PM 2016:1

Coordinated health and care services

An analysis of the coordination challenges in a fragmented system for health and care services

vårdanalys

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ISBN: 978-91-87213-50-2
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Preface

It has been a well-known problem for a long period of time that patients and users perceive the health and care services as being fragmented. Previous analyses of insufficient coordination within the health and care services and the social services have, however, often taken their starting point in an organisational perspective and a specific target group or operation has constituted the focus. There are currently insufficient descriptions of what coordinated health and care services mean from a patient and user perspective. The problem with insufficient coordination is not limited to a single patient- or user group either; several groups are affected but this is seldom emphasized in the debate.

The objective of this memorandum is to provide a patient- and user perspective of coordination, a perspective that emphasizes the fact that patients and users are participating and contributing agents in the coordination process. The memorandum does thus contribute to provide a broader perspective of the coordination problem in the health and care services and the social services.

We hope that this work will be useful in many ways, for example by:

- studying what it means from a patient- and user perspective when the health and care services are coordinated.
- a framework for describing the need for coordination of different groups, where the individual's ability to be a contributing participant in the coordination is taken into consideration.
- an estimate of the size and consumption of resources for those groups that are included in the framework.
- discussing those main challenges that we encounter when trying to create more coordinated health and care services.

The analysis constitutes an important starting point for the continued work by The Swedish Agency for Health and Care Services Analysis on coordination issues. The objective of the study is to constitute a basis for different in-depth studies with the objective of, among other things, evaluating on-going national and local ventures and initiatives in this area. Our aim is also to continue to develop the presented frameworks.

However, we do hope that already existing memoranda might serve as a valuable basis for the work on coordination issues. Our terminology work can hopefully be useful in discussions of what the need for coordinated health and care services looks like for different patient and user groups. Moreover, our work at creating a framework can serve as a basis – for example in order to create a common picture of the problem – in local discussions on coordination and cooperation between the two principals.

The work has been led by the analyst Peter Nilsson. Annika Stjernquist and Nils Janlöv have also been members of the project group. Jesper Olson has also participated in the work on the project. Health Navigator AB has provided external support. As part of our work at providing a quality guarantee, a number of external people have also read and commented on an earlier draft of the report. In particular, we would like to thank Malin Bruce (The National Board of Health and Welfare), Jonas Gumbel (SVID), Helena Henningsson (Swedish Association of Local Authorities and Regions), Marianne Lidbrink (The National Board of Health and Welfare), Lisbeth Löpare-Johansson (The Swedish Association of Health Professionals), Tilsith Lacouture (Sigtuna Municipality), Jonas Lundberg (Health Navigator AB), Mats Tyrstrup (Leading Health Care) and Bengt Åhgren (Karlstad University) for valuable comments on the report.

Finally, we would like to give our sincere thanks to all those people who participated in those interviews that have constituted part of the work on this report. Your contributions have been very valuable!

Stockholm January 2016

Fredrik Lennartsson

Summary

One of the great challenges for the health and care services and the social services in Sweden is to coordinate the services for patients and users. It is of great importance that the services are coordinated, for several reasons. Insufficient coordination does often lead to a worse experience for patients and users, in certain cases also to qualitatively inferior health care or care services. The shortcomings might also lead to higher costs, for example due to unnecessary repetitions of treatments or examinations.

When there is no coordination between the health and care services, a large part of the coordinating role is transferred to the patient, the user or her close relatives. If the health and care services do not at the same time take the ability and preferences of the individual to contribute to the coordination into consideration, there might be serious consequences. According to our estimates, there are about 1 million individuals in Sweden with several simultaneous needs who also have a reduced ability to coordinate their health and care services themselves. Moreover, this group is expected to grow every year as the population becomes older, which makes the coordination challenge even greater.

Altogether, the growing group of patients and users with several complex and related needs creates new demands on the health and care services, in particular as concerns creating coordinated health and care services with a focus on the individual. The operation is currently largely organised to meet patients and users with more clearly defined needs. Thus, we can see that the health and care services need to find new solutions in order to adjust to a more complex and extensive picture of needs.

THE ANALYSIS TAKES AN OVERALL PERSPECTIVE OF THE HEALTH AND CARE SERVICES AND THE SOCIAL SERVICES

This report has a broad approach. The ambition is to consider the whole system for health and care services and thus identify overall structural challenges for achieving coordinated health and care services from a patient and user perspective. The objective of the report is to contribute with three new approaches to the coordination problem in a Swedish context:

- a description of what coordinated health and care services mean for patients and users.
- a framework to describe the needs for coordination of different groups, where the need includes the individual’s ability to contribute to the cooperation.
- an estimate of the size and use of resources for those groups that are included in the framework.
- A discussion of the main challenges that we see for creating more coordinated health and care services.

The report uses the term health and care services in order to describe all operations within the health and care services, elderly care as well as the social services. Many patients and users do, however, also have a number of other contacts with different authorities and operations in society. These also need to be coordinated within and between operations. For example, the services offered for vulnerable children and young people by the social services also need to be coordinated with school activities, as well as with different kinds of leisure activities. In accordance with the mission of The Swedish Agency for Health and Care Services Analysis, this report is limited to studying the coordination within and between the health and care services and the social services.

THE ANALYSIS WAS CARRIED OUT IN THE FOLLOWING WAY

The work can be characterised as exploratory. We started by trying to get a picture of the current level of knowledge, both at the national and international level. In order to get deeper insights into the core of the coordination problems, we have, together with the agency's patient and user council, worked at trying to pinpoint how coordinated health and care services can be understood and interpreted from a patient and user perspective. In order to identify common challenges at the system level, we carried out 38 interviews with both local operation representatives and national experts, both from the health and care services and the social services. Then, we developed a theoretical framework in order to identify different general patient- and user groups and their need for coordinated health and care services. After that, we made a quantitative estimation of the size and costs of the groups.

RESULTS

- *There are currently large shortcomings in the coordination of the health and care services*

Both international and national studies show that patients and users are dissatisfied with the coordination in Swedish health and care services. Even if the problem is the same in many comparable countries, the insufficient coordination for Sweden is particularly evident from a patient- and user perspective.

Patient surveys within primary care do, for example, show that only slightly more than half of the patients feel completely secure with the coordination that is done by their contacts in the health and care services. A similar picture emerges in international comparisons of the health and care services: Only slightly more than 45 per cent of the patients in Sweden, for example, consider that doctors always or often assist in coordinating the health and care services from other operators. In this survey, Sweden performs the worst on this question as compared to other countries.

Those who work in the health and care services also experience that there is insufficient coordination. About half of the doctors in primary care do, for example, report that at least one of their patients has had problems in the last month due to the fact that there has not been any coordination in the health and care services. Similar shortcomings have also been observed in different ways in the social services.

- *It is estimated that about one million patients and users have a relatively complicated need for coordination while they also need extensive support in coordinating the health and care services*

Our survey also shows that one million patients and users have complex coordination needs. Besides little ability to coordinate their own health and care services, the group is characterised by a high complexity in those services that are required. For these individuals, support that facilitates the coordination is of particular importance.

Individuals with complex needs do often need several health and care services from a large number of organisations and principals. If they also have limited abilities to be active and participate in their health and care services, the need for coordination becomes particularly large. In many cases, the total needs for these individuals can only be fulfilled by different agents coordinating their services.

Previous studies of the coordination challenges in the Swedish health and care services have often focused on specific patient and user groups within this general group, often the most ill elderly people. Our study shows that there is a considerably larger number of groups with similar coordination needs, for example individuals with serious mental and somatic comorbidity, individuals who have been subject to violence in close relationships, individuals with serious self-harm behaviour and individuals in a late palliative stage.

- *The need for coordinated health and care services differs between groups*

The need for coordination differs between different patient and user groups. Thus, the challenges for obtaining a better coordination also differ. We have seen that there exists no general Swedish framework for discussing and analysing what the need for coordinated health and care services looks like for different patient and user groups. Swedish studies have almost always focused on an individual target group, often the elderly. Thus, there exists considerably less knowledge about several other groups but also about an overall perspective of how the need for coordination differs between different groups. The report also presents a framework for how the need for coordination can be described and analysed.

The framework takes its starting point in the assumption that groups with similar needs for coordination are close to each other on a scale that consists of the following two dimensions:

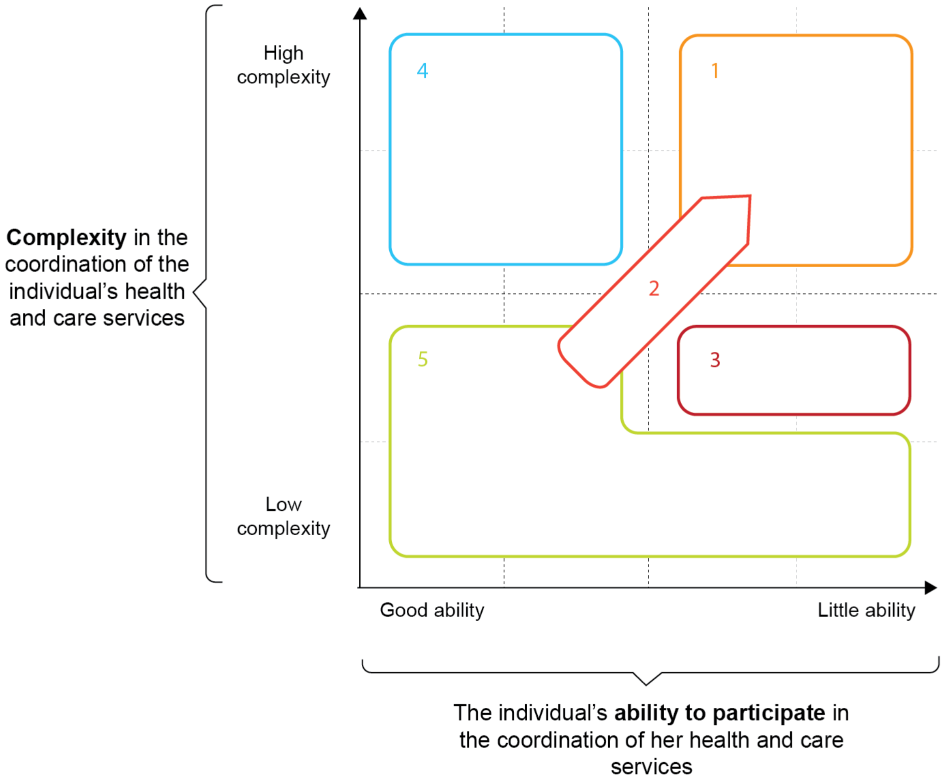
- *The degree of complexity in the coordination of the individual's needs for health and care services.* Complexity here means how many of the services provided to the individual that need to be coordinated in relation to the organisational conditions that facilitate the coordination or make it more difficult.

- *The individual's abilities to participate in the coordination of his/her health and care services.* This means how much help and support the individual needs from the health and care services in order to drive the health and care services process forward. For example, this is about making those contacts that are needed to satisfy one's needs, to be a carrier of information and deal with part of the implementation on one's own.

Based on its location in the framework, the Swedish population has been divided into five patient- and user groups:

- *Group 1: Individuals with complex needs and little ability to participate in the coordination of their health and care services*
- *Group 2: Individuals who have recently become ill and need swift services from several agents and where the swift course of events affects the individual's coordination ability*
- *Group 3: Individuals who are largely somatically healthy with little ability to participate in the coordination of their health and care services*
- *Group 4: Individuals with complex needs, but with good ability to participate in the coordination of their health and care services*
- *Group 5: Individuals with largely good mental and somatic health*

Figure 1. Framework that describes the needs for coordinated health and care services for different general groups.



Those groups that are part of the framework are general enough to cover all patients and users in the health and care services. The objective is to be able to use the groups for an overall system analysis of the coordination problems, while they must also be sufficiently specific to be used as support for management and control of coordination and cooperation in county councils and municipalities.

CONCLUSIONS

- *There will be an increase in the need for coordination, mainly due to the growing group of patients and users with complex needs*

The Swedish health and care services are facing a great challenge since patients and users with several simultaneous needs for health and care services constitute a continuously growing group. There are several reasons for this. The medical trend has led to individuals with chronic diseases living increasingly longer and having the time to develop more diseases. Alongside this trend, we can also observe an increasing specialisation in the health and care services, which leads to patients meeting a larger number of agents. Chronic diseases can now be considered as a normal condition among the elderly. In a previous study from The Swedish Agency for Health and Care Services Analysis it did, for example, emerge that 85 per cent of the population aged 65 or above did at least have one chronic disease and 66 per cent of these had two such diseases or more. And out of all elderly people who have home-care services or live in sheltered housing, the majority has one or several chronic diseases. The larger the number of chronic diseases, the larger is the need for contact with both the health and care services. Within medical care, there is also often a need for contacts with several different specialists besides the care centre where the patient is enrolled.

