

# Utilization of Health and Social Services: A New Evaluation Method for Linking Individual Data from Providers

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# Master of Public Health

## – Examensarbete –

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| Nyttjandet av resurser inom hälso- och sjukvård samt social sektor:<br>En ny modell för utvärdering byggd på sammanförda individdata från utförare |                       |                        |                          |                   |
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### Sammanfattning

Det svenska välfärdssystemet är ett komplext system som inkluderar en mängd olika servicefunktioner, olika former av stödjande verksamheter och olika finansieringsmodeller. Det kombinerar ett professionellt utförande med en serviceinriktning. Där finns en avsaknad av utvärderingar om hur individer utnyttjar de olika samverkande komponenterna i systemet. Komplexiteten begränsar möjligheterna till att studera interaktioner mellan dess olika delar.

Termen ”kommundiagnos” introducerades i Sverige under 1970-talet. Under 1980- och 90-talet skapades inom flera svenska landsting speciella enheter vilka skulle ta fram ny kunskap för styrning baserat på information från dessa kommundiagnoser.

I kommundiagnosen skulle administrativa, medicinska och samhällsdata vägas samman på ett systematiskt sätt för att ge information om befolkningen. Dessa resultat skulle sedan användas i politiska såväl som administrativa diskussioner om fördelning av resurser.

Utnyttjandet och genomslaget av dessa kommundiagnoser har diskuterats. Resultat från gränsöverskridande analyser av särskilda behovsgrupper, förtidspensionerade, reser frågor om effektiviteten i välfärdssystemet.

I denna uppsats föreslås en ny form av metodik för att sammanställa information om olika delar av välfärdssystemet. En utvärderingsmodell utvecklades under det s.k. Oxelösundsprojektet, efter att ett försök att genomföra en kommundiagnos inte gett avsett resultat.

Modellen resulterade i värdefull ny information om konsumtionen av välfärdens resurser. Ny kunskap framkom även om individuell konsumtion av tjänster under processen ledande till förtidspension.

### Nyckelord

integration, samverkan, nyttjande, kommundiagnos, hälso- och sjukvårdssystem, sociala välfärdssystem, ledningsinformation, planering



# Master of Public Health

## – Thesis –

|                                                                                                                                            |                   |                     |                          |                   |
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| Title and subtitle of the thesis                                                                                                           |                   |                     |                          |                   |
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### Abstract

The Swedish welfare system is complex and includes a range of health and social services, varying providers, and numerous financial methods. Such complexity makes it difficult to evaluate the components and study their interactions. Although the system combines a professional problem solving approach with a service concept, it currently lacks evaluative analyses to offer perspective on how individuals might benefit from the different components of the system.

During the 1980s and 1990s, many county councils in Sweden established special units to elicit new knowledge, using the community diagnostic model (CDM) to collect and analyze medical and administrative data about welfare recipients. The system intended to use such data in policy discussions, especially to improve the health system, and also in planning processes between component providers who sometimes respond as individual participants. Others have discussed the use and impact of such data in managing health and social services. Further, intersectoral studies, e.g. how individuals utilize services, have raised questions regarding the effectiveness and efficiency of the welfare system that might relate to differing internal and external expectations regarding supplied services.

This thesis proposes a new methodology for collecting information from the different components of the welfare system. The evaluation model, D5, described here was developed and tested during a “community diagnosis” in the small municipality of Oxelösund, which is located south of Stockholm. The model produced valuable information on service utilization predictors for and also added new data that will enhance the identification of appropriate services during the application process for disability pensions.

### Key words

integration, co-operation, utilization, community diagnosis, health and social services, management information systems, planning

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# INTRODUCTION

## The problem statement

The focus of this thesis is the use of a new methodology linking together information from different integrated providers, about individuals' use of health and social services. This methodology may enable a more efficient organisation, planning, management, and evaluation of health and social services. The method, named D5, was developed during a "community diagnosis", in the small municipality of Oxelösund, which is situated south of Stockholm (1).

Why is it important to introduce another evaluation method? The main reason is the increasing interest in what external effect integration of health and social services (2) really have on or for the citizen (3). New knowledge presented have also pointed out the difficulties in collaboration (4). One way of analysing the functionality of integration between different providers or actors is to use individual information. On the other hand it is obvious that there are restrictions on using individual information about the citizen due to the confidentiality as well as ethical considerations. In the suggested evaluation methodology both these aspects have been addressed and considered.

The Swedish welfare system where the D5-model was developed is like all welfare systems a complex collection of different services (5). It involves intervention programmes, cure and care, and a social welfare component as well as a social insurance system, which is built on reimbursement. It combines a professional problem solving approach with a service delivery concept. Edgren has discussed this dual view in his thesis (6). Øvretveit has also proposed a three dimensional view including the client, the professional and the management service quality (7).

The evaluation of today's welfare system is built up on centralised models, which include a lot of collected data but have slow feedback (8,9,10). This makes the users of the data very vulnerable in the process of trying to understand "what causes what?" Because compiled information does not explain a pattern identified, there is no way to choose a path, understand or change the situation at decision-making level. This type of descriptive data is therefore of little use for both the clinical and the administrative management process. What is needed is a system that provides data pooled at the individual level, data that describe the activity of each provider, and data about the consumer's trajectories through the complete system (11). The same conceptual thinking is found in other works discussing linking need to services through management (12).

In practice, however, using evaluation models like this is not that simple. There is an obvious need to assess the outcome of the health care and social services systems (13). This is because one ought to be able to state what effect a welfare system aimed at improving the individuals situation (function) is meant to achieve, and then see whether it actually does so (result), and if those results can be used to improve the performance of the system (14,15,16). There is a lack of such evaluative analyses based on pooled

data with the perspective how individuals benefit from the different components – separately or in combination – of the system.

Due to the organisational structure of the system the links between achievement and results contain elements of uncertainty. One such element of uncertainty is the fragmentation of providers in the welfare system. Some studies (17,18,19) assessing the problem have been made but most studies are concentrated on output from separate organisations or parts of the system or how the policymaking process behind the change took place (20,21,22), not the combined and final outcome in the population. The value of this information might be doubtful, because the demands for health and social services are affected by more than just the prevalence of health and social problems (23). In spite of the fact that health and social service facilities are available to everyone in Sweden, not everyone in need of service actually seeks it.

So what is it that gives a person access to the health and social services provided by the Swedish welfare system?

The problem itself and the individual's own assessment of his or hers state is obviously the basic reasons for seeking the provided service (24). Then, an evaluation with the perspective of how the individual benefits from and uses the different components in the welfare state is essential for understanding the process (25,26,27). Several studies have shown that the inclination to seek treatment also varies with age and sex, the prospects of receiving care in the home, the individual's social situation and their educational background, as well as the economic and geographical availability of health and social services (28,29).

New knowledge of different utilisation patterns based on the new method introduced in this thesis may show the relationship between health and social services in the welfare system and in what way the level of integration (2) influences the individual's choice of utilisation. It is of key importance for the management and evaluation, aimed at improving health and social services, to get information about the system's provision and the population's consumption of services (30).

## **The Community Diagnostic Model – the compiled data set**

By the end of the 1970's politicians, managers and civil servants recognised the fact that they had to evaluate the welfare services to see if the set goals had been achieved. For this purpose the Community Diagnostic Model (CDM) was introduced and used as a tool, equivalent to a medical examination of a person, to measure health and social status in the population. (31-35). "Community analysis" and "Community needs assessment" are other terms used to describe the process of mapping the different resources as well as the demand for them in the community (36). The results from these studies were then supposed to be used in the planning and management process (37,38).

Despite many advantages, studies like this also have a number of shortcomings, due to the problem of interpreting the results. One shortcoming is that it is impossible to relate

different findings with each other, due to the fact that they do not share a common denominator. Another shortcoming of the CDM is its inability to measure the influence of each of the different service providers on the same population, at a population level. This major restriction is related to the fact that the regularly used compiled statistics only indicate the changes in the welfare state – not the possibilities to analyse what causes the demand of services (39).

Each provider does of course provide service to the population. But, depending on administrative or economical restrictions, they only serve their “own” population, which fulfils the administrative criteria (or in clinically departments diagnosis) stated for the use of the provider’s service. The output from those services will be strictly related to the service given by each provider, not how well they collaborate.

Collecting and presenting official compiled statistics has been the responsibility for most public organisations and administrations since the beginning of the Swedish welfare system (40-47). In most countries there are different independent organisations as well as ministries and other public bodies that regularly present compiled statistics covering the use of different components of the welfare system. This type of statistics has over the years been used to follow up changes in the welfare of the population (48,49). The collected statistics have been of very high quality and have sometimes been used for more specific evaluations e.g. in epidemiological research projects (50). But during the different shifts in economy as well as in politics there have been changes made to the welfare system as well as different subsystems. Due to this, the compiled statistics produced have been problematic to understand or interpret. There have sometimes been changes made in the administrative definition of the services, delivered in the welfare system, which have caused translation problems, misleading the evaluator, when trying to figure out what the statistics tell (51,52).

To overcome this problem a more individually orientated form of statistics should be introduced. This, “consumer” look-a-like system would then reflect what have been used by each individual, consumer, of the different services in the pattern of support inside the welfare state (53). Any change of the systems different components can then be seen directly in the utilisation pattern of the individual.

This would then solve the problem with gross-statistics, or compiled statistics, were it is impossible to figure out if it is one or five individuals who are responsible for the utilisation of a service. With the use of consumer orientated statistics it would be possible to calculate the net-utilisation per year or any other chosen time frame. An individualised form of statistics would also support longitudinal evaluations to bring forward the result and impact of provided resources specifically targeted on different groups (54).

Another advantage is that with individualised statistics there is the possibility to do complementary calculations based on selected matching with other registers to support the understanding of the observed results. Qualitative and quantitative studies could be combined in a new way (55).

The main difference between the suggested model and the compiled model is that in the compiled model the information available is information on how each provider serves their exclusive population. The epidemiologically orientated D5-model uses a well-defined population. Information related to this population is then selected from each provider and combined. This makes it possible to study the information on the utilisation patterns of the population.

This gives the following advantages over the compiled model;

1. It will make it possible to study the network or the level of integration of the providers from the user's perspective - and
2. It will enhance the possibilities to study the interaction processes in the "grey" zones between the different providers.
3. It will make it possible to study the non-users of specific services since there is a pre-knowledge on the structure of the defined population.

## **The aim of this thesis**

Against this background, the aim of this thesis is to describe a new method, the D5-model, for evaluating the utilisation of health and social services and their level of integration. The potentials of this model will be illustrated by using data from a defined population database and analysing the patterns of utilisation of health and social services within defined groups in a Swedish community.

Based on the results of this analysis, the strengths and weaknesses of the D5-model will be discussed in relation to the commonly used methodology.

## THE SETTING

Although a "pure-bred" welfare system does not and has not existed anywhere in Europe, in rough terms one can place countries into three main categories: the Beveridge model, whose flagship has been the British National Health Service, established in 1948; the Bismarckian Sickness Insurance model, founded in Germany in 1881, which has remained unchanged in its basic elements since the reform of the "Reichsversicherungsordnung" (Health Insurance Ordinance) of 1924; and the Semashko model, which was developed in the early days of the Soviet Union and was based on tightly centralised state control. The more or less social-democratic governments in the Nordic countries - Denmark, Finland, Iceland, Norway and especially Sweden - believed in the values of the Welfare State and already in the 1930s began to introduce a model similar to the British Beveridge model (56).

### The Swedish welfare system.

The basic elements of present-day welfare system in Sweden are as shown in Figure 1.

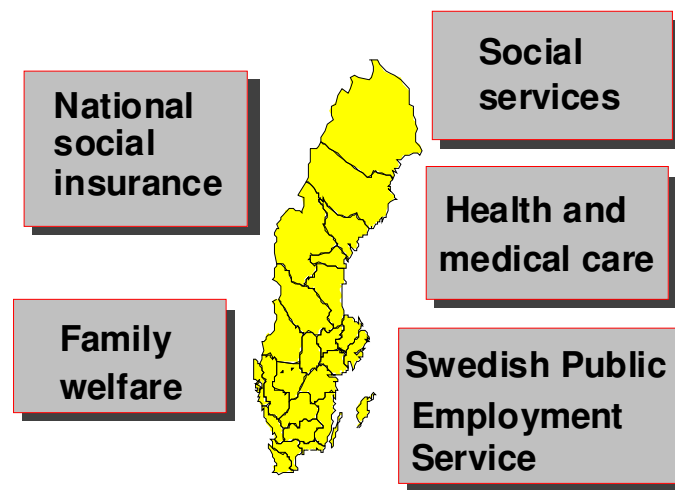


Figure 1. The basic elements of present-day welfare system in Sweden

Health and medical care as well as social services, are the corner stones of the Swedish welfare system. Its fundamental principle is that all citizens are entitled to good health and equal access to health and medical care, regardless of where they live and of their economic circumstances (45). In line with this principle, health and medical care is seen as a public sector responsibility, which is supported by a national health insurance system. County Councils and the Regional Councils, are responsible for health and medical care, both inpatient and outpatient (57). These organisations, with populations ranging from some 60.000 to 2.2 million, also operate the public dental service. Responsibility for social welfare services and environmental hygiene rests primarily

with the municipalities, which are currently 290 in number and have populations ranging from approx. 5000 to 700.000 inhabitants.

The County Councils were established in the 1860s, mainly to finance and manage hospitals for somatic illnesses. Over the years their health care tasks have increased. In the mid-1960's they took over the responsibility from central government for primary care (which includes general practitioners) and psychiatric care. The Health and Medical Services Act of 1983 extended still further the areas of responsibility of the County Councils. Health care now accounts for 75-80% of the total expenditure of most country councils. The latter are required, under the Act; to promote the health of residents in their areas and to offer them equal access to good medical care (including transport services in the case of illness). The Act requires County Councils to plan the development and organisation of health and medical care with reference to the massed needs of the county populations. This planning must also include the health and medical care provided by private practitioners, occupational health physicians, etc.

The state is responsible for the national social insurance and the state public employment service. It is also responsible for ensuring that the health care system develops efficiently and is keeping with its overall objectives, based on the goals and the constraints of social welfare policy and macroeconomic factors (5,57). Central government administration under the Parliament and the Government is illustrated in Figure 2.

