granted that family members have to commit themselves to the care of frail elderly relatives to the same degree as before. Consistent with these slow but deep changes, in recent years the research community has increasingly paid attention to the intangible costs borne by family relatives (e.g. Censis, 1999; Zanetti et alii, 1997). In our project we asked some questions on the topic and the findings are striking. Principal informal carers were asked whether their own health changed since they started caring for the elderly: 42 per cent of the respondents answer that it worsened. Carers were also asked whether the amount of time available for themselves (to read the newspaper, to watch television and so on) has changed since they started caring: 72 per cent of the respondents state that it decreased. Finally, carers were asked how frequently in the last month they have been worried about the conditions of the elderly: 65 per cent of the respondents answered "always" or "often" (the other answers available were "sometimes" and "never"). The data on intangible costs show a high degree of consistency, prove the prominence of this issue and show it concerns most of the carers. They seem particularly important as they prove what everyone involved in looking after frail elderly knows very well: the care burden rests mostly on the shoulders of the informal carer and that it has a dramatic impact on their own lives.

We are going to compare the costs of community and residential care for two different groups of users, following a division previously used. In chapter 5 we divided the latter into three groups, according to their degree of dependency: those dependent in 0-1 ADL functions (24 per cent of the sample), those dependent in 2-5 ADL functions (29 per cent) and those dependent in all the 6 ADL functions (47 per cent). In this chapter we present comparisons concerning the second and the third groups; a short summary of their profile (more widely described in chapter 6) is presented in boxes 1 and 4. We do not include those dependent in 0-1 ADL because residential care would not be a valid option for them: their institutionalisation would not be appropriate. As residential care would not suit them, such an option is not going to be discussed in the analysis.

The comparison is based on the costs of the alternative options for an average week. With reference to residential care we consider the economic costs borne the public sector and the charges paid by users and their families (Municipalities bear those costs only when they cannot afford it; see box 3). With reference to community care we consider the amount of time principal informal carer spend with users and the intangible costs they have to stand, the economic costs of private paid carers (borne by users and their families) and the economic costs of ADI borne by the public sector (box 2). In detail, the following costs are taken into consideration:

Principal informal carers = the costs are estimated using data on amount of time spent with the users (drawn from chapter 6) and data on intangible costs whose overall results are described above.

Private paid carers = the costs are estimated from the amounts of time spend with the users (drawn from chapter 6) and data on their cost drawn from a study conducted by Gori and Da Roit (2001). As the majority of private carers are employed in the "grey market", these authors consider the salary provided in such a market. They estimate the salary for an hour of private care between

12.000 and 15.000 lire (some 6 and 7,5 Euro)[1] but stress that there is a high degree of variability. As the number of hours worked by private carers is often high, they tend to agree with their employers on a lump-sum payment that is smaller than the multiplication of number of hours and hourly salary (Gori and Da Roit, 2001). The estimates presented thus have to be taken with extreme caution.

ADI = costs are calculated using data on the number of weekly visits (drawn from chapter 6) and data on the unit cost of a visit concerning the District of Merate, belonging to the Lecco Health Authority (involved in the project). A visit of home nursing is costed – on average – at 42.000 Lire (some 21 Euro) and a visit of physio at 52.000 Lire (some 26 Euro). These estimates of unit costs are to be treated with caution. In order to identify the average unit costs a number of assumptions were, in fact, introduced. It must be also considered that the unit costs of physio and home nursing visits can vary substantially between districts and health authorities, for a variety of reasons. Nevertheless, the Merate estimates are reliable and seem to fit our own analytical aim.

Residential care = we refer here to the findings of study conducted by IRER-PROGEA in a sample of 38 RSAs in Lombardy, where the cost of a day in the *Residenze Sanitarie Assistenziali* (RSA) is estimated for different kind of users (IRER-PROGEA, 1999). According to this project, the unit cost of a day for users with high dependency is on average 138.000 Lire (some 69 Euros) with a range that spans from 71.000 to 197.000 Lire. The unit cost of a day for users with intermediate dependency is on average 101.000 Lire (some 69 Euros) with a range that spans from 53.000 to 146.000 Lire. These unit costs have to be considered cautiously because they tend to vary a lot among different nursing homes. Users and/or their families pay on average a charge of 55.000 a day if they have an intermediate level of dependency and 60.000 a day if they have a high level of dependency (Pesaresi, 1999). When they cannot afford it the municipality steps in and covers these costs. These estimates have to be used with caution as well because any RSA sets its own charges (the regional government fixes a minimum and a maximum value) and there is a high variability among them.

Box 1 – ADI users with intermediate dependency: main needs-related characteristics

Degree of dependency: *2-5 ADL*
Size of the group: *29 per cent of the users*
Cognitively impaired: *31 per cent of the group*
Behavioural disturbance: *10 per cent of the group*
Living alone: *19 per cent of the group*

---

[1] It should be noted that in several cases the private carers live with the frail elderly – particularly if they come from non European countries. If this is so, beside the salary they get board and lodging for free.

Box 2 – Care inputs in the community and their costs

Principal informal carer

Meets user on a daily basis in 90 per cent of the cases and they spend together – on average – 8.3 hours out of the 12 between 8.00 am and 8.00 pm

Intangible costs: 44 per cent of the group own health worsening since started caring, 74 per cent less time available for themselves since started caring and 67 per cent worried "always" or "often" about the conditions of the elderly in the last month.

Private paid carer

41 per cent of the users receive private paid care at least once a week. If it is the case they meet – on average – 4.4 days of the week and each time spend together 7.2 hours. We estimate a free payment, in the "grey market", of 1,200,000 Lire a month, that is some 270,000 lire a week (some 135 Euros).

ADI

The most common package comprises home nursing only. 34 per cent of this group receive only this care input, with an average of 3.5 visits a week. Inserting the unit costs presented above, the cost of the package is 147,000 Lire (some 73 Euros).

The second most common package is composed by two inputs: it is the case for 34 per cent of the users. Most of them receive both home nursing and physio (on average 4.1 visits a week for the latter and 2.9 of the former[2]). The cost of the package is here 323,000 Lire (some 161 Euros).

This is the only group of users with several elderly receiving a package comprising only physio in full. 29 per cent of them receive it, with an average of 2.8 visits a week. The cost of the package is here 145,600 Lire.

Box 3 – Care inputs in residential care and their costs

Principal informal carer and private paid carer

Charges are on average 55,000 a day, that is 385,000 Lire a week (some 192 Euros). Users and/or their relatives pay these charges unless they cannot afford it. If this is the case, the Municipality steps in.

RSA

The unit cost presented above is here 101,000 Lire a day, that is 701,000 (some 350 Euros) Lire a week

---

[2] The small size of those belonging to this group and receiving a package composed by home nursing and physio (17 cases) suggest to consider these data with extreme caution.

The cost comparisons between ADI and residential care provide a number of insights. First, it is necessary to enter a caveat about both the reliability of the data and the time dimension. With reference to the former, the difficulties in costing community are well known and characterise such an exercise in any country, be it Italy, Sweden or Great Britain (Hanau, 1991; Svensson, Edelbalk and Persoon 1991; Netten and Beecham (eds.), 1993). It is difficult to get reliable data and to consider all the costs that matter. Furthermore, there are important differences in unit costs between one provider and another, so we usually work either with average values that abstract from such a high variability or with the costs recorded in a single provider. The second caution concerns the issue of time: our findings regard a comparison between a week receiving ADI and a week living in RSA. We do not look at how long users receive one service or how long they receive the other. Our comparison focuses, thus, on a certain length of time whereas we miss the longitudinal perspective. We look at the unit costs in a given length of time without multiplying them for the actual spans along which users receive them. Several contributions in the literature underline the difference between the two kind of exercise and the different findings they produce (e.g. Davies and Challis, 1986).

Having inserted this note of caution, we can state that the evidence gathered provides several intriguing insights in the comparison between the two service typologies. The evidence can be interpreted in several ways, depending on the perspective one chooses. The different lenses with which one looks at these data – in fact – can lead to different results. What matters is the stakeholder from whose point of view one considers the costs: it seems of particular interest to look at the different perspectives of the public sector and the families. From the economic perspective of the public sector, community care is cheaper for most users. The difference between the two services can vary, but it tends to be big (with one exception, see below). Our evidence, thus, supports the view that the substitution of residential care by community services produces savings for the public sector. These findings are true for most of the users belonging to these groups, i.e. those receiving only home nursing or only physio. The picture changes bringing in the 34 per cent of the group that receive two or more care inputs (mostly home nursing and physiotherapy), that is some 10 per cent of the overall sample. The weekly costs for those receiving both physio and home nursing are – on average – more than double the costs for those receiving only one of these two inputs. Such a difference is due to the higher number of weekly visits received by those with a package composed of two inputs. We estimate that the cost of their ADI package is 323,000 Lire a week (please notice that this package is composed of health care inputs and the costs are thus entirely borne by the public sector). Assuming a weekly cost of 701,000 Lire and that the users (or their families) can afford the charges (385,000 a week), the gap between the two services tends to vanish. We find a weekly cost for the public sector of 316,000 Lire in residential care and 323,000 in ADI. Following the conservative assumptions made above, we can state that with reference to two/thirds of elderly dependent in 2-5 ADL functions, community care is for the public sector cheaper than residential care, whereas for a third of them this is not the case.

The picture changes when one looks at the cost comparison from the point of view of the families of the dependent elderly. Following this perspective in our exercise, we have to consider direct, indirect and intangible costs. When the elderly live in the community, families have to bear a number of direct costs for items such as auxiliaries, drugs and others. A direct cost which is particularly high is that of private workers, who care for 41 per cent of this group of ADI users. Including these costs, the weekly cost is on average 270,000 Lire and relatives are often called to cover it (partially or entirely). With reference to indirect costs, data show the huge amount of time that principal informal carers (mostly relatives) spend with the elderly. They meet the users on a daily basis in 90 per cent of the cases and spend with them – on average – 8.3 hours out of the 12 between 8.00 am and 8.00 p.m. Our project pays particular attention to the intangible costs, showing the stress suffered by the carers and the limitations on their own lives they have to assert. The data show that these costs are born by most of the carers belonging to this group as 44 per cent of them worsened since they started caring for the frail elderly, 74 per cent have less time available for themselves since then, and 67 per cent worried "always" or "often" about the conditions of the elderly in the last month. If the elderly live in RSAs instead of in the community, the costs borne by relatives change. The indirect costs narrow because the time that could otherwise have been spent in paid work or in other activities decreases. Also the intangible costs due to the burden of caring for the frail elderly on a daily basis decrease. Comparing the costs of alternative care options from the perspective of the family, however, it is important to stress what we do not measure. We do not examine the features and strengths of the relatives' desire that elderly can keep on living in their own environment. With reference to the direct costs, if the elderly person lives in residential care the family has to spend less on some items. On the other hand, nursing home charges are quite high. The overall balance between residential care charges and direct costs to bear in the community is quite variable among families. There are situations where the high charges are an incentive for families not to apply for residential care and to maintain the elderly at home.

Bringing the main stakeholders – the users themselves – into the picture one has to consider firstly their own preferences. It is well known that they prefer living in the community to living in institutions, a trait common to the European countries (Walker and Maltby, 1997). On the other hand, an increasing number of elderly people would prefer the burden of their dependency not to be borne by their children. They keep on preferring the community but along with it they desire that it would not mean a huge task and commitment for their relatives (Cioni, 1999). From an economic point of view, we refer to what we wrote above with reference to the direct costs borne by the families. These are all costs than can be borne by the elderly, their relatives or shared between them, and how they are shared will vary from case to case.

Most data about the costs borne by different stakeholders shed a different light on the comparison between community and residential care. They suggest several inferences and policy implications. The results are not clear cut, it is not possible to state simply that "community care is cheaper" without specifying with reference to what stakeholders and costs, and to which degree. The overall picture is complex and changes radically according to the perspective one chooses. Long-term care policies should take this complexity into account and try to handle it with fine-tuned strategies.

3.2 Elderly persons of high dependency

The comparison of the costs of different care options is conducted with reference to two alternative typologies of users. We compared above ADI users dependent in 2-5 ADL functions and RSA residents with intermediate dependency. We present now a comparison between ADI users dependent in six functions and RSA residents with high dependency. Box 4 presents the main needs-related features of the ADI users considered here and boxes 5 and 6 compare the costs of their care with those borne for elderly persons in residential care (these boxes are organised exactly as boxes 1,2,3).

There are several similarities between our results for elderly people with high dependency and those with intermediate dependency, but also there are some interesting differences. For 73 per cent of the users, those receiving only one care input, community care is far cheaper for the public sector. The gap in costs between the two alternatives is here bigger than for the elderly persons of intermediate dependency, the weekly costs rise substantially for the users receiving more than one care input (27 per cent of the group, 13 per cent of the overall sample). For elderly people with high dependency, however, there is a difference from the group considered earlier. For them, community care is cheaper than residential care for those receiving at least two care inputs as well, also assuming that users and/or families cover the charges. For those receiving both home nursing and physio the weekly ADI costs are 329,200 Lire whereas residential care (overall costs minus charges) is 529,000 a week, but the difference in the average charge is quite small. The time principal informal carers spend with the elderly is similar to that recorded for users with intermediate costs. There is, instead, a rise in the percentage of carers suffering from intangible costs. However, a bigger difference the direct costs due to private care: the percentage of users receiving it increases from 41 per cent to 58 per cent and the average weekly cost from 270,000 to 405,000 Lire. To summarise: it is economically cheaper for the public services to maintain elderly persons of high dependency in the community but costs borne by carers are increased.