- *There are insufficient conditions for the staff in the health and care services to work in a more coordinated way*

In order to achieve coordinated health and care services for patients and users, it is required that those professions that the individual meets from the health and care services coordinate their services. This might be about information sharing with each other or that they do, in practice, cooperate on a patient or user in their daily work. It is also those people who work closest to the patient and user who have the responsibility to see to it that the coordination works. At the same time, these professions work and act in a complex system. This system consists of different organisations and logistics for control as well as multifaceted objectives and requirements as concerns legislation and regulations, for example. The possibilities for the operations and the professions to coordinate their services are thus largely determined by the different conditions and incentives that the overall system will provide them with. We find that there are mainly four conditions that need to be fulfilled by the system for health and care services in order to obtain more coordinated health and care services:

1. a patient and user oriented organisation culture that works for a common vision of the health and care services.
2. overall system policies, laws and guidelines that provide conditions for coordination
3. a formal coordination between organisations that creates conditions for coordination across the organisational borders
4. administrative systems that facilitate coordination.

Based on our interviews and the overall analysis, it emerges that the health and care services system in Sweden faces considerable challenges as concerns all these issues.

- *There is insufficient knowledge about what coordination is about and what each individual profession can achieve together with other professions through coordination.* For example, the different professions in the health and care services do not always understand each other's perspectives; what others can contribute and what can be achieved together.
- *There is a lack of management and control as concerns the coordination issues.* The operation managers find that it is difficult to lead and control in the direction of improved coordination. They have insufficient knowledge about what coordination means and how they can, in their role as managers, create conditions for coordination and what the results of this might be.
- *Municipalities and county councils find it hard to create coordination contracts that have a real effect for patients and users.* The contracts do, for example, tend to focus on a division of responsibility rather than on improving the coordination. Thus, for many questions, there is a grey zone where nobody takes any responsibility. There is often also a missing representative for patients and users when the agreements are made.
- *Plans for care and coordinated plans do currently tend to be considered as a product of the drawing board rather than as a well-working plan for coordination.* For example, it is common that, for various reasons, important agents do not participate when the

coordination plan is drawn up. The plan does thus often have a limited effect on coordination.

- *Primary care does not have sufficient conditions to take the coordinating role for the various care services that it is expected to have.* The reasons for this can be traced back to the fact that primary care is, for example, characterised by an unclear definition of its mandate and its assigned tasks.
- *The funding system does not create sufficient coordination incentives.* Most remuneration systems do not specifically reimburse the coordination of services; coordination is rather often expected to be done within the regular funding. When coordination is not remunerated, such services runt the risk of being considered as a cost for the operation and are thus given lower priority.
- *The current information structure of IT support does not provide sufficient conditions for coordination.* Information about patients and users is seldom stored in such a way that it is easy for other people to use the information. The existing legislation does also prevent information sharing between county councils and municipalities. It makes coordination more difficult for patients and users with complex needs who are in need of support from both principals.

There is no common view of what coordinated health and care services mean for patients and users

Coordinated health and care services is a term that is frequently used but there is no established definition. In the Health and Medical Services Act, there are clear requirements for coordination and continuity, but it is not exactly defined what is the exact meaning of coordinated health and care services. It is also clear that there is still a lack of coordination despite the legal requirements. One reason why the coordination is often insufficient is that there is no common view of what coordination is, something that has, for example, been emphasized in our interviews with operation representatives. In practice, it is difficult to coordinate with other agents if there is no common view of what is to be coordinated. This also constitutes an obstacle to making demands for and evaluating the coordination, both at the local and the national level.

In this report, we thus present a working definition of coordinated health and care services. The objective is to try to pinpoint what the term means from a patient and user perspective. We hope that this definition can contribute to, and facilitate, a continued discussion of both problems and possibilities for improvement in this area:

From a patient and user perspective, health and care services are coordinated when all activities are actively organised as a well-functioning entity from that individual's perspective and where she is given the possibility, according to ability and preferences, to participate as an active contributor.

Our starting point is to particularly study what it means when the health and care services are coordinated from the patient and user perspective, i.e. coordination as a quality dimension for the final user. But the definition does also have consequences for citizens, organisations and the health and care services system as a whole. Coordinated health and care services can, in turn, be achieved through a number of organisational solutions, with varying extents of cooperation.

CONTINUTED WORK BY THE SWEDISH AGENCY FOR HEALTH AND CARE SERVICES ANALYSIS IN THIS AREA

This report constitutes the initial work of The Swedish Agency for Health and Care Services Analysis in the area of coordination. On basis of this, largely exploratory, work, the objective is to, in the next stage, more specifically continue to work on possible solutions in order to achieve more coordinated health and care services. The framework of this report will constitute the basis for exactly defining principles for coordination and using these as the starting point to present examples for how a patient- and user adapted coordination can be achieved. Here, the frameworks make an in-depth analysis possible of how well different national and local coordination services are adjusted to the differences in the needs for coordination in different patient and user groups. In this way, we would like to illustrate how the current remuneration system, the organisation and the view of the health and care services need to be developed in order to meet the coordination needs of patients and users. We do, however, hope that already this report might be of use for more people who aim at working on coordination issues, at both the national and the local level.

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1 Introduction

When the health and care services are coordinated, patients and users consider these to be an entity where the professions cooperate in order to meet the individual's needs. Patients and users do then not need to be concerned about how the system is organised in order to get the required health and care services. A number of different sources do, however, unanimously indicate that insufficient coordination constitutes one of the major challenges for the health and care services in Sweden, in particular for patients with chronic diseases (Vårdanalys 2014b). In the OD (2013) report on the quality of health care and medical care in Sweden, the insufficient coordination among hospitals, primary care and the social services is emphasized as the largest challenge for the relatively good health and care services in Sweden.

Insufficient coordination does often lead to a worse experience for patients and users, but in certain cases also to inferior health or care services. When there is insufficient coordination, a large share of the coordinating role is also shifted to the patient, the user or a close relative. This might have serious consequences for patients and users with several simultaneous needs who also have a reduced ability to coordinate their health and care services themselves. We estimate that about one million people in Sweden have these kinds of needs. The group is also growing each year, as the population in the country becomes older, which emphasizes the coordination challenge.

There are several reasons why it is important that the health and care services become more coordinated. For patients and users, it has an intrinsic value that the health and care services coordinate their efforts. The term covers functions and characteristics that aim at promoting the safety of patients and users and their ability to participate and, through good coordination, strengthen the possibilities for patients and users to participate in the health and care services according to their own ability. A well-functioning cooperation is thus an important aspect in health and care services with a focus on the individual (Vårdanalys 2012) and the importance of coordinated health and care services is also emphasized in the wording of the legislation (for example, in the Health and Medical Services Act, 1982:763).

At the system level, a great deal is still unknown about the total consequences of insufficient coordination. A number of studies do, however, indicate that this is likely to be an important part of the problems as concerns quality and patient security that lead to a decrease in the medical results, increased costs and that the resources are not used in the best possible way (European Observatory 2014).

1.1 AN ANALYSIS OF COORDINATED HEALTH AND CARE SERVICES WHICH TAKES ITS STARTING POINT IN THE PATIENT AND USER PERSPECTIVE

Insufficient coordination in the health and care services has been a well-known problem for a long time. We have identified a number of previous reports on the health and care services which have emphasized this problem. However, there is no general definition of what coordinated health and care services mean from a patient and user perspective in a Swedish context.

The objective of this report is to study, interpret and define what is the meaning of coordinated health and care services from a patient and user perspective and what the consequences are from an organisational perspective. Our aim is also to identify overall structural challenges for obtaining coordinated health and care services. Part of the work consists of an analysis of what patients and users that are in special need of coordination and what the consequences are if and when there is insufficient coordination. The ambition is thus to study in what way the challenges within the area of coordination differ between different patient and user groups. In the next stage, the objective is to specifically continue to work on possible solutions and recommendations in order to achieve more coordinated health and care services.

The report uses the term health and care services in order to jointly describe operations within the health and medical care services and the social services. However, many patients and users do also have a number of other contacts with different authorities and operations in society. These also need to be coordinated within and between operations. For example, the services provided by the social services for vulnerable children and youths also need to be coordinated with school activities and different kinds of leisure activities. In this report, we have limited ourselves to studying the coordination between health and care services and the social services.

1.2 THE REPORT TAKES ITS STARTING POINT IN FOUR QUESTIONS

The main questions that we try to answer in the report are the following:

- *What do coordinated health and care services mean from a patient and user perspective?*
- *How can groups with special coordination needs be identified?*
- *For what groups are coordinated health and care services of particular importance and what are the consequences of insufficient coordination?*
- *What are the main challenges for achieving more coordinated health and care services?*

1.3 THE DESIGN OF THE REPORT

The report starts with Chapter 2 which provides a background to the fact that coordination constitutes a general challenge for Swedish health and care services. Chapter 3 focuses on what the term coordinated health and care services means from a patient/user perspective. In chapter 4, we present a framework for identifying groups with special coordination needs. In chapter 5, we both study those general groups that we can identify with the framework from chapter 4 and study five groups more in-depth to better understand those problems encountered by the specific groups and what their requirements are. Finally, in Chapter 6, we summarise the main challenges that we can see for achieving coordinated health and care services.

1.4 WE HAVE PROCEEDED IN THE FOLLOWING WAY

The objective of this report is to contribute new insights within the area of coordination. The need for improved coordination has been mentioned in a number of previous studies but we find that there is no broad system approach. We also see that in a Swedish context, there is no common view of what the term coordinated health and care services means from a patient- and user perspective, and that there is thus a need for developing frameworks and dimensions that can contribute to how coordination challenges are to be understood and analysed. For this purpose, we have thus aimed at understanding the level of knowledge in this field, both at the national and international level. Together with our patient and user council, we have also produced a description of how coordinated health and care services can be understood, interpreted and more exactly defined. We have also developed a theoretical framework for identifying different general patient and user groups and their need for coordinated health and care services. Then, we have made a quantitative estimate of the framework where we try to describe the size and costs of the groups at a general level (the method is described in more detail in Appendix 1). To get an insight into the overall challenges within the area of coordination, we have also made 38 interviews with different local representatives for local operations and national experts, both from health and medical care and the social services.

2 Coordination is a challenge for Swedish health and care services

A number of different sources do uniformly indicate that insufficient coordination constitutes one of the main challenges for the health and care services in Sweden. The OECD (2013) report on quality in health and care services in Sweden in particular emphasizes insufficient coordination among hospitals, primary care and the social services as the largest challenge for Sweden with its relatively good health and care services.

Insufficient coordination does often lead to a worse experience for patients and users, but in certain cases also to worse health care or care services. When there is insufficient coordination, a large part of the coordinating role is also shifted to the patient, the user or her close relative. This might have serious consequences for patients and users with several simultaneous needs while also having a reduced ability to coordinate their own health and care services.

At the system level, a great deal is still unknown about the total consequences of insufficient coordination. However, a number of studies do still indicate that this is probably an important part of the quality and patient security problems that lead to deteriorated medical results, increased costs and that the resources are not used in the best possible way (European Observatory 2014).

This chapter provides a short description of the current coordination of health and care services in Sweden. For example, we present the fact that patients, users and the profession perceive large shortcomings in the coordination of health and care services. Initially, we describe coordination problems for two fictitious individuals who have fallen between the cracks among different agents in the health and care services.

2.1 PATIENTS AND USERS PERCEIVE THERE TO BE INSUFFICIENT COORDINATION

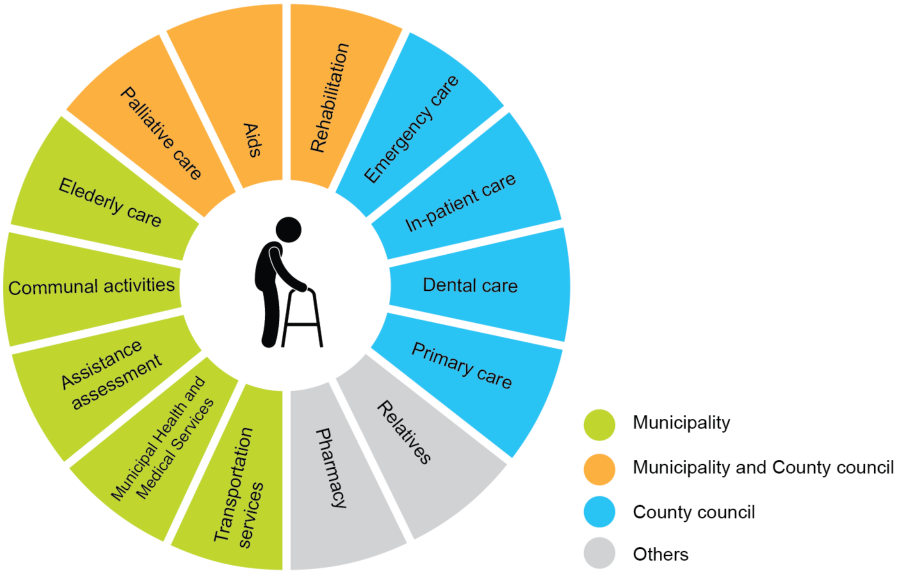
Both international comparisons and national studies show that patients and users are currently dissatisfied with the coordination in the Swedish health and care services. Even if the same problems exist in many other countries, Sweden appears to have particular shortcomings from the patient and user perspective. In this section, we have, based on previous literature and interviews, created descriptions of two fictitious cases with the aim of illustrating the patient and user situation. The cases are called Emilia and Robert and they show what a normal day might look like for an individual with several needs from the health and care services. Finally, a number of estimates are presented that show the experiences of patients and users as concerns whether they have encountered a well-working coordination.