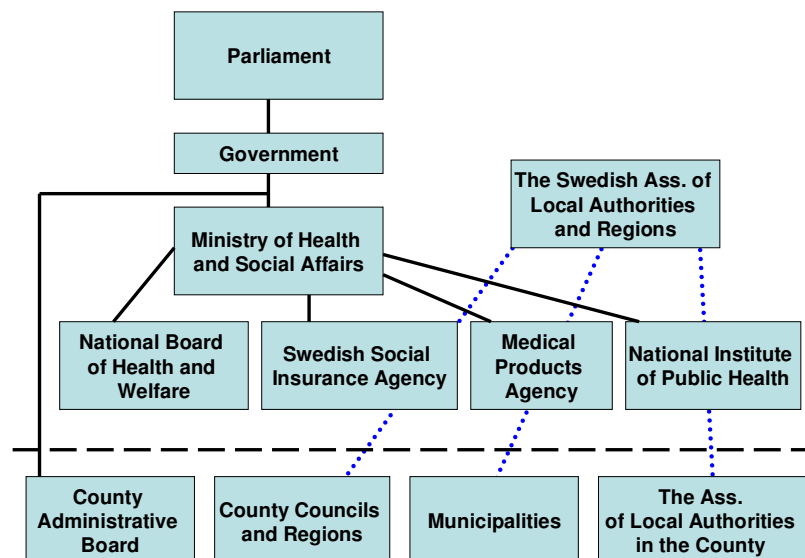


Figure 2. The organisational structure of the health and social services in the SWS

Below the Ministry of Health and Social Affairs are relatively independent administrative agencies, chiefly the National Board of Health and Welfare and the National Institute of Public Health. The County Councils, the Regional Councils and the municipalities are affiliated to the Swedish Association of Local Authorities and Regions, which provides services to its members and represents their interests. It also

serves as a central negotiating body for concluding financial agreements with the national government and for resolving pay issues. The regional medical care system is responsible for those patients whose problems require the collaboration of a large number of specialists and perhaps also medical equipment. For such purposes, Sweden is divided into six medical regions, (not to be mistaken as the administrative Regional Councils), each serving a population averaging more than one million. Their activities are regulated by agreements between County Councils within each region. Each medical region has one (sometimes more) regional, highly specialised hospital, usually affiliated to a medical school, which also functions as a research and teaching hospital. Medical care at county level covers patients with critical conditions or other illnesses requiring access to staff or medical technical resources, which, for various reasons, must be concentrated to one or a few hospitals within each County Council area (58). These county hospitals are divided, according to their size and degree of specialisation, into Central county hospitals with 15-20 specialities and District county hospitals with at least four specialities (internal medicine, surgery, radiology and anaesthesiology

Primary care is organised into primary care districts. They are primarily responsible for public health care in their area. Each district has one or more local health centres and at least one nursing home for long-term care. At the health centres, district physicians, normally general practitioners but sometimes also specialists, provide medical treatment, advisory services and preventive care. The outpatient system also includes district nurses and midwives and runs clinics for child and maternity health care. The primary care level system also runs mass health screening, such as the health control of four-year-olds, cervical cancer screening, mammography and vaccination services. The school health services, for which the municipalities are responsible, examine pupil's health on a regular basis. Since 1992, the municipalities are also legally or contractually responsible for elderly care, social services as well as support for the physically and intellectually disabled.

## **The study setting (Oxelösund)**

The County Council of Södermanland initiated the Oxelösund project in 1987, in co-operation with SPRI – The Swedish institute for Health Services Development, and the Department of Health Economics at the University of Linköping (59,60,61). The geographical location is shown in Figure 3.

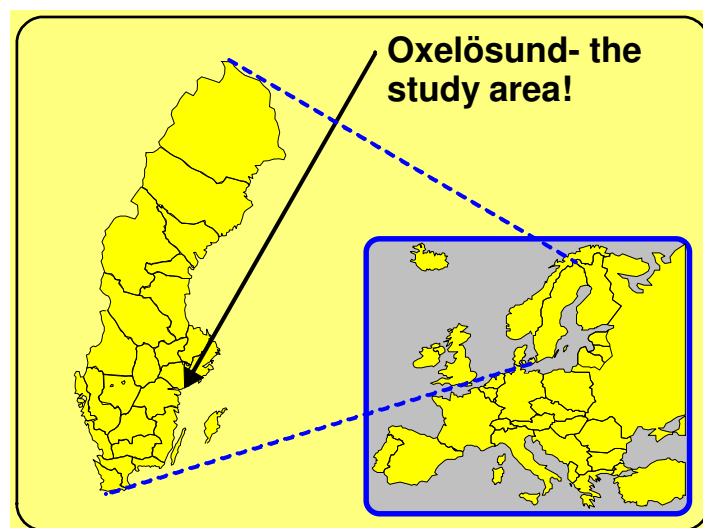


Figure 3. The study setting, geographic location.

The basic idea behind the project was born out of a "marriage" between community (social) medicine and a need for a better resource allocation information system for the managers of the welfare system at local level. The municipality of Oxelösund was chosen due to the close geographical location to the community medicine research unit at the County Council of Södermanland. Some descriptive statistics of Oxelösund are presented in appendix 2.

It was decided that all the providers involved in the project should be an active part of the Swedish welfare system. Using the Oxelösund material it would be possible to try a new model for public health description and apply it on a population. The method would then be used as a tool in a health orientated planning process involving all actors, and give evaluative information, which would help to decide if the society's collective resources were being used effectively to fulfil the needs of the population.

All of the providers, as mentioned earlier, are in one way or another, responsible for the well-being of the population. In the municipality of Oxelösund the following providers responsible for the well-being of the individual were identified;

- the health centre
- social welfare office
- occupational health units
- the local pharmacy
- employment service office
- regional social insurance office
- child care unit
- The National Labour Market Board including the rehabilitation unit
- the local police authority

To this list the hospital in the neighbouring municipality of Nyköping should be added. At the time when the study was conducted there was a regulated access to the hospitals. This hospital then did handle inpatients from Oxelösund municipality as well as emergency care patients.

The data used in this thesis is extracted from those sources.

## THEORETICAL PERSPECTIVE

The original intention to use the CDM technique in the Oxelösund project was to develop a key regulating mechanism to distribute the resources between various primary care areas. Due to the complexity of reforming in the area of health and care there was an increased need of a cross-sectored view in favour of planning and development. Additionally, a calculation on the overall consequences for the national economy the reconstruction was needed. There was also a need for a good basis of knowledge and experience during the development phase, in order to provide the society with effective strategic guiding in the choice of future directions of operation. The project would also try to create a model for how to co-operate with a local community perspective within a municipality. The CDM approach did not work sufficiently well. There was a lack of information about how different groups in Oxelösund utilised the different providers. This resulted in an intention to go further and develop a more accurate tool for management based on individual utilisation with the focus on improving integration.

Assessments of the outcome of the Swedish welfare system are complicated for several reasons, due to the fact that by using compiled statistics from registers we find ourselves confronting problems of many perspectives. It includes measuring a multiphase process involving interactions within and between different welfare system components. The real difference between measuring between two of the main perspectives, **OUTPUT *in* the structure** and **OUTCOME *of* the structure**, is shown in Figure 4. These perspectives could also be looked upon as “Indoor” as well as “Outdoor” analysis due to the fact that the output perspective is based on internal effectiveness and the outcome perspective is the “need orientated” efficiency of the provided process.

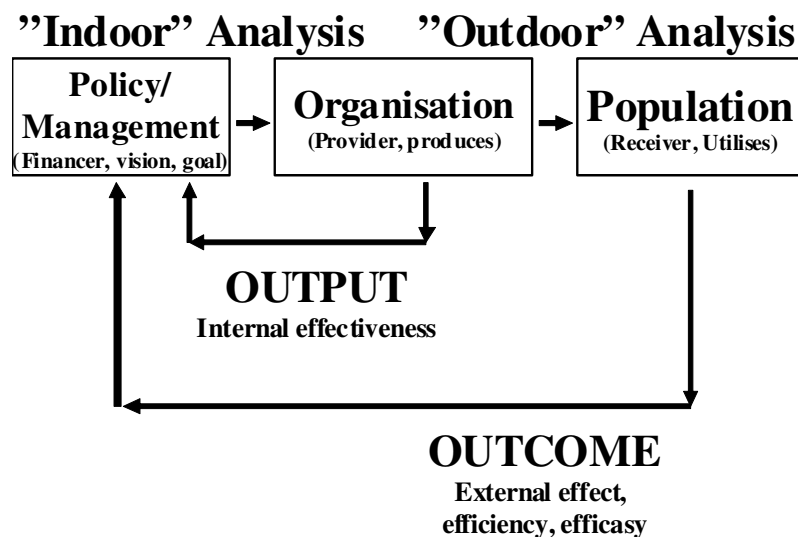


Figure 4. Internal and external analysis.

A major work in the understanding of how a system can influence the utilisation was conducted in a Finnish evaluation of a new universal sickness insurance scheme (62). In the study, the consumption of medical commodities (goods and services) was looked upon from the framework of a set of processes between and within different systems (or elements inside a system), which the health field encompasses.

The actual needs to be found in a population are just as complex to measure. The state of health has many dimensions, which makes it difficult to carry out a complete evaluation of the need. The World Health Organisation (WHO) described this in 1948 in the preamble to its constitution, as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”. Many have criticised the WHO’s description of health, due to the problems to evaluate or measure it. As a substitute, the supply of services can be used as an approximation of the need by measuring the utilisation of the provided services (63). By using this definition and at the same time accepting the fact that if there is no knowledge of a service then there cannot be a need for it, the evaluation of utilisation will give guidance. From a management perspective this is often quite sufficient for decision-making.

The normal utilisation situation is as shown in Figure 5. Each individual normally accesses one single provider. Due to different actions taken within the organisation, e.g. the type of service and how different users will be prioritised; the output or the effect of services will be the result. The individual efficacy with the result of the provided service then depends how effective and efficient the provision of the required service was and if it was available.

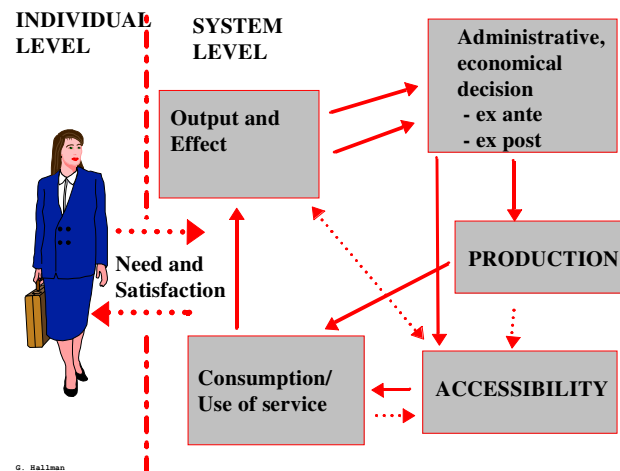
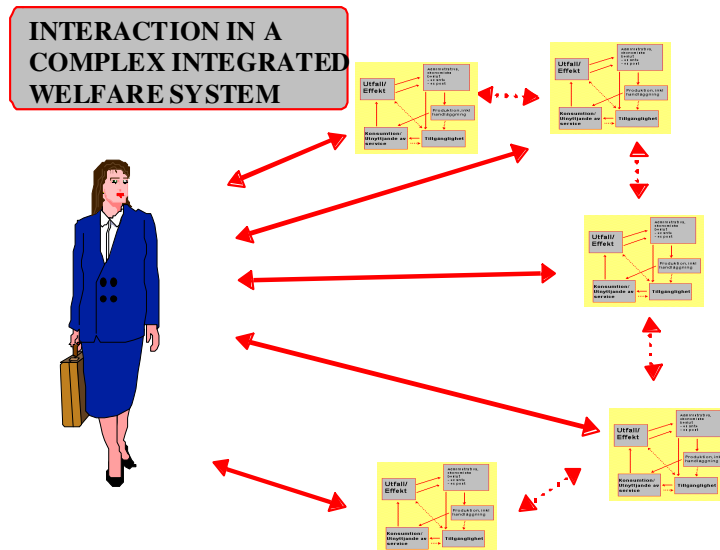


Figure 5. The normal utilisation.

This is no problem as long as those individual effects or the output information are used for managing a single provider. But a multidimensional problem occurs when the utilisation of the individual involves more than one provider and more than one incident. The situation of the individual in the welfare system is then as is shown in Figure 6.

This is a complex fragmented structure of different providers, each effectively providing their service with high internal effectiveness, but from the individual perspective the

services sometimes overlap. This overlap might be planned for, but in the worst scenario the level of integration of supplied services can even restrict the positive outcome for the individual. The result of this could be a reduction of the effectiveness in the welfare structure of service providers, in relation to the expressed requirements of the individual.



G. Hallman

Figure 6. The multidimensional utilisation.

There are also other restrictions to be found when measuring and calculating the total outcome of such a complex system of service components, in terms of effectiveness in the care taking process, costs etc. This is related to the compiled statistics available, which do not cover information regarding one well-defined population and its use of single or multiple providers. This might cause or hide low external effectiveness. But due to the lack of a defined population in the denominator this is difficult to study. The same problem restricts us from carrying out a constructive discussion about co-operative work to cut the “costs”, financial as well as human.

## METHODS AND DATA

### Study design

While the population statistics in most countries are still based on censuses, Sweden has, since the 18th century, had a unique church-record system for the continuous recording of individual demographic changes at parish level, which is known as the Swedish Register of Population. Each newborn child and immigrant is assigned a national registration number indicating the date of birth and sex. This number, name, address and family relations have hitherto been entered in a personal file drawn up by the registration office of the parish in which the individual is registered. The file records marriage, childbirth, divorce, and change of address and death. This centuries-old tradition has been broken, however, and as of July 1, 1991; the local tax authorities now keep these records. Good national population registers with personal identification are a prerequisite for successful longitudinal follow-up studies with data that are often sensitive as pointed out in a publication by the Swedish Council for Planning and Coordination of Research (64).

The information used in this work is based on the file drawn up by the registration office of the parish. For each year of the 11-year study period a new cohort sample was drawn. The same selection criterion was used. The sample population is, then, an open cohort in which participants can be present or not present. This gave us 11 years of a sequential data file to use in the process of analysis. Before the study could proceed it was necessary according to the permit allotted by the Data Inspection Board, to notify each individual by letter (65,66). The reason for registration had to be explained and also the purpose for which the information would be used. There was also a telephone number, for anonymous use, in case of direct questions. Almost all of the people calling in were positive about giving us their permission to use information about themselves and their consumption, as the purpose was to improve the welfare system. The result was an individually based register, covering the use of all services in a municipality from a randomised population during a defined time period.

### Study population

The Study population is built up by collecting a randomised population using three dates of birth as selecting criteria. From the Swedish Register of Population the information of all individuals born on the three days the 5<sup>th</sup>, 15<sup>th</sup>, and 25<sup>th</sup> of each month, were collected and registered in a database. This model was originally given the name “D5“, which should be translated as “born on day 5, 15 or 25 in each month“. This allowed us to include information regarding each individual’s civil status, place of birth, nationality (country of birth) and their present habitation.

A letter was sent out to the selected population of 2365 individuals (100%), present during the 11 year period that matched the selection criteria, asking them if they would

agree to let us collect and use their individual records. A total of 322 (13.6%) refused. This left us with 2043 (86.4%) individuals in the final study population, of which 761 lived in the area during all of the 11 years and 1282 lived there for a shorter period of time than 11 years. The average annual study population was 1327. The population is described in Table 1.