Box 4 – ADI users with high dependency: main needs-related characteristics

Degree of dependency: *6 ADL*
Size of the group: *47 per cent of the users*
Cognitively impaired: *66 per cent of the group*
Behavioural disturbance: *34 per cent of the group*
Living alone: *6 per cent of the group*

Box 5 – Care inputs in the community and their costs

Principal informal carer

Meets user on a daily basis in 87 per cent of the cases and they spend together – on average – 8.2 hours out of the 12 between 8.00 am and 8.00 p.m.

Intangible costs: 48 per cent of the group own health worsened since started caring, 82 per cent less time available for themselves since started caring and 72 per cent worried "always" or "often" about the conditions of the elderly in the last month.

Private paid carer

58 per cent of the users receive private paid care at least once a week. On average, they meet 5.3 days per week and each time spend 11,5 hours together. We estimate for it a payment, in the "grey market", of 1.800.000 Lire a month, that is some 405.000 lire a week (some 202 Euros).

ADI

The most common package is constituted of home nursing only. 62 per cent of this group receives only this care input, with an average of 3.9 visits a week. Inserting the unit costs presented above, the cost of the package is 163.800 Lire (some 82 Euros).

The second most common package is composed by two inputs: it is the case for 27 per cent of the users.

Most recipients use both home nursing and physio (on average 4 visits a week for the latter and 3.1 of the former[3]). The cost of the package is 329,200 Lire (some 165 Euros).

Box 6 – Care inputs in residential care and their costs

Principal informal carer and private paid carer

Charges are on average 60,000 a day, that is 420,000 Lire a week (some 210 Euros). Users and/or their relatives pay these charges unless they cannot afford it. If it is the case, the Municipality steps in.

RSA

The unit cost presented above is here 138,000 Lire a day, that is 966,000 Lire a week (some 483 Euros)

---

[3] The small size of those belonging to this group and receiving a package composed by home nursing and physio (27 cases) suggest to consider these data with extreme caution.

3.3 How to avoid institutionalisation in residential care? How to support dependent elderly in the community?

The comparison between community and residential care begs two policy questions. The higher economic costs of residential care (in most cases) and the preference of several elderly to live in the community raise the question about how to avoid institutionalisation. On the other hand, when dependent elderly live at home relatives have to bear huge direct and intangible costs. Increasingly, it has been recognised that dependent elderly people want to live at home but do not want the burden to fall too heavily on their relatives. One has thus to wonder how to support dependent elderly that continue to live in the community.

Experience and literature suggest that it is unlikely that ADI plays a key role in avoiding institutionalisation. For several dependent elderly the delivery of home nursing and physio (that make up the overall majority of the ADI intervention) can be essential in helping older people to continue to live in the community but it does not seem sufficient. These inputs aim to meet health needs and are effective in avoiding hospitalisation (see below), but they ease the burden on the family only to a small degree. The decision to admit an elderly person to residential care is mostly a consequence of the difficulties of the family in continuing to provide care. In Lombardy, as in the rest of Italy, elderly people enter residential homes because families cannot continue to bear the burden of caring and they give up. Some studies have shown that the most powerful variable in explaining institutionalisation is the family capacity to cope with the care burden, and more important than their needs-related features (e.g. Gori, 2000; Montanelli, 1999).

The social care inputs and the other interventions to support the family (self-help groups, informative services, respite care and so on) are what makes the difference. They are more appropriate to relieve the family and more effective in reducing institutionalisation. Social care inputs are underprovided in ADI, only some 15 per cent of the users get them, and other interventions to support the family are utilised even less frequently. Our findings show that professionals and decision-makers disagree – at least to some degree – on this point. The data on predicted outcomes, reported in the previous chapter, are clear: UVGs predict "a lot/enough" degree of ADI impact in avoiding institutionalisation for 81 per cent of the cases, whereas principal informal carers, interviewed on this matter three months after their elderly relative has been receiving the service, state it happens in 32 per cent of the cases. It seems important, therefore, that an understanding is developed among decision-makers and practitioners of what are the effective care inputs in avoiding institutionalisation. To improve the delivery of these inputs would be effective in avoiding institutionalisation and thus in saving public money. There is an economic argument to support the growth of their delivery by the public sector. It should be emphasised that such an argument has not often been voiced in the debate up to now. Whereas the development of the health inputs of ADI has been strongly supported on this ground, we have not seen something like this on the social care side.

It should be noticed that these kinds of interventions were advocated in previous chapters on different grounds. Data shown in chapter 6 indicate that a third of carers (mostly those caring for elderly entirely dependent) ask for additional services aimed to support them. Their request is strengthened by the data on the huge amount of time they spend with the elderly and the intangible costs they bear. Data shown in chapter 7, on the other hand, indicate that a good relationship between users and principal informal carers is statistically significantly linked to a positive impact of ADI on the psychological conditions of the former and the satisfaction with the support provided by the service. These data about effectiveness show the need to increase and improve the delivery of services to support carers and their relationship with the users. Therefore, the arguments to promote the growth of social care inputs and of other services to support the carers concern not only their key role in avoiding institutionalisation but also their importance in supporting both dependent elderly and their carers.

4. The substitution of domiciliary care for hospital care

Compared with those concerning residential care, the outcomes of the comparison between ADI and hospital care are clearer about both costs and impact. With reference to the former, it is well known that the hospital unit costs borne by the public sector are far higher than those borne for ADI are. Therefore, the substitution of domiciliary for hospital care would clearly be convenient for the public sector. Also the effectiveness in avoiding hospitalisation is greater than that in avoiding institutionalisation in residential care. It was suggested in the previous chapter, in fact, that ADI has a clear impact on decreasing the hospitalisation rate. The data presented again in table 1, in fact, show that almost one user out of two (45 per cent) was admitted to hospital in the six months before ADI but wasn't in the six months since she/he started receiving it. The comparison between before and after starting to receive ADI is unanimously considered the better indicator of the impact of ADI on hospitalisation rates in studies - like the one presented in this thesis – without control group. ADI is, therefore, a service that does not seem to be highly effective in avoiding institutionalisation in residential care, while our evidence suggests that it decreases hospitalisation use.

This finding is consistent with the results of other projects run in Italy in the last decade, both with control group (Ferrucci et alii, 1996; Bernabei et alii, 1998) and without (e.g. Bavazzano et alii, 1996). As previously stressed, the different impact of ADI on hospitalisation and institutionalisation is strictly linked to the features of the care packages provided, in most cases constituted only of health care inputs (home nursing and physio). It is not a surprise, that there is a huge emphasis on ADI as a tool to avoid hospitalisation and to make the public sector save money and the relevance of this argument in supporting the development of this service.

Table 1

Users admitted to hospital in the six months before starting ADI by users admitted to hospital in the six months after starting ADI, per cent

	Admitted to hospital in the six months after starting ADI	Not admitted to hospital in the six months after starting ADI	Total
Admitted to hospital in the six months before starting ADI	13	45	59
Not admitted to hospital in the six months before starting ADI	8	33	41
Total	21 (N= 45)	79 (N= 170)	100 (N= 215)

5. Resource allocation, outcomes and costs

During the nineties, the allocation of public resources – the "who gets what?" question – received increasing attention in some European countries. In the context of a growing elderly population, increasing care needs and scarce resources, several commentators advocated the development of an open debate concerning this issue. It is well known, in fact, that in several European countries a proper debate on resource allocation and priority setting has been missing. In many of them it is still missing today but in others – mostly UK and partially Sweden – the debate developed during the last decade (Davies et alii 1990; Bergmark, 1997). The core of this debate consists of making the main options explicit and discussing their pros and cons. It would be necessary to consider how different needs should be taken into consideration, how the availability of family support is looked at and what are the effects of different choices. Countries that start an open discussion on this issue, mostly face it promoting the same answer: the targeting strategy, i e the concentration of public resources towards the frailest elderly. Both Sweden and UK, in fact, have focused community care resources on the frailest elderly, at the expense of those with intermediate needs and/or relevant informal care support. Such a choice was supported on different grounds. The main argument was the effectiveness of this strategy in increasing the number of elderly people who can live in the community instead of being institutionalised in residential care.

As shown in chapter two, Italy has never had an explicit debate on the allocation of public resources in community care. We lack an open discussion on who should receive community care, who should be prioritised and why. The low provision of this service would make this discussion particularly useful. Most of the municipalities and local health authorities do not set explicit indications and guidelines about how to allocate resources and what are the needs to prioritise. Even if they do not face the priority setting issue, in a context of growing needs and scarce resources this issue is impossible to avoid. The choices are thus left to the professionals and managers at the field level. In the absence of any clear indication, the "street-level bureaucrats" (Lipksy, 1980) are called to make the choices on resource allocation. An important consequence of such a situation is that any Health Authority allocates community care in different ways.

In such a situation it seems useful to contribute to an explicit debate on resource allocation and priority setting in ADI. To do so, we are going to highlight the current situation in terms of resource allocation and to introduce some alternative scenarios, discussing their pros and cons. In this exercise we divide the users into two groups: those receiving 1 or 2 visits a week and those receiving 3 or more visits. We make this classification because, as shown in the previous chapter, ADI has a more positive impact for those receiving at least 3 visits a week in a number of domain (user's health according to PIC, Principal informal carer, user's ADL functions according to PIC, user's psychological conditions, carer's overall satisfaction with ADI, user's overall satisfaction with ADI). The difference between receiving 1-2 visits or 3 or more is key in terms of outcomes. Table 2 presents the current situation: 28 per cent of the users receive 1-2 visits (they are some 10 per cent in Lecco, some 40 per cent in Monza and some 30 per cent in Milan) and 72 per cent 3 or more. Considering the different care inputs that constitute ADI, the first group on average receives

1.6 visits a week[4], the other 4.4 visits a week[5]. Looking at these data, one has to bear in mind how the sample was selected. Only ADI recipients for whom a multidimensional assessment was made and a care plan arranged were included, the terminally ill also being omitted. Those with light needs or requiring a spot intervention were not part of the sample. Otherwise, the average number of weekly visits would have been smaller. The average packages are costed using the unit costs shown above: the package for those receiving 1-2 visits turns out to be 71,000 Lire (some 35 Euros) and the package for those receiving 3 or more visits is 194,000 Lire (some 97 Euros) (table 2).

Our simulation will be conducted distinguishing between two main scenarios that depend on the overall amount of economic resources available to ADI. In the first scenario the resources committed to ADI are considered to be those available now. Given the current budget, we consider two alternative strategies: "give less to more users" (the spreading strategy) and "give more to less users" (the targeting strategy). These are the main existing options: it was stated above that in the 1990s, some countries – such as Sweden and the UK – moved from the former to the latter. We will simulate the differences between the two strategies, calculating the changes in number of users, weekly visits they receive and ADI outcomes. From a methodological point of view, this exercise has several shortcomings: it is not exactly precise in terms of costs[6], it simulates changes in resource allocation without considering differences in users' needs, it does not distinguish among the three Local Health Authorities (we look at the overall aggregate) and among the different care inputs (we consider only the average care packages described above).

Even with these shortcomings, such an exercise can be useful in highlighting the main differences among allocative strategies. Box 7 presents the spreading strategy at a given budget, i.e. a growth in the number of users and a drop in the number of visits without changing the resources available. Two alternatives are introduced, at different degrees of redistribution. The first one consists in a drop of 10 per cent in the group of those receiving 3 visits or more. Re-allocating the resources made available by this drop it is possible to increase the percentage of those receiving 1-2 visits by 27 per cent. The net effect is an increase of users of 17 per cent. The aggregate costs are unchanged but there is a flow of public resources from users with better outcomes (3 visits or more) to those with worse outcomes (1-2 visits). In the second spreading scenario, there is a drop of 15 per cent in the users receiving 3 visits of more, that leads to an increase of 40 per cent of those receiving 1-2 visits. Again the total costs are unchanged but there is a bigger flow of public resources from users with better outcomes to those with worse outcomes. To sum it up, the spreading strategy is quite ambivalent. On one hand, it allows a relevant growth in the number of users (in the stronger version it is an increase of 25 per cent). On the other hand, there is a flow of resources from users with

---

[4] The 1,6 visits a week are – on average – divided as follow among the different care inputs: 1,0 visits of home nursing, 0,5 visits of physio and 0,1 visits of home help.

[5] The 4,4 visits a week are – on average – divided as follow among the different care inputs: 3,3 visits of home nursing, 0,9 visits of physio and 0,2 visits of home help.

[6] After costing the average care packages of the two main alternatives (1-2 visits and 3 or more visits), for any allocative strategy introduced we calculate the amount of resources released by the drop in one group of users and the growth in the other group that can be achieved with those resources.

better outcomes (3 visits or more) to those with worse outcomes (1-2 visits). It seems that – without increasing the budget – it is possible to care for more elderly only doing it with worse outcomes.