2.1.1 Fictitious case: When there is insufficient coordination for an elderly person with several different contacts with the health and care services, the example of Emilia

Figure 1 shows Emilia, aged 86, and her contacts within the health and care services. With increasing age, Emilia has developed a number of chronic diseases which require that she has regular contacts with both the care centre and different specialists in medical care. Emilia is also beginning to have walking problems and has difficulties in moving around at home. Since she lives on her own, she also needs support in her home from elderly care in order to cope with her daily tasks. Moreover, she needs physical aids to facilitate her daily life. All those contacts that are shown in figure 1 are thus necessary to fulfil Emilia's total needs for health and care services.

The relatively complex network around Emilia does, among other things, consist of agents from different principals, organisations and professions. Moreover, these are often subject to a separate legislation, varying budgets and sometimes also different political leadership. In many cases, there is insufficient contact between the agents and when Emilia meets them, she feels that they have not talked to each other about how the health and care services can be best organised for her. Several times, Emilia has had to tell the same story over and over again to new people. She is also getting tired of meeting different doctors every time she goes to the care centre and that they always seem to be in such a hurry. She also worries about what would happen if she were not as clear in the mind as she is today.

Figure 1. Examples of agents that an elderly person with several chronic diseases and home care services normally encounters in the health and care services.



2.1.2 Fictitious case: When the coordination is insufficient for an individual who is an addict and suffers from mental health problems, the example of Robert

Robert is aged 52 and suffers from an addiction problem in combination with mental health problems. He was no diagnosed with ADHD until a couple of years ago. He did not finish comprehensive school due to large concentration problems. Already at that age did he start to develop his addiction problems. Since then, he has had a hard time keeping jobs and has thus been supported by social security (income support) for long periods of time. He has also lost his housing several times. Several other people in his family suffer from or have suffered from addiction problems so he can thus not count on their support when he has difficulties in coping on his own. The last time that Robert saw a doctor, he also learnt that he has developed a liver disease due to his alcohol addiction.

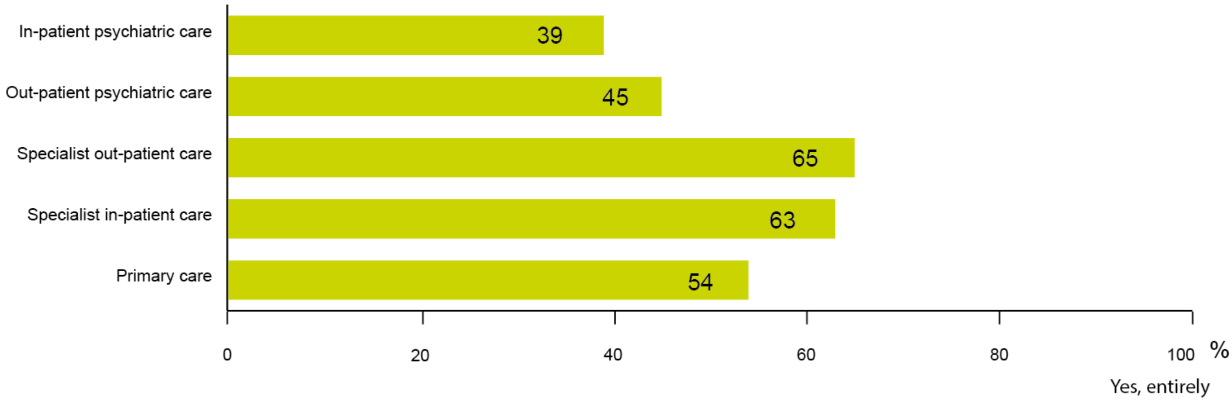
Figure 2: *Examples of agents that an individual who is an addict and who has comorbidity normally encounters within the health and care services.*

Figure 2 shows Robert's contacts with the health and care services. Robert has, to different extents, been in contact with the administrative officials in the social services for assistance assessment and housing allowance. He also has sporadic contact with the addiction services within both the county council and the municipality, but his addiction has never been so serious that he has been taken into compulsory care. Sometimes he goes to a care centre to get help from a doctor and he has been in contact with emergency care on a few occasions. He has also been in contact with different parts of psychiatric care on several occasions. He has also participated in the labour market programmes of the Employment Agency several times, but has still been openly unemployed for longer periods of time. He does not have the time or the strength to keep track of everyone that he is expected to keep in contact with. Sometimes he wonders if it would be better if he became heavily addicted or a criminal – then they would lock him into one place and he would not have to spend so much time and energy on familiarising himself with various things.

2.1.3 National and international patient surveys show insufficient coordination

Emilia's and Robert's situations are not unique in Sweden. The results of different patient and user surveys indicate a number of shortcomings in the coordination. In the patient survey carried out by SKL (2015b), patients do, among other things, get to answer the question of whether they feel secure about the coordination of their contacts in medical care, see figure 2b. In primary care, it is only slightly more than half of the patients who feel entirely secure about the coordination of their contacts in the health and care services. This is remarkable since primary care is supposed to have a coordinating function for the patient.

Figure 2b Percentage of patients that feel secure about the coordination of their contacts in the health and care services 2014.

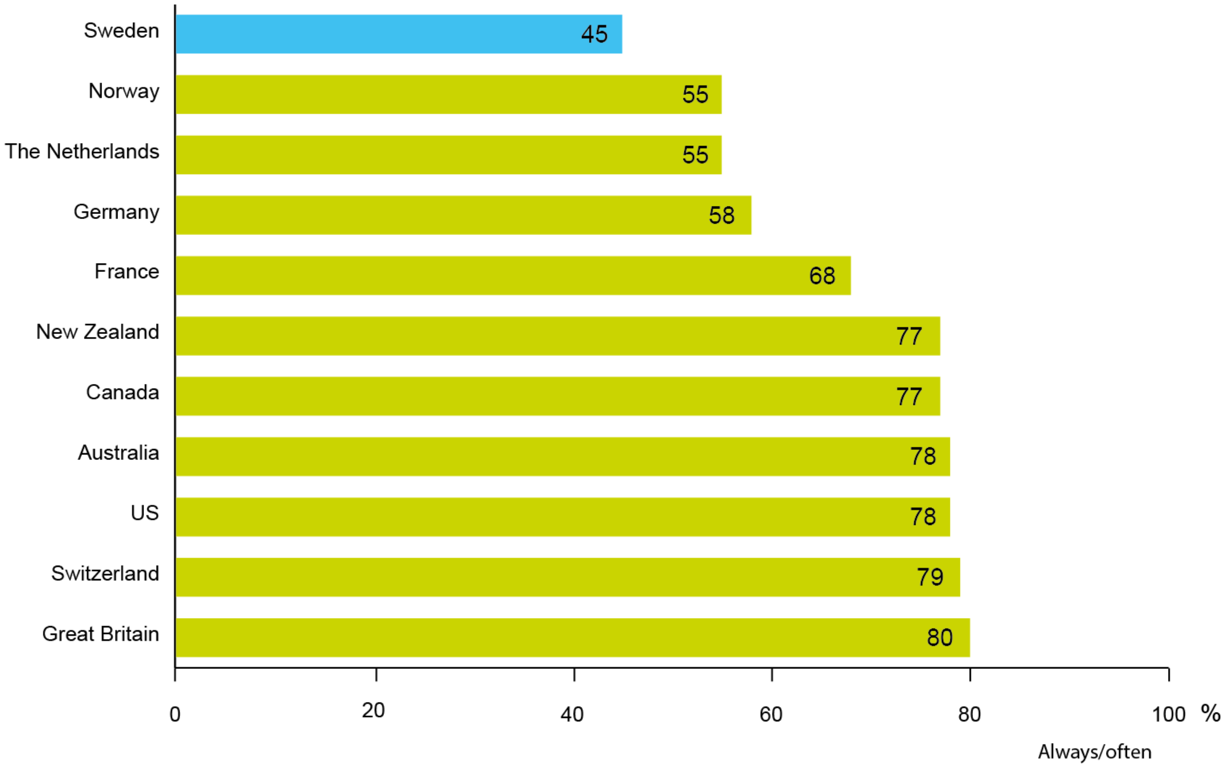


Source: National Patient Survey (Nationell patientenkät), Swedish Association of Local Authorities and Regions.

A similar picture emerges in international comparisons. A comparative study between eleven countries (International Health Policy Survey, or IHP) does, for example, show that Sweden is the country in the survey where the patients experience the lowest degree of well-functioning coordination. The below figure (2c) shows that only slightly more than 45 per cent of the patients in

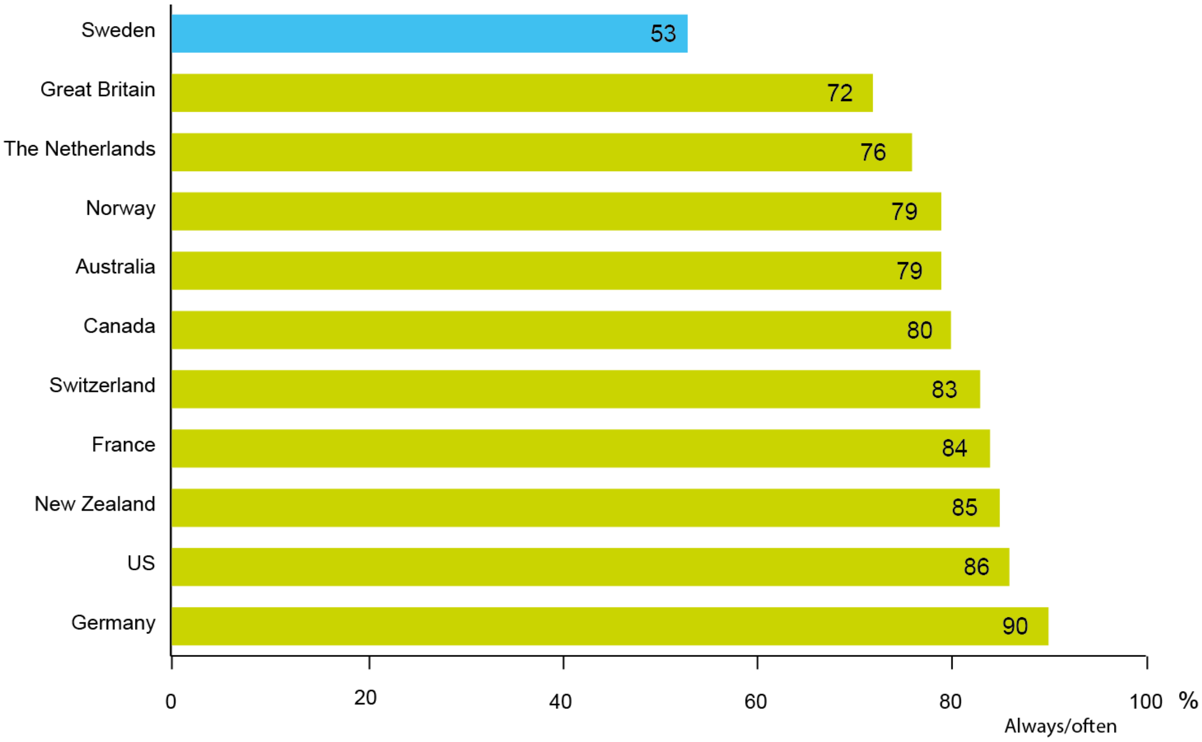
Sweden who were included in the IHP-study (Vårdanalys 2014c) consider that doctors always or often provide help in coordinating the care from other agents. The same study also shows that only 53 per cent of the patients consider that the care centre that they usually attend seems to be informed and updated on what care they have received in the hospital (figure 2d). The survey also shows how the patients answer the question of whether the doctors or the staff seemed informed about the patient's previous care; about 50 per cent of the patients answered that this is always or often the case. Sweden also shows worse results as concerns other questions that are related to coordination than other countries in this comparison. Overall, both studies show that coordinated health and care services constitute an area where Sweden has large shortcomings from the perspective of patient experience.

Figure 2c Percentage of patients who claim that doctors or other staff often or always provide help in coordinating health and care services, 2014.