Table 1. The study population by age, sex and year

| Age<br>Year        | 00 – 14      | 15 - 19      | 20 - 44      | 45 - 64      | 65 +         | Total        | Total |
|--------------------|--------------|--------------|--------------|--------------|--------------|--------------|-------|
|                    | Women<br>Men | Women<br>Men | Women<br>Men | Women<br>Men | Women<br>Men | Women<br>Men |       |
| 1978               | 145 167      | 54 61        | 241 308      | 141 154      | 54 66        | 635 756      | 1391  |
| 1979 <sup>3</sup>  | 136 158      | 60 62        | 239 315      | 144 154      | 55 73        | 634 762      | 1396  |
| 1980               | 132 153      | 69 59        | 241 297      | 138 156      | 59 74        | 639 739      | 1378  |
| 1981               | 123 135      | 62 72        | 232 292      | 151 156      | 66 79        | 634 734      | 1368  |
| 1982               | 127 118      | 63 72        | 220 281      | 148 155      | 65 75        | 623 701      | 1324  |
| 1983 <sup>3</sup>  | 115 109      | 66 75        | 215 278      | 150 156      | 70 81        | 616 699      | 1315  |
| 1984               | 115 105      | 58 71        | 220 280      | 154 165      | 70 80        | 617 701      | 1318  |
| 1985               | 117 107      | 45 60        | 227 269      | 153 158      | 75 79        | 617 673      | 1290  |
| 1986               | 107 97       | 39 50        | 217 265      | 151 162      | 74 86        | 588 660      | 1248  |
| 1987               | 101 111      | 45 53        | 218 274      | 160 169      | 75 87        | 599 694      | 1293  |
| 1988               | 106 103      | 39 48        | 212 262      | 163 182      | 76 89        | 596 684      | 1280  |
| Total <sup>1</sup> | 281 283      | 68 77        | 385 451      | 170 182      | 67 79        | 971 1072     | 2043  |

|                                    |       |     |       |       |       |         |     |
|------------------------------------|-------|-----|-------|-------|-------|---------|-----|
| Refuser<br>population <sup>2</sup> | 18 10 | 7 9 | 77 36 | 56 53 | 26 30 | 184 138 | 322 |
|------------------------------------|-------|-----|-------|-------|-------|---------|-----|

<sup>1</sup>) Numbers of persons at given age included at least one observation year.

<sup>2</sup>) Refusers age 1988-12-31.

<sup>3</sup>) The numbers for 1979 and 1983 have been corrected due to error in the registration process.

To control if there was any selection bias caused by missing information about those who refused, a comparative study about utilisation patterns among the resident population was made, using the available aggregated data. The results from this sensitivity study did not show any selection bias.

## Data collection procedures

The register covering 10% of the population was used as a key, using the birth number, to collect data from the different providers. Due to practical as well as legal problems it was necessary to devise a procedure to collect and keep the data with each provider, until the time when all data could be brought together. The Swedish Data Law is restrictive regarding the use of birth numbers as a key in an electronic database, and the Swedish Secrecy Act regulates which type of information it is possible to store in the database. The model used for solving these problems included a specially designed electronic registration sheet, using the birth numbers of interest. The confidential

information covering all services used by each individual during the time period of 01/01/78 to 31/12/88, collected from each provider, was kept on location until that time when all the data was put together. Information from each of the providers regarding the individuals was combined with the corresponding birth number, after which the key-birth number was deleted and replaced by an individual identifier. The data from all the various providers was then finally linked together by using this individual identifier. The permit to conduct the study based on the above principle is presented in Appendix 1.

## **Available data**

The database includes socio-demographic information (e.g. age, sex), social information (marital status), pathways of contact (e.g. referred or not), and type of/reason for contact (e.g. diagnosis, reimbursement). The list of variables is presented in Appendix 4. The providers were divided in to two subgroups, according to their area of responsibility within the Swedish welfare system. Subgroup HEALTH includes primary health care, outpatient and in-patient care, occupational care as well as child-care. Dental care is not included. Subgroup SOCIAL includes social services, employment services and public social insurance.

## **Data used in this thesis**

Out of the database were selected the appropriate data that should be used in the analysis for this thesis. These data include the following independent variables; sex, age group, marital status, socio-economic status, number of years in the study population, land of origin and unemployment.

Socio-economic status is defined by area. Area 1 is a wealthy, residential area on the coast, with large private dwellings, area 3 is a non-wealthy inner-city area close to a major steelwork industry, and area 2 is all other areas. Unemployment is defined as when a person is actively applying for a new job. Country of origin is defined as Sweden, Nordic and non-Nordic countries. The term disability pension in this thesis includes two kinds of benefits, 1) long-term benefits received, due to loss of working capacity, up until the age of 65, when the general old age pension comes into force, and 2) benefits received due to lack of working capacity caused by illness, and paid out during a period of at least one year.

## **Data transformation procedure.**

Depending on the different types of sources from which the information was going to be collected, a new strategy to select and collect the information was developed. Many of the sources were still bound to registration routines based on paper files.

The strategy model included a specially designed electronic registration sheet using a one-way encryption procedure. The confidential personal information, covering the use of all services by each individual, was collected from the provider. The data were then kept on location until that time when all the data was put together, thus preventing misuse. The collected data reflects utilisation during the time period of 01/01/78 to 31/12/88. The result of this was, after each information unit with individualised utilisation data, had been combined by using the model, an individually based register, covering the use by a randomised population of all the services available in a municipality, during a defined period of time.

This huge transaction-based data pool then was aggregated at an individual level, resulting in a transformed, structured database. This new data set included individual utilisation of different welfare components calculated as e.g. the number of times each individual visited the local primary health care centre (PHC) per time frame, and the total reimbursement received per time frame. The used time frame for aggregating data in this thesis is by year.

The next step was to build a knowledge based matrix grouped on different characteristics, e.g. individuals with 0 visits, one to three visits and more than three visits per year to the PHC. This matrix, named D5FOUBAS, has been used for the calculations and results presented in this thesis. In Figure 7 the procedure from the “pool” to the complete matrix is presented as a graphical flow.

| D5-population | Individual characteristics<br>ex. diabetes | Geographic code | PHC visits<br>(coded) | In-patient care | N:o of days reimbursed | a.s.o. |
|---------------|--------------------------------------------|-----------------|-----------------------|-----------------|------------------------|--------|
| Id 1          | 0                                          | 3               | 2                     | 4               | 4                      | ..     |
| Id 2          | 1                                          | 6               | 3                     | 3               | 1                      | ..     |
| a.s.o.        | ..                                         | .....           | ....                  | ..              | ..                     | ..     |

**”D5-matrix”**, based on unidentifiably, coded data,

Aggregated at an **common analytical basic level = individual level**.

**All presentation is done at aggregated level. NB numbers in matrix is not reel numbers, but recoded values.** PHC visits=2 is related to 3-5 visits conducted by the individual. PHC visits=3 conducted 6 – 9 visits a.s.o.

The same type of recoding took place at each provider.

**”Pre-analysis”** of data, all activities or transactions are aggregated at **each single provider on the basic analytical level = individual level. The data is made unidentifiable by encryption using one common algorithm.**

**”The Pool of data”** e.g. all activities or transactions registered at each single provider.

|        | Diagnosis<br>1.....12 | Days on<br>sick- leave |
|--------|-----------------------|------------------------|
| Id 1   |                       |                        |
| Id 2   |                       |                        |
| a.s.o. |                       |                        |

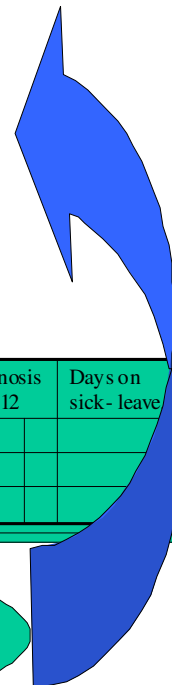
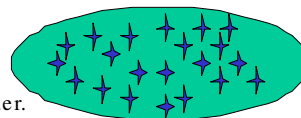


Figure 7. The data transformation procedure, (graphical presentation).

The total process of putting the data through all these steps is very time consuming. This is also one of the reasons why the original timetable was not kept in the project.

## **Statistical and analytical procedures**

All results are tested by means of chi-square test or by Fisher's exact test. The factors predicting utilisation are explored by the use of a categorical multivariate model. All analyses are carried out separately for men and women. The predictor variables are marital status, unemployment, age, sex, number of years in the study population, SES, and country of origin. Computation used the SAS version 9, CATMOD procedure (67). Three analyses with identical sets of predictor variables and with separate response variables, use of health services, use of social services, and use of both health and social services are presented.

The analyses in the study concerning disability pension refer to incidents, not persons. The socio-economical factors used are marital status (single, married, divorced, widow/widower) nationality (Swedish, Nordic, non-Nordic) social class (measured by deprivation of living area), unemployment (no present employment and applying for a job) and years of stable living in the community.

Utilisation was divided into two subgroups, utilisation of HEALTH and SOCIAL services. HEALTH includes primary health care, outpatient and inpatient care, occupational care as well as child-care. SOCIAL includes social services, employment services and social insurance. The disability pensioner's utilisation of services is calculated during the year of allocation of the pension. For the remaining study population utilisation is calculated for a standardised time frame, the year 1985.

## RESULTS

### Summaries of two test studies

Two test studies were conducted on the D5FOUBAS to test the strength of the method. The results are presented in the form of “articles” (in appendices 5 and 6) due to the forum where the results were presented originally.

#### Test study 1

The objectives of this test study were

- 1) to demonstrate the potential of an alternative to the community diagnosis model based on individually pooled data, and
- 2) to describe the pattern of utilisation of health care and social services in a Swedish municipality during a one year period in relation to basic socio-demographic characteristics.

The distribution of visits to HEALTH and SOCIAL services is presented. The results indicate that use of HEALTH services increases with age. In the age group 20-44 the utilisation is higher among women than men (OR=0.541, CI=0.368-0.797, Fisher's exact test 0.0012).

It was also shown that the proportion of the study population using combinations of HEALTH and SOCIAL services did differ. Among women 15% did not use any kind of service and the corresponding figure for men is 23% (OR=1.612, CI=1.213-2.144, Fisher's exact test 0.0006). There was a significant difference in age structure of non-users (n=254) between men and women. The proportion of male and female non-users are: 00-14 years 48%, 52%, 15-19 years 37%, 63%, 20-44 years 22%, 78%, 45-64 years 35%, 65%, and 65+ years 48%, 52%, ( $\chi^2=10.480$  df=4 p=0.0331).

The multivariate, categorical regression analysis was carried out in a series of steps, starting with the full model. Predictor variables, which showed no significant effect, were deleted from the model one by one and the reduced model was re-applied to the data.

- Significant predictors of use of HEALTH services for men: use of social services, unemployment, age; for women: age group.
- Significant predictors of use of SOCIAL services for men: use of health services and age; for women: unemployment and age.
- Predictors of at least one service for men: age; for women: unemployment, non-Nordic origin.

- The final model for prediction of use of HEALTH services shows the following predictors for men: use of SOCIAL services, unemployment, and age outside 20 - 44; for women: age 15 - 19.
- Among men the predictors for high use of SOCIAL services are; use of HEALTH services, age 20 - 44 and age 45 - 64, as well as low socio-economic status; for women: unemployment and age 20 - 44 as well as age 45 - 64.
- Finally, the analysis of predictors for any service ('HEALTH' and 'SOCIAL') shows the following significant predictors for men: age 20 - 44 and age 45 - 64, as well as low socio-economic status; for women: unemployment, age 20 - 44 and age 45 - 64, as well as non-Nordic.

A problem when evaluating a welfare system or any service system - publicly or privately financed - is that the outcome of the system is dependent on how the individual chooses to utilise it (68,69,70). Little is known about this choice. Using the D5 register model may help to bring forward new information about the patterns of service utilisation (71). Most of the previous studies of service utilisation are based on survey studies. The D5 register provides an alternative, which uses data pooled at an individual level to describe utilisation of services in the welfare system.

Another interesting finding relating to the predictors of use of services is that: The highest proportion using combinations of HEALTH and SOCIAL services is clearly related to the age group 20-64 for both sexes. Socio-demographic characteristics as unemployment and socio-economic status might be confounding factors. This is partly supported by findings in a study of frequent attendees to the Finnish public primary health care, where socio-demographic data was used (72). One reason for the utilisation pattern identified in D5 could be that those in the age group 20-64 might have a better knowledge of the Swedish welfare system, and how to "use" the different providers. Another reason might be related to the fact that many of the components in the welfare system have been more or less free of charge or accessible at a very low fee, for the individuals in this age group.

Elderly people (65+) are frequent consumers of HEALTH services. This is probably due to an age related increase in chronic illnesses, as well as to the fact that older people, when affected by injuries or illnesses, have a slower recovering process, which in turn implies more return visits. In contrast to this, it is interesting that the proportion of elderly people (65+) that does not use HEALTH services during one year is 24% (women 22,4%, men 25,8%). These findings correspond with available data from a survey study in California published by Shapiro and Ross (73).

The register has yet another, less obvious, potential. It is possible to identify high consumers as well as low consumers and then study their use of welfare components during a period of time. By doing this it might also be possible to identify the characteristics of such groups. The D5-model is also a better tool than the CDM for

studying the pattern behind utilisation in the form of visits, the pathways between services and also for introducing a new model for a systematic assessment of a welfare system. There are few studies on how individual users actually use the web of different providers in a welfare system, to promote their own health. More studies should be introduced to identify what effect welfare systems actually have on the population. The D5-model, due to its design, only uses quantitative information from administrative sources.

A complementary qualitative study introduced to answer questions about needs, demands for services, obstacles to utilisation, how the service was delivered, degree of satisfaction as well as the effect, would give valuable additional information at an individual level. This is important for two reasons, first of all in order to study the utilisation patterns and pathways of individuals by certain characteristics (sex, age, marital status, socio-economic status etc.), secondly to provide explanations for findings as well as to compare those with other studies concerning utilisation.

Due to the organisational structure of the welfare system, as well as to the enormous variety of services it provides for Swedish citizens, it has until now been impossible to study the actual patterns of utilisation. For the first time this is now possible, in a pilot study from one Swedish locality. This approach also gives information about those who do not use the services.

## **Test study 2**

The objective of this test study was to describe individuals' utilisation of services during the two years before allocation, the actual year of allocation, and the two years after allocation of disability pension, compared to that of the general population.

The results indicate that there are socio-demographic differences between incident disability pensioners and the reference population. These differences are tested for homogeneity by chi-square test, separately for women and men. The individuals given disability pension were older than the reference population, (Fishers exact test, men:  $p=0.0000$ , women:  $p=0.0000$ ), fewer were not married (Fishers exact test, men:  $p=0.0030$ , women:  $p=0.0037$ ) and a greater part of the men was non-Swedish (Fishers exact test, men:  $p=0.0459$ , women:  $p=0.1723$ ).

The calculations shows that the utilisation measured as contacts increases from two years before receiving a disability pension, until the year of receiving it, thereafter it decreases again. These results are summarised in Table 2.

Table 2. Total number of contacts among incident disability pensioners (n=59) type of contact and age group

|                               | Two years before | One year before | Disability pension year | One year after | Two year after |
|-------------------------------|------------------|-----------------|-------------------------|----------------|----------------|
| Only Social utilisation       | 45               | 47              | 47                      | 46             | 45             |
| Only Health utilisation       | 0                | 0               | 0                       | 0              | 0              |
| Social and Health utilisation | 256              | 270             | 286                     | 214            | 214            |
| Total number of contacts      | 301              | 317             | 333                     | 260            | 259            |

The results also bring forward that the average number of contacts do indicate that there is a higher utilisation in the incident as well as the prevalent disability pensioners group compared to the reference population. This is shown in Table 3.

Table 3. Average number of contacts per individual by age group and group

| Age group            | 1985 Reference population N=741 | 1985 Prevalent Disability N=32 | Incident Disability pensioners N=59 |                 |                         |                |                |
|----------------------|---------------------------------|--------------------------------|-------------------------------------|-----------------|-------------------------|----------------|----------------|
| (year of disability) |                                 |                                | Two years before                    | One year before | Disability pension year | One year after | Two year after |
| 20 – 44              | 4.7                             | 2.0*                           | 4.7                                 | 5.9             | 5.9                     | 5.9            | 5.9            |
| 45 – 64              | 3.7                             | 5.9                            | 5.0                                 | 4.6             | 4.7                     | 4.8            | 4.9            |

\*few individuals

The main findings in this study are that (a) the use of health and social services increase steadily during the process of application for disability pension and decrease considerably after allocation of services, and (b) the use of services among both prevalent and incident disability pensioners are continuously higher compared to the remaining population, both before and after the allocation of services.