The alternative allocative strategy that can be pursued without changing the amount of economic resources available is named targeting and consists in "giving more to less people". Box 8 presents the targeting strategy at a given budget, i.e. a drop in the number of users and a growth in the number of visits without changing the overall resources available. Two alternatives are introduced, at different degrees of redistribution. The first one consists in a drop of 14 per cent in the group of those receiving 1-2 visits. Re-allocating the resources made available by this drop it is possible to increase the percentage of those receiving 3 or more visits of 5 per cent. The net effect is a drop of users of 9 per cent. The costs are unchanged and there is a flow of public resources from users with worse outcomes (1-2 visits) to those with better outcomes (3 visits or more). In the second targeting scenario, there is a drop of 28 per cent in the users receiving 1-2 visits, that leads to an increase of 10 per cent of those receiving 3 or more visits. The net effect is a decrease of 18 per cent in the size of the users' group. Again overall costs are unchanged, but there is a bigger flow of public resources from users with worse outcomes to those with better outcomes. To sum it up, the targeting strategy is ambivalent as well, but in the opposite direction than the spreading one. On one hand, it improves the ADI outcomes but, on the other hand, it decreases the number of elderly reached. Without changing the budget, it seems possible to improve the outcomes but only by decreasing the number of users. The comparison between spreading and targeting strategy shows that – without increasing the public budget devoted to ADI – there is trade-off between numbers of elderly cared for and positive outcomes.

The comparison between two strategies was conducted in the same scenario as now, the given budget. Different allocate alternatives were simulated assuming that the amount of public resources committed to ADI remains the same as now. The alternative scenario consists in a change in the amount of public resources devoted to such a service. It could be a growth or a drop in the amount of these resources. The possibility of a decreasing amount of public resources committed to ADI is not further explored here. The amount of resources currently devoted to this service is very low and it would not be advisable do decrease them. The main arguments against their reduction concern care needs and overall budget policies. The ongoing ageing of the population is well known and it produces a growth in the need for ADI. On the other hand, the resources currently devoted to ADI are particularly small when compared with those provided to sectors such as health care. In general, the public resources devoted to long-term care for the frail elderly are really small if compared with the other sectors of the welfare state. Among them, furthermore, those committed to residential care are utterly dominant. These arguments support a growth of public resources committed to ADI. In the circumstances of such a growth, decision-makers should face two main issues. One – discussed above - concerns the trade-off between outcomes and number of users. Is it better to use the additional resources to reach less elderly with better outcomes or more elderly with worse outcomes? The second issue – not tackled in this chapter - regards the kind of care inputs provided.

It particularly concerns the necessity to increase the provision of social care inputs, underprovided everywhere, and physiotherapy, underprovided in several areas.

Table 2

Resources' allocation: the current situation

	1-2 visits	**3 or more visits**
Users' percentage *(average weekly visits)* *(average weekly costs)*	28 (1.6 visits) (71.000 Lire)	72 (4.4 visits) (194,000 Lire)
Outcomes		Statistically significant positive link with: - ADI impact on user's health according to Pic - ADI impact on user's ADL functions according to Pic - ADI impact on user's psychological conditions - Carer's overall satisfaction with ADI - User's overall satisfaction with ADI

Box 7

Changes at a given budget in the resources allocation: the spreading strategy

Spreading strategy 1

Changes:

Users' receiving 3 or more visits from 72 per cent to 62 per cent (minus 10 per cent)
Users' receiving 1-2 visits from 28 per cent to 55 per cent (plus 27 per cent)

New situation:

Growth in the users' group size: plus 17 per cent
New composition of the group: 53 per cent receiving 3 or more visits and 47 per cent receiving 1 or 2 visits
Outcomes: growth of the users with worse outcomes
Public economic resources committed to ADI: unchanged

Box 7 (continues)

Changes at a given budget in the resources allocation: the spreading strategy

Spreading strategy 2

Changes:

Users' receiving 3 or more visits from 72 per cent to 57 per cent (minus 15 per cent)

Users' receiving 1-2 visits from 28 per cent to 68 per cent (plus 40 per cent)

New situation:

Growth in the users' group size: plus 25 per cent

New composition of the group: 46 per cent receiving 3 or more visits and 54 per cent receiving 1 or 2 visits

Outcomes: growth of the users with worse outcomes

Public economic resources committed to ADI: unchanged

Box 8

Changes at a given budget in the resources allocation: the targeting strategy

Targeting strategy 1

Changes:

Users' receiving 3 or more visits from 72 per cent to 77 per cent (plus 5 per cent)

Users' receiving 1-2 visits from 28 per cent to 14 per cent (minus 14 per cent)

New situation:

Reduction in the users' group size: minus 9 per cent

New composition of the group: 85 per cent receiving 3 or more visits and 15 per cent receiving 1 or 2 visits

Public economic resources committed to ADI: unchanged

Targeting strategy2

Changes:

Users' receiving 3 or more visits from 72 per cent to 82 per cent (plus 10 per cent)

Users' receiving 1-2 visits from 28 per cent to 0 per cent (minus 28 per cent)

New situation:

Reduction in the users' group size: minus 18 per cent

New composition of the group: 100 per cent receiving 3 or more visits

Public economic resources committed to ADI: unchanged

6. Summary: main findings and policy implications

The chapter presented evidence concerning the different kind of costs borne by several stakeholders involved in community care. This final section aims to summarise the main findings and highlight their policy implications. The following are the most important issues that come to the surface:

- ADI does not seem to decrease the rate of admission to *residential care,* even if our evidence shows that professionals and decision-makers believe it does. For several dependent elderly persons the utilisation of ADI – mostly constituted by home nursing and physiotherapy - can be essential to live in the community, but it does not suffice to keep them home. The decision to admit an elderly person to residential care is mostly due to the difficulties of the family in continuing to care for him/her. The key variable in explaining the institutionalisation is the family capability of coping with the care burden and this factor is more important than the elderly needs-related features. The social care inputs and the other interventions to support the family (self-help groups, informative services, respite care and so on) are those that make a difference to avoid or postpone residential care. They are the most appropriate to relieve the family and the most effective in avoiding institutionalisation. In ADI, however, social care inputs are underprovided (some 15 per cent of the users get them) and other interventions to support the family are even less available. The key policy message is that if we want to promote strategies to provide an alternative to residential care, we have to increase the provision of these inputs. From a financial point of view, there is a strong argument to support the growth in the delivery of these inputs, as they are effective in avoiding the higher costs of residential care. This argument has not been raised that much in the Italian debate till now. As the financial pressures are those decision-makers are most reactive to, it would be appropriate to do so. There is here another key message: social care inputs and interventions to support the family have the potential to make public sector save money and it is an argument that should get more attention in the debate;

- ADI is, on the other hand, an effective tool to decrease the admissions to *hospital.* Our evidence proves it and this finding confirms the results of other projects in Italy. These results are consistent with the features of the care packages provided, in most of the cases constituted only of health care inputs (home nursing and physio). By decreasing hospitalisation rates, ADI generates important savings for the public sector. The argument that ADI reduces the overall health expenditure has played a major role in the Italian debate of the 1990s. As the growth of this service has been smaller than expected and there is a huge need for it among the elderly population, it seems important to insist more and more on this argument in order to develop the service;

- Our data show that, in most cases, *ADI is cheaper than residential care* with reference to the economic costs borne by the public sector. The results support the view that the substitution of residential care with community care produces savings for the public sector. If we look at the cost comparisons from the point of view of the families of the dependent elderly, however, the picture changes dramatically. When the frail elderly live in the community, families have to bear a number of direct costs; we paid particular attention to those concerning private workers. Moving to indirect costs, data show the huge amount of time that principal informal carers (mostly relatives) spend with the elderly. Our project focused on the intangible costs, showing the stress suffered by the carers and the constraints on their own lives they experience. The policy implication we draw is that families should be supported in caring for the frail elderly, in order to decrease the burden of these costs.

- In the chapter we paid attention to various *allocative strategies* in community care. The first point to stress is that we need to develop a debate about "who gets what" in ADI. It must be noticed that – in the most recent years – some Local Health Authorities have increasingly paid attention to the topic: it would be useful to increase this attention in the future. In the previous pages we simulated alternative strategies of resource allocation, looking at their costs and outcomes. We considered two main options: "give less to more users" (the spreading strategy) and "give more to less users" (the targeting strategy). Adopting the former strategy would allow growth in the number of users (in the stronger version it is an increase of 25 per cent). On the other hand, there is a flow of resources from users with greater inputs (3 visits or more) to those with less inputs (1-2 visits). Adopting the targeting strategy would improve the ADI outcomes but it would decrease the number of elderly reached.

Conclusions

1. Introduction

The thesis was based on an original study of the *assistenza domiciliare integrata (ADI)* in three local health authorities of Lombardy. The analyses conducted and reported in the previous chapters applied the intellectual framework, logic and tools provided by the "Production of Welfare" (POW) approach, developed at the Personal Social Services Research Unit (PSSRU) from the mid-1970s. I deployed this approach to analyse three key aspects of community care - service utilisation, outcomes and costs – and the links between them. The overall aim of this work was twofold: to obtain a better understanding of community care policies and to explore the relevance of the POW approach in the Italian environment. The concluding chapter will examine both aspects. With respect to community care policies, I will draw together the main suggestions from the analyse in the previous chapters. With respect to the methodology, I will reflect upon the experience and speculate about the possible development of the POW in Italy.

The chapter will be divided into two sections. Section 2 will present the main policy suggestions. Section 3 will reflect on the use of the Production of Welfare approach in this thesis and will highlight the main challenges to be faced if the approach was to be considered for more widespread use in Italy.

2. Policy recommendations

Many data concerning ADI in Lombardy were analysed in the thesis. The main findings and their policy implications were summarised at the end of each chapter. As a final effort, I want to highlight what are the most important policy recommendations we can draw from the thesis. The aim is to pinpoint, among the many results emerging in our research, what are the key policy messages for decision-makers. It should be noted that these policy suggestions have already been presented in the seminars held to share the results of the projects with the managers and professionals of the local health authorities involved. Their reactions to these findings have been embodied in what follows.

- To pursue a preventive strategy

In Lombardy – as in Italy more generally – the *assistenza domiciliare integrata* acts often as a last resort, getting in touch with the elderly only when their conditions have deteriorated to quite a degree and there is small room for individual people to improve. The analysis of the evidence gathered in the previous chapters strongly supports the development of a more preventive strategy in ADI. Such a strategy is capable of strongly increasing the productivity of the service. According to our work, there are two ways to pursue such a strategy.

One way concerns the role of GPs in suggesting ADI to frail elderly people and their families. The project shows that those elderly people who were advised to approach ADI by General Practitioners are in better health conditions than those suggested by other public or private welfare agencies. As their condition has deteriorated less than that of the others, there are higher probabilities that the service can actually be effective for them. Our work suggests, therefore, strengthening the role of the GPs as links between dependent elderly and ADI. This aim can be pursued by increasing their presence and role among prospective ADI users and improving the link between the practitioners and the UVGs.

The second way to pursue a preventive approach concerns the service's target. The analysis of the impact of the *assistenza domiciliare integrata* concluded that for users with a lower ADL score the service has better impact with respect to several outcome domains (health, dependency, users' worries and overall users' satisfaction) compared to the impact for users with a higher ADL score. When users' conditions have not deteriorated too greatly in terms of dependency, there is a better probability of a positive impact of the service. The policy implication is to try to catch users before they are too dependent.

- To pursue an explicit allocative strategy

The lack of explicit choices made by the local health authorities with respect to who should get what (and how many) care inputs in ADI was stressed in several parts of the thesis. This is a trait that the authorities studied in our project share with most other Italian authorities, and it is consistent with the really limited attention paid to this topic in national or local debate. The issue is always highly sensitive from a political perspective and especially in an environment like Italy, where demand far outstrips supply. In the final seminars to present the main findings to the different stakeholders of the authorities involved in the project, the professionals asked many questions about the lack of explicit choices and the managers were quite elusive. It is also important to notice that – from a technical point of view – the heterogeneity (in terms of needs and other sources of care available) within the group of users and differences in the care inputs available in this service makes the allocative issue quite difficult to deal with.

In our work we reinforced the importance of developing a more explicit allocative strategy and provided some suggestions (such as to provide more room for a preventive approach targeted towards users in less deteriorated condition and to target elderly people previously living in hospital). We also conducted an exercise to simulate alternative strategies of resource allocation in order to estimate their costs and outcomes. The aim was to highlight the pros and cons of the main alternative strategies. We compared the "spreading" strategy ("give less to more users") and the "targeting" strategy ("give more to less users"). Adopting the former strategy would allow growth in the number of users (in the stronger version it is an increase of 25 per cent). On the other hand, there is a flow of resources from users with greater inputs (3 visits or more) to those with less inputs (1-2 visits). Adopting the "targeting" strategy would improve the ADI outcomes but it would decrease the number of elderly reached.

- To obviate the need for frail elderly people to enter hospital and (if it happens) to take care of them afterwards

The relationship with the hospital is crucial for the design and delivery of the *assistenza domiciliare integrata* from several points of view. The evidence gathered in this project led us to focus on two issues that currently raise great interest in the Italian debate: the effectiveness in decreasing hospitalisation rates and the service outcome for elderly people living in hospital prior to getting ADI.