Source: Vårdanalys, 2014

Figure 2d. Percentage of patients who state that doctors or other staff at their usual surgery/practice/clinic are often or always informed and updated about the care that they received in hospital

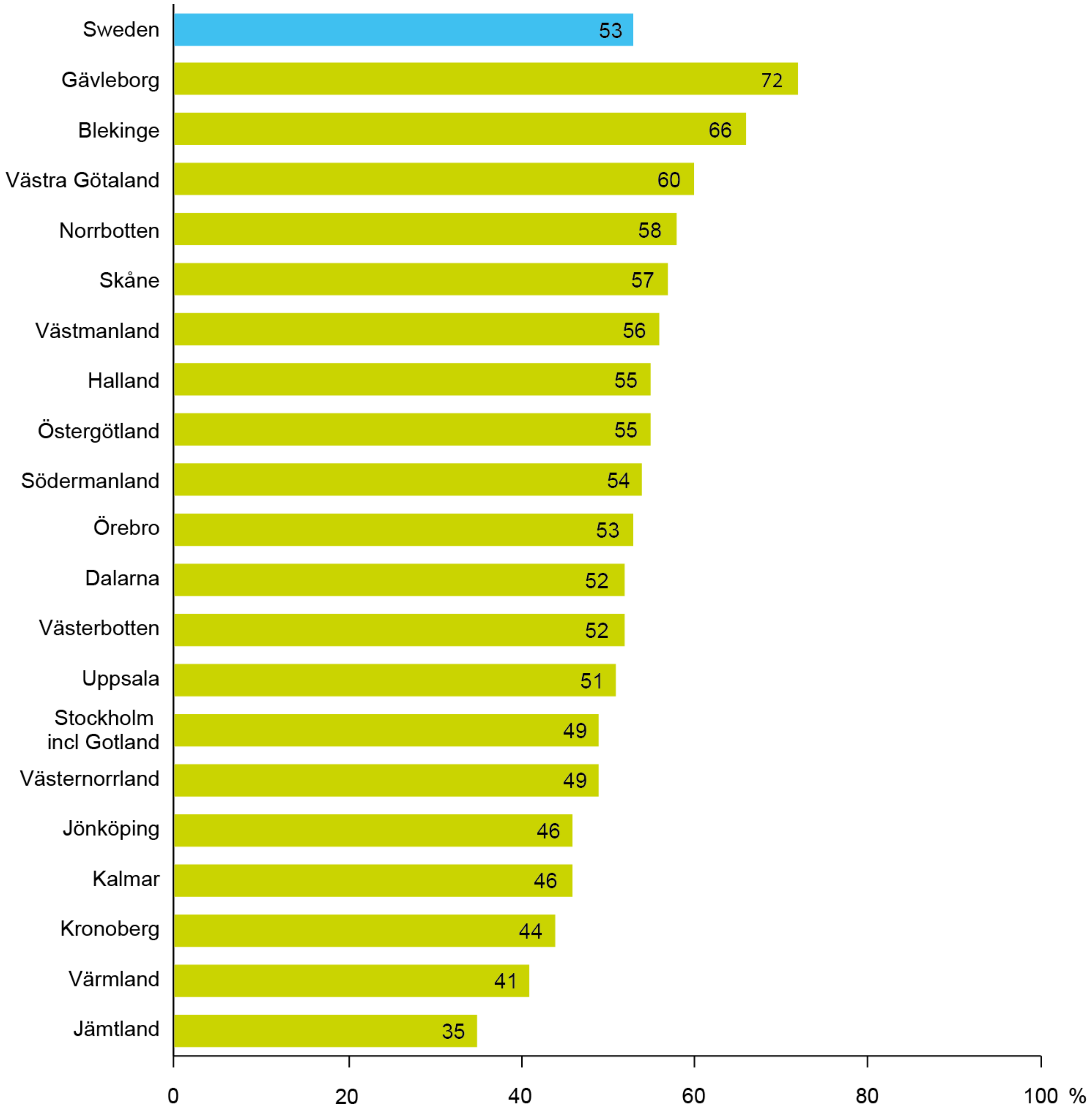


Source: Vårdanalys, 2014

2.2 THE PROFESSION DOES ALSO EXPERIENCE INSUFFICIENT COORDINATION

Those who work in the health and care services do also experience insufficient coordination. Doctors or social welfare secretaries do, for example, state that the possibilities for coordination are limited by the fact that the organisation within which they work is divided into different areas of responsibility. About half of the doctors within primary care do also report that at least one of their patients has had problems in the last month since the health and care services have not been coordinated, see figure 2e (Vårdanalys 2015). The question, to which the answer is given above, is, however, asked more in general and does not provide any closer definition of what kinds of problems that are involved.

Figure 2e. *Share of doctors who state that at least one patient in the last month had problems since the health and care services were not coordinated among care providers*



Source: Vårdanalys, 2015

Staff within the social services does also state in our interviews that there is insufficient coordination. However, there are no major studies within the social services that correspond to those that exist for the health and medical services.

2.3 THERE ARE ALSO OTHER STUDIES THAT CONFIRM THE PICTURE SUPPLIED BY THE PATIENTS, THE USERS AND THE PROFESSION

In the last few years, several research reports and reports from the authorities have pointed at insufficient coordination in the health- and care services. The largest focus has been on the most ill elderly people, where the problem has been well-known for a long time. There is also a large number of studies focusing on other groups.

2.3.1 Insufficient coordination of the health- and care services for the elderly

Insufficient coordination in the care of those individuals who are most ill is a problem that has been given much attention. Here is a short summary of the conclusions of some of the latest studies focusing on this group.

In a report from The National Board of Health and Welfare (Socialstyrelsen 2013), with the objective of studying the waiting times within the health and care services for elderly people with multiple illnesses, it is found that the largest problem is insufficient coordination within the health and care services. The National Board of Health and Welfare considers that there is a tunnel vision within the health and care services, i.e. the responsibility is split between different levels of health and care services and between different principals. According to The National Board of Health and Welfare (Socialstyrelsen 2013), there is nobody who takes the overall responsibility for the elderly person and follows up the overall result of the health and care services

Öppna jämförelser – vård och omsorg om äldre (Open Comparisons: Health and Care Services for the Elderly) presents several indicators that illustrate coordinated health and care services for elderly people with geriatric care on a yearly basis (SKL and Socialstyrelsen 2015). The indicators show results for users and patients in areas where both the municipalities and the county councils are responsible for providing good health and care services. The result shows that there are several areas where there might be insufficient coordination and there is a large distribution in the results between municipalities and county councils. Among other things, this concerns an increase in falling injuries, insufficient health and care services after a stroke, the lack of work on risk prevention and shortcomings when it comes to treatment with pharmaceutical drugs.

The Swedish Association of Local Authorities and Regions (SKL) has identified a number of challenges in the Swedish health and care services system for creating good health and care services for the most ill elderly people (SKL 2012). One of the greatest challenges is, in fact, the insufficient coordination between different agents in the health and care services for the elderly with multiple diseases. When being discharged from the hospital, coordinated planning of care did only exist in 30 per cent of the cases. There are also large shortcomings in the planning and communication between care centres and the municipality home care services. Lack of communication has also been pointed out as a problem by The Health and Social Care Inspectorate (IVO). In a report, IVO (2014) described several serious shortcomings in the information transfer between different care providers. The Inspectorate showed that the information transfer was often insufficient in the transfers between different teams or units of care; this was both about how to deal with referrals, test results or x-ray pictures and about communication, such as phone calls or e-mails. It is pointed out that the shortcomings are systematic and in several of the cases studied, the lack of information transfer has had serious consequences for the patients.

2.3.2 Insufficient coordination of other groups

Even if most reports have focused on the group consisting of the most ill elderly people, there are also a few reports that have highlighted other groups with similar challenges.

The Swedish National Audit Office (Riksrevisionen 2011) does, for example, show that there are large shortcomings in the coordination for children with functional disabilities and that too much responsibility for the coordination falls on the relatives. No agent in the child's vicinity considers that she has an explicit mandate to pursue cooperation and nobody feels that she has the main responsibility for the coordination. The Swedish National Audit Office does here point out that the presence of a strong relative with a strong driving force is very decisive for whether the coordination will work.

Patients with chronic diseases constitute another group where insufficient coordination has been found (Vårdanalys 2014b). About 40 per cent of those with chronic diseases claim that their doctor in primary care does not know what has been done in their visits to specialist care. More than 70 per cent also claim that they have not had any help from the hospital in booking a return visit, despite the fact that this would have been needed.

Attention has also been given to individuals with mental health problems, for example in the government venture PRIO, where much attention is, in particular, focused on the coordination of services (Vårdanalys 2014a). Despite recurring coordination ventures, there is, however, a need for continued development work in this area.

3 What are coordinated health and care services?

In the Swedish legislation, there are clear requirements for coordination and continuity in the health and care services. According to the Health and Medical Services Act (1982:763), health- and medical care is to "fulfil the patient's need for continuity and security in care". The regulation also stipulates that "different kinds of care for the patient must be coordinated in an appropriate way". The Patient Act (2014:821) contains the same requirements for coordination as well as, under certain circumstances, requirements for a permanent contact in care and a permanent contact with a doctor. When services are needed from both the social services and health care and medical care, the Social Services Act (2001:453) and The Health and Medical Services Act require that an individual plan for care is drawn up. However, the legislation does not specify what coordination is. It is also clear that the problems with insufficient coordination still exist despite the legal requirements.

Since the problem with insufficient coordination has been well-known for a long period of time, there has also been a great deal of research and much has been written in this area, both at the national and international level. Moreover, coordination can be studied from many different perspectives, the most common being from an organisatory or economic perspective. This means that many different research fields have described the coordination problem from different perspectives and scientific traditions. This report does not constitute a summary of the contributions of different research fields in the area of coordination, the focus is rather on making progress as concerns what coordinated health and care services mean from a patient and user perspective.

Sometimes, terms that are closely related to coordination are used, *unified health and care services*, *cooperation* and *coordination*. In Sweden, a great deal has been written about coordination; see, for example, Anell and Mattsson (2009) for a knowledge survey. Research on cooperation takes a clear organisational perspective, even if the objective is often to achieve better coordination for the individual. However, it is important to clarify that that cooperation does not necessarily lead to improved coordination from a patient and user perspective. Our starting point is the patient and user and what it means that the health and care services are coordinated for this individual. The organisation can then solve this in different ways, for example by cooperating, which means that there is a formal agreement about coordination between different organisations. Taking what is favourable for coordination from an individual perspective as a starting point, a number of organisational solutions – from cooperation between different individuals to cooperation between organisations – can then be considered as different kinds of coordination services

As has been mentioned, insufficient coordination is also a problem in other countries, which has led to some national and European initiatives and research in the field. At the international level, the terms *integrated care* or *coordination of care* are often used, which approximately correspond to coordinated health and care services. Those definitions and theories that are used in international research have partly constituted the basis for those definitions and analytical frameworks that we use in this report. In international research on *integrated care,* there is also an abundance of definitions and terms without any consensus; see, for example, Ködner (2009) and Nolte and McKee (2008) for a survey. As in the case of research on cooperation, *integrated care* does often primarily have a system- and organisational perspective.

Coordinated health and medical care services is a term that is frequently used but which has no formal definition. In this chapter, we do thus present our working definition of coordinated health and care services and study and define its meaning, taking our starting point in a patient and user perspective. We hope that this can contribute to a continued discussion about both the problems and the possibilities for improvement in this area. In order to further clarify what coordination means, we also describe what it means when there is a lack of coordination.

3.1 A WORKING DEFINITION OF COORDINATED HEALTH AND CARE SERVICES FROM A PATIENT AND USER PERSPECTIVE

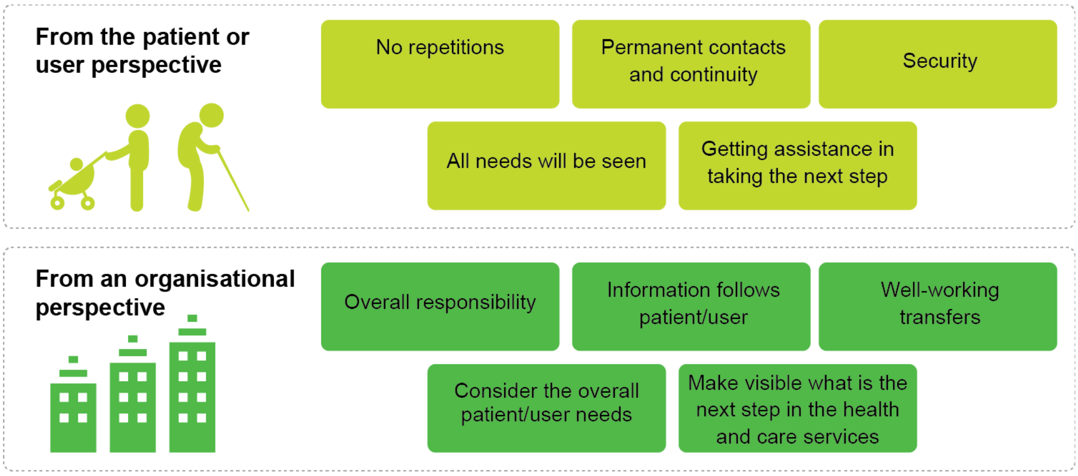
In this section, we try to define what coordinated health and care services mean from a patient and user perspective and what the consequences of the definition are from an organisational perspective and the perspective of society. The definition has been created together with the patient and user council of the agency. The definition takes its starting point in an ideal situation, i.e. when coordination works as desired. The objective of this kind of theoretical definition is that it should be possible to use it as a measurement stick for evaluating real projects and initiatives with the aim of making the health and care services more coordinated. It should not be considered as final, but as a first attempt to examine a new perspective of the question which has largely been missing in Sweden, in particular in a broad context which considers the entire health and care services. The definition also constitutes an important starting point for the continued work of the agency in this area.