These findings are consistent with the previously described study concerning frequent attendees of the Finnish public primary health care, where disability pension was a factor of great importance for utilisation of services (72).

One factor that has to be taken in to consideration is that the reference population has a bias in favour of younger age groups. The decrease in the use of health and social services that takes place after a disability pension has been granted could depend on a greater acceptance, due to a long and positive work period with increasing physical restrictions at the end or as a release from financial problems and depression (74).

In this study there are more married people than were expected. The high proportion of married people among the disability pensioners in this study could indicate that the social network supports the application for disability pension and supports the applicants during this period, as is indicated in a Norwegian study about unemployed published by Ytterdahl and Gulbrandsen (75). In a study by Maule (76) there are indications that show that discussing early retirement with their spouse influenced the individual's decision to apply.

It was expected that low socio-economic status would be a predictor of allocation of disability pension. This was not the case, but some of the underlying factors point to the fact that immigrants do lead a higher risk of receiving disability pension. This was also one of the findings presented in a paper by Eden et al. (77). Another notable point is that it seems that the impacts on the weaker social groups are stronger. The implication for this is not clear, but is consistent with findings by Claussen (78).

The results give some indications as to the differences between genders and nationalities (79). More men of non-Swedish origin were granted disability pension. The absence of a shift during the year of disability pension in the age group 45-64 could depend on better acceptance, due to a long and positive work period, but with growing physical restrictions towards the end. This might be related to a feeling of relief for being in the process of receiving a disability pension (80).

The findings must be assessed in relation to the possible advantages and disadvantages of the study. The study's main strength lies in the representative study population and the combination of many data sources at the individual level. Its main weakness lies in the fact that the validity of the data is as good as unknown. The material is originally administrative data, based on paper files. By using a single individual identifier it was possible to carry out follow-up studies across administrative borders and to study the common outcome of a process, which involves more than one authority. The register does not include data on the individual pension scheme, which can substitute the regular disability pension. The design of the study gave access to information regarding utilisation, while at the same time it was restrictive with any other information concerning the individual's choice. The data consists of quantitative information from administrative sources. A complementary qualitative study of needs, demands for services, obstacles to utilisation, how the service was delivered, degree of satisfaction as well as effect, would give valuable additional information at an individual level.

Another advantage of the study is the possibility to follow the same individuals from one year to another. Unfortunately, the register does not include data on unemployment as a cause of disability pension. Another disadvantage is that occupation is not specified in the analysis.

Administrative materials are full of decisions regarding all sorts of investigations and research, made on all other ground than scientific. This must be taken in to consideration when interpreting the results. For example, during the study period a few of the individuals participating received disability pension twice. The effect of this is

unclear. The data material concerns one local municipality, and cannot be generalised for Sweden as a whole. The age and sex structure of the study population used is not significantly different from the general population of Sweden. Another advantage is the relatively low percentage of non-respondents. Some survey studies have indicated that the non-respondents might have a higher utilisation than the normal population (72).

The findings in this study suggest that the authorities initiate a high proportion of the utilisation, since the utilisation drops after allocation of disability pension. So given the resources invested in the process of disability pension, we might question the effectiveness of this process. In a report from early 1990s by the EU Commission, it is pointed out that the pension systems in the EC countries did adapt poorly to the transformation of early retirement in working life (79). This might have changed during latter time.

This study has used utilisation to measure and analyse the effect of a disability pension process, irrespective of the reason for disability pension. It is suggested that the decision process increases the utilisation. This utilisation does decrease after the allocation of disability pension, but there is also an indication of a higher utilisation afterwards, compared to the general population.

## DISCUSSION

A paradigm shift, towards a process-oriented integration management (81), is rapidly forming within the health and social service sector. This is due to several factors. Some of the most important are the rising costs of health and social services, as well as the development of new medical technologies. Another important factor is the different views that exist, internally as well as externally, of the health and social services (82,83). The internal view of (and focus on) being a highly professional organisation, does not correspond to the users view of the service concept. This has certain implications on how to evaluate two such different perspectives. One result of this is that there is a need for more consumer-orientated information of managing health and social services (84,85,86)

The suggested D5-model could for this purpose be a more useful tool due to the fact that the underlying data is based on individual characteristics and the context of the society where the data is collected. Locally based information also gives the different actors in the community possibility to act and react on the information. This is clearly related to the “tacit knowledge” that is available in the interpretation of the observed variations. In the model all data concerning individuals on personal matters is kept at a local level. The data at regional and central level are still based on individual data, presented as regular compiled statistics, related to regional or nationally stated targets (87,88). Øvretveit discusses this by introducing six different evaluation models (89). The D5-model, using existing antecedent data, fulfils the criteria on the data to be included in all of those models.

The best way to find out if the observed problem is related to the user or to the provider is by using the collected individual related information. Then, by aggregating it and linking sources to the utilisation patterns of different groups of individuals it will be possible to study the interactive relationship in the processes. The link between the information sources is then the individual and how this individual chooses to utilise the supplied services. But the focus is not on the individual, him/herself; it is on the information regarding utilisation, and how to be able to use this in the development of health and social services in a welfare system.

This will probably reduce the risk of misuse of data, as well as improve the local work in the public health arena. Due to the tacit knowledge held by the various public servants who serve the public, action can be more specific and public health programmes targeted to the actual recipients. There is also the possibility to evaluate how different providers act separately or in interaction, influencing each other. This is possible because the model includes information relating to the factor connecting the providers, and the individual who has a requirement and who is trying to fulfil this requirement.

The basic principle when introducing health and social service in a welfare system is to provide the population with a safe and supportive network. The citizens of most Western countries take the fact for granted that this network exists and is there for them

when individual sickness or social constraints become apparent (90,91,92). This is why many changes and reforms in a welfare state demand that follow-up studies and evaluative programs are undertaken, in order to study how the changes affect the system and what results this causes in the population (93-97).

Depth of need is sometimes difficult to assess, and we usually judge it in terms of the “amount” of response, or in comparison to the depth of other needs. That the available services should be based on needs is a simple idea but difficult to realise. One reason for this is that it is easier to think about a need by thinking about a ready-made way of meeting the need. We can sometimes work out a better way of meeting the need, if we try to understand the need itself, by comparing different users of service to those who choose not to utilise the services (68,70).

In conclusion it is necessary to create an information system that contains data from all elements of the integrated welfare system, if we are going to be able to identify the impact one sector's processes have on others. Without such an evaluation the possible achievements in effectiveness and efficiency, which are the goals of most reforms, will be restricted. Using a defined population will make it possible to evaluate this outcome, wanted or not wanted, from each provider in the welfare system but it will also provide information on the outcome for the individual (69).

There is a need to focus on the expectations of professionals and patients, needs and goal formulations as a basis for analysis, which will require the same data elements. Research concerning the contents and the use of resources in episodes of e.g. ambulatory care and some specialities with long and/or complex patterns of care, such as in psychiatry, has been difficult. This is due to the fact that the contacts are numerous and sometimes brief in time, and the gathering of data expensive. This is now changing, because of the increasing use of computerised medical record systems (98,99). This means that data can be collected without added expense. However, this development is in its infancy. It is likely that different minimum data sets (MDS) will be used for different patients and purposes. Regardless of the level of description (individual, aggregate or grouped) in order to make a uniform description applicable to a variety of applications (clinical, managerial, for quality development or pure economical purposes), it is of prime importance that several types of data about the patient (clinical, sociological, demographic and administrative) are obtained. This information is essential, in order to be able to explain and explore the utilisation patterns.

## **Management and confidentiality**

The process approach is restricted without information systems, but linking episodes of service is absolutely impossible, without creating a secure link between individual episode records within the service's information systems. It is vital to be able to identify the same patient in all systems uniquely and securely. The balance between activities by

the society and the individual to support and improve health is a chapter of its own (100-103). Too much activity from society might reduce the individual's own responsibility to reduce health risks, while on the other hand too much respect for individual integrity could reduce the chance of an early discovery as well as the impact of an early prevention. This must be taken into account and these two facts should be well balanced when the decision is made as to what type of data will be included.

Epidemiological research programmes, based on registered data of identified individuals, are not harmful to anyone, provided that they are carried out with due respect to confidentiality, as in fact was done in this case (104). The result implies the use of a more epidemiological orientated model as a prerequisite for a more effective planning, with a special interest in and with focus on the field of intervention and evaluation.

It is therefore by using this method possible to both evaluate complex health and social services structures from the consumer perspective as well as securing the individuals right to confidentiality.

Many researchers turn down the use of administrative data in health evaluation, especially at municipal level because they are concerned that the numbers may be too few (3, 105-108). It is true that small numbers make it impossible to perform statistical testing of significance. But a manager may not have time to wait for the accumulation of enough data for such tests. Therefore it is better for managers to have a little information instead of none at all, because decisions have to be made regardless. A more frequent use of these locally based registers may in the end give us better registers and a higher data quality, due to the fact that not only their validity will be questioned, but the question will also be asked as to why we continue to collect information from them (106).

In conclusion then, in order to help the welfare state perform more efficiently, it is important to make use of the information available and it would indeed be most unethical not to take advantage of the abundant sources of data, contained in the different types of administrative registers, available at municipal level. For this reason the D5-model should be used for management purposes.

## **Strengths and weaknesses of the employed assessment method**

The restrictions of the original CDM make it impossible to study and evaluate the outcome of multidimensional services given by different providers to one common group of individuals, e.g. treatment for a common factor of ill health. The D5-model does make it possible for us to study and identify different factors when suggesting a rehabilitation program. Using the information this way would also reflect the process of treatment and care in the welfare system.

Figures based on aggregated statistics are useful for planning. They indicate changes over time (yearly, monthly) of illness and social deprivation in the community. For those

in direct contact with the users of the welfare system these figures provide background and perspective. They could also be used to inform the public of the magnitude of the problem (109). When used as an evaluating tool to measure the utilisation and as a tool in interorganisational collaboration, information and figures of this kind are not sufficient. It would have been impossible to gain the results in this thesis without the individually linked information database. In a database like the D5 it is possible to follow administratively organised groups such as the disability pensions group at different providers, as well as to break down each individual case, in order to study the possible background factors for the individual's use of service.

It is important to consider strengths and weaknesses in the data-material. The major strengths are the uniqueness of a register which pools individual data about utilisation, and the presumed high quality of the data: The high quality of the D5-register is related to the fact that those responsible for registration were selected from the different provider's own staff, e.g. at the health centre one district nurse and one general physician went through all patient records and added the diagnosis.

One major weakness is the cost: It was immensely time-consuming to create the register and unfortunately the project was closed down before we were able to produce a continuous supply of results. This was due to underestimation of the resources needed to establish a register of this type. Another weakness is the reduced information on the validity of the data material.

The D5-model does have its limits. The administrative data, which was gathered in, was originally not aimed for research. Therefore, it was necessary to invent methods to increase the reliability and validity of the data and we did this in two steps. First of all, the appropriate variables were selected in consensus with the providers. Secondly, the provider's own staff and their tacit knowledge were used in registering the selected information.

There is a major investment in the establishment of a new pilot register such as the D5-register, due to the enormous workload entailed in transforming paper files into computer files. Relating to this we have shown that individually pooled data is a useful and powerful source of information for gaining new knowledge when evaluating the processes of utilisation in a welfare system.

## **The findings**

The differences when seeking service, which is found between e.g. men and women, can be related to the fact that they do have different expectations on the service provided and the likelihood of being cured. This is directly connected with the individual's own characteristics, such as pre-knowledge and experience, but could also be connected to the provider. Other factors of importance besides sex could be age, education and socio-economic status in the pattern and dynamic process in giving service and as a result this could have consequences on the impact of the service at population basis. The increase

as well as the decrease of consumption produced can be seen as a real increased need from the individual or produced due to the lack of an effectively organised welfare (health) system. The main conclusion from the test studies is that the use of services is strongly connected to the absence of information, “lack of overflow“, between the providers in the system.

## **Recommendations for policy**

This is the first time that a complete database, covering the use of a society's total resources by a defined population of identifiable individuals, is available. This was made possible by the introduction of a new model to collect and evaluate the system components, namely the D5 model. The main interest in evaluating the welfare system using epidemiological tools is that already tested and accepted models can be applied to the data (110,111). By keeping the information available for use at management level, in (computerised) databases together with interpretations of the result, it can then be used in the evaluation and managing of the services (112).

Many of the discussions regarding reformation of the Swedish welfare system are about how to evaluate the outcome of different reforms, as well as if the available data are useful or not.

There are many changes taking place in the health care system. Many of the old structures and methods are being questioned or discarded, and new models or approaches are being introduced. Using a defined population will probably make it possible to evaluate the outcome, wanted or not wanted, from each provider in the welfare system, at the same time as it will provide us with information of the outcome for each individual. Whether these studies are labelled as epidemiology, medical care research, or health services research makes little difference (113). The model itself does not present any such restrictions. The only notable restriction is if there is a misuse of available information, then confidence will be lost for allowing researchers to evaluate the welfare system components using individual information. But the use of data collected at an individual level is important if effectiveness and efficiency, as well as high quality are to be the target for the ongoing reforms of the welfare system.

## **Recommendations for further research and development of the method.**

There is another, not so obvious potential, of the register. Based on the fact that it is possible to select defined groups such as e.g. high consumers as well as low consumers, it is thus possible to study their use of welfare components over time. By doing this it might also be possible to identify the characteristics of the utilisation of such groups. The D5-model also provides a better tool than the CDM for studying and analysing the pattern behind visits, the pathways between services and also for introducing a new

model for a systematic quality assessment of a welfare system. There are few current studies on how individual users actually use the web of different providers in a welfare system, to promote their own health. It is also suggested that more studies should be introduced to find out what effect welfare systems actually have on the population.

The D5-model used in this thesis is, due to its experimental design, only using quantitative information from administrative sources. A complementary qualitative study introduced to answer questions about needs, demands for services, obstacles to utilisation, how the service was delivered, degree of satisfaction as well as effect would give valuable additional information at individual level (53,114,115). Another way to improve the use of the D5-model is to include data from regular health surveys where the individuals themselves have rated the risk factors in their life (116). This information would be of great value to the evaluators and scientists when combining this with D5-data, and transforming it into new knowledge for those who administer and manage the health and social services. This would then make it possible to concentrate and transfer the most suitable resources to those with the greatest need (117).

There are some recent research results that fully support the ideas of this thesis. One is a recent work by Wihren (118) which illustrates and discusses the use and usefulness of population based registers on the one hand, and specific research questions in epidemiology and healthcare research on the other hand. Another is the analyse presented by Wigertz and Westerling (119) of the usefulness of such registers, concluding that a central register is needed with information on patient diagnosis across all types of healthcare to make reasonable prevalence utilisation estimates. As is shown by Wihren (118) these administrative databases may also be used to address problems in epidemiology and healthcare research. This would then make it possible to study the determinants behind utilisation from a medical perspective.