Decreasing the hospitalisation rate is one of the outcomes of the *assistenza domiciliare integrata* that has most attracted the interest of Italian decision-makers in the nineties, in a public welfare context deeply affected by a general interest in cost-containment. Our findings are consistent with other Italian projects (Ferrucci et alii, 1996; Bernabei et alii, 1998) and show the strong impact of ADI in reducing the hospitalisation rate. In the final seminar to present the findings to the authorities involved it was this result that was most stressed by decision-makers (and the lack of an explicit allocative strategy was the one they mostly dismissed). ADI is successful in avoiding hospitalisation and it is going to be a key force in driving its possible further development. To continue to avoid hospitalisation (also to get better and better results with respect to this outcome) is extremely important with respect to both the well being of the elderly and for appealing maintaining the good profile of the service with decision makers.

The other key issue that emerged concerns elderly people previously in hospital. Those who were in hospital in the six months before the commencement of ADI experienced a really positive impact on ADL functions (according to PICs). What is of particular interest is that the ADI impact on users' health (according to both users themselves and PICs) is far better for those who were discharged from hospital. Such a result is quite consistent with the needs-related characteristics of the users discharged from hospitals, quite often elderly with a relevant potential to improve their conditions. The aim for the future should be to continue to target elderly people previously in hospital as ADI users.

- To strengthen the governance of ADI and community care

In several parts of the thesis we discussed the bundle of complex issues concerning the governance of ADI and community care more generally. How to co-ordinate the work of the different subjects involved in community care (public and private, formal and informal) and how to shape the care process in its different steps over time are issues at the centre of the Italian debate. Neither the theory nor the practice, however, has until now found ultimate answers to the complex issues concerning governance. Our work does not provide these answers, but it suggests a consistent strategy to deal with this topic. The overall strategy suggested consists in strengthening the governance of ADI and community care. There are three main policy indications, regarding the care process, the collaboration and the provision of information and suggestions. With respect to the care process, the key message is to promote the role of General Practitioners as the link between frail elderly people and ADI. This would allow ADI to target users in less deteriorated conditions, with a better probability to improve (see above).

With respect to collaboration, our project shows the bundle of subjects involved in community care and the difficulties in their relationships. Users of *assistenza domiciliare integrata* have the support of a principal informal carer and this tends to be a full-time commitment. In some half of the cases in our sample a privately paid carer is involved as well. The elderly often visit GPs (sometimes medical consultants) and may also receive other public services. It is therefore crucial to ensure good relationships between the different stakeholders. The *Unità Valutativa Geriatrica* could play an important role here, increasing its functions and responsibility.

The third key issue regards information and suggestions regarding the other services and agencies available. The Italian debate has increasingly acknowledged the scarcity of information and advice as an important weakness of community care. Our evidence shows the presence of such a gap in the authorities studied. This evidence suggests a need to promote a wider role for ADI professionals, encouraging them to provide information and advice on other welfare services. Also with respect to this issue, the *Unità Valutativa Geriatrica* could play a leading role in providing information and suggestions as its work of assessment and care planning would put it in the best position to do so.

- To increase the delivery of social care inputs and of other inputs to support the families

The low provision of social care inputs in the ADI packages was highlighted in several parts of thesis: roughly speaking only 1 user in 10 receives them. The discussion of this key gap in the provision of *assistenza domiciliare integrata* was linked to the overall scarce provision of social care in the Italian welfare system. With reference to the subject of this research, the analysis of the evidence raises some important arguments to support the growth of social care inputs in ADI. The claim for more social care inputs can be supported from both an objective and a subjective point of view. With respect to the objective perspective, our data proved the high dependency of most of the users and the demanding tasks requested of the informal carers. From a subjective perspective, in several items gathered for this project many carers state that they would like more support in caring for the elderly relatives.

The evidence analysed leads also to a call for other inputs aimed to support the carers, to provide them with some respite and psychological support. Respite care and counselling with a psychologist are two services requested by carers themselves and the huge intangible costs borne by informal carers were widely documented in chapter 8. Among the findings supporting the call for other inputs to support carers, one that can be mentioned here concerns outcome analysis. We showed that the quality of the relationship between users and principal informal carers is significantly linked to the impact of ADI on the psychological conditions of the former: the better the relationship, the better this outcome. The capability that ADI has to improve users' well being depends crucially on the quality of this relationship. If the service is interested in this outcome, the delivery of inputs to support the relationship between users and principal informal carers is crucial.

The suggestion to increase the delivery of social care inputs and other inputs to support the families is backed by several findings regarding users' and carers' well being. To pursue such a strategy, furthermore, would mean not only to meet users' and carers' needs but also to save public money. ADI does currently play a key role in avoiding the need for elderly people to enter hospitals but not to enter residential homes. It is the design of the service – almost entirely focused on users' health-related needs – that leads to such an impact. It should be noticed that the impact on institutionalisation is the only one – within those monitored – to record a sharp disagreement between professionals and carers. The former think that the service has a positive impact in avoiding the institutionalisation of the frail elderly whereas the latter reckon that this is not the case. The delivery of home nursing and physiotherapy can be essential in helping older people to continue to live in the community but it does not seem sufficient. In Lombardy, as in the rest of Italy, the decision to claim residential care for an elderly person is mostly a consequence of families' difficulties in continuing to provide care. Increased delivery of social care and other inputs to support families could be pivotal in avoiding institutionalisation. Decision-makers are particularly sensitive to cost-containment arguments: the main reason driving the development of ADI in the nineties, in fact, was the widespread opinion that this service can make the Italian health system decrease hospital expenditure. There is room to promote the increase of social care inputs as a means to save residential care expenditure.

3. Production of Welfare, PhD experience and further developments: some final remarks

As the final step of the thesis some reflections on the POW research are presented here, concerning both the candidate's experience and a wider view on the Italian environment. To assess the former experience leads to some remarks on the possible development of the approach in this Mediterranean country.

3.1 The PhD experience: the candidate's view

When the project was designed, how it would be carried out was not entirely clear to me. How the PhD work would develop over the years was, in fact, not at all predicted at the beginning. It probably could not really be predicted, for a variety of reasons. Even though I was already working in social policy research (as a research fellow at IRS), I did not have previous experience of projects such as that undertaken for the PhD. Additionally, the Italian research environment could not be of very much help, because the evidence-based research of the POW kind is really scarce in the Mediterranean country. As far as I know, this study was the first of its kind ever conducted in Italy and there are in my country very few projects similar to those conducted in the UK by PSSRU; in a wider perspective, research on community care is quite scarce in Italy. To sum it up, I embarked upon on a kind of project I never experienced before and, additionally, there were few previous similar experiences in Italy to provide guidance. In the following years some weaknesses and strengthens of the project's design emerged quite clearly.

- **Weaknesses:** The crucial point to stress is that the design was too ambitious. As one of the supervisors suggested in the early steps of work, it would have been better to conduct a smaller and more focused thesis. This argument is particularly consistent if one remembers that – as just mentioned – when I started the thesis I didn't have previous experience of POW/PSSRU work and this kind of research is in Italy really scarce. The project was too ambitious in its size. It was excessive in the number of issues taken into consideration and the number of questionnaires compiled. The choice to look at all of targeting, effectiveness and costs – as in the major PSSRU projects – was not wise. The idea to compile a number of questionnaires at different moments and the choice to take several stakeholders into consideration too made the overall task too big to handle. In retrospect I would have been better advised to focus on one single issue, for example targeting. The over-ambitious design had some negative consequences: one of the most important has been the under-utilisation of the data gathered. In the fieldwork I got data concerning hundreds of variables and in the analysis conducted to date several of them were not examined in depth. I built up, in other words, a dataset too large to analyse by a single person in this timescale. Another negative consequence regards the overall timing of the Doctorate: it was completed in six years, quite a long period of time and more than expected. In order to conduct the fieldwork planned, in fact, more time than originally predicted was necessary and also the data analysis required a period longer than originally thought.

With reference to the methodology, there were some problems too. When the research was designed, in fact, it was planned that the data gathered would be examined through statistical tools, such as multiple regression analysis (to follow, once again, the Production of Welfare approach as it is used in PSSRU work). When it was planned to do so, the statistical skills of the candidate were quite limited and a lot of training was needed to meet the goals stated.

Along with the difficulties created by the over-ambitious aims of the project, the development of my own professional activities was an additional source of problems. Over the PhD years, in fact, my professional commitments beyond the thesis grew a lot and I became *de facto* a part-time student. Consistent with this change, since Autumn 1998 I spent most of my time in Italy. On the other hand, this made it much easier to oversee the extensive data collection.

- **Strengths**: After underlining what turned to be the main weaknesses of the research design, I want here to look at its positive side. The design's strengths regard, first of all, the outcome of all the efforts, i e the thesis. Even if I was frank in stressing some shortcomings of the thesis and several problems faced in preparing it, I think they hindered the quality of the final product only to a certain degree. That is to say, even if I have exploited only part of the evidence gathered I have been able to present several interesting results. And even if I didn't run several of the statistical analyses initially planned, the treatment of the data was – in my view - nevertheless good enough to produce interesting results. To sum it up, I think (to put it better, I hope) that the mistakes made in designing the project certainly increased the difficulties faced while preparing this thesis and set aims I could not reach, but they did not prevent me from conducting a coherent piece of work. I am supported in this hope by the fact that the Production of Welfare is a really flexible approach that can be adapted to the work of a PhD candidate in a context like Italy.

The strengths of the research design concern not only the contents of the thesis itself but also the impact of the PhD experience on me personally. This is – in my opinion – a very important point that deserves particular attention. Such a complex design – it was stressed above – made the thesis quite difficult to prepare and caused a number of problems to be faced in the process (I several times cursed myself for setting this design!). This meant that working for the PhD was a really formative process, from which I am sure I will really benefit in the future. This is particularly true because of the choice of setting the thesis in Italy and conducting the fieldwork in this country, where I plan to work in the next years.

I believe that the PhD experience had a majpr impact in shaping my way of researching social policy, as is clear from looking at the other works I completed in the doctorate years. The books I edited in the last two years (Gori (ed.), 2001a, 2001b, 2002), for example, are influenced by the PhD experience from several points of view. The three main influences the PhD experience had on my current (and hopefully future) work concern how to gather evidence, how to analyse it and how to use it to produce policy suggestions. The PhD was an important experience of gathering new evidence, how to co-ordinate the work of other people to pursue this aim and how to involve the professionals to do so. It was also an important experience with reference to how to analyse the data and what tools should be used. Last, but not least, the PhD experience was particularly important in learning how to conduct research aimed at drawing policy implications and suggestions. To summarise, I am really satisfied with the PhD experience because it shaped my way of analysing social policy and I am persuaded I am going to benefit from it over the years.

3.2 An agenda for Italian research

The discussion of the strengths and weaknesses of this project lead me finally to reflect upon the possibilities of development of the Production of Welfare approach in the Italian environment. The experience of running this project has persuaded me of the need for such an approach to develop in this country. The current period seems particularly favourable for its development, for various reasons. Both decision-makers and institutions funding research are increasingly calling for more projects on community and long term care. An increasing amount of funds is devoted to research on this topic and this is probably going to be the case in the coming years. What matters most is that there is a demand for evidence-based research, aimed at providing policy indications and that is also quite sophisticated in analytical terms so as to approach the complexity of reality. This mix of traits does not currently characterise Italian research on long-term care, as illustrated in chapter 2, but is a feature of the POW. There are, thus, resources and room available for the development of this approach in Italy. The actual capability to get this chance will depend on how some challenges concerning the methodology and the topics to examine will be addressed.

With respect to the methodology, I expect there to be three challenges of greater importance. The first – and most important – resides in adapting the Production of welfare approach to a research environment quite different from the UK. It means adapting its tools to projects funded less generously than POW is often used to (the funds available – even if increasing – are in Italy usually smaller than in the UK). It also means runing POW projects that gather less evidence than in the UK (Italians are not used to gathering evidence for research on long term care policies). It is also necessary, finally, to deploy analytical tools that are less sophisticated than those usually deployed in the UK (Italian scholars - and readers - are not used to them). To summarise, the aim would be to maintain the POW logic while adapting it to a different environment and different tools available.

The second challenge is to exploit the POW in order to provide policy suggestions defined in details that decision makers could translate into practice. There is a big demand for research capable of assisting decision makers, whereas the supply of this kind of work is quite scarce; it is a ground where the boundary between research and consultancy is quite blurred. Such a challenge should be tackled not only because it would be a sure route to many research funds(!) but also – and obviously foremost – because it would an important contribution to a more informed policy making environment.

The third challenge consists of integrating POW with other research streams, especially organisational studies. In chapter 2 the traditional prominence of organisational studies in the Italian research on community care was stressed, stating that the debate would benefit from the contribution of a different approach. It would be important, in my view, to link organisational studies to POW work, so as to get a more comprehensive view of community and long-term care.

The possible development of POW in Italy will crucially depend also on the topics studied . I think that – among the many related to long-term care – three are of particular interest. One topic to study through the POW would be residential care. Much public money is used to finance residential care and there is a huge debate in Italy about its possible reform, particularly on how to improve its effectiveness and efficiency. Such a debate could greatly benefit from POW analysis of these services, something which has to date never been conducted in Italy (to my knowledge). [Another topic to examine using the POW is the new modes of care delivery – cash allowances and vouchers – that are increasingly spreading in Italy. There is a huge interest in them and high expectations about the benefits that their introduction could generate. The debate – however – is not at all evidence-based and it is becoming more and more ideological (focusing on issues such as freedom of choice and role of the family, which are clearly important, but are not the only matters that need to be considered). It is the right time to examine cash allowances and vouchers through the POW. The third topic is the overall system of services for continuing care at local level. The idea would be to conduct – at local level - studies of different services devoted to the elderly (domiciliary, residential and others) and how they interact. This would be an important contribution to better local governance of long-term care.