➢ Our definition of coordinated health and care services

In our continued discussion, we will take the following definition as our starting point:

From a patient and user perspective, the health and care services are coordinated when all activities are actively organised as a well-working unity from her perspective and where she is given the possibility to, according to ability and preferences, participate as an active contributor.

Figure 7. Description of what coordinated health and care services mean from a patient and user perspective and what the consequences are from an organisational perspective.



A well-functioning overall picture from the patient and user perspective means that:

- *The patient or user must not be obliged to make any unnecessary repetitions of information or undergo any unnecessary treatments, investigations or tests when she has given her approval to information sharing.*

  According to the legislation, information about a patient or user must not be shared without that individual's approval. When such an approval exists, the information is to be shared between units in the same organisation or, for example, between the municipality and the county council, so that the patient or user does not have to retell her story unless she wishes to do so.

- *To the largest possible extent, the patient or user should be offered permanent contacts and staff continuity in the health and care services.*

  Many patients and users would really like to meet the same person each time they visit the care centre for example. According to the Patient Act, this wish should be fulfilled within the health and care services. The same legislative requirement does not exist for care services, but to the extent that it is possible, the municipality should offer contact with for example the same official or care staff if the user so desires.

- *The patient or user should feel secure that the health and care services take all her needs into account.*

  Those people that the patient or user meets must take the individual's entire needs for health and care services into account. This requires a kind treatment and a proactive attitude so that the health and care services pinpoint the complex and interrelated needs of the whole person. This is about being allowed to feel that one constitutes the focus and that the needs are considered to be credible and that one participates in the decisions that are being made.

- *Based on her ability and wishes, the patient or user should get the support she needs to contribute to the coordination.*

  The patient and user should receive the support that she needs and desires in order to contribute to the coordination, for example with information and guidance in a health and care services process about how the individual should proceed and what contacts should be taken next.

➢ Consequences from an organisational perspective

In order to create coordinated health and care services for patients and users, active work is required from all organisations that the patient and user meets in the health and care services. We find that it becomes important for the organisation to fulfil the following points:

- *There is a work-culture which is centred around the individual where the individual's total needs constitute the focus and that is characterized by a common responsibility for the individual without any organisational territory.*

  The agents involved should take joint responsibility for those patients and users that they meet and should know what parts they are responsible for. It should be impossible for any part of the patient's or user's possible needs to fall between the cracks.

- *Information about the patient or user is easily available at the right point in time for those who need it.*

  There must be routines for how and when information is to be shared and when the patient or user has given her approval, the information must be shared among the agents involved without any delay.

- *A well-functioning transfer between different agents.*

  There must be routines for how the transfer is to be made, notwithstanding if it is within an organisation where day staff transfer the responsibility to night staff, or if it is between different units or principals. A transfer covers both the above points, i.e. the transfer of both information and responsibility.

- *Strengthen the possibilities for patients and users to contribute to the coordination.*

  Since the patient and user has have the ability as well as the desire to be a contributing agent in the coordination, the organisation needs to make use of and strengthen this ability if the individual so desires. This might include providing the patient and user with the information she needs in order to take the next step in her health and care services process.

- *There is a joint picture of the patient and user's total need for health and care services and a common objective and follow-up of services.*

  When several agents are responsible for the outcome for a patient or user, a joint picture is required of the individual's total needs as well as a joint objective for how the needs are to be met. Many patients and users are in need of coordination for a longer period of time and it is important to capture the fact that the needs might change along the way. The needs of the patient or user must thus be subject to continuous evaluations together with all agents involved in order to see whether those services that have been implemented get the desired effect.

- *It is obvious for all agents involved what is required in the next stage in the health and care services in order to get closer to the objective of fulfilling the patient's or user's needs.*

  All those agents who are involved in the patient's or user's health and care services should have an overall perspective. Thus, they should be able to guide the patient or user in the next step, even when this step is not something that takes place within the agent's unit.

”Active” is a keyword in this definition since the responsibility for the organisation becomes that of those services that the patient and user encounters. There are patients and users who want to take the responsibility for their own health and care services, and to the extent that they want to do this, they should be given the possibility to do so. The patient as a co-participant is an important building block in the health and care services with a focus on the individual. ”Active” should thus not be interpreted as municipalities or county councils being allowed to talk over the patient's or user's head.

Coordination is one of several other quality variables that must be the objective of the health and care services. From an organisational perspective, coordination is, however, mainly a process that might also have other positive effects on quality, both when it comes to patient experience and medical and social results. Increased coordination should thus be considered to be a quality aspect for the individual which, in turn, needs to be weighed against other quality aspects and the costs for the coordination services. Before focusing on improving the coordination, it should be ensured that what one does today is right from a patient and user perspective. There is no point in coordinating several services if all services are incorrect or can be replaced by another service

➢ The consequences from a societal perspective

From a societal perspective, it is important that the health and care services are carried out as efficiently as possible. There are examples that show that insufficient coordination contributes to inefficiency and waste of resources. For example, the 2015 IHP study, which was sent out to general practitioners, shows that 61 of all general practitioners in Sweden have at some point in the past month met a patient whose medical records or other relevant clinical information were not available at the point in time of the patient's visit. The study also shows that, in the past month, 35 per cent of the general practitioners have been obliged to rerun a test or repeat some other action since the results were not available (Vårdanalys 2015). These kinds of estimates make it clear that insufficient coordination might have economic consequences.

Certain solutions to improve the coordination can initially and locally appear as increased costs even if this becomes more resource efficient if considering the whole economy. An extensive international literature survey of different coordination services shows that there is a great deal to indicate than increased coordination often has positive economic effects but, at the same time, it is hard to prove a uniform effect (European Observatory 2014). The effect is difficult to prove due to the fact that there are no common definitions of coordination and how to measure costs and quality.

3.2 WHAT HAPPENS WHEN THERE IS NO COORDINATION?

When there is no or insufficient coordination, the following serious problems might emerge, both for the individual and the health and care services. The below points are based on a compilation made by two researchers who are active within the field of *integrated care* (Goodwin and Alonso, 2014):

- *An insufficient overall perspective creates anxiety and frustration for the individual.*

When there is insufficient coordination, it is the patient or user herself that has to take responsibility for fulfilling her overall needs. Those agents that the individual meets do then only deal with part of the individual's needs and do not take the whole picture into account. This might mean that important needs are not identified and given attention which creates anxiety and frustration for the individual.

- *Insufficient communication between professions leads to patients and users having to describe their situation again and that important information runs the risk of being lost.*

An important part of the coordination is that agents within the health and care services communicate well with each other and that they have access to the necessary information about the patient's or user's previous contacts with the health and care services. When there is insufficient communication, this might mean that the patient needs to repeat information about previous contacts with health care, take the initiative for contacts herself, that incorrect decisions are made since there is a lack of valuable information or that necessary visits do not take place at all.

- *Worse experience, health and situation for patient and user.*

The patient or user feels that she herself must be the carrier of information and take the initiative for contacts. The risk is that different kinds of advice come from different people and that there is no overall picture of the individual's needs. There might be confusion as concerns what is really the next step and in what order things should be done, in particular if the information is contradictory. All this means that the patient or user gets a bad experience of the health and care services but also that the ability to deal with one's own situation and one's own care deteriorates.

- *Increased costs due to health and care services being repeated unnecessarily.*

When there is insufficient coordination, there is an increased risk that the patient needs to repeat medical tests, or retell her medical history, for example. This leads to increased costs and a less efficient use of resources.

- *Threat to patient security and the risk for deteriorated medical and social results.*

When there is no overall perspective, and there is insufficient communication between professions, there is a large risk that the patient or user needs are not met in a satisfactory way by the health and care services. The illness or the need for care might deteriorate due to insufficient coordination.

4 A theoretical framework for identifying groups that are in need of coordination

Here, we present a theoretical framework that makes it possible to identify general patient and user groups whose common characteristics are the need for coordination of efforts from both the health care and the care services. The starting point is that we see that there is a need for an overall system analysis, in particular since there is no framework for discussing coordinated health and care services in a Swedish context at the general level. For example, most studies of Swedish conditions have focused on an individual target group, often the elderly, and there is thus insufficient knowledge about several other groups. Altogether, there is thus no general view of the need for coordination and the related challenges, for different groups of patients and users.

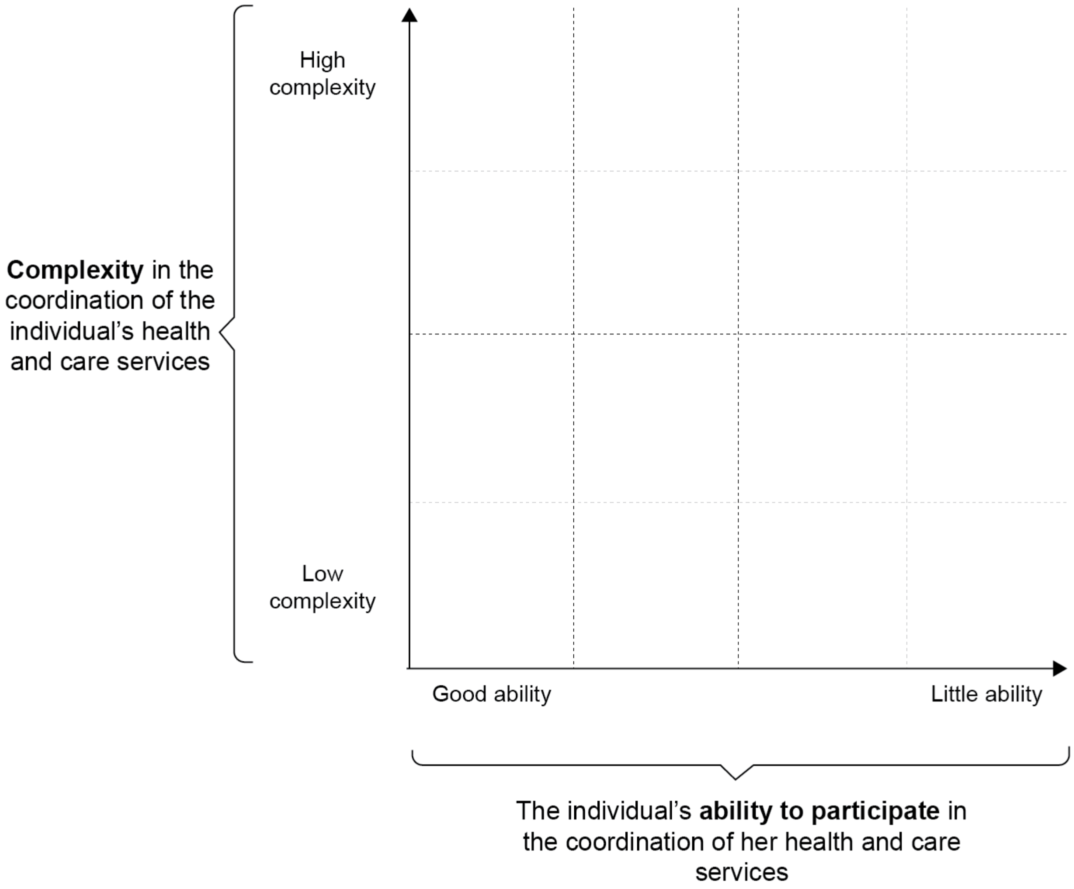
Those groups that are identified in the framework are general enough to cover all patients and users in health care and medical care and the care services. The objective is for it to be possible to use the groups for an overall system analysis of coordination problems, while they must be sufficiently specific to be used for management and control in county councils and municipalities.

4.1 THE DIMENSIONS WITHIN THE FRAMEWORK

The framework takes its starting point in an assumption about groups with similar needs for coordination services being close to each other on a scale consisting of the following two dimensions (Figure 8):

- ***The complexity*** *in the coordination of the individual's health and care services. Complexity here means how many of the individual's services that need to be coordinated and the organisational conditions that facilitate or make coordination more difficult.*
- ***The individual's ability to participate and contribute to*** *the coordination of the health and care services. This includes how much aid and support the individual needs from the health and care services in order to drive the health and care services process forward. For example, this is about the individual's ability to take those contacts that are needed to have one's needs fulfilled, be the carrier of information and deal with part of the implementation herself.*

Figure 8. Framework for describing general groups of patients and users and their needs for coordinated services from the health and care services.