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## APPENDICES

- Appendix 1: Permit by the Data Inspection Board.
- Appendix 2: Distribution of the population in Oxelösund and in Sweden by sex and 5-year age groups, pct.
- Appendix 3: Proportion of the population in Oxelösund and in Sweden who get disability pension and distribution by household and employment status, pct.
- Appendix 4: Information included in the D5-register per individual and year, during the period 01/01/1978 - 31/12/1988.
- Test study 1: Utilisation of health and social services during one year: Information from a register with data pooled at individual level.
- Test study 2: Utilisation of services by disability pensioners compared to a reference population.

## APPENDIX 1:

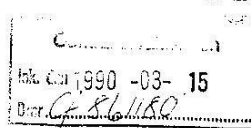
### Permit by the Swedish Data Inspection Board.

DATAINSPEKTIONEN

BESLUT  
1990-03-13

Dnr  
3604-89

Sörmlands läns landsting  
Förvaltningsutskottet  
Berndt Jonsson  
611 88 Nyköping



Ansökan om tillstånd för personregistret "D5-studien".

(2 bilagor)

Datainspektionen meddelar enligt datalagen (1973:289) tillstånd för förvaltningsutskottet att inrätta och till den 31 augusti 1990 föra personregistret.

Följande föreskrifter meddelas.

1. Ändamålet med registret skall vara att framställa ett avidentifierat register som skall vara underlag för en statistisk undersökning som syftar till att belysa de lokala hälsoförhållandenas relation till kostnaden för viss samhällsservice.
2. Registret får endast innehålla de uppgifter som framgår av ansökan.
3. Den registeransvarige skall tillse att enskild person inte avslöjas i de statistiska redovisningarna.
4. Den registeransvarige skall informera den som kan komma att registreras om
  - registrets ändamål och användning
  - vilka uppgifter som skall bearbetas med automatisk databehandling och varifrån de hämtas
  - sekretessskyddets innebörd och omfattning
  - att deltagandet i undersökningen vilar på frivillig grund och att den som så önskar kan avstå från att delta i undersökningen.

Härav följer att beträffande den som inte vill delta i undersökningen får inga uppgifter registreras.

5. Den registeransvarige skall tillse att personuppgifterna i de register som uppkommer vid insamling av uppgifterna samt i det sammanställda registret avidentifieras så snart som möjligt och senast vid tillståndstidens utgång.

Datainspektionen erinrar om att när registret upphör att föras (avidentifieras) skall anmälan härom inges till datainspektionen enligt 12 § datalagen.

Ansökan framgår av bilaga 1.

Datainspektionens överväganden framgår av bilaga 2.

Avgift enligt SFS 1989:693 bestäms till 1 980 kronor.

Beslut i detta ärende har fattats av undertecknad generaldirektör i närvaro av byråchefen Ulf G. Berg och avdelningsdirektören Gunilla Grahn, föredragande.

*Stina Wahlström*

Stina Wahlström

*Gunilla Grahn*  
Gunilla Grahn

Kopia till  
justitiekanslern  
riksarkivet (för samråd).

### Hur man överklagar datainspektionens beslut

Om Ni vill överklaga beslutet skall Ni skriva till datainspektionen. Tala om i brevet vilket beslut Ni överklagar genom att ange beslutets nummer. Tala också om vilken ändring i beslutet Ni vill ha. Uppge även Ert namn, adress och telefonnummer.

Datainspektionen måste ha fått Ert överklagande inom tre veckor från den dag Ni fått del av beslutet, annars kan överklagandet inte prövas.

Datainspektionen sänder överklagandet vidare till regeringen för prövning, om inspektionen inte själv ändrar beslutet på det sätt Ni har begärt.

Om något är oklart kan Ni vända Er till inspektionen.

Datainspektionen upplyser om att även justitiekanslern får överklaga beslutet för att ta till vara allmänna intressen.

| Postadress       | Besöksadress    | Telefon     | Exp.tid     |
|------------------|-----------------|-------------|-------------|
| Box 8114         | Fleminggatan 14 | 08-57 61 00 | 09.00-11.30 |
| 104 20 Stockholm | Plan 8          | Telefax     | 12.30-15.00 |
|                  |                 | 08-52 86 52 |             |

## APPENDIX 2:

### Distribution of the population in Oxelösund and in Sweden by sex and 5-year age groups, pct.

| <b>Oxelösund</b> | <b>Men</b> | <b>Women</b> | <b>Sweden</b> | <b>Men</b> | <b>Women</b> |
|------------------|------------|--------------|---------------|------------|--------------|
| 00-04            | 2.9        | 2.6          | 00-04         | 3.0        | 2.8          |
| 05-09            | 2.9        | 2.9          | 05-09         | 2.9        | 2.8          |
| 10-14            | 3.3        | 3.5          | 10-14         | 3.3        | 3.1          |
| 15-19            | 4.1        | 3.8          | 15-19         | 3.5        | 3.3          |
| 20-24            | 4.2        | 3.2          | 20-24         | 3.7        | 3.5          |
| 25-29            | 3.2        | 2.8          | 25-29         | 3.4        | 3.2          |
| 30-34            | 3.3        | 2.9          | 30-34         | 3.5        | 3.4          |
| 35-39            | 3.7        | 3.9          | 35-39         | 3.8        | 3.7          |
| 40-44            | 4.3        | 4.4          | 40-44         | 4.0        | 3.8          |
| 45-49            | 3.9        | 3.5          | 45-49         | 3.0        | 2.8          |
| 50-54            | 3.5        | 2.9          | 50-54         | 2.5        | 2.5          |
| 55-59            | 3.0        | 2.9          | 55-59         | 2.5        | 2.7          |
| 60-64            | 2.7        | 2.8          | 60-64         | 2.6        | 2.8          |
| 65-69            | 2.1        | 2.3          | 65-69         | 2.5        | 2.9          |
| 70-74            | 1.9        | 1.9          | 70-74         | 2.1        | 2.5          |
| 75-79            | 1.2        | 1.2          | 75-79         | 1.6        | 2.2          |
| 80-84            | 0.5        | 1.1          | 80-84         | 0.9        | 1.5          |
| 85-89            | 0.2        | 0.5          | 85-89         | 0.4        | 0.7          |
| 90-94            | 0.0        | 0.1          | 90-94         | 0.1        | 0.2          |
| 95-              | 0.0        | 0.1          | 95-           | 0.0        | 0.1          |
| Total n:o        | 6684       | 6450         |               |            |              |

### APPENDIX 3:

#### **Proportion of the population in Oxelösund and in Sweden who get disability pension and distribution by household and employment status, pct.**

|                                                    | <b>Sweden<br/>1986 (%)</b> | <b>Oxelösund<br/>1986 (%)</b> |
|----------------------------------------------------|----------------------------|-------------------------------|
| <b>Disability Pension</b>                          |                            |                               |
| 16-64 year                                         | 6.2                        | 7.8                           |
| 60-64 year                                         | 38.1                       | 29.8                          |
| <b>Proportion with foreign citizenship</b>         | 7                          | 5                             |
| <b>Household</b><br>(n:o of persons the household) |                            |                               |
| 1                                                  | 36                         | 33                            |
| 2                                                  | 31                         | 32                            |
| 3                                                  | 14                         | 15                            |
| 4                                                  | 13                         | 15                            |
| 5-                                                 | 6                          | 5                             |
| <b>Household (type of)</b>                         |                            |                               |
| Single, men                                        | 16                         | 19                            |
| Single, women                                      | 20                         | 14                            |
| Single w. kids                                     | 3                          | 3                             |
| Cohabiting w. no kids                              | 33                         | 37                            |
| Cohabiting w. kids                                 | 22                         | 23                            |
| Non of above                                       | 6                          | 4                             |
| Total n:o of households                            |                            | <b>5674</b>                   |
| <b>Gainfully employed in different sectors</b>     |                            |                               |
| Agriculture, forestry, hunting and fishing         | 5                          | 1                             |
| Mining, quarrying and manufacturing                | 22                         | 41                            |
| Electricity, gas and water supply                  | 1                          | 0                             |
| Construction                                       | 6                          | 4                             |
| Wholesale and retail trade, Hotels and restaurants | 13                         | 10                            |
| Transport, storage and communication               | 7                          | 7                             |
| Real estate, renting and business activities       | 7                          | 7                             |
| Public sector                                      | 37                         | 28                            |

#### APPENDIX 4:

#### **Information included in the D5-register per individual and year, during the period 01/01/1978 - 31/12/1988.**

| Variable                                                  | Source of information                                                 |
|-----------------------------------------------------------|-----------------------------------------------------------------------|
| Socio-demographic information                             |                                                                       |
| Age                                                       | The Swedish civil registration register                               |
| Year of birth                                             | The Swedish civil registration register                               |
| Sex                                                       | The Swedish civil registration register                               |
| Nationality (Country of origin)                           | The Swedish civil registration register                               |
| County of birth                                           | The Swedish civil registration register                               |
| Income (using the income qualifying for sickness benefit) | Social insurance office                                               |
| Education (uncompleted)                                   | Employment service                                                    |
| Social information                                        |                                                                       |
| Marital status                                            | The Swedish civil registration register                               |
| Area of living (Seven defined socio-economical areas)     | The Swedish civil registration register                               |
| Profession                                                | Social insurance office, Employment service                           |
| Employer                                                  | Social insurance office, Employment service                           |
| Pathways of contact                                       |                                                                       |
| Referral (in out-patient care)                            | Primary Health Care unit, Occupational Health Care (3 separate units) |
| Path of admittance                                        | Each provider                                                         |
| Contact (if established with other providers)             | Each provider                                                         |
| Year of visit                                             | Each provider's administrative data                                   |
| Day of visit                                              | Each provider's administrative data                                   |

Type of/reason for contact

|                                                                 |                                                                                                 |
|-----------------------------------------------------------------|-------------------------------------------------------------------------------------------------|
| Diagnosis (complete: ICD-8, ICD-9)                              | In-patient care 1978 - 1982, In-patient care 1983 - 1988                                        |
| Diagnosis (main diagnosis, ICD-9)                               | Primary Health Care unit, Occupational Health Care (3 separate units), Child Health Care Centre |
| Clinic of treatment                                             | In-patient care 1978 - 1982, In-patient care 1983 - 1988                                        |
| Code for surgery (uncompleted)                                  | In-patient care 1978 - 1982, In-patient care 1983 - 1988                                        |
| Sick leave (duration)                                           | Social insurance office                                                                         |
| Handicap (work related)                                         | Employment service                                                                              |
| Alcohol, Use of (indirect measure)                              | Social services office - Family care, the local police office (traffic related)                 |
| Prescription (type of pharmaceutical drug and dose, ATC-code)   | Health services, the local pharmacy                                                             |
| Actual action                                                   | Each provider                                                                                   |
| Admitted mission                                                | Each provider                                                                                   |
| Kind of contact                                                 | Each provider                                                                                   |
| Reimbursement                                                   | Social insurance office                                                                         |
| Date of old age pension                                         | Social insurance office                                                                         |
| Date of disability pension                                      | Social insurance office                                                                         |
| Transport service (elderly and/or disabled)                     | Social services office - Old age care                                                           |
| Public home help service                                        | Social services office - Old age care                                                           |
| Different kinds and amount of financial support, subsidies etc. | Social services office - Family care, Employment service, Social insurance office               |

APPENDIX 5:

**Test study 1: Utilisation of health and social services during one year: Information from a register with data pooled at individual level.**

## **Abstract**

Community diagnoses compile statistical information on utilisation of health and social services. The objectives of this study are,

- 1) to demonstrate the potential of an alternative to the community diagnosis model based on individually pooled data, and
- 2) to describe the pattern of utilisation of health care and social services in a Swedish municipality during a one year period in relation to basic socio-demographic characteristics.

The study population is a 10% random sample from a Swedish municipality (n=2043). The data set extracts utilisation information from approx. 15 service providers over a period of eleven years. The utilisation pattern presented comprises 1280 individuals in the year 1988.

Utilisations of services vary by sex and age. Fifteen percent of the women and 23% of the men did not use any service. The highest utilisation rate for health care among men and women is in age group 65 plus. The proportion not using health care in the age group 65+ is 24%. Use of health services increases with increasing age for both men and women above age of 15 years. Use of social services increases until age of 20-44 and then decreases. Socio-demographic predictors of utilisation differ among men and women.

Keywords: health services research, community diagnoses, utilisation of health and social services.

## Introduction

In the Swedish Welfare System, SWS, it is a fundamental principle that all citizens have the right to good health and equal access to both health care and social services (Svallfors 1991), The Swedish Health and Medical Services Act 1982, The Swedish Social Services Act 1980). During the 1980's SWS provided services without means testing and regardless of the citizen's social circumstances. The Swedish Government provides legislation and guidelines. The Government sometimes issues guidelines through the National Board of Health and Welfare. The regional and local authorities - counties and municipalities - run the health and social systems. The people directly elect the County Councils and Municipality Councils. County Councils have been commissioned by the Parliament to run the health care services. Their responsibilities include preventive health care and medically orientated services as well as dental care through the national dental service system. Municipality Councils run most of the social services. The privately financed and managed sector of health and medical care (excluding dental care and pharmaceuticals) is relatively small, less than 4% of the total health care expenditure (Berleén et al. 1992).

The County Councils and municipalities, levy taxes directly on the population. Other sources of income are national government block grants and a fee for certain services. From January 1992, the responsibility for nursing homes and their financing as well as home care has been transferred from the county council's primary care to the municipalities. The main part of health care expenditure in Sweden is tax financed, 86% in 1992 (Rehnberg et al. 1995).

The use of the community diagnosis model, CDM (HS 90 1984, Morris 1975, Dever 1980), is well established. CDM provides compiled information about health and social indicators from available sources and attempt to diagnose the condition (health status) of the population in a defined geographical area. This descriptive information is often used in the planning of the SWS and/or for health promotion activities (Haglund 1985, Haglund et al. 1990).

The Oxelösund Study used the CDM as a tool to collect the necessary descriptive information (Collaboration in favour of health and economy. Final report 1991, Collaboration in favour of health and economy. Appendix 1991, Gertz & Hallman 1992). It became clear that the information provided was not sufficient. The information from the CDM described the situation on a population level, not on an individual level. The article presents data from a research register based on individual data, a random sample of the population from which individual information is collected from the providers of services.

The objectives of this study are,

- 1) to demonstrate the potential of an alternative to the community diagnosis model based on individually pooled data, and
- 2) to describe the pattern of utilisation of health care and social services in a Swedish municipality during a one year period in relation to basic socio-demographic characteristics.

## Methods

### Sampling and Study population

The Swedish civil registration register is a public database with all the birth registration number of the citizens living in a certain geographical area. The sample population is a 10% random sample of the resident population in Oxelösund municipality selected from this register. Due to the restriction of three birthdays the new register was given the name “D5“, read as “born on the Day 5, 15 or 25:th in each month“. The sample comprises the juridical resident population during each of the years in the period 1978 - 1988; i.e. we made a new sample each of the 11 years. The sample population is, then, an open cohort in which participants can be present or non-present each of the 11 years in the observation period.

Due to ethical aspects, as well as political, a letter was sent out to the selected population of 2365 surviving individuals (100%) present during the 11 year period that matched the selection criteria asking them if they would agree to let us collect and use their individual records. A total of 322 (13.6%) refused. This left us with 2043 (86.4%) individuals in the study population of which 761 lived in the area during all 11 years and 1282 lived there less than 11 years. The average annual study population was 1327. To control if there was any selection bias caused by missing information about the refusers a comparing study about utilisation patterns among the resident population was done using the available aggregated data. The results from this sensitivity study did not show any selection bias.