Appendices

Appendix 1

The questionnaires

1. First-wave interviews

This appendix presents the contents of the questionnaires compiled in this project. In the first wave of interviews, four questionnaires were used:

- Questionnaire aimed to get information on the new user, compiled by ADI (*Assistenza Domiciliare Integrata*) professional (in the following tables named P).
- Questionnaire aimed to evaluate the health conditions of the new ADI user, compiled by Geriatricians/General Practitioners involved in ADI (in the following tables named G/GP).
- Interview with new user, by IRS (*Istituto per la Ricerca Sociale*) employees (in the following tables named USER).
- Interview with their principal informal carer, by IRS employees (in the following tables named CARER).

The following tables present all the variables gathered in the first wave, specifying in which of the four questionnaires listed above they were inserted. The variables are divided into main groups (user's characteristics, principal informal carer's characteristics, paid care, volunteers, overall map of non-public care, ADI and other public services' main features, UVG's opinions).

Table 1 – Variables concerning user's characteristics and related questionnaires

Variable	Questionnaire
Age	P
Gender	P
Marital status	P
Siblings (how many)	P
With whom do you live?	P
Presence of house impairments (professional's opinion)	P
(If yes) Their impact on the user's daily activities (professionals' opinion)	

Table 1 - Variables concerning user's characteristics and related questionnaires (continues)	Questionnaire
Events occurred in the six months before starting to receive ADI	USER
Do you receive the care allowance (*indennità di accompagnamento*)?	P
ADL and IADL score (Objective)	P
Short Portable Mental Status Questionnaire Score	P
Geriatric depression scale (GDS, reduced version) score	P
Behavioural disorders	P
Activities normally conducted during the day	USER
Activities desired to conduct during the day	USER
Telephone contacts with friends and relatives	USER
Desire to have more telephone contacts with them	
Frequency of visits received by friends and relatives	USER
Desire to receive more visits from them	
Frequency of going out	USER
Activities conducted when out	
Desire to go out more often	
Frequency of being at home alone	USER
Medicines currently taken and frequency	G/GP
Other treatments currently taken and frequencies	
Cumulative Illness Rating Score (CIRS):	G/GP
Diseases diagnosed	
Severity index	
Comorbidity index	
Hearing patterns	G/GP
Vision patterns	G/GP
Communication patterns	G/GP
Presence of pressure/stasis ulcer	G/GP
Perceived health conditions	USER
Degree to which user's needs and attitudes were taken into consideration in the assessment and care plan setting process by ADI professionals	USER
Assessment of the relationship with the principal informal carer	USER
Changes in the relationship with the principal informal carer since he/she started caring for you	
Embarrassment created by the care provided by the principal informal carer	USER
Attitudes towards institutionalisation	USER

Table 2 - Variables concerning principal informal carer's characteristics and related questionnaires

Variable	Questionnaire
Age	CARER
Gender	CARER
Marital status	CARER
Siblings (how many)	CARER
Relation to the user	CARER
With whom do you live?	CARER
Do you live with the user?	CARER
(If no) Frequency of visit	
(If no) Frequency of sleeping in his/her house	
(If no) Hours spent with the user in an average day you meet	
Do you work?	CARER
(If yes) Full time or part time	
Objective health conditions (assessed by professionals)	P
Perceived health conditions	CARER
Health problems over the last 12 months	
(If any) Impact on the caring activity	
Other dependants	CARER
(If any) Frequency of meeting	
Anyone you can rely on for little favours	CARER
Anyone you can rely on in case of emergency	
Degree to which carer's opinions on the user's conditions were taken into consideration in the assessment and care plan setting process	CARER
Attitudes towards user's institutionalisation	CARER
Assessment of the relationship with the user	CARER
Length of time since started to care for the user	CARER
Changes in the relationship with the user since started caring for him/her	CARER
Tasks conducted on the user's behalf	CARER
Main task conducted on the user's behalf	
Change occurred in lifestyle since started caring for the user	CARER
Change occurred in your relationship with family/friends since started caring	CARER
How often do you think:	CARER
"I need to rest"	
"I cannot deal with it"	
"I am worried for the user"	
"I am learning new things"	
"I am doing something useful"	

Table 3 – Variables concerning paid care and related questionnaires

Variable	Questionnaire
Do you regularly receive paid care?	USER
(If yes) Continue with the questions of this block	
Number of paid carers	USER
Age of the principal paid care	USER
Gender of the principal paid care	
Country of origin of the principal paid care	
Does the principal paid carer live with you?	USER
(If no) Frequency of visits	
(If no) Frequency of him/her sleeping in your house	
(If no) Hours spent with the principal paid care in an average day you meet	
Tasks conducted by the principal paid care on your behalf	USER
Main task conducted by the principal paid care on your behalf	
Length of time since started to care for you	USER
Are you satisfied with how he/she cares for you?	USER
Is there a second paid carer?	USER
(If yes) does he/she live with you?	
(If yes) Frequency of visits	
(If yes) Frequency of him/her sleeping in your house	

Table 4 - Variables concerning volunteers and related questionnaires

Variable	Questionnaire
Do you regularly receive care by any volunteer?	USER
(If no) Would you like to receive it?	
(If no) To do which tasks?	
(If yes) Continue with the questions of this block	
Organisation the volunteer/s belong/s to	USER
Frequency of meetings	USER
Tasks conducted by the volunteer/s on your behalf	USER
Main task conducted by the volunteer/s on your behalf	
Length of time since started to care for you	USER
Are you satisfied with how the volunteer/s care/s for you?	USER

Table 5 – Variables concerning overall map of non-public care and related questionnaires

Variable	Questionnaire
For 16 tasks (mostly ADL and IADL tasks): Do you receive care during an average week from anyone apart from public services? (If yes) Who provides you most care? How many days a week? Is there a second person providing care apart from public services providing you care? How many days a week?	USER

Table 6 – Variables concerning ADI and other public services' features and related questionnaires

Variable	Questionnaire
Days in hospital in the six months before starting to receive ADI	P
Weeks in residential care in the six months before starting to receive ADI	P
Number of meetings with the GP in the two months before starting to receive ADI	G/GP
Number of days in day hospital in the two months before starting to receive ADI	G/GP
Number of meetings with consultants in the two months before starting to receive ADI	G/GP
User received ADI in the past (If yes) Till how many months ago?	P
Who referred the user to ADI	P
Where was the user before receiving ADI (home, hospital, residential care)	P
(If he was in hospital) Was it a planned discharge?	P
Professionals involved in setting up the plan	P
Plan set up in a formal meeting or informally	P
A date for a formal review of the case arranged (If yes) When (If no) Why	P
Professionals who visited the user at home in the setting up period	P
(If the user receives the care allowance) The fact that the user receives the care allowance taken into consideration in setting up the care plan	P
(If the user receives private paid care) The fact that the user receives private paid care taken into consideration in setting up the care plan	P

Table 6 – Variables concerning ADI and other public services' features and related questionnaires (continues)	Questionnaire
(The care plan, 1)	P
Weekly visits of	
Home help	
Home nursing	
Physiotherapy	
Number of professionals involved in any visit	
Number of them which are public sector' employees	
(The care plan, 2)	P
Regular visits by the GP been planned	
(If yes) How many a week	
Regular visits by a consultant been planned	
(If yes) How many a week	
Delivery of aids been planned	
(If yes) Which one(s)	
Involvement of people belonging to voluntary organisations been planned	
Provision of care inputs by voluntary organisation been arranged in setting up the care plan	P
(If yes) Tasks to do	
(If no) Opinion on this option	

Table 7 – Variables concerning UVG's opinions and related questionnaires

Variable	Questionnaire
Things to change in the care plan	P
Most appropriate service for the user	P
Impact ADI is going the produce on the user's ADL and IADL capabilities	P
Degree to which ADI is going to affect the user's health conditions	P
Degree to which ADI is going to effectively support the principal informal caregiver	P
Degree to which ADI is going to affect the user's possibility to live at home	P
Could the setting up phase could have been handled better?	P
(If yes) How?	

2. Second-wave interviews

After some 15 weeks users started to receive ADI, those still receiving it and their principal informal carers were interviewed again. This wave consisted of:

- Second interview with the user, by IRS employees (in the following tables named USER1).
- Second interview with the principal informal carer, by IRS employees (in the following tables named CARER1).

All the variables gathered in the second wave are presented in the following tables, specifying in which of the two questionnaires listed above they are inserted. The variables are divided into main groups (user's characteristics, principal informal carer's characteristics, paid care, volunteers, overall map of non-public care, other public services' features).

Table 8 – Variables concerning user's characteristics and related questionnaires

Variable	Questionnaire
Perceived health conditions	USER1
Assessment of the relationship with the principal informal carer	USER1
User's satisfaction with:	USER1
information obtained before receiving ADI	
professionals' kindness	
how the professionals consider user's needs	
schedule of ADI provision	
frequency of ADI provision	
overall satisfaction with ADI	
Perceived impact of ADI on:	USER1
health	
capabilities (ADL-IADL)	
relationship with the carer	
relationship with other people	
daily mood	
concern for user's own conditions	
Unmet needs	USER1
Attitudes towards institutionalisation	USER1
User's mood	USER1
User's concern for own conditions	USER1
Events occurred since started to receive ADI	USER1

Table 8 – Variables concerning user’s characteristics and related questionnaires (continue)	Questionnaire
Since started to receive ADI changes in:	USER1
health	
capabilities (ADL-IADL)	
Going out	
Being at home lonely	
Mood	
Concern for own conditions	
Frequency of phone calls	
Frequency of visits received	
Advice/suggestions by ADI professionals on:	USER1
how to obtain other public services	
how to obtain care from volunteers	
how to obtain private paid care	
how to use care allowance	
(If no) Would you have liked to have advice/ suggestions?	

Table 9 – Variables concerning principal informal carer’s characteristics and related questionnaires

Variable	Questionnaire
Since the user started to receive ADI changes in:	CARER1
health	
spare time	
relationship with the user	
Besides ADI, other support received in caring for the user	CARER1
(If none) Would you like any?	
(If yes) What?	
Days a week you meet the user	CARER1
Hours spent with the user in an average day you meet	
Frequency of sleeping at the user’s home	
User’s unmet needs	CARER1

Table 9 – Variables concerning principal informal carer's characteristics and related questionnaires (continue)	Questionnaire
Principal informal carer's satisfaction with : information obtained before receiving ADI professionals' kindness how the professionals consider carer's opinions on user's needs schedule of ADI provision frequency of ADI provision overall support provided by ADI in caring for the user	CARER1
Perceived impact of ADI on: user's health user's capabilities (ADL-IADL) relationship with the user user's relationship with other people amount of spare time likelihood of user's institutionalisation	CARER1
Since the user started to receive ADI, did your help to him/her increase/decrease/remain the same?	CARER1
Since the user started to receive ADI, in which tasks have you provided more help to him/her than earlier?	CARER1
Since the user started to receive ADI, in which tasks have you provided less help to him/her than earlier?	CARER1

Table 10 – Variables concerning paid care and related questionnaires

Variable	Questionnaire
Do you regularly receive paid care? (If yes) When did you start to receive it? (If no) Did you receive it for some time since ADI started? (If yes) Continue with the questions of this block	USER1
Number of paid carers	USER1
Does the principal paid carer live with you? (If no) Frequency of visit (If no) Frequency of him/her sleeping in your house (If no) Hours spent with the principal paid care in an average day you meet	USER1

Table 10 – Variables concerning paid care and related questionnaires (continue)	Questionnaire
Is there a second paid carer? (If yes) Does he/she live with you? (If no) Frequency of visit (If no) Frequency of him/her sleeping in your house	USER1
Since started to receive ADI did the weekly hours of paid care you receive increase/decrease/ remain the same?	USER1
Since started to receive ADI, in which tasks you receive more help by private paid helpers than earlier?	USER1
Since started to receive ADI, in which tasks you receive less help by private paid helpers than earlier?	USER1

Table 11 – Variables concerning volunteers and related questionnaires

Variable	Questionnaire
Do you regularly receive care by any volunteer? (If yes) When did you start to receive it? (If yes) Since started to receive ADI do/does the volunteer/s visit you more/less/the same than earlier? (If no) Did you receive it for some time since ADI started?	USER1

Table 12 – Variables concerning overall map of care and related questionnaires

Variable	Questionnaire
For 16 tasks (mostly ADL and IADL tasks): Do you receive care during an average week from anyone (including ADI)? (If yes) Who provides you most care? How many days a week? Is there a second person providing care apart from public services providing you care? How many days a week?	USER1

Table 13 – Variables concerning other public services' features and related questionnaires

Variable	Questionnaire
Number of meetings with the GP since started to receive ADI	USER1
Number of days in Day hospital since started to receive ADI	USER1
Number of meetings with consultants since started to receive ADI	USER1
Social services received since started to receive ADI	USER1

3. Telephone follow-up

A telephone follow-up was conducted some 6 months since the users started to receive ADI. Both those still receiving the service and those who interrupted it but are still alive were considered. The interview was conducted by phone by IRS employees with users and PICs. Therefore the follow up consisted of:

- Telephone interview with the user, by IRS employees (USER2).
- Telephone interview with their principal informal carer, by IRS employees (CARER2).