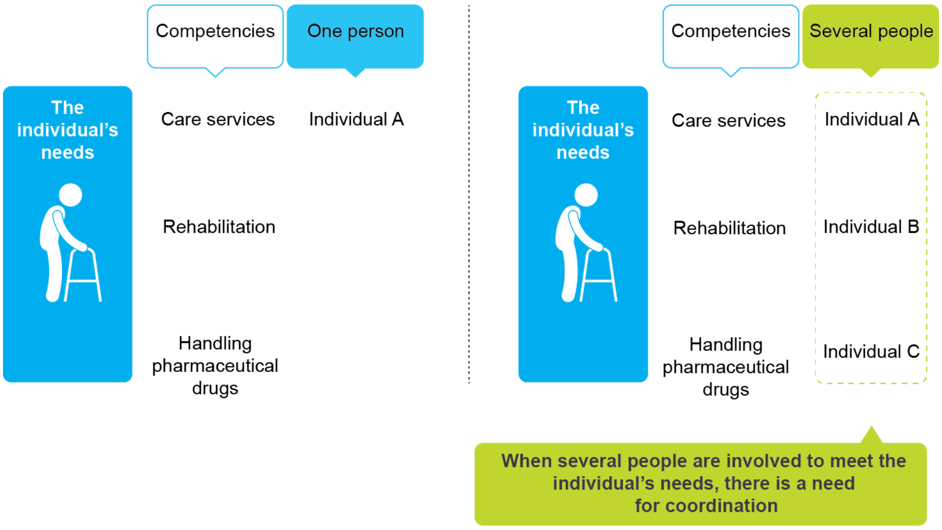


An important dimension that has not been included in the above framework is the degree of seriousness that leads to the individual's need for coordination. The reason is that we consider that the degree of seriousness itself is not decisive for the coordination needs of the individual. How different solutions can contribute to meet the coordination challenges is in general not affected by how serious the situation is either. However, the degree of seriousness is a very important aspect to take into consideration when analysing the consequences of insufficient coordination or deciding what measures that are to be given priority in order to improve the coordination for specific patient or user groups.

Complexity in the coordination of the individual's health and care services – when do the services need to be coordinated?

According to our definition of coordinated health and care services, good coordination is characterised by all health and care services activities around the individual having been actively organised into a well-working unity. In turn, the individual's needs determine what competencies that are needed and what individuals that should be involved to meet the needs for coordination. When one person has all competencies, there is no need for coordination. The need for coordination does instead emerge when the competency of several people is needed to meet the needs of the patient or user (see figure 9). The need for coordination can also be affected by what areas of competency that are included in different educations for professions and specialists.

Figure 9 . Illustration of how the needs of the individual and the competencies that are needed are related to the need for coordination.



4.1.2 Dimension A: Coordination complexity

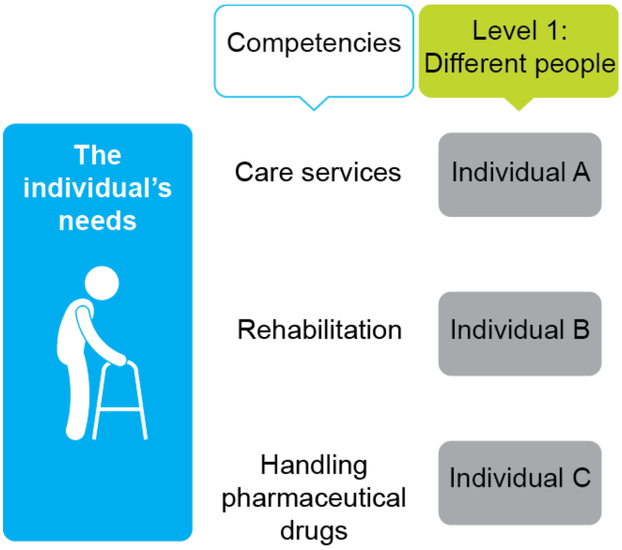
The complexity in the coordination of activities increases the more people that are involved in the health and care services. It also increases the further these activities are from each other at the organisatorial level. It is less complex to coordinate services within one unit of care than between three different units that belong to different principals. How we choose to organise and regulate the health and care services in different units, organisations or principals does thus affect how complex the coordination is. We have identified five general levels where there is a clear increase in the complexity at each level:

- Level 1: Coordination between different individuals and professions
- Level 2: Coordination between different units
- Level 3: Coordination between different organisations
- Level 4: Coordination between different domains
- Level 5: Coordination between different principals

Figure 10 illustrates how the complexity of the coordination increases at different levels. It is worth noting that the coordination challenges at level 1 (between individuals in the same unit) also remain at level 5 (different principals). What happens when the health and care services need to be coordinated at higher levels is that there are even more challenges.

Level 1: Different individuals and professions

Figure 10. Description of level 1: Coordination between different individuals and professions.



When several people within one unit provide assistance to one patient or user, the services need to be coordinated. This means that a clear and overall division of responsibility is needed and that a well-working communication is needed between those working in the unit. Otherwise, there is an increased risk that the information about the patient or user is not available in a useful way and at the right point in time for the person who needs it.

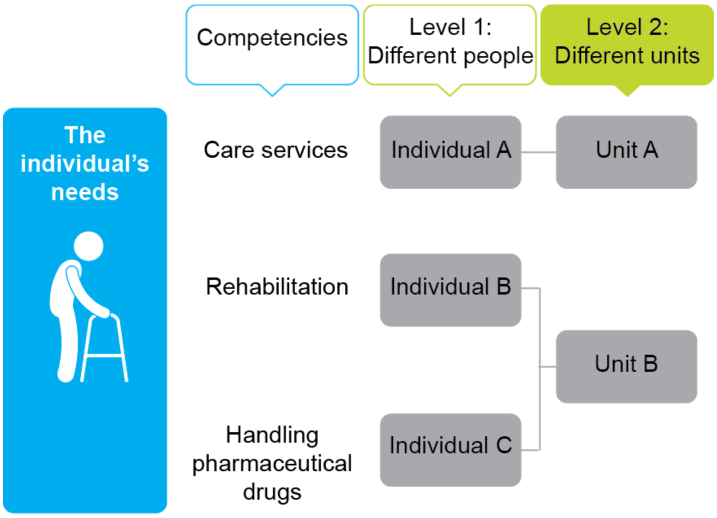
The coordination challenges between individuals within a unit can also emerge when the routines for documentation and information transfer are unclear or due to the fact that they are not adhered to.

Another example is when different colleagues at a unit meet the patient at different visits and at different points in time, including day or night. The use of temporary staff might make coordination more difficult, for example.

Another challenge that might emerge is when the individual's needs for different competencies are also collected in different professions. Already in the education, there is a kind of division of competency among different professions in the health and care services which can contribute to there not always existing a uniform view of the patient or user. According to Abbott (1988), it is common for there to be competition between different professions about who is to carry out a certain task and thus get the benefits that this entails. The fact that, for example, the areas of responsibility of doctors have been extended over time shows that they have been successful in their organisation as compared to other professional groups. Abbott considers that specialisation and professional competition might lead to operations moving away from their basic task – solving the patient's or user's problem.

Level 2: Different units

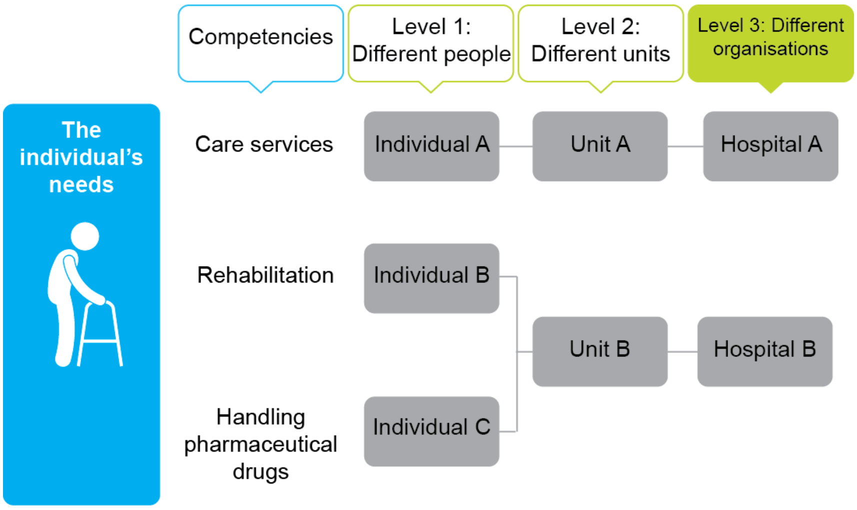
Figure 11. Description of level 2: Coordination between different units.



As soon as the individual's needs must be met by staff at different units, there is an increase in the complexity when coordinating the services from the patient's or user's perspective. For example, different units at a hospital or larger sheltered housing often have different schedules and different managers. This might, for example, mean that the scheduling must be coordinated and that possible differences in priorities between different managers must be dealt with.

Level 3: Organisations

Figure 12. Description of level 3: Coordination between different organisations.

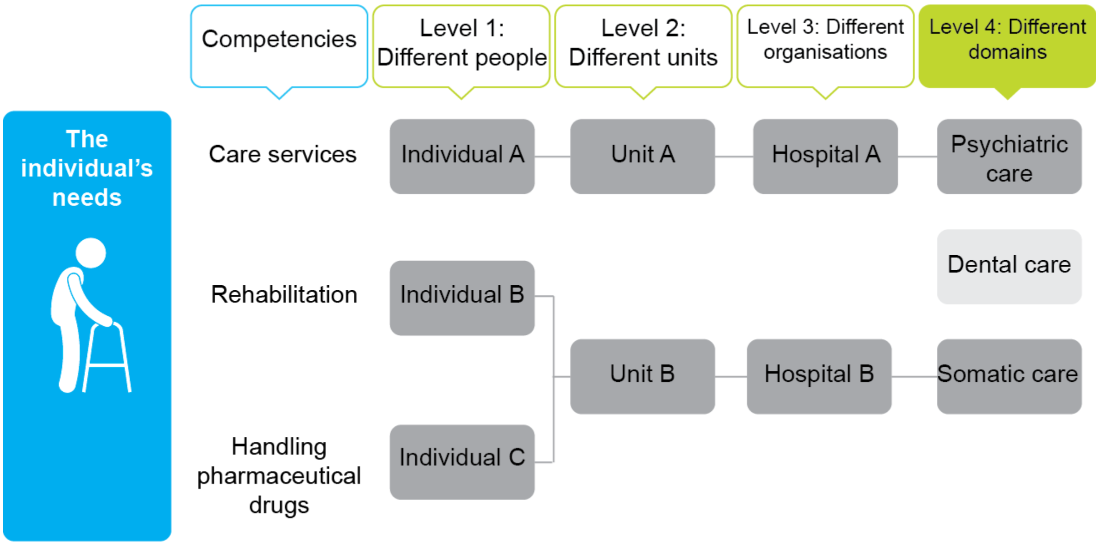


If the patient's or user's needs must, in turn, be met by individuals in different organisations, the coordination becomes even more complex. Organisations in this sense are, for example, different hospitals, individual units for specialist care and care centres. Several factors contribute to this complexity. Different organisations in the health and care services do often have different IT systems for documentation, time reservations and scheduling, which makes information transfer and coordination more difficult. When the organisations are separate economic units, it might also be difficult to agree on how the work efforts should be distributed in relation to the economic remuneration that each respective organisation receives. The fact that the organisational culture and the management system often differ between organisations might also contribute to increased difficulties in creating coordinated health and care services.

Among Swedish health and care services, there has lately been an increase in the purchases made by the county councils of operations from private firms and associations and foundations, for example due to the introduction of the Act on Systems of Choice (LOV) (SCB 2015). This might increase the need for coordination, both if more agents become involved and if private and public agents that need to coordinate on a patient or user use different IT-systems or similar ones.

Level 4: Different domains

Figure 13 Description of level 4: Coordination between different domains.

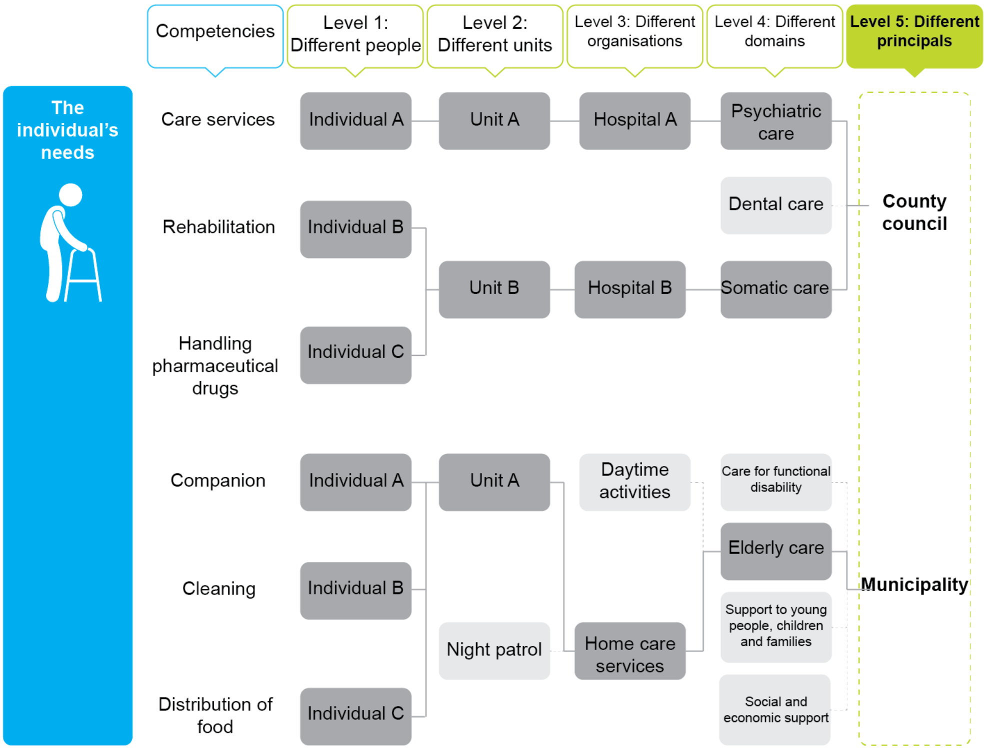


A fourth level of complexity is reached if the individual's needs are met by organisations that are active in different "domains". From the perspective of medical care, domains do, for example, mean different areas of care such as psychiatric care, dental care and somatic care. From a municipal perspective, one does instead mean different services and operations such as support to the functionally disabled, elderly care, support to young people, children and families and social and economic support. These domains are also often characterised by there being a common professional culture within the domain and those who work within a domain do often have a common academic or professional background. One aspect that contributes to an increased complexity at this level is that there might be a lack of consensus between different domains on how the total health care or care services for the patient or the individual should be implemented. Those individuals within the respective organisation who are to carry out the respective services are usually also more used to cooperating with other people within the same domain. Coordination between domains can also be made more difficult by the fact that they are partly regulated by different legislations and regulatory frameworks.