The utilisation pattern presented in this article comprises the 1280 individuals included in the year 1988. The resident population in Oxelösund in the year 1988 was 12,924 individuals (women 6,302, men 6,622).

During the coding process we discovered that approximately 1/6 of the population was missing in 1979 and 1983. A decision was made that if each individual was registered the year before and after 1979 and all socio-demographic variables were exactly the same, then it was accepted that the individual was present 1979. The same procedure was used for 1983. Table 1 describes the distribution of the study population and the refuser's population.

### Data collection

The Swedish civil registration register comprises information about birth registration number, age, sex, marital status, place of birth, nationality, street address etc. The birth registration number was used as the key to select the appropriate information during the time period 01011978 - 31121988. The information was collected from all providers of health and social services to the population in the municipality of Oxelösund. The reform "free choice of a provider" had not yet been introduced into the SWS at this point of time. The D5 register also includes data on utilisation of formal services by the citizens of Oxelösund outside the local community and thereby provides a total picture of the study population's use of services.

## Data

The database includes Socio-demographic information, Social information, Pathways of contact and Type of/reason for contact. (Appendix 1)

The article presents utilisation of services, calculated as numbers of contacts in which some kind of service is delivered.

The providers were divided in to two subgroups; HEALTH includes primary health care, outpatient and in-patient care, occupational care as well as childcare. Dental care is not included. SOCIAL includes social services, employment service and public social insurance.

The analysis includes the following independent variables; sex, age group, marital status, socio-economic status (SES), number of years in the study population, land of origin and unemployment. SES is defined by area. Area 1 is a wealthy coastal residential area with large owner-occupied dwellings, area 3 is a non-wealthy inner-city area close to a major steelwork industry, and area 2 is all other areas. Unemployment is defined as a person actively applying for a new job. Country of origin is defined as Swedish, Nordic and non-Nordic.

The use of services during the one year 1988 is tested for homogeneity across sex and age groups by means of chi-square test or by Fisher's exact test. The factors predicting utilisation are explored by use of a categorical multivariate model. All analyses are carried out separately for men and women. The predictor variables are marital status, unemployment, age, sex, number of years in the study population, SES, and country of origin. Computation used the SAS version 9, CATMOD procedure, (SAS 2002).

The article reports three analyses with identical sets of predictor variables and with separate response variables, use of health services, use of social services, and use of both health and social services.

Use of social services includes individuals that are unemployed and receive help for job application. Help for job application is also a predictor variable for the unemployed. Job application was excluded in analyses of utilisation of social services due to the problem with redundancy.

## Results

The study population is tested for age bias in distribution by comparison with the original population of Oxelösund (women  $\chi^2=16.571$ , df=19, p=0.6189 and men  $\chi^2=25.396$ , df=18, p=0.1144).

Table 2 displays the proportion of each age group who utilises each of the services. The total is given for each kind of provider. The age group 00-14 does not use SOCIAL services according to administrative rules.

Table 3 presents the distribution of visits to HEALTH and SOCIAL services. The use of HEALTH services increases with age. In the age group 20-44 the utilisation is higher among women than men (OR=0.541, CI=0.368-0.797, Fisher's exact test 0.0012).

Table 4 shows the proportion of the study population using combinations of HEALTH and SOCIAL services (- = no use, + = use). Among women 15% did not use any kind of service and the corresponding figure for men is 23% (OR=1.612, CI=1.213-2.144,

Fisher's exact test 0.0006). The age structure of non-users (-/-) (n=254) differs significantly between men and women. The proportion of male and female non-users are: 00-14 years 48%,52%, 15-19 years 37%,63%, 20-44 years 22%,78%, 45-64 years 35%,65%, and 65+ years 48%,52%, ( $\chi^2=10.480$  df=4 p=0.0331).

The multivariate, categorical regression analysis was carried out in a series of steps, starting with the full model. Predictor variables, which showed no significant effect, were deleted from the model one by one and the reduced model was re-applied to the data. This process was repeated until all remaining predictor variables were significant. Age group, however, was included in all steps of the analyses regardless of the level of significance. Age group 00 - 14 was excluded from the analyses of SOCIAL services due to the administrative rules of access.

Significant predictors of use of health services were: Men: Use of social services, unemployment, age. Women: Age group. Significant predictors of use of social services were: Men: Use of health services and age. Women: Unemployment and age. Predictors of at least one service were: Men: Age. Women: Unemployment, non-Nordic origin.

The final model for prediction of use of HEALTH services shows the following predictors for men: Use of SOCIAL services, unemployment, and age outside 20 - 44; for women: Age 15 - 19.

Among men the predictors for high use of SOCIAL services are use of HEALTH services, age 20 - 44 and age 45 - 64, as well as low SES; for women: unemployment and age 20 - 44 as well as age 45 - 64.

Finally, the analysis of predictors for any service ('HEALTH' and 'SOCIAL') shows the following significant predictors for men:

age 20 - 44 and age 45 - 64, as well as low SES; for women: unemployment, age 20 - 44 and age 45 - 64, as well as non-Nordic.

Table 5 shows the key information from the CATMOD analyses.

## Discussion

A problem in evaluating a welfare system or any service system - publicly or privately financed - is that the outcome of the system is dependent of how the individual do choose to utilise it (Hallman & Rehnberg 1991, Rehnberg & Hallman 1992, Hallman 1994). Little is known about this choice. In Sweden, as in other countries, the CDM has mainly been used to describe the consumer's choice and to support the implementation of health action programs and strategies (Persson 1989, Rosen 1987, Boonstra & Fugelli 1990, Bjärås 1992, Nyhammer et al. 1992, Bjärås 1993, Surles & Blue 1993, Bjärås et al. 1997). CDM however gives no real indication of choice and the processes behind. Another restriction is that the CDM does not provide sufficient information for the evaluation and validation of different programs run by one of the providers. As an example, in a program aimed at reducing alcohol intake in the population there might be no obvious outcome for the single provider but the outcome might be clearly seen in another provider's statistics. The D5-model gives us the possibility to study and identify different factors in such a program. This way of using utilisation information also reflects the process of treatment and caretaking by the SWS.

In an important work by Pill et al. (1995) the ability to study the factors behind CDM statistics was pointed out as one of the main restrictions in using descriptive, aggregated information.

Using the D5 register model will help to achieve new information about the patterns of service utilisation (Penning 1995). Most prior studies of service utilisation are based on survey studies. The D5 register provides an alternative, which use individually pooled data to describe utilisation of services in the SWS.

The proportion of the study population presented in table 2 which use primary health services is consistent with earlier findings as well as findings about the higher utilisation by women (47%) compared to men (38%) (Ejlertsson 1981). This higher utilisation might be explained by female specific diagnosis (Gijbers et al. 1992). One other finding of interest in this study is the proportion of the non-users. Of the study population 19% (women 15%, men 23%) do not use any services at all during one year. This corresponds with findings in the earlier mentioned work by Ejlertsson (1981) for use of primary health and outpatient care.

The lower proportion of non-users in this study is probably related to a better developed occupational health care and that both in-patients as well as child care have been included. We do not know if this proportion of non-users illustrates no need for services or hesitance to use services. Some persons in this group might have access to other providers, e.g. if they are commuters they might have access to occupational health care at their workplace. The difference between women and men in not using the providers is not related to a single age group. This information gives us another piece in the process of describing the differences between men and women and the way the individuals act to promote their own health (David & Kaplan 1995).

Another interesting finding relate to the predictors of use of services: The highest proportion using both HEALTH and SOCIAL services is clearly related to the age group 20-64 for both sexes. Socio-demographic characteristics as unemployment and SES might be confounding factors. This is partly supported by findings in a study of frequent attendees to Finnish public primary health care where socio-demographic data was used (Karlsson et al. 1994). One reason for the utilisation pattern identified in D5 could be that the age group 20-64 might have a better knowledge of the structure of the SWS and how to "use" the different providers. Another reason might be related to the fact that many of the components in the SWS have been almost free of charge or accessible at a very low fee for the individuals in this age group.

Elderly people (65+) are frequent consumers of HEALTH services. This is probably related to the increase in chronic illnesses by age and to the fact that older people when affected by injuries or other illnesses have slower recovering processes which imply more return visits. In contrast to this, it is interesting that the proportion of elderly people (65+) that do not use HEALTH services during one year is 24% (women 22,4%, men 25,8%). Those findings correspond with available data from a survey study in California published by Shapiro and Roos (1985).

Another interesting finding is that the predictors of use of social services differ by sex, since low SES is a predictor among men but not woman, and unemployment is a predictor among woman but not men. Non-Nordic origin is a predictor off use of

services among women but not men. A number of findings are confirmed by other studies about utilisation of one or two provider's (Ejlertsson 1981, Shapiro & Roos 1985, Hallman & Rehnberg 1991, Rehnberg & Hallman 1992, Hallman 1994, LeClere et al. 1994, Gliksman et al. 1995, Joung et al. 1995, Keskimäki et al. 1995, Kaprio et al. 1996, Sundqvist & Johansson 1997).

The SWS has been reformed due to economical and political changes during the 11 years study period. There have been recent changes in administrative rules; e.g. reduction of income compensation but the main structure of the SWS is intact. The data material concerns one local municipality that can't be generalised to the whole country. Strength of the data material is that the age structures and sex of the study population used is not significantly different from the general population. Another strength is the relatively low percentage of non-respondents. It has been indicated in survey studies that the non-respondents might have a higher utilisation than the normal population (Karlsson et al. 1994).

There are limitations to the use of the introduced D5-model. The collected administrative information used was originally not aimed for use in research. To use it we had to identify means to improve the reliability and validity of the information. We discussed available information sources with each of the providers and we used each provider's own staff and their tacit knowledge to transfer the selected information (mainly paper files) to electronic media. There is a major investment in the establishment of a new pilot register as the D5 register due to the labour intensive work of transforming paper files into computer files. The quality of the D5 register is probably high because the transformation was carried out by the provider's own staff. At the primary health care centre (P.H.C.) one district nurse and one medical doctor went through all patient records and added the diagnoses. It is of course a success that information based on individual utilisation of health care and social services can be presented.

There is another less obvious potential of the register. It is possible to identify high consumers as well as low consumers and then study their use of welfare components over time. By doing this it might be possible to identify the characteristics of such groups. The D5-model also gives us a better tool than the CDM to study the causes behind visits, study the pathways between services and also to introduce a new model for a systematic quality assessment of a welfare system.

There are few studies of how individual users actually use the web of different providers in a welfare system to promote their own health. More studies should be introduced to identify what effect welfare systems actually have on the population. The D5-model is due to its design, only using quantitative information from administrative sources. A complementary qualitative study introduced to answer questions about needs, demands for services, obstacles to utilisation, how the service was delivered, degree of satisfaction as well as effect would then give valuable additional information on the individual level. This is important for two reasons, first to study utilisation patterns and pathways of individuals by certain characteristics (sex, age, marital status, socio-economic status etc.), second to provide explanations for findings as well as compare those with other studies concerning utilisation.

Due to the organisational structure of the SWS as well as the enormous variety of services it provides for the Swedish citizens it has until now been impossible to study the actual patterns of utilisation. For the first time this is now possible in a pilot study from one Swedish locality. This approach also gives information about those who do not use the services.

## References study 1

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## **Tables and Appendices study 1.**

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### **Appendix 1**

Table 1: The study population by age, sex and year

| Age<br>Year                        | 00 – 14<br>Women Men | 15 - 19<br>Women Men | 20 - 44<br>Women Men | 45 - 64<br>Women Men | 65 +<br>Women Men | Total<br>Women Men | Total |
|------------------------------------|----------------------|----------------------|----------------------|----------------------|-------------------|--------------------|-------|
| 1978                               | 145 167              | 54 61                | 241 308              | 141 154              | 54 66             | 635 756            | 1391  |
| 1979 <sup>3</sup>                  | 136 158              | 60 62                | 239 315              | 144 154              | 55 73             | 634 762            | 1396  |
| 1980                               | 132 153              | 69 59                | 241 297              | 138 156              | 59 74             | 639 739            | 1378  |
| 1981                               | 123 135              | 62 72                | 232 292              | 151 156              | 66 79             | 634 734            | 1368  |
| 1982                               | 127 118              | 63 72                | 220 281              | 148 155              | 65 75             | 623 701            | 1324  |
| 1983 <sup>3</sup>                  | 115 109              | 66 75                | 215 278              | 150 156              | 70 81             | 616 699            | 1315  |
| 1984                               | 115 105              | 58 71                | 220 280              | 154 165              | 70 80             | 617 701            | 1318  |
| 1985                               | 117 107              | 45 60                | 227 269              | 153 158              | 75 79             | 617 673            | 1290  |
| 1986                               | 107 97               | 39 50                | 217 265              | 151 162              | 74 86             | 588 660            | 1248  |
| 1987                               | 101 111              | 45 53                | 218 274              | 160 169              | 75 87             | 599 694            | 1293  |
| 1988                               | 106 103              | 39 48                | 212 262              | 163 182              | 76 89             | 596 684            | 1280  |
| Total <sup>1</sup>                 | 281 283              | 68 77                | 385 451              | 170 182              | 67 79             | 971 1072           | 2043  |
| Refuser<br>population <sup>2</sup> | 18 10                | 7 9                  | 77 36                | 56 53                | 26 30             | 184 138            | 322   |

<sup>1</sup>) Numbers of persons at given age included at least one observation year.

<sup>2</sup>) Refusers age 1988-12-31.

<sup>3</sup>) The numbers for 1979 and 1983 have been corrected due to error in the registration process.