The variables gathered in the second wave are presented in the following tables, specifying in which of the two phone interviews they were obtained. The variables are divided into two main groups (user's characteristics, principal informal carer's characteristics).

Table 14 – Variables concerning user's characteristics and related questionnaires

Variable	Questionnaire
Elderly currently receiving ADI	CARER2
Where the elderly lives	CARER2
Days in hospital in the six months after starting to receive ADI	CARER2
Weeks in residential care in the six months after starting to receive ADI	CARER2
Number of meetings with the GP in the last two months	CARER2
Number of days in Day hospital in the last two months	CARER2
Number of meetings with consultants in the last two months	CARER2
Does the elderly regularly receive care by any volunteer?	CARER2
Does the elderly regularly receive paid care?	CARER2
Since started to receive ADI changes in the elderly: health capabilities (ADL-IADL)	CARER2
Events occurred in the six months since the elderly started to receive ADI	CARER2
Perceived health conditions	USER2
Telephone contacts with friends and relatives	USER2
Frequency of visits received by friends and relatives	USER2
Frequency of going out	USER2
Daily mood	USER2
Degree of worry on own conditions	USER2
Assessment of the relationship with the carer	USER2
Since started to receive ADI changes in the elderly: health capabilities (ADL-IADL)	USER2

Table 15 – Variables concerning principal informal carer's characteristics and related questionnaires

Variable	Questionnaire
Carer's health perceived	CARER2
Assessment of the relationship with the elderly	CARER2
How often do you think: "I need to rest" "I cannot deal with it" "I am worried for the user"	CARER2
Since the elderly started to receive ADI changes in amount of care provided by the principal informal carer	CARER2

4. Monitoring care inputs

On a regularly basis the professionals involved in the project compiled a questionnaire where they specified the typology and the amount of care inputs (visits) provided. This questionnaire included also a page to fill at the case closure with some general information on it.

Table 16 – Variables concerning care inputs considered in the monitoring questionnaire

Variable
Number of visits
For each visit, professionals involved
For each visit, public or contracted out professionals involved

Table 17 – Variables concerning case closure considered in the monitoring questionnaire

Variable
User dead or alive
Main cause of the case closure
(If user dead) Where did he die?
(If user alive) User's destination after the case closure
(If user alive) Did other public services were put into action at the case closure?

Appendix 2

The PhD in steps

The overall process from the beginning of the doctorate to the submission of the thesis took six years and consisted in a number of steps. We provide here a description of the different steps of the PhD process and of their timing.

- The PhD was started in <u>October 1997</u> and in the first year the candidate attended courses and worked on the research proposal, which was approved by the departmental committee in <u>June 1998</u>.

- The spell from <u>June 1998</u> to <u>December 1998</u> was spent looking for the funds and the local health authorities to involve in the project. In the second half of 1998 the candidate worked on the chapters of the thesis not directly dealing with the fieldwork.

- By December 1998 everything was agreed and in <u>January 1999</u> we had the first meeting of the working group, which marked the actual start of the fieldwork.

- From <u>February to April 1999</u> the candidate visited the headquarters of the three authorities and the fourteen districts involved in the project. He conducted the semi-structured interviews with the authorities' managers and the *Unità valutativa geriatrica* of each district. In this period he also had a meeting in each authority with the professionals then involved in the project, in order to introduce it to them.

- In <u>April 1999</u> another meeting of the working group took place. It was there decided that the fieldwork – originally planned to start in May – would start in late September. In June 1999 the candidate had another meeting in two of the authorities involved in order to explain to the professionals involved the causes of this delay and to maintain their interest in the project.

- From May to August 1999 the candidate was mostly busy with writing the questionnaires, that were illustrated to the managers of the local health authorities in a meeting of the working group at the end of August. Over the summer the candidate also wrote a handbook on the questionnaires and the project for the professionals involved.

- In September 1999 Clara Colombo, the geriatric consultant, and the candidate had a series of meetings to train the professionals then involved in the fieldwork. In each authority two half-day meetings with the ADI professionals who then compiled the questionnaire aimed to get information on the users and a half-day meeting with the Geriatricians/GPs who then compiled the questionnaire aimed to evaluate the health conditions of the new ADI users were hold. All of them received the handbook of the project. In the same period the candidate had two half-day meetings with the people employed by IRS who then interviewed the users and their principal informal carers.

- Between the end of September and the beginning of October 1999, the fieldwork (first-wave interviews) started in all the districts. The first district ended the cases' recruitment in February 2000, the last one in April 2000. The development of the fieldwork was discussed in a meeting of the working group in December 1999. In the second half of 1999 the candidate was busy with the management o the setting up and the beginning of the fieldwork.

- The second wave interviews started in January 2000. In April 2000 the six-month telephone follow up started. In spring 2000 the candidate commenced the data analysis and the writing of the chapters directly related to the fieldwork; this task took more than two years.

- By November 2000 the fieldwork was finished. In December 2000 the candidate presented the first report on the findings to the local health authorities involved. Since then to September 2001, four different reports were presented to the authorities. Each report showed findings both at an overall level and disagreggated by authority and it was presented in different meetings held in any authority.

- Between October 2001 and January 2002, the main findings of the overall project were illustrated in two seminars held in each of the Local Health Authorities involved. In each Authority the same framework was deployed: an internal seminar to present the main findings to managers and professionals and an open seminar to present them to the public.

- In September 2002 the thesis was completed.

Appendix 3

Additional tables

In this appendix we present the answers to some questions asked in chapters 6 and 7. The answers are here disaggregated at a lower territorial level than in the chapters. Items discussed in chapter 6 with respect to local health authority level are here disaggregated by districts and items discussed in chapter 7 with respect to overall sample level are here disaggregated by local health authorities.

1. APPENDIX TO CHAPTER 6

APPENDIX TO PARAGRAPH 2.1

Districts by who suggested to request ADI, per cent

	Gp	Others	Total
Lecco 1	84	16	100
Lecco 2	91	9	100
Monza 1	50	50	100
Monza 2	17	83	100
Monza 3	37	63	100
Monza 4	53	47	100
Milano 1	38	62	100
Milano 2	64	36	100
Milano 3	73	27	100
Milano 4	72	28	100
Milano 5	54	46	100
Milano 6	64	36	100
Milano 7	67	33	100
Milano 8	50	50	100
Total	55	45	100 (N= 215)

APPENDIX TO PARAGRAPH 2.3

Districts by formal meeting to arrange care-plan, per cent

	Yes	No	Total
Lecco 1	30	70	100
Lecco 2	17	83	100
Monza 1	23	77	100
Monza 2	90	10	100
Monza 3	63	37	100
Monza 4	3	97	100
Milano 1	100	0	100
Milano 2	100	0	100
Milano 3	81	19	100
Milano 4	15	85	100
Milano 5	94	6	100
Milano 6	100	0	100
Milano 7	0	100	100
Milano 8	90	10	100
Total	53	47	100 (N= 343)

Chi-Square (Pearson): Value 191,70701, DF 13, Significance $p < 0.01$

Districts by arranged re-assessment, per cent

	Yes	No	Total
Lecco 1	58	42	100
Lecco 2	42	58	100
Monza 1	18	82	100
Monza 2	5	95	100
Monza 3	7	93	100
Monza 4	0	100	100
Milano 1	91	9	100
Milano 2	90	10	100
Milano 3	62	38	100
Milano 4	74	26	100
Milano 5	100	0	100
Milano 6	70	30	100
Milano 7	25	75	100
Milano 8	100	0	100
Total	49	51	100 (N= 340)

APPENDIX TO PARAGRAPH 3.3

(If the users need hygiene) Local Health Authority by do the ADI health professionals provide it?

per cent

	Yes	No	Total
Lecco 1	57	43	100 (N= 14)
Lecco 2	22	78	100 (N= 36)
Monza 1	0	100	100 (N= 20)
Monza 2	0	100	100 (N= 14)
Monza 3	0	100	100 (N= 21)
Monza 4	0	100	100 (N= 29)
Milano 1	44	56	100 (N= 9)
Milano 2	94	6	100 (N= 18)
Milano 3	0	100	100 (N= 6)
Milano 4	6	94	100 (N= 16)
Milano 5	54	46	100 (N= 13)
Milano 6	53	47	100 (N= 15)
Milano 7	87	13	100 (N= 8)
Milano 8	0	100	100 (N= 15)
Total	26	74	100 (N= 236)

2. APPENDIX TO CHAPTER 7

APPENDIX TO PARAGRAPH 4.

Users after 3 months, per cent

	Lecco	Monza	Milan	Total
Still receiving ADI	66	50	61	59
Living at home, not receiving ADI	9	32	25	25
Living in residential institutions	0	6	2	3
Dead	25	12	12	13
Total	100	100	100	100 (N= 348)

Users after 6 months, per cent

	Lecco	Monza	Milan	Total
Still receiving ADI	37	42	43	41
Not receiving ADI anymore	63	58	57	59
Total	100	100	100	100 (N= 347)

APPENDIX PARAGRAPH 5.

Stayed in in hospital in the 6 months before starting ADI by stayed in hospital in the 6 months after starting ADI, Lecco, per cent

	Stayed in hospital in the 6 months after starting ADI	Didn't stay in hospital in the 6 months after starting ADI	Total
Stayed in hospital in the 6 months before starting ADI	5	45	50
Didn't stay in hospital in the 6 months before starting ADI	2	48	50
	7	93	100 (N= 44)

Stayed in in hospital in the 6 months before starting ADI by stayed in hospital in the 6 months after starting ADI, Monza, per cent

	Stayed in hospital in the 6 months after starting ADI	Didn't stay in hospital in the 6 months after starting ADI	Total
Stayed in hospital in the 6 months before starting ADI	14	50	64
Didn't stay in hospital in the 6 months before starting ADI	5	31	36
	19	81	100 (N= 72)

Stayed in in hospital in the 6 months before starting ADI by stayed in hospital in the 6 months after starting ADI, Milano, per cent

	Stayed in hospital in the 6 months after starting ADI	Didn't stay in hospital in the 6 months after starting ADI	Total
Stayed in hospital in the 6 months before starting ADI	16	42	58
Didn't stay in hospital in the 6 months before starting ADI	12	29	41
	28	72	100 (N= 92)

APPENDIX TO PARAGRAPH 6.

To which degree has ADI improved user's health and capabilities in ADL function (user's own assessment) by Local Health Authority, per cent

	On user's health	On user's ADL
Lecco	A lot/pretty= 80	60
	A little/Not at all= 20	40
Monza	70	30
	30	70
Milano	46	27
	54	73
Total	60	33
	40	67
	(N= 100)	(N= 100)

To which degree has ADI improved user's health and capabilities in ADL function and decrease the likelihood of institutionalisation (pic's assessment) by Local Health Authority, per cent

	On user's health	On user's ADL	On likelihood of institutionalisation
Lecco	A lot/pretty= 71	24	34
	A little/Not at all= 29	76	66
Monza	49	15	25
	51	85	75
Milano	54	25	35
	46	75	65
Total	47	22	32
	53	78	68
	(N= 168)	(N= 168)	(N= 168)

To which degree will ADI improve user's health and capabilities in ADL function and decrease the likelihood of institutionalisation (UVG's assessment at the referral) by Local Health Authority, per cent[1]

	On user's health	On user's ADL	On likelihood of institutionalisation
Lecco	A lot/pretty= 97	36	91
	A little/Not at all= 3	64	9
Monza	77	53	79
	23	47	21
Milano	76	54	78
	24	46	22
Total	80	50	81
	20	50	19
	(N= 148)	(N= 148)	(N= 148)

To which degree ADI has improved user's health according to user by Local Health Authority, per cent

	A lot/pretty	A little/not at all	Total
Lecco	80	20	100
Monza	70	30	100
Milano	46	54	100
Total	60	40	100 (N= 97)

---

[1] The table considers the cases for whom the carers answered after three months the questions on the impact.

To which degree ADI has improved user's ADLs capabilities according to user by Local Health Authority, per cent

	A lot/pretty	A little/not at all	Total
Lecco	55	45	100
Monza	24	76	100
Milano	16	84	100
Total	33	67	100 (N= 99)

APPENDIX TO PARAGRAPH 7.

To which degree has ADI decreased users' worries on their own health conditions and dependency by Local Health Authority, per cent

	On user worries
Lecco	A lot/pretty= 62
	A little/Not at all= 38
Monza	58
	42
Milano	51
	49
Totale	56
	44
	(N= 100)

APPENDIX TO PARAGRAPH 8.