Level 5: Different principals

The coordination becomes most complex when several principals are involved. This does, among other things, mean that the operations of the municipalities/regions are largely subject to different legislations, which does, for example, make the information transfer more difficult. Municipalities and county councils do also have different political leaderships and separate taxes and fees serve to fund the respective operation. For example, the coordination of services is made more difficult if there are no agreements and contracts between the parties. In certain areas, the allocation of responsibility between municipalities and county councils might be unclear, which makes the coordination of services more complex.

Figure 14 Description of level 5: Coordination between different principals.



4.1.1 Dimension B: The individual’s ability to participate in and contribute to the coordination of her health and care services

The health and care services are currently usually organised in such a way that the patient or user should herself initiate those contacts that are needed. This means that the individual herself often needs to be the information provider and, for example, follow up referrals and seek the right level of care. When this ability is reduced, there is, however, a change in the ability to coordinate one’s own health and care services and to see what solutions that might contribute to improved coordination. Thus, it is important that those supplying the health and care services continuously evaluate the individual’s life situation and what people that exist close to the individual that might act as support people.

For an individual with good abilities to participate, IT solutions that make it easier for the individual to make appointments herself or follow up test results might be important contributions. For other people, this is not a good solution, however, since they do not have the ability to use the new IT solutions and instead need individually adapted support. In the same way, an individual with good abilities might welcome a trend where there are large possibilities for individual choice at several levels (at the price of increased complexity in the coordination), while an individual with little ability to participate in the coordination in contrast needs more hands on solutions that deal with the coordination challenges, even if these occur at the price of less individual choice .

A large number of different factors might contribute to the individual’s ability to participate in and contribute to the coordination of her health and care services being small or decreasing. Examples of such factors that we have identified are:

- reduced cognitive ability, for example dementia
- mental health problems, for example depression, anxiety or paralysis
- reduced physical functional ability
- low age
- high age
- language barriers or insufficient knowledge about society

In several cases, the patient’s or user’s own abilities might be compensated for by the services of a close relative. When there is no such relative, there is, however, nobody to take on this coordinating responsibility and there is thus a risk that the individual does not get the health and care services that she needs.

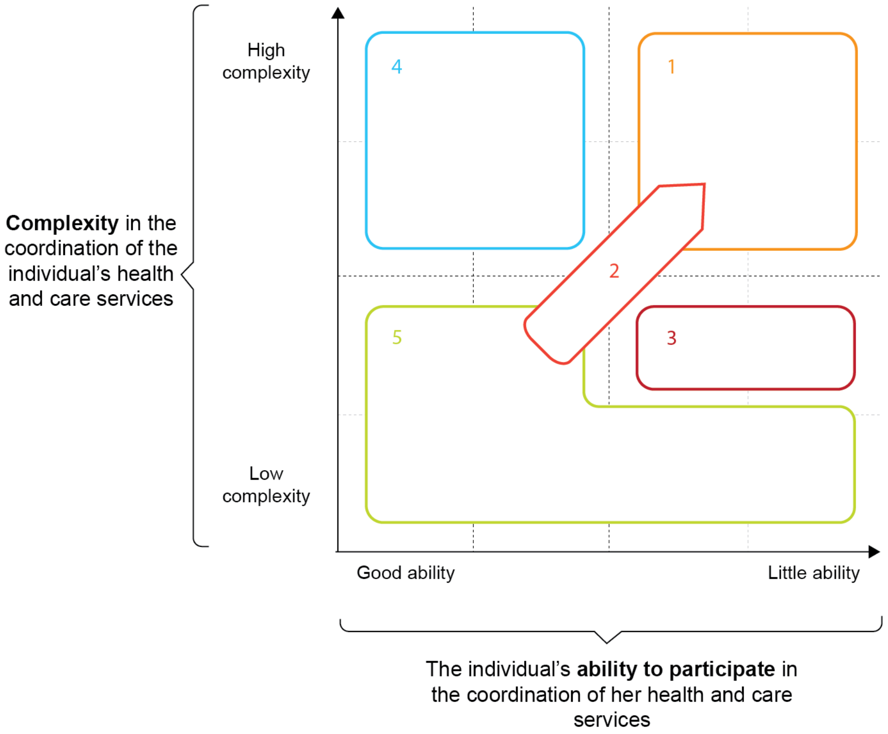
4.2 GENERAL PATIENT- AND USER GROUPS DIVIDED ACCORDING TO COORDINATION NEEDS

As initially mentioned, one objective of the framework is to try to identify general patient and user groups where the common characteristics are their need for coordination. The first stage in creating the framework was to describe how the needs for coordination emerge and what main dimensions that drive the need for coordination; that step was described in the above section. Based on the dimensions in the framework, a number of general patient and user groups are then identified where the need for coordination might be assumed to be similar. The groups are described below figure 15.

In order to proceed one more step with the analysis, a quantitative estimate is then made of the size of those groups that are included in the framework, based on the total consumption of health and care services by the Swedish population. Optimally, the division into groups should be based on an analysis of each individual's total contacts with the health and care services and her ability to participate in the coordination of these contacts herself. This analysis is currently not possible. Instead, we have been obliged to take the existing categories of a number of patient and user groups as the starting point. Traditionally, these have been based on the fact that patient and user groups get similar kinds of services, are in contact with the same operations or have certain common diagnoses, and not on differences in the coordination needs between groups. In our classification, we do instead try to identify what characteristics that distinguish the different groups from a coordination perspective.

Individuals who are in great need of coordination and several kinds of services are often part of several traditional patient and user groups at the same time. When applying the framework, we have, however, chosen to only allocate each individual to one group. This means that individuals who have needs that are captured by certain traditional patient and user groups might seem to be missing in the framework. They are then instead included in a broader group, due to the fact that they have additional needs. For example, people with economic support or vulnerable children or young people often get other services from the health and care services. These individuals do then belong to another group when the framework is applied. Vulnerable children are, for example, often included in the group of children with mental health problems.

Figure 15. General patient and user groups.



The starting point has been that the groups should be so general that they can cover all patients and users in health care, medical care and the care services. The groups should also be useful for an overall system analysis of the coordination problem, while also being sufficiently specific for it to be possible to use them for management and control at the county council and municipal level. The five general patient and user groups are:

- *Group 1:* Individuals with complex needs and little ability to participate in the coordination of their health and care services
- *Group 2:* Individuals who have recently become ill and need swift services from several agents and where the swift course of events affects the individual's ability to participate in the coordination of her health and care services
- *Group 3:* Individuals who are largely somatically healthy with little ability to participate in the coordination of their health and care services
- *Group 4:* Individuals with complex needs, but with good ability to participate in the coordination of their health and care services
- *Group 5:* Individuals with largely good mental and somatic health

The general patient and user groups are described in more detail in the following section. It is then possible to identify more specific patient and user groups in each general group.

Group 1: Individuals with complex needs and little ability to participate in the coordination of their health and care services

Individuals with complex needs are often in need of several kinds of health and care services from a large number of organisations and principals. If these individuals also have a limited ability to be active and participate in their health and care services, their need for coordination will be particularly large. In many cases, the total needs of these individuals can only be fulfilled by different agents coordinating their services.

Previous studies of the coordination challenges in the Swedish health and care services have often focused on specific patient and user groups in this general group. This does then often concern the most ill elderly people or individuals with a serious mental illness. However, we also find that a number of other specific patient and user groups belong to this group.

Exemple, group 1:

- The most ill elderly people
- Individuals with serious mental and somatic comorbidity
- Individuals who are exposed to violence in close relationships
- Individuals with serious self-injury behaviour
- Individuals who are in a late palliative stage

Group 2: Individuals who have recently become ill who need swift services from several agents and where the swift course of events affects the individual's ability to participate in the coordination of her health and care services

Patients and users who have recently been affected by a serious illness or accident and thus have a limited ability to coordinate their services have a large and often urgent need for coordination. For them to get a satisfactory rehabilitation, good coordination and swift services from several organisations and principals are needed. Many of these individuals might before mainly have had good somatic and mental health before falling ill and it is often a great challenge to adjust to the new situation.

Exemple, group 2:

- People who have recently had a stroke
- Elderly people who have had a falling accident

Some of these people will get well after some time and will regain their lost functions, while others might also be in need of support from the health and care services in the future.

*Group 3: I*ndividuals who are largely somatically healthy with little ability to participate in the coordination of their health and care services

These patients and users are mainly somatically healthy and their coordination thus entails less complexity than, for example, those individuals who have considerable contacts with both mental and somatic medical care. At the same time, due to different background factors such as low age or a cognitive disability, these individuals have less ability to participate in the coordination of their health and care services. The same underlying reasons do, in many cases, lead to support from municipal care. If there is a need for mental or somatic medical care, there is a swift increase in the complexity of the coordination since different principals need to be involved. Moreover, many of these individuals run the risk of developing additional chronic diseases, which a good coordination of the services might contribute to prevent.

Exemple, group 3:

- Individuals with cognitive or neuropsychological disabilities
- Children with mental health problems

Group 4: Individuals with complex needs, but with good ability to participate in the coordination of their health and care services

There is a large number of individuals who need health and care services from many different organisations and principals, but who, at the same time, both can and might prefer to participate in the coordination of these services. For these individuals, different tools that facilitate the coordination might be very useful, for example IT solutions that create possibilities to book appointments oneself and follow up the test results.

Example, group 4:

- Younger people with several simultaneous chronic diseases but good mental health

Group 5: Individuals with largely good mental and somatic health

There is very little complexity when it comes to coordination for individuals who mainly have good somatic and mental health. Their need for health and care services is primarily fulfilled by primary care and these individuals have limited contact with other agents in the health and care services. A large share of these individuals has a good ability to coordinate their services.

Example group, 5:

- Individuals who are entirely healthy
- Individuals who have a simple chronic disease
- Individuals suffering from reduced mental well-being

Other individuals would find it more difficult to coordinate their services, if the need for contacts with more parts of the health and care services were to increase. This might, for example, be individuals with insufficient knowledge of the language or some physical disability.

5 The extent of the coordination problem and special needs for coordination

In this chapter, we present a quantitative estimate of the framework that was presented in chapter 4. The estimate is based on a survey of the number of individuals within the respective group and the cost that is related to the services currently provided to this group by the health and care services. The approach is to try to pinpoint everyone who is in contact with the Swedish health-, medical- and care systems, even those who are largely healthy. Then, there are in-depth examples of five traditional groups with needs that we consider to have a particularly large need for coordinated health and care services. These five groups are here given the headings mental health problems, certain individuals with disabilities, addiction/comorbidity, violence in close relationships and the most ill elderly people. When looking at this in detail, we make a general presentation of the group. However, the focus is on with what agents that the individuals in the group are in contact and how the coordination currently works for this group.