Table 2. Proportion of the study population who use services per provider 1988.

| Sex                                            | Men            | Women          | Men           | Women         | Men            | Women          | Men            | Women          | Men          | Women        | Men            | Women          |
|------------------------------------------------|----------------|----------------|---------------|---------------|----------------|----------------|----------------|----------------|--------------|--------------|----------------|----------------|
| Age group                                      | 00-14<br>N=103 | 00-14<br>N=106 | 15-19<br>N=48 | 15-19<br>N=39 | 20-44<br>N=262 | 20-44<br>N=212 | 45-64<br>N=182 | 45-64<br>N=163 | 65 +<br>N=89 | 65 +<br>N=76 | Total<br>N=684 | Total<br>N=596 |
| Primary Health Care unit                       | 14.6           | 15.1           | 33.3          | 35.9          | 37.8           | 49.5           | 34.6           | 56.4           | 73.0         | 68.4         | 37.7           | 46.8           |
| Out-patient care                               | 62.1           | 67.9           | 56.3          | 56.4          | 49.2           | 61.3           | 58.2           | 68.1           | 79.8         | 81.6         | 58.0           | 66.6           |
| In-patient care                                | 8.7            | 5.7            | 0.0           | 0.0           | 5.0            | 15.1           | 8.8            | 4.3            | 19.1         | 13.2         | 8.0            | 9.2            |
| Occupational Health<br>Care (3 separate units) | 0.0            | 0.0            | 2.1           | 0.0           | 15.3           | 9.9            | 20.9           | 17.2           | 2.2          | 0.0          | 11.8           | 8.2            |
| Child Health Care Centre                       | 37.9           | 37.7           | 10.4          | 5.1           | 0.0            | 0.0            | 0.0            | 0.0            | 0.0          | 0.0          | 6.4            | 7.0            |
| Social insurance office                        | 0.0            | 0.0            | 14.6          | 28.2          | 70.6           | 74.5           | 48.4           | 54.0           | 2.2          | 0.0          | 41.2           | 43.1           |
| Social services office -<br>Old age care       | 0.0            | 0.0            | 0.0           | 0.0           | 0.0            | 0.0            | 0.5            | 0.6            | 6.7          | 6.6          | 1.0            | 1.0            |
| Social services office -<br>Family care        | 0.0            | 0.0            | 0.0           | 7.7           | 9.2            | 6.1            | 1.6            | 1.2            | 2.2          | 0.0          | 4.2            | 3.0            |
| Employment service                             | 0.0            | 0.0            | 2.1           | 15.4          | 10.3           | 17.5           | 6.0            | 8.6            | 0.0          | 0.0          | 5.7            | 9.6            |

Table 3 The distribution of the study population by the number of visits 1988.

| Number of visits | 00-14 Men<br>N=103 | 00-14 Women<br>N=106 | 15-19 Men<br>N=48 | 15-19 Women<br>N=39 | 20-44 Men<br>N=262 | 20-44 Women<br>N=212 | 45-64 Men<br>N=182 | 45-64 Women<br>N=163 | 65 + Men<br>N=89 | 65 + Women<br>N=76 | Total Men<br>N=684 | Total Women<br>N=596 |
|------------------|--------------------|----------------------|-------------------|---------------------|--------------------|----------------------|--------------------|----------------------|------------------|--------------------|--------------------|----------------------|
| HEALTH           |                    |                      |                   |                     |                    |                      |                    |                      |                  |                    |                    |                      |
| 0 visits         | 34%                | 31%                  | 42%               | 41%                 | 41%                | 28%                  | 33%                | 26%                  | 15%              | 17%                | 35%                | 28%                  |
| 1 visit          | 25%                | 34%                  | 22%               | 26%                 | 7%                 | 9%                   | 17%                | 15%                  | 19%              | 11%                | 15%                | 16%                  |
| 2 visits         | 9%                 | 16%                  | 19%               | 10%                 | 9%                 | 10%                  | 13%                | 9%                   | 12%              | 20%                | 11%                | 12%                  |
| 3 visits         | 13%                | 7%                   | 4%                | 0%                  | 11%                | 14%                  | 9%                 | 10%                  | 9%               | 12%                | 10%                | 10%                  |
| 4 visits         | 6%                 | 3%                   | 0%                | 3%                  | 5%                 | 9%                   | 7%                 | 5%                   | 8%               | 11%                | 5%                 | 7%                   |
| 5 or more visits | 13%                | 9%                   | 13%               | 20%                 | 27%                | 30%                  | 21%                | 35%                  | 37%              | 29%                | 24%                | 27%                  |
| Total            | 100%               | 100%                 | 100%              | 100%                | 100%               | 100%                 | 100%               | 100%                 | 100%             | 100%               | 100%               | 100%                 |
| SOCIAL           |                    |                      |                   |                     |                    |                      |                    |                      |                  |                    |                    |                      |
| 0 visits         | 100%               | 100%                 | 83%               | 68%                 | 25%                | 21%                  | 48%                | 42%                  | 89%              | 93%                | 55%                | 53%                  |
| 1 visit          |                    |                      | 0%                | 3%                  | 12%                | 13%                  | 12%                | 7%                   | 3%               | 3%                 | 8%                 | 7%                   |
| 2 visits         |                    |                      | 7%                | 3%                  | 15%                | 10%                  | 13%                | 12%                  | 1%               | 1%                 | 10%                | 7%                   |
| 3 visits         |                    |                      | 2%                | 0%                  | 11%                | 15%                  | 9%                 | 8%                   | 0%               | 1%                 | 7%                 | 8%                   |
| 4 visits         |                    |                      | 0%                | 8%                  | 6%                 | 11%                  | 4%                 | 5%                   | 0%               | 1%                 | 3%                 | 6%                   |
| 5 or more visits |                    |                      | 8%                | 18%                 | 31%                | 30%                  | 14%                | 26%                  | 7%               | 1%                 | 17%                | 19%                  |
| Total            | 100%               | 100%                 | 100%              | 100%                | 100%               | 100%                 | 100%               | 100%                 | 100%             | 100%               | 100%               | 100%                 |

Table 4. The distribution of the study population by use of HEALTH/SOCIAL services 1988 by age and sex.

| Use of HEALTH/SOCIAL | 00-14 Men<br>N=103 | 00-14 Women<br>N=106 | 15-19 Men<br>N=48 | 15-19 Women<br>N=39 | 20-44 Men<br>N=262 | 20-44 Women<br>N=212 | 45-64 Men<br>N=182 | 45-64 Women<br>N=163 | 65 + Men<br>N=89 | 65 + Women<br>N=76 | Total Men<br>N=684 | Total Women<br>N=596 |
|----------------------|--------------------|----------------------|-------------------|---------------------|--------------------|----------------------|--------------------|----------------------|------------------|--------------------|--------------------|----------------------|
| - / -                | 35.0               | 31.1                 | 39.6              | 28.2                | 17.6               | 6.1                  | 22.0               | 13.5                 | 14.6             | 15.8               | 22.5               | 15.3                 |
| - / +                | 0.0                | 0.0                  | 2.1               | 12.8                | 24.0               | 21.7                 | 11.0               | 12.9                 | 0.0              | 1.3                | 12.3               | 12.2                 |
| + / -                | 65.0               | 68.9                 | 43.8              | 41.0                | 7.6                | 15.1                 | 26.4               | 28.8                 | 74.2             | 77.6               | 32.5               | 38.1                 |
| + / +                | 0.0                | 0.0                  | 14.6              | 18.0                | 50.8               | 57.1                 | 40.6               | 44.8                 | 11.2             | 5.3                | 32.7               | 34.4                 |
| Total                | 100%               | 100%                 | 100%              | 100%                | 100%               | 100%                 | 100%               | 100%                 | 100%             | 100%               | 100%               | 100%                 |

Table 5. Significant predictors of use of HEALTH and SOCIAL services, separately for men and women, OR and 95% CI.

|                                    |                                 | OR   | CI (lower limit – upper limit) |
|------------------------------------|---------------------------------|------|--------------------------------|
| Health services,<br>Men            | Use of social services / no use | 1.92 | 1.55 – 2.37                    |
|                                    | Unemployed / employed           | 1.68 | 1.11 – 2.55                    |
|                                    | Age group 00 – 14               | 1.28 | 0.85 – 1.95                    |
|                                    | 15 – 19                         | 0.81 | 0.49 – 1.33                    |
|                                    | 20 – 44                         | 0.35 | 0.25 – 0.49                    |
|                                    | 45 – 64                         | 0.76 | 0.55 – 1.05                    |
|                                    | 65 +                            | 1.00 |                                |
| Health services,<br>Women          | Age group 00 – 14               | 0.96 | 0.64 – 1.45                    |
|                                    | 15 – 19                         | 0.57 | 0.33 – 0.98                    |
|                                    | 20 – 44                         | 0.87 | 0.60 – 1.27                    |
|                                    | 45 – 64                         | 1.01 | 0.69 – 1.41                    |
|                                    | 65 +                            | 1.00 |                                |
| Social services,<br>Men            | Use of health service / no use  | 1.89 | 1.52 – 2.34                    |
|                                    | Age group 15 – 19               | 0.40 | 0.21 – 0.77                    |
|                                    | 20 – 44                         | 6.70 | 4.61 – 9.75                    |
|                                    | 45 – 64                         | 2.17 | 1.50 – 3.14                    |
|                                    | 65 +                            | 1.00 |                                |
|                                    | Area High social area           | 0.75 | 0.56 – 1.01                    |
|                                    | Mid social area                 | 0.84 | 0.64 – 1.10                    |
|                                    | Low social area                 | 1.00 |                                |
| Social services,<br>Women          | Unemployed / employed           | 1.75 | 1.19 – 2.56                    |
|                                    | Age group 15 – 19               | 0.62 | 0.34 – 1.13                    |
|                                    | 20 – 44                         | 5.55 | 3.78 – 8.15                    |
|                                    | 45 – 64                         | 2.13 | 1.46 – 3.12                    |
|                                    | 65 +                            | 1.00 |                                |
| Health & Social services,<br>Men   | Age group 15 – 19               | 0.55 | 0.29 – 1.04                    |
|                                    | 20 – 44                         | 2.87 | 2.05 – 4.02                    |
|                                    | 45 – 64                         | 1.90 | 1.32 – 2.72                    |
|                                    | 65 +                            | 1.00 |                                |
|                                    | Area High social area           | 0.93 | 0.70 – 1.22                    |
|                                    | Mid social area                 | 0.80 | 0.62 – 1.03                    |
|                                    | Low social area                 | 1.00 |                                |
| Health & Social services,<br>Women | Unemployed / employed           | 1.63 | 1.20 – 2.23                    |
|                                    | Age group 15 – 19               | 0.60 | 0.30 – 1.19                    |
|                                    | 20 – 44                         | 3.84 | 2.57 – 5.72                    |
|                                    | 45 – 64                         | 2.39 | 1.58 – 3.62                    |
|                                    | 65 +                            | 1.00 |                                |
|                                    | Country of origin Swedish       | 0.74 | 0.47 – 1.17                    |
|                                    | Nordic                          | 0.53 | 0.30 – 0.94                    |
|                                    | Non Nordic                      | 1.00 |                                |

## Study 1, Appendix 1

Information included in the D5-register per individual and year,  
during the period 01/01/1978 - 31/12/1988

| Variable | Source of information |
|----------|-----------------------|
|----------|-----------------------|

### Socio-demographic information

|                                                           |                                         |
|-----------------------------------------------------------|-----------------------------------------|
| Age                                                       | The Swedish civil registration register |
| Year of birth                                             | The Swedish civil registration register |
| Sex                                                       | The Swedish civil registration register |
| Nationality (Country of origin)                           | The Swedish civil registration register |
| County of birth                                           | The Swedish civil registration register |
| Income (using the income qualifying for sickness benefit) | Social insurance office                 |
| Education (uncompleted)                                   | Employment service                      |

### Social information

|                                                       |                                             |
|-------------------------------------------------------|---------------------------------------------|
| Marital status                                        | The Swedish civil registration register     |
| Area of living (Seven defined socio-economical areas) | The Swedish civil registration register     |
| Profession                                            | Social insurance office, Employment service |
| Employer                                              | Social insurance office, Employment service |

### Pathways of contact

|                                               |                                                                       |
|-----------------------------------------------|-----------------------------------------------------------------------|
| Referral (in out-patient care)                | Primary Health Care unit, Occupational Health Care (3 separate units) |
| Path of admittance                            | Each provider                                                         |
| Contact (if established with other providers) | Each provider                                                         |
| Year of visit                                 | Each provider's administrative data                                   |
| Day of visit                                  | Each provider's administrative data                                   |

### Type of/reason for contact

|                                                                 |                                                                                                 |
|-----------------------------------------------------------------|-------------------------------------------------------------------------------------------------|
| Diagnosis (complete: ICD-8, ICD-9)                              | In-patient care 1978 - 1982, In-patient care 1983 - 1988                                        |
| Diagnosis (main diagnosis, ICD-9)                               | Primary Health Care unit, Occupational Health Care (3 separate units), Child Health Care Centre |
| Clinic of treatment                                             | In-patient care 1978 - 1982, In-patient care 1983 - 1988                                        |
| Code for surgery (uncompleted)                                  | In-patient care 1978 - 1982, In-patient care 1983 - 1988                                        |
| Sick leave (duration)                                           | Social insurance office                                                                         |
| Handicap (work related)                                         | Employment service                                                                              |
| Alcohol, Use of (indirect measure)                              | Social services office - Family care, the local police office (traffic related)                 |
| Prescription (type of pharmaceutical drug and dose, ATC-code)   | Health services, the local pharmacy                                                             |
| Actual action                                                   | Each provider                                                                                   |
| Admitted mission                                                | Each provider                                                                                   |
| Kind of contact                                                 | Each provider                                                                                   |
| Reimbursement                                                   | Social insurance office                                                                         |
| Date of old age pension                                         | Social insurance office                                                                         |
| Date of disability pension                                      | Social insurance office                                                                         |
| Transport service (elderly and/or disabled)                     | Social services office - Old age care                                                           |
| Public home help service                                        | Social services office - Old age care                                                           |
| Different kinds and amount of financial support, subsidies etc. | Social services office - Family care, Employment service, Social insurance office               |

APPENDIX 6:

**Test study 2: Utilisation of services by disability pensioners compared to a reference population.**

## Abstract

Most countries in Europe offer some kind of pre-retirement benefits or disability-pension for persons with reduced ability to work. The process, by which an individual realises that his or her working capacity is insufficient, applies for disability pension and finally receives this pension, is long and troublesome. The process itself requires a number of examinations to be carried out by health and social authorities. There is, however, a lack of information about whether the allocation of disability pension itself is a relief or an excessive stress factor for the recipient. The way in which an individual utilises the health and social service system may, in itself, indicate relief or stress.

The sample population consists of a 10% random sample of the resident population in Oxelösund municipality. The analysis in this article is restricted to the working age group 20-64, since only those from this age group are eligible for disability pension and pre-retirement benefits. Three sub-groups were defined; containing those who had never received disability pension during the study period and who were present during the year 1985 (n=741); those who had already received (prevalence, n=32) and those who were granted disability pension (incidence, n=59) during the study period.

The main findings in this study are that (a) the use of health and social services increase steadily during the process of application for disability pension and decrease considerably after allocation of services, and (b) the use of services among both prevalent and incident disability pensioners are continuously higher compared to the remaining population, both before and after the allocation of services.

This study has used utilisation to measure the effect of a disability pension process, irrespective of the reason for disability pension. It is suggested that the decision process increases the utilisation. This utilisation does decrease after the allocation of disability pension, but there is also an indication of a higher utilisation afterwards, compared to the general population. The findings in this study suggest that the authorities initiate a high proportion of the utilisation, since the utilisation drops after allocation of disability pension.

**Keywords:** Disability pension, evaluation, utilisation, health system research, administrative data.

## Introduction

Most countries in Europe offer some kind of pre-retirement benefits or disability-pension for persons with reduced ability to work. (1) The same policies can be found behind the introduction.

There are three different phases concerning disability pension, clearly identifiable in Europe since the 1970's. Originally disability pension was only granted for medical reasons. In the second phase, during the 1980's, new rules made it possible to provide disability pension to the older part of the work force. In the third phase, in the 1990's, it was found that the relatively liberal use of disability pension had had an enormous effect on the various social insurance systems. As from the 1<sup>st</sup> October 1991 disability pension is not granted to individuals on long-term unemployment in Sweden. (1).

The process, by which an individual realises that his or her working capacity is insufficient, applies for disability pension and finally receives this pension, is long and troublesome.

It has been demonstrated that this "waiting" time is extremely stressful and that it sometimes turns out that even after an initial rejection approx. 25% will be granted a disability pension within 2 years (2). The process itself requires a number of examinations to be carried out by health and social authorities. It has also been shown that early retirement caused by inability to work causes stress and an increased utilisation of health and social services. (3)

There is, however, a lack of information about whether the allocation of disability pension itself is a relief or an excessive stress factor for the recipient. The way in which an individual utilises the health and social service system may, in itself, indicate relief or stress. This paper addresses the pattern of utilisation of health and social services during this process, from two years before to two years after allocation of pension.

The objective of this article is to describe individuals' utilisation of services during the two years before allocation, the actual year of allocation, and the two years after allocation of disability pension, compared to that of the general population.