To which degree are users satisfied with the following items by Local Health Authority, per cent

	Information Received	Take what you say into consideration	Visits' timetable	Visits' Frequency	Overall satisfaction with ADI
Lecco	A lot= 29	83	62	75	94
	Pretty= 21	17	38	25	6
	A little/not at all = 50	0	0	0	0
Monza	0	49	27	19	30
	35	46	57	51	62
	65	6	16	30	8
Milano	4	64	56	59	62
	28	32	39	25	36
	68	4	5	16	2
Total	6	62	47	47	56
	30	34	45	35	40
	64	4	8	18	4
	(N= 97)	(N= 97)	(N= 97)	(N= 97)	(N= 97)

To which degree are users satisfied with ADI by Local Health Authority, per cent

	A lot	Pretty/A little/not at all	Total
Lecco	94	6	100
Monza	30	70	100
Milano	62	38	100
Total	56	44	100 (N= 107)

To which degree are carers satisfied with the following items by Local Health Authority, per cent

	Information Received	Take what you say into consideration	Visits' timetable	Visits' frequency	Overall support with care
Lecco	A lot= 21	68	53	50	65
	Pretty= 44	32	41	47	29
	A little/not at all= 35	0	6	3	6
Monza	11	60	44	32	36
	47	40	51	50	38
	42	0	5	18	26
Milano	11	56	36	40	49
	38	34	53	45	27
	52	10	11	15	24
Totale	13	60	42	40	49
	42	35	50	47	31
	45	5	8	13	20
	(N= 152)	(N= 152)	(N= 152)	(N= 152)	(N= 152)

Local Health Authorities by by carers' satisfaction with ADI, per cent

	A lot	Pretty	A little/Not at all	Total
Lecco	65	29	6	100
Monza	36	38	26	100
Milano	49	27	24	100
Total	49	31	20	100 (N= 152)

References

AAVV, 1997, *Le cure a domicilio come evoluzione dei sistemi sanitari e sociali. Atti del III congresso europeo*, Milano 29-31 maggio 1997, Milano: CEIS.

AAVV, 1998, *Care in Europe. Joint Report of the "Gender and Employment" and the "Gender and Law" Groups of Experts*, Brusselles, European Commission, DG 5.

AAVV, 1999, *Il progetto Reteargento*, paper given at the 44 congress of the Italian gerontologican and geriatrician society, Napoli, November.

AAVV, 2001, *L'ADI: il punto e le prospettive*, in "Prospettive Sociali e Sanitarie", 1, pp 2-6.

Abate, G, Bavazzano, A, Di Iorio, A, 1995, *Assistenza domiciliare integrata (ADI). Indagine conoscitiva sulla situazione nazionale*, Roma, CNR: Progetto Finalizzato Invecchiamento.

Andreoni, B (ed.), 2000, *Assistenza domiciliare integrata*, Milano: Masson.

Antonnen, A, Sipila, J, 1996, *European Social Care Services: is it Possible to Identify Models ?,* in "Journal of European Social Policy", 6, pp 87-100.

Ambroset, S, *La qualità percepita in assistenza domiciliare*, in "Prospettive Sociali e Sanitarie", 14, pp 21-24.

Barbetta, GP, 2000, *Il nonprofit italiano*, Bologna: Il Mulino.

Battistelli, F, 1998, *Burocrazia e mutamento*, Milano: Angeli.

Bavazzano, A et alii, 1996, *L'organizzazione del distretto sanitario vista dal geriatra*, in "Giornale di gerontologia", 44, pp 61-68.

Bebbington, A, Davies, B, 1983, *Equity and Efficiency in the Allocation of Personal Social* Services, in "Journal of Social Policy", 12, pp 309-330.

Bebbington, A, Davies, B, 1993, *Efficient Targeting of Community Care: the Case of the Home Help Service*, in "Journal of Social Policy", 22, pp 373-391.

Becchi, M A, Bernini Carri, E, 1998, *Qualità ed efficienza nell'assistenza domiciliare*, Milano: Angeli.

Bergmark, A, 1997, *From Reforms to Rationing? Current Allocative Trends in Social Services in Sweden*, in "Scandinavian Journal of Social Welfare", 6, pp 74-81.

Bernabei, R et alii, 1998, *Randomised Trial of Impact of Model of Integrated Care and Case Management for Older People Living in the Community*, in "British Medical Journal", 316, pp 1358-1351.

Bianchetti, A, Trabucchi, M, 1994, *L'impatto economico della demenza: una ipotesi per l'Italia*, in "Giornale di Gerontologia", 42, pp 687-692.

Bianchi, M, 1991, *Policy for the Elderly in Italy: Innovation or Modernization ?*, in Evers, A, Svetlik, I (eds), "New Welfare Mixes in Care for the Elderly", Vienna: European Centre for Social Welfare Policy and Research, pp 101-124.

Blangiardo, G C, 2000, *Tendenze e problematiche della popolazione lombarda. Aspetti strutturali e territoriali,* Milano: Regione Lombardia – Direzione Generale Interventi Sociali.

Bortoli, B, 2001, *Case management*, in "Lavoro sociale", 1-2, pp 273-281.

Bursi, G, Cavazza, G, Messora, R, 1999, *Strategie di politiche familiari*, Milano: Angeli.

Cavallo, M C, Fattore, G, 1997, *Economic and Social Burden of Alzheimer Disease on Families in the Lombardy Region of Italy,* in "Alzheimer Disease & Associated Disorders", 11, 4, pp 184-190.

Challis, D, 1999, *Assessment and Care Management: Developments since the Community Care Reforms*, in Royal Commission on Long-Term Care, "With Respect to Old Age", Research Volume 3, pp 69-85.

Challis, D, Carpenter, I, Traske, K, 1996, *Assessment in Continuing Care Homes: Towards a National Standard Instrument*, University of Kent at Canterbury: PSSRU.

Censis, 1999, *La mente rubata*, Milano: Angeli.

Challis, S, Darton, R, Johnson, L, Stone, M, Traske, K, 1995, *Care Management and Health Care of Older People*, Aldershot: Arena.

Chappell, N, 1990, *Ageing and Social Care*, in Binstock, R, George, L (eds.), "Ageing and the Social Sciences", New York: Academic Press.

Cerfe, 2000, *L'assistenza privata alle famiglie*, Rome: unpublished paper.

Challis, D, Darton, R, 1990, *Evaluation Research and Experiment in Social Gerontology,* in Peace, SM (ed.), "Researching Social Gerontology", London: SAGE, pp 75-100.

Cioni, E, 1999, *Solidarietà tra generazioni*, Milano: Angeli.

Consoli, MT, 2001, *Street-level bureaucrats*, in "Prospettive Sociali e Sanitarie", 10, pp 8-11.

Contegni, S, Ristori, L, 2001, *I servizi domiciliari*, in Facchini, C (ed.), "Anziani, pluralità e mutamenti: condizioni sociali e demografiche, pensioni, salute e servizi in Lombardia. Rapporto 2000 Spi-Cgil Cadef", Milano: Angeli, pp 273- 283.

Cortesi, A, 2001, *Il servizio di informazione sociale (segretariato sociale) e la legge quadro 328-2000: nuove prospettive di sviluppo*, in EISS, "Rapporto sulla situazione del servizio sociale. 1° Rapporto", Roma: EISS, pp 113-120.

CRESA, 1993, *Aspetti economici della demenza senile*, Milano: Angeli.

Davies, BP, 1992, *Care Management, Equity and Efficiency. The International Experience*, Canterbury: PSSRU.

Davies, BP, 1993, *Costs Estimations and Community Care: Why we Must Run Fast to Stan Still*, in Netten, A, Beecham, J (eds.), 1993, "Costing Community Care", Arena, Aldershot, pp 197-207.

Davies, B, Challis, D, 1986, *Matching Resources to Needs in Community Care*, Aldershot: Arena.

Davies, B, Challis, D, 1981, *Evaluating Community care: a Production of Welfare Approach*, in Goldberg, E, Connolly, N. (eds.), "Evalutating Social Care", London: Heinemann.

Davies, BP, Bebbington A, H Charnley, 1990, *Resources, Needs and Outcomes in Community-Based Care. A Comparative Study of the Production of Welfare for Elderly People in Ten Local Authorities in England and Wales,* Aldershot: Averbury.

Davies, B, Fernandez, J, 2000, *Equity and Efficiency Policy in Community Care. Needs, Services Productivities, Efficiencies and Their Implications*, Aldershot: Ashgate.

Davies, B, Knapp, M (eds.), 1988, *The Production of Welfare Approach: Evidence and Argument from the PSSRU*, "British Journal of Social Work", 18, 6, 1988 (supplement).

Department of Health (White Paper), 1989, *Caring for People: Community Care in the Next Decade and Beyond*, Londra: HMSO.

De Ambrogio, U, Gori, C, 1997, *Bisogni degli anziani e assistenza domiciliare. Una scheda valutativa sperimentata nella Provincia di Milano*, in "Prospettive Sociali e Sanitarie", 15-16, pp. 14-19

De Ambrogio, U, Setti Bassanini, M C (eds.), 1996, *Tutela dei cittadini e qualità dei servizi*, Milano: Angeli.

Dentizzi, C. et alii, 1996, *Studio multicentrico italiano ADI: tipologia degli utenti ed ammissione all'ADI (differenze tra i centri),* in "Giornale di gerontologia", 12, pp 852-853.

Department of Health, 1992, *Progetto obiettivo anziani 1992-1994*, Roma.

De Vincenti, C, Gabriele, S (eds.), 1999, *I mercati di qualità sociale. Vecchi e nuovi modelli di consumo. VIII Rapporto CER-SPI*, Roma-Bari: Laterza.

Di Iorio, A et alii, 1996, *Tipologia degli utenti dei servizi di ADI: indagine multicentrica nazionale*, in "Giornale di gerontologia", 44, pp 795-799.

Diwan, S et alii, 1997, *Composition of the Home Care Service Package: Predictors of Type, Volume and Mix of Services Provided to Poor and Frail Elderly People*, in "The Gerontology", 37, 2, pp 169-181.

Drummond, M F, 1980, *Principles of Economic Appraisal in Health Care*, Oxford: Oxford University Press.

European Commission, "Comunicazione della Commissione sul lavoro sommerso", 1998

Facchini, C, 2001, *Caratteristiche socio-familiari e specificità degli anziani lombardi*, in Id (ed.), "Anziani, pluralità e mutamenti", Milano: Angeli, pp 49-124.

Facchini, C (ed.), 2001, *Anziani, pluralità e mutamenti*, Milano: Angeli.

Fernandez, J, 1998, *Equity and Efficiency in Post-Reform Community Care of Elderly People: an Empirical Investigation*, Research proposal, LSE – Department of Social Policy and Administration.

Ferrario, P, 2001, *Politica dei servizi sociali*, Roma: Carocci (new edition).

Ferrera, M, 1996, *The Southern-European Model of Welfare State*, in "Journal of European Social Policy", 3. Ferrucci, L et alii, 1996, *Efficacia dell'assistenza domiciliare integrata (ADI) in soggetti anziani: risultati di un trial controllato*, in "Giornale di gerontologia", 44, pp 779-787.

Fine, M, 1998, *Acute and Continuing Care for Older People in Australia: Contrasting New Balances of Care,* in Glenninding, C (ed.), "Right and Realities. Comparing New Developments in

Long-Term Care for Older People", Bristol: Policy Press, pp 105-126.

Fiorentini, G (ed.), 2000, *I servizi sanitari in Italia 2000*, Bologna: Il Mulino.

Fiorentini, G (ed.), 2001, *I servizi sanitari in Italia 2001*, Bologna: Il Mulino.

Gagliardi, C M, 2001, *Residenze sanitario assistenziali: la distribuzione delle strutture e le caratteristiche dell'utenza*, in Facchini, C. (ed.), "Anziani, pluralità e mutamenti: condizioni sociali e demografiche, pensioni, salute e servizi in Lombardia. Rapporto 2000 Spi-Cgil Cadef", Milano: Angeli, pp 259-272.

Ghidorzi, M (ed.), 2000, *Residenze sanitarie assistenziali. Guida pratica per l'attivazione da parte di cooperative sociali*, Milano: Angeli.

Gibson, D, 1996, *Reforming Aged Care in Australia: Change and Consequence*, in "Journal of Social Policy", 25, 2, pp 157-179.

Gori, C, 2000, *Comparare i servizi sociosanitari per gli anziani: i costi economici e sociali delle diverse alternative*, in "Economia Pubblica", 1, pp 95-115.

Gori, C, 2000a, *Solidarity in Italy's Policies Towards the Frail Elderly: a Value at Stake*, in "International Journal of Social Welfare", 9.

Gori, C, 2001, *Gli assegni di cura: una rivoluzione silenziosa del welfare italiano?* In Ranci, C (ed.), "Il mercato sociale dei servizi alla persona", Roma: Carocci, pp. 85-118.

Gori, C (ed), 2001, *I servizi sociali in Europa*, Roma: Carocci.

Gori, C (ed.), 2001a, *Le politiche per gli anziani non autosufficienti. Analisi e proposte*, Milano: Angeli

Gori, C, 2002, *Il futuro dei servizi sociali: quali condizioni per lo sviluppo?* in "Il Mulino", 1, pp 97-102.

Gori, C, 2002a, *I dilemmi della selettività*, in "Animazione Sociale", forthcoming.

Gori, C (ed.) 2002, *Il welfare nascosto. Il mercato privato dell'assistenza in Italia ed in Euro*pa, Roma: Carocci, forthcoming.

Gori, C, Da Roit, B, 2001, "Emersione e regolazione dell'assistenza privata a pagamento", in Gori, C (ed.), 2001, *Le politiche per gli anziani non autosufficienti. Analisi e proposte*, Milano: Angeli, pp 305-347.

Gori C, Torri R, 2001, Gli assegni di cura, in Ranci, C (ed.), *L'assistenza agli anziani in Italia e in Europa. Verso la costruzione di un mercato sociale dei servizi*, Milano, Angeli, pp 280-325.