5.1 OVERVIEW OF THE SIZE AND COSTS OF THE GENERAL PATIENT AND USER GROUPS

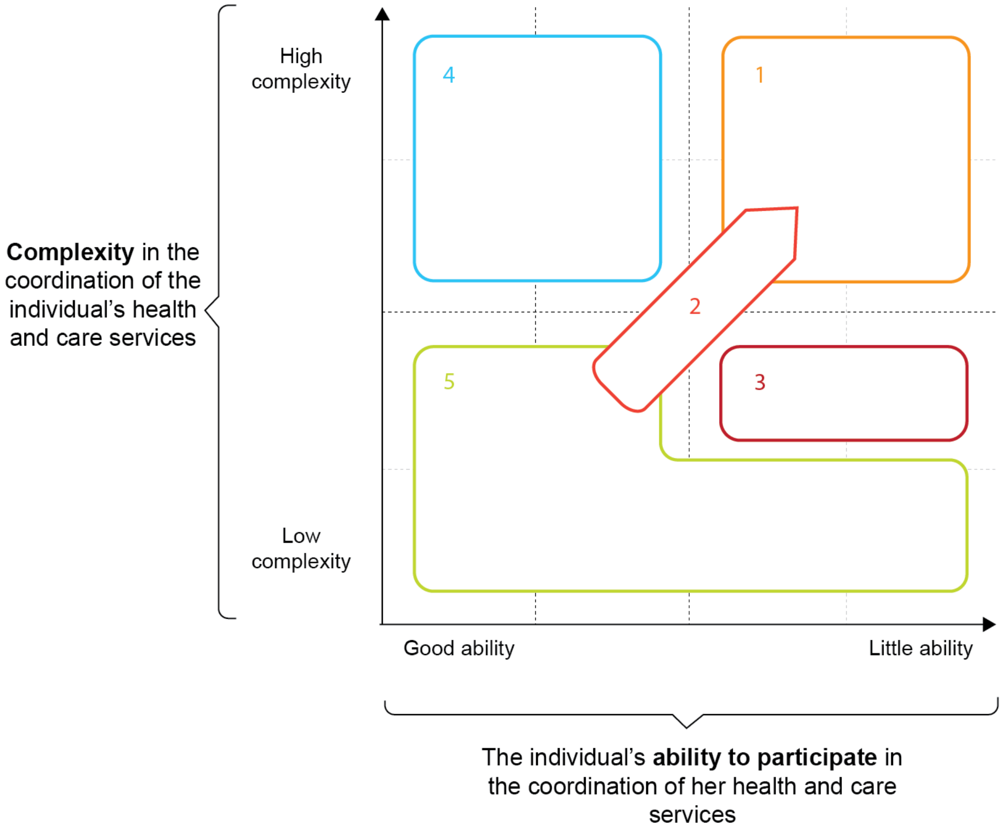
The five general patient and user groups that were presented in the previous chapter (see figure 16) are:

- *Group 1:* Individuals with complex needs and little ability to participate in the coordination of their health and care services
- *Group 2:* Individuals who have become ill and need swift services from several agents and where the swift course of events affects the individual's ability to participate in the coordination of her health and care services
- *Group 3:* Individuals who are largely somatically healthy with little ability to participate in the coordination of their health and care services
- *Group 4:* Individuals with complex needs, but with good ability to participate in the coordination of their health and care services
- *Group 5:* Individuals with largely good mental and somatic health

In this section, we make an estimate of the size and costs of the groups based on an analysis of the specific patient and user groups that are considered to be included in the groups. In a first stage, 28 subgroups were identified within the five groups. The subgroups were selected so that they would together cover the major part of the individuals in the respective general group. For each subgroup, a survey was then made of the number of individuals and the yearly costs of the group for municipalities and county councils. The results of the subgroup analyses were then summed up in order to estimate the size and costs of the general groups. The 28 subgroups are presented in the methodological description in Appendix 1.

It is important to keep in mind that the estimate is to be considered as a first empirical estimate of the size of the groups. The cost estimate is also based on the actual consumption of health or care services, which only constitutes a proxy for the total need for health and care services. For several reasons, there are many people who do not consume health or care services despite the fact that they would need to. For example, the hidden statistics are large as concerns individuals who are subject to violence in close relationships and only a small share of those who really need to do so actually do get into contact with the health and care services. This group is described in more detail in chapter 5.2.4. These people will thus not be included in the estimates. The theoretical framework takes its starting point in individual needs for coordination but when this is applied to real life, it is instead consumption patterns that govern the division into groups

Figure 16. Patient- and user groups.

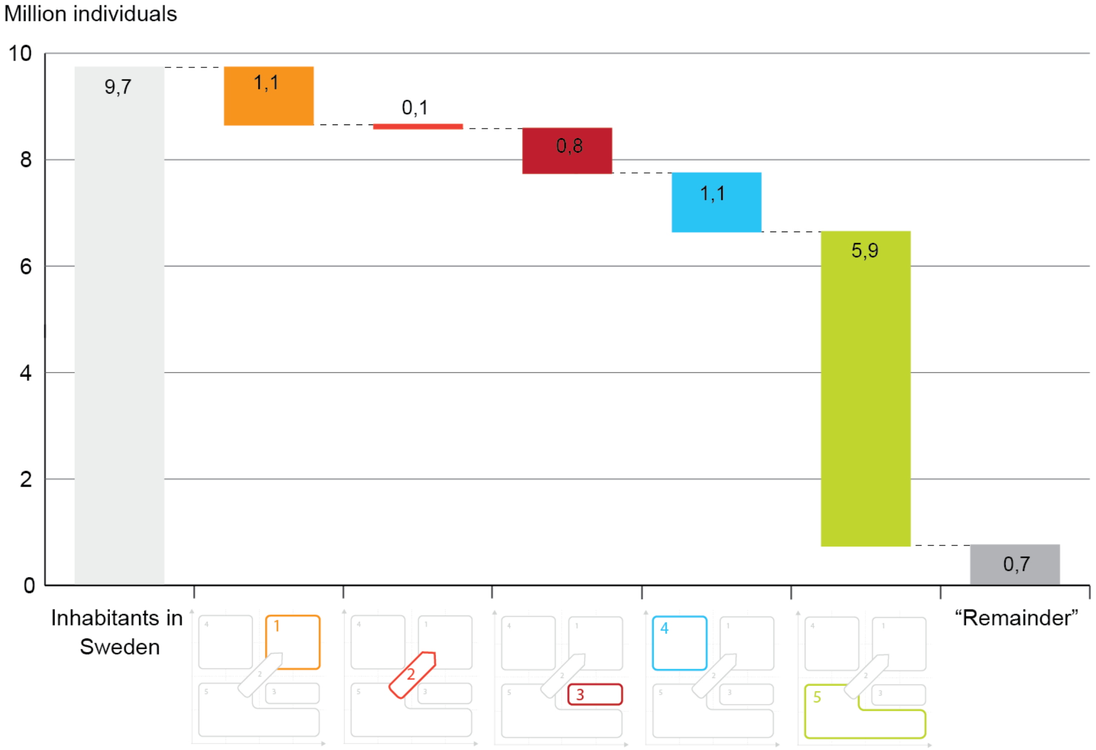


Our survey shows that about one million individuals belong to *group* 1, a vulnerable group which, besides having little ability to coordinate its health and care services, is characterized by high complexity in the services that are needed. Support that facilitates the coordination is of particular importance for these individuals. The survey also shows that a majority of the population (about 60 per cent) have good somatic health and do not encounter any major problems as concerns the coordination of services.

It is important to keep it in mind that this survey only gives a snapshot of the situation. An individual can move from one group to another over time for various reasons. For example, healthy individuals with a disability or insufficient knowledge of the language are included in *group 5*. If their need for health and care services were to increase, many would need help with coordination and would thus end up in *general groups 1 or 3*. It is important that the support and those services that are offered correspond to the changes in the needs. In the longer run, there can also be a change in the size of the groups. Since the population is ageing, it is likely that an increasing number of individuals will need more extensive health and care services. The number of people who is in need of many different kinds of health and care services (*groups 1-4)* will most likely increase more quickly that the number who is largely in good health (*group 5*).

The survey also shows that specific patient and user groups, which belong to the same group, differ when it comes to size, cost, clinical picture and psychosocial situation. For example, the subgroups *dementia* and *violence in close relationships* are both included in *group 1*. Even if both subgroups normally have, or would need, contact with agents from both the municipality and the county council, this is largely about different types of agents within one of these domains. Thus, it is important that those services that are to improve the coordination are adapted to the individual needs and abilities and to what specific agents that are involved.

Figure 16b. The number of individuals in groups 1-5. ”Remainder” consists of the number of individuals that remain when The Swedish Agency for Health and Care Services has estimated the general groups.



Our estimates show that a majority of the Swedish population (about 60 per cent, six million individuals) are estimated to have simple needs for coordination and in general have good abilities to contribute to the coordination of their services themselves (see *group 5* in Figure 16b). At the same time, about a third of the Swedish population (about three million individuals) is estimated to have larger needs for coordination (*groups 1-4*). About two thirds of these (two million individuals) do, according to our survey, have little ability to participate in the coordination of their health and care services themselves (*groups 1-3*). For example, both our interviews and previous studies show that the coordination is often insufficient for these groups. This means that in many cases, the patient or user might have worse health and care services and that the situation feels insecure for the affected individual. Relatives often carry a great deal of responsibility for serving as a coordinator. When the patient, the user or the relative cannot participate in the coordination, the support from the health and care services is often insufficient. The coordination is estimated to be very complex for about one million individuals while they have a good ability to participate in the coordination of their services (*group 4)*. Thus, 700 000 individuals (8 per cent) of the total population in Sweden remain that cannot really be allocated to any of the general groups (see figure 16b).

5.1.1 Total picture of the number of individuals and costs

Figure 16c provides an overview of the relationship between the size of the groups and the costs for health and care services. *Groups 1* and *2* are estimated to cover about 12 per cent of the population and do, at the same time, constitute about 60 per cent of the costs for care services and 30 per cent of the costs for medical care.

High costs for medical care do, however, not always mean that the costs for care services are also high. *Groups 4 and 5* constitute a large share of the costs for medical care (about 60 per cent) and a small share (about 4 per cent) of the costs for care services. The relationship is the opposite for *group 3*. This group has a smaller share (8 per cent) of the costs for medical care, but about one fourth of the costs for care services.

Figure 16c. Overview of the number of individuals in groups 1-5 and the costs for medical care and care services.

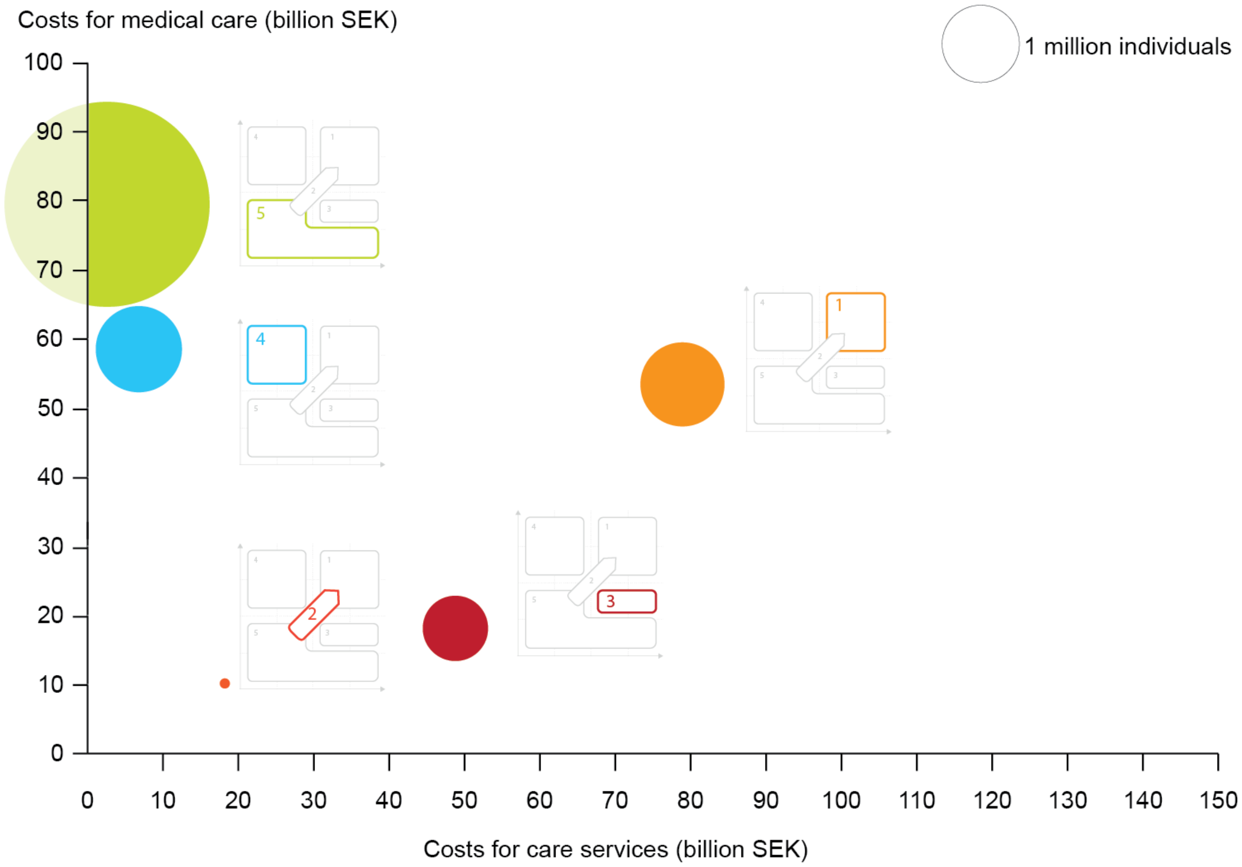