The analysis takes in consideration the health and socio-demographic characteristics of incident disability pensioners.

## Material and Methods:

### Sampling and Study population

The Swedish civil registration register is a public database, which contains the birth numbers of the individuals living in a certain geographical area. The sample population consists of a 10% random sample of the resident population in Oxelösund municipality selected from this register. The sample comprises the juridical resident population during each of the years during the period 1978 - 1988 i.e. we made a new sample for each of the 11 years. The sample population is an open cohort in whom participants can be present or non-present during each of the 11 years of the observation period. The sample population is described in detail elsewhere (4).

The municipality where the data was collected is mainly an industrial area. In the mid 1950's the steel plant, as well as the harbour, was built. From this time and up to 1970 the population increased by threefold and reached its peak in 1970, with 15000 inhabitants. Since then, due to recession as well as to the restructuring of the steel industry, the n:o of inhabitants has fallen to a current 11000.

Taking the ethical as well as political aspects into consideration, a letter was sent out to the sample population of 2,365 individuals who matched the selection criteria (100%), asking for their permission to allow us to collect and use their individual information. A total of 322 (13.6%) declined participation.

In order to check if there was any selection bias, caused by missing information concerning those who had refused, a comparative study about utilisation patterns among the resident population was made, using the available aggregated data. The results from this non-response study did not show any selection bias.

This left us with 2,043 (86.4%) individuals in the study population.

The analysis in this article is restricted to the working age group 20-64, since only those from this age group are eligible for disability pension and pre-retirement benefits. Three sub-groups were defined; containing those who had never received disability pension during the study period and who were present during the year 1985 (n=741); those who had already received (prevalence, n=32) and those who were granted disability pension (incidence, n=59) during the study period.

### Data collection

Information about birth number, age and sex, marital status, place of birth, nationality and geographical area of living was available from the start of the study. The birth number was then used as the key to select the appropriate information during the time frame through 1st January 1978 until 31 December 1988, from all providers of health and social services within the Swedish welfare system. They also had to provide and deliver services in the municipality of Oxelösund.

This resulted in an individually based register, covering the use of all services in a random population sample, in one specific municipality during a defined time-frame, 01/01/1978 - 31/12/1988.

## Data description

The database comprises *Socio-demographic information*, *Social information*, *Pathways of contact* and *Type of/reason for contact* (Appendix 1). The article compares individuals with and without disability pension, regarding socio-demographic and service utilisation data. The article also analyses the pattern of service utilisation among individuals who receive disability pension, during the two years before allocation, the actual year of allocation, and the two years following the allocation. The term disability pension in this article includes two kinds of benefits, 1) long-term benefits paid out due to loss of working capacity, until the age of 65 when the individual receives the general old age pension, and 2) benefits paid out due to lack of working capacity on account of illness, during a period of at least one year. Disability pension can be granted in different degrees. This is the reason why some individuals receive disability pension more than once. The main difference between type 1 and type 2 is that in type 1 the individual does not have to leave the labour market. The individual can activate the disability pension process or it can be activated by the social insurance system or after an application from a state or municipality pension board.

The analyses in this study refer to incidents, not persons. The socio-economical factors used are marital status (single, married, divorced, widow/widower) nationality (Swedish, Nordic, non-Nordic) social class (measured by deprivation of living area), unemployment (no present employment and applying for a job) and years of stable living in the community.

Utilisation was divided into two subgroups, utilisation of HEALTH and SOCIAL services. HEALTH includes primary health care, outpatient and inpatient care, occupational care as well as child-care. SOCIAL includes social services, employment services and social insurance. The disability pensioner's utilisation of services is calculated during the year of allocation of the pension. For the remaining study population utilisation is calculated for a standardised time frame, the year 1985.

## Results

Table 1 describes the study population by sex, age, observation year and pension status. Non-pensioners are those who, during the study period were not granted disability pension and who are present during the year 1985.

Table 2 indicates that there are socio-demographic differences between incident disability pensioners and the reference population. These differences are tested for homogeneity by chi-square test, separately for women and men. The individuals granted disability pension were older than the reference population, (Fishers exact test, men:  $p=0.0000$ , women:  $p=0.0000$ ), fewer were not married (Fishers exact test, men:  $p=0.0030$ , women:  $p=0.0037$ ) and the majority of men were non-Swedish (Fishers exact test, men:  $p=0.0459$ , women:  $p=0.1723$ ).

Table 3 shows that the utilisation increases from two years before disability pension is granted until the year it actually is granted. Thereafter it decreases again.

In table 4 the average number of contacts indicates that there is a higher utilisation in the incident as well as the prevalent disability pensioners group, compared to the reference population.

## Discussion

It is strange indeed that there is this lack of knowledge about the processes leading to a disability pension, but could be due to the fact that the costs involved in granting a person disability pension are high. The process leading to this decision is well known from the administrative side, but there is still a lot to learn about how this process influences the individual. One of the problems in evaluating any service system is that both the utilisation and the outcome of the system are dependent on how the individual chooses to utilise it (5,6,7). Little is known about this choice. On the other hand there are registers, which describe the consumers contacts with the different service providers. In Sweden, as in other European countries, those registers are mainly used for administrative purposes.

The results presented in this study are based on a detailed account of the process of utilisation of services, throughout a five-year period.

The main findings in this study are that (a) the use of health and social services increase steadily during the process of application for disability pension and decrease considerably after allocation of services, and (b) the use of services among both prevalent and incident disability pensioners are continuously higher compared to the remaining population, both before and after the allocation of services.

These findings are consistent with a study concerning frequent attendees of the Finnish public primary health care, where disability pension was a factor of great importance for utilisation of services (8).

One bias factor that has to be taken in to consideration is that the reference population has skewness in favour of younger age groups.

The decrease in the use of health and social services that takes place after a disability pension has been granted could depend on a greater acceptance, due to a long and positive work period with increasing physical restrictions at the end or as a release from financial problems and depression (9). The unexpected high proportion of married people among the disability pensioners in this study could indicate that the social network supports the application for disability pension and supports the applicants during this period, as is indicated in a Norwegian study about unemployed published by Ytterdahl and Gulbrandsen (10). In a study by Maule (11) there are indications that show that discussing early retirement with their spouse influenced the individual's decision to apply.

In this study there are more married people than were expected and this might give some background information.

It was expected that low socio-economic status would be a predictor of allocation of disability pension. This was not the case, but some of the underlying factors point to the fact that immigrants do lead a higher risk of receiving disability pension. This was also one of the findings presented in a paper by Eden et al. (12). Another notable point is that

it seems that the impacts on the weaker social groups are stronger. The implication for this is not clear, but is consistent with findings by Claussen (13).

The results do give some indications as to the differences between genders (14). More men of non-Swedish origin were granted disability pension.

The absence of a shift during the year of disability pension in the age group 45-64 could depend on better acceptance, due to a long and positive work period, but with growing physical restrictions towards the end. This might be related to a feeling of relief for being in the process of receiving a disability pension (15).

The findings must be assessed in relation to the possible advantages and disadvantages of the study. The study's main strength lies in the representative study population and the combination of many data sources at the individual level. Its main weakness lies in the fact that the validity of the data is as good as unknown. The material is originally administrative data, based on paper files. By using a single individual identifier it was possible to carry out follow-up studies across administrative borders and to study the common outcome of a process, which involves more than one authority. The register does not include data on the individual pension scheme, which can substitute the regular disability pension. The design of the study gave us access to information regarding utilisation, while at the same time it was restrictive with any other information concerning the individual's choice. The data consists of quantitative information from administrative sources. A complementary qualitative study introduced to answer questions about needs, demands for services, obstacles to utilisation, how the service was delivered, degree of satisfaction as well as effect, would then give valuable additional information at an individual level.

Another advantage of the study is the possibility to follow the same individuals from one year to another. Unfortunately, the register does not include data on unemployment as a cause of disability pension. Another disadvantage is that occupation is not specified in the analysis. During various periods of time disability pension has been used as a measure to solve long-term unemployment. Administrative practice of this type could very well be interpreted as a "medicalisation" of unemployed people. A special committee in Sweden made an evaluation of those granted disability pension during the year 1993. This showed that 60% of them had long-term sick leave and 35% were unemployed (1). In this study however, it was not possible to follow the whole process from the start of a period of unemployment until the time when a disability pension was granted. We were therefore restricted in the analyses regarding the impact of unemployment. Selander et al. (16) clearly indicate that for individuals with a period of sick leave the likelihood of a temporary disability pension being granted is about three times greater for the unemployed than for those with jobs. There were no data on sick leave included in the analysis in this study.

Administrative materials are full of decisions regarding all sorts of investigations and research, made on all other ground than scientific. This must be taken in to consideration when interpreting the results. For example, during the study period a few of the individuals participating received disability pension twice. The effect of this is unclear. The data material concerns one local municipality, and cannot be generalised

with Sweden as a whole. The age and sex structure of the study population used however, is not significantly different from the general population of Sweden. Another advantage is the relatively low percentage of non-respondents. Some survey studies have indicated that the non-respondents might have a higher utilisation than the normal population (8).

During the process leading to disability pension, the individual has to pass different examinations as well as evaluations. The patient has to respond to the agenda set by the evaluators, not necessarily to their own needs. During this process it is not always obvious who is responsible for the utilisation of services – the individual or the authorities. The difference between a physical disorder such as a stroke, and an administrative orientated, is the fact that there is no pre-knowledge of the physical disorder. This might give some understanding as to why a higher utilisation of services is found before the event of disability. This result is consistent with findings about utilisation of acute care services in the year before and after first stroke by Leibson CL et al. (17).

The findings in this study suggest that the authorities initiate a high proportion of the utilisation, since the utilisation drops after allocation of disability pension. So given the resources invested in the process, we might question the effectiveness of this process. In a report (14) it is pointed out that the pension systems in the EC countries have been shown to adapt poorly to the transformation of early retirement in working life.

Due to the organisational structure as well as to the variety of services included, there have been very few studies to the present date on processes involving data from more than one service provider including the actual patterns of utilisation. For the first time a pilot study from one specific Swedish locality, makes this possible.

Unfortunately, this study does not provide enough information regarding the reasons for the higher utilisation, which was observed here. Generally speaking we need further research on the marginalisation of the older workers, as well as the different factors involved in processes where more than one service provider is included.

This study has used utilisation to measure the effect of a disability pension process, irrespective of the reason for disability pension. It is suggested that the decision process increases the utilisation. This utilisation does decrease after the allocation of disability pension, but there is also an indication of a higher utilisation afterwards, compared to the general population.

## References study 2

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## **Tables and Appendices test study 2.**

- Table 1: The study population by sex, age, observation year and pension status.
- Table 2. Characteristics of incident disability pensioners compared with the reference population 1985
- Table 3 Total number of contacts among incident disability pensioners (n=59) type of contact and age group.
- Table 4. Average number of contacts per individual by age group and group.

Table 1: The study population by sex, age, observation year and pension status.

| Category<br>Year | 20-64<br>non-pensioners |     | prevalent<br>pensioners |     | Incident<br>pensioners |     | Incidence rate<br>per 1000 |       |      |
|------------------|-------------------------|-----|-------------------------|-----|------------------------|-----|----------------------------|-------|------|
|                  | Women                   | Men | Women                   | Men | Women                  | Men | All                        | Women | Men  |
| 1978             | 364                     | 449 | 17                      | 12  | 1                      | 2   | 3.7                        | 2.7   | 4.5  |
| 1979             | 365                     | 454 | 18                      | 12  | 0                      | 3   | 3.7                        | 0.0   | 6.6  |
| 1980             | 362                     | 435 | 15                      | 13  | 2                      | 5   | 8.8                        | 5.5   | 11.5 |
| 1981             | 363                     | 431 | 16                      | 15  | 4                      | 2   | 7.6                        | 11.0  | 4.6  |
| 1982             | 348                     | 417 | 17                      | 13  | 3                      | 6   | 11.8                       | 8.6   | 14.4 |
| 1983             | 345                     | 415 | 16                      | 15  | 4                      | 4   | 10.5                       | 11.6  | 9.6  |
| 1984             | 354                     | 421 | 19                      | 20  | 1                      | 4   | 6.5                        | 2.8   | 9.5  |
| 1985             | 357                     | 405 | 15                      | 17  | 8                      | 5   | 17.1                       | 22.4  | 12.3 |
| 1986             | 348                     | 404 | 20                      | 19  | 0                      | 4   | 5.3                        | 0.0   | 9.9  |
| 1987             | 358                     | 422 | 19                      | 18  | 1                      | 3   | 5.1                        | 2.8   | 7.1  |
| 1988             | 353                     | 424 | 17                      | 19  | 5                      | 1   | 7.7                        | 14.2  | 2.4  |
|                  |                         |     |                         |     | 29*                    | 39* |                            |       |      |

\* These 68 incidents refer to 59 individuals of which 9 had disability pension two times.

Table 2: Characteristics of incident disability pensioners compared with the reference population 1985

|                                  | Incident DP 1978-1988 (n=59) |        |       | Reference population 1985 (n=741) |        |       |
|----------------------------------|------------------------------|--------|-------|-----------------------------------|--------|-------|
|                                  | Male                         | Female | Total | Male                              | Female | Total |
| <i>Pct. &gt; 40 years</i>        | 11.0                         | 8.3    | 10.2  | 51.4                              | 50.0   | 50.7  |
| Pct. not married                 | 14.3                         | 4.2    | 10.2  | 37.9                              | 30.2   | 34.3  |
| Pct. non-Swedish                 | 31.4                         | 25.0   | 28.8  | 17.8                              | 15.5   | 16.7  |
| Pct. Area 3                      | 45.7                         | 25.0   | 37.3  | 32.3                              | 25.7   | 29.3  |
| Pct. unemployed                  | 5.7                          | 4.2    | 5.1   | 6.1                               | 14.9   | 10.3  |
| Pct. Stable residents <=10 years | 68.6                         | 87.5   | 76.3  | 75.8                              | 72.1   | 74.1  |

Table 3 Total number of contacts among incident disability pensioners (n=59) type of contact and age group

|                               | Two years before | One year before | Disability pension year | One year after | Two year after |
|-------------------------------|------------------|-----------------|-------------------------|----------------|----------------|
| Only Social utilisation       | 45               | 47              | 47                      | 46             | 45             |
| Only Health utilisation       | 0                | 0               | 0                       | 0              | 0              |
| Social and Health utilisation | 256              | 270             | 286                     | 214            | 214            |
| Total number of contacts      | 301              | 317             | 333                     | 260            | 259            |

Table 4      Average number of contacts per individual by age group and group

| Age group               | 1985<br>Reference<br>population<br>N=741 | 1985<br>Prevalent<br>Disability<br>N=32 | Incident Disability pensioners<br>N=59 |                       |                               |                   |                      |
|-------------------------|------------------------------------------|-----------------------------------------|----------------------------------------|-----------------------|-------------------------------|-------------------|----------------------|
| (year of<br>disability) |                                          |                                         | Two<br>years<br>before                 | One<br>year<br>before | Disability<br>pension<br>year | One year<br>after | Two<br>year<br>after |
| 20 – 44                 | 4.7                                      | 2.0*                                    | 4.7                                    | 5.9                   | 5.9                           | 5.9               | 5.9                  |
| 45 – 64                 | 3.7                                      | 5.9                                     | 5.0                                    | 4.6                   | 4.7                           | 4.8               | 4.9                  |

\*few individuals