Gostick, C, Davies, B, Lawson, R e Salter, C, 1997, *From vision to reality. Changing Direction at Local Level*, Aldershot: Arena.

Gruppo di Lavoro – Fondazione Smith-Kline, 2000, *Un contributo al dibattito sulle politiche per gli anziani*, in "Tendenze nuove", 2.

Guaita, A, 2001, *Nuove modalità di organizzazione e finanziamento per i servizi socio-sanitari: a favore degli anziani o contro di loro?,* in Gori, C (ed.), "Le politiche per gli anziani non autosufficienti. Analisi e proposte", pp 339-349, Milano: Angeli.

Hanau, C, 1987, *Introduzione*, in Id. (ed), I nuovi vecchi. Un confronto internazionale, Milano: Angeli, pp 7-39.

Hanau, C, 1991, *Assistenza in ospedale o assistenza a domicilio ?,* in "Prospettive Sociali e Sanitarie", 8, pp 7-10.

Hanau, C, 1994, *Efficienza e qualità dei servizi. La verifica economica nell'USL 15 di Mirandola,* in "Prospettive Sociali e Sanitarie", 11, pp 6-12.

Jacobzone, S, 1999, *Ageing and Care for Frail Elderly Persons: an Overview of International Perspectives*, OECD, Labour market and social policy occasional papers N 38.

Irer, 2000, *Anziani: stato di salute e reti sociali. Un'indagine diretta sulla popolazione anziana della Lombardia*, Milano: Guerini e Associati.

IRER-PROGEA, 1999, *Residenza sanitario-assistenziali per anziani: analisi della qualità delle prestazioni, individuazione costi-standard e analisi economico finanziaria*, Milano: Regione Lombardia, mimeo.

ISMU, 1999, *L'immigrazione in Italia*, Milano: Angeli.

ISTAT, 1999, *Indagine Multiscopo*, Roma: Istat.

ISTAT, 2000, *Gli anziani in Italia*, Bologna: Il Mulino.

ISTAT, 2000a, *Rapporto annuale. La situazione sociale del paese nel 1999*, Roma.

ISTAT 2001, *Rapporto annuale. La situazione sociale del paese nel 2000*, Roma.

Istat, 2000, *Rapporto annuale. La situazione sociale del paese nel 1999*, Roma.

Istat 2001, Rapporto annuale. La situazione sociale del paese nel 2000, Roma.

Katz, S, et alii, 1963, *Studies of Illness in the Aged: the index of ADL. A Standardized Measure of Biological and Psycological Function*, in "Journal of the American Medical Association", 1985.

Katz, S, et alii, 1970, *Progress in the Development of the Index ADL*, in "Gerontologist", 10, 1970.

Irer, 2000, *Anziani: stato di salute e reti sociali*, Milano: Guerini e associati.

Kazepov, Y, 1996, *Le politiche locali contro l'esclusione sociale*, Roma: Quaderni della Commissione Povertà, Presidenza del Consiglio.

Knapp, M, 1984, *The Economics of Social Care*, London: MacMillan.

Knapp, M, 1993, *Principles of Applied Cost Research*, in Netten, A, Beecham, J (eds.), 1993, "Costing Community Care", Arena, Aldershot, pp 61-72.

Knapp, M, Baines, B, Fenyo, A, 1988, *Consistencies and Incosistencies in Child Care Placements,* in Davies, B, Knapp, M (eds.), 1988, "The Production of Welfare Approach: Evidence and Argument from the PSSRU", "British Journal of Social Work", 18, 6, 1988 (supplement), pp 107-131.

Knapp, M, Cambridge, P, Thomason, C, Beecham, J, Allen, C, Darton, R, 1992, *Care in the Community: Challenges and Demonstrations*, Aldershot: Ashgate.

Koutsoyiannis, A, 1979, *Modern Microeconomics*, 2d edition, London: Macmillan.

Laing, W, 1993, *Financing Long-Term Care: the Crucial Debate*, London: Age Concern.

Landi, F et alii, 1996, *L'assistenza domiciliare integrata e il modello organizzativo del case management*, in "Giornale di Gerontologia", 44, pp 801-805.

Lawton, M P, Brody, E M, 1969, *Assessment of Older People: Self-maintaining and Instrumental Activities of Daily Living*, in "Gerontologist", 9.

Linn, B S, Linn M W, Gurel, L, 1968, *Cumulative Illness Rating Scale*, in "Journal of the American Geriatrician Society", 16.

Lipksy, M 1980, *The Street-Level Bureacrats,* New York: Sage.

Longo, F, Baldino, L, 1996, *Utenti e controllo di qualità*, in "Prospettive Sociali e Sanitarie", 10, pp 5-10.

Lucchetti, M, 1999, *Qualche rovello, due nuove idee e un approccio operativo a proposito di assistenza domiciliare integrata*, in "La rivista di servizio sociale", 4, pp 43-52.

Lucchetti, M, 2001, *L'assistenza domiciliare integrata basata sull'utente. Il modello operativo GIADA per la gestione degli utenti, degli operatori e per il controllo della spesa*, in "Giornale di Gerontologia", 49, pp 155-160.

Mapelli, V, 1999, *Il sistema sanitario italiano*, Bologna: Il Mulino.

Martin, C, Math, A, Renadaut, E, 1998, *Caring for Very Young Children and Dependent Elderly People in France: Towards a Commodification of Social Care?,* in Lewis, J (ed.), "Gender, Social Care and Welfare State Restructuring in Europe", Aldershot: Ashgate, pp 139-174.

Mastriforti, R et alii, *2000, Stress del caregiver: lo studio SIGG*, in "Giornale di Gerontologia", 48, pp 777-780.

Mengani, M, 1995, *La quantificazione della disabilità nella popolazione anziana*, in "L'assistenza sociale", 1, pp 37-42.

Mengani, M et alii, 1996, *Studio multicentrico italiano ADI: tipologia degli utenti ed ammissione all'ADI (situazione nazionale),* in "Giornale di gerontologia", 12, pp 856-7.

Montanelli, R, 1999, *L'assistenza agli anziani in ADI e in RSA: confronto tra politiche alternative e analisi dei costi,* in "Home care news", 2, pp 1-9.

Netten, A, 1993, *Costing Informal Care*, in Netten, A, Beecham, J (eds.), "Costing Community Care", Arena, Aldershot, pp 43-57.

Netten, A, Beecham, J (eds.), 1993, *Costing Community Care*, Arena: Aldershot.

Netten, A, Davies, B, 1991, *The Social Production of Welfare and Consumption of Social Services*, in "Journal of Public Policy", 10, pp 331-347

Nobili, A, Perilli, A, Focarile F, 1997, *Valutare l'efficacia dell'assistenza domiciliare agli anziani.* , in "Prospettive Sociali e Sanitarie", 2, pp 9-17.

Nobili, A, Tettamanti, M, 1997, *Caratteristiche ed evoluzione dello stato di salute a 6 mesi di un campione di anziani in carico ai servizi di assistenza domiciliare*, Milano: Istituto di ricerche farmacologiche "Mario Negri", unpublished paper.

Nocon, A, Qureshi, H, 1996, *Outcomes in Community Care*, Buckingham: Open University Press.

OECD, 1996, *Caring for Frail Elderly People. Policies in Evolution*, Paris: OECD.

Pavan, G., 1999, *Un progetto integrato di assistenza domiciliare per gli anziani*, in "La rivista di servizio sociale", 3, pp 41-52.

Peduzzi, P, 1995, *L'assistenza domiciliare integrata: aspetti normativi ed organizzativi*, in "L'Assistenza Sociale", 1, pp 68-71.

Pesaresi, F., 1999, *Le RSA nelle regioni italiane: organizzazioni e costi*, in "ASI", 37, pp 9-24.

Pesaresi F, Simoncelli M, 1999), *Le RSA nelle regioni italiane: tipologie e dimensioni*, in "*ASI*", 1, pp: 14–36.

Pfeiffer, E., 1975, *A Short Portable Mental Status Questionnaire*, in "Journal of the American Geriatrician Society", 23.

Pickard, L, 1999, *Policy Options for Informal Carers of Elderly People*, in Royal Commission on Long-Term Care, "With Respect to Old Age", research volume 3.

Presidenza del Consiglio dei Ministri – Dipartimento per gli Affari Sociali, 1999, *Relazione biennale al parlamento sulla condizione dell'anziano 1998-1999*, Roma.

Presidenza del Consiglio dei Ministri – Dipartimento affari sociali, 2001, *Guida alla legge sull'immigrazione*, Roma.

Prospettive Assistenziali (editorial), 1999, *Un preoccupante decreto sugli oneri economici a carico delle famiglie con congiunti handicappati o malati cronici non autosufficienti*, in "Prospettive assistenziali", 127, pp 6-10.

Ranci, C, Lembi, P, Costa, G, 2000, *La costruzione del mercato sociale dei servizi alla persona. Il caso lombardo*, Politecnico di Milano. Laboratorio politiche sociali, Camera di commercio di Milano.

Ranci Ortigosa, E, 1990, *La politica dell'assistenza*, in Dente, B (ed.) "Le politiche pubbliche in Italia", Bologna: il Mulino, pp 345-376.

Ranci Ortigosa, E (ed.), 2000, *La valutazione di qualità nei servizi sanitari*, Milano: Angeli.

Rebba, V, 2000, *Le residenze sanitarie assistenziali nei processi di integrazione dei servizi sociali e sanitari*, in Fiorentini, G (ed.), "I servizi sanitari in Italia 2000", Bologna: Mulino, pp 161-229.

Rinaldi, A, 1998, *La legge di riforma*, in "L'Assistenza Sociale", 1, pp 141-150.

Rossi, G, 1995, *Famiglie, servizi pubblici, privati e di volontariato: utilizzo ed orientamenti di politica sociale*, in Colozzi, I, Donati, P (ed.), "Famiglia e cure di comunità", Milano: Angeli, pp 224-309.

Rostggard, T, Friedberg T, 1998, *Caring for Children and Older People. A comparison of European Policies and Practices*. Copenhagen: The Danish Institute of Social Research.

Salvioli, G, Cucinotta, D, 1996, *Il paziente geriatrico e la nuova normativa del pagamento a prestazione: le esperienze regionali*, in "Giornale di Gerontologia", 44, pp 55-59.

Saraceno, C, 1998, *Famiglia e politiche sociali in Italia*, Bologna: Il Mulino.

Schneider, F, 2001, "The Size and Development of the Shadow Economies and Shadow Economy Labor Force of 18 Asian and 21 OECD Countries: First Results for the Nineties", www.economics.uni-linz.ac.at/Members/Schneider/ShadEcASIA.PDF

Scortegagna, R, 1996, *Progetto anziani*, Roma: NIS.

Social Services Inspectorate, 1991a, *Care Management and Assessment: Practitioners' Guide*, London: HMSO.

Social Services Inspectorate, 1991b, *Care Management and Assessment: Managers' Guide,* London: HMSO.

Spector, W, Kemper, P, 1994, *Disability and Cognitive Impairment Criteria: Targeting Those Who Need the Most Home Care*, in "The gerontologist", 34, 5, pp 640-651.

Svensson, M, Edelbalk, P G, Persoon, U, 1991, *Home Service Costs: the Swedish Experience*, in "Health Policy", 19, pp 197-209.

Taccani, P (ed.), 1994, *Dentro la cura*, Milano: Angeli.

Taccani, P (ed.), 1996, *Storie dentro le storie*, Pinerolo: Edizioni l'altro mondo.

Taccani, P, 2001, *Le politiche di sostegno per le reti informali*, in Gori, C (ed.), "Le politiche per gli anziani non autosufficienti. Analisi e proposte", pp 247-282.

Tarabelli, D et alii, 2001, *Qualità della vita del familiare caregiver di anziani non autosufficienti: principali risultati di un'indagine in tre Aziende USL dell'Italia centrale*, in "Giornale di Gerontologia", 49, pp 244-252.

Tjadens, F, Pijl, M (eds.), 2000, *The Support of Family Carers and Their Organisations in Seven Western-European Countries*, Utrecht: NIZW.

Trabucchi, M (ed.), 1996, *I cittadini ed il servizio sanitario nazionale*, Bologna: Il Mulino.

Twigg, J, 1993, *Integrating Carers into the Service System: Six Strategic Responses*, in "Ageing and Society", 13, pp 141-170.

Twigg, J, 1996, *Issues in Informal Care*, in OECD, "Caring for Frail Elderly People: Policies in evolution", Paris: OECD.

Ungerson, C, 1997, *Social Politics and the Commodification of Care*, in "Social Politics", 4, 3, pp 362-381.

Zanetti, O, et alli, 1997, *Depressione e stress in 103 caregiver di pazienti affetti da malattia di Alzheimer*, in "Giornale di gerontologia", 3, p 294

Verry, D, Davies, BP, 1975, *University Costs and Outputs*, Amsterdam: Elsevier.

Walker, A, Maltby, T, 1997, *Ageing Europe*, Buckingham, Open University Press.

Weekers, S, Pijl, M,1998, *Home Care and Care Allowances in the European Union*, Utrecht: NIZW.

Weissert, W G, Cready, C M, Pawelak, J E, 1988, *The Past and Future of Home – and Community-based Long-term Care*, in "The Milibank Quarterly", 2, pp 309-389.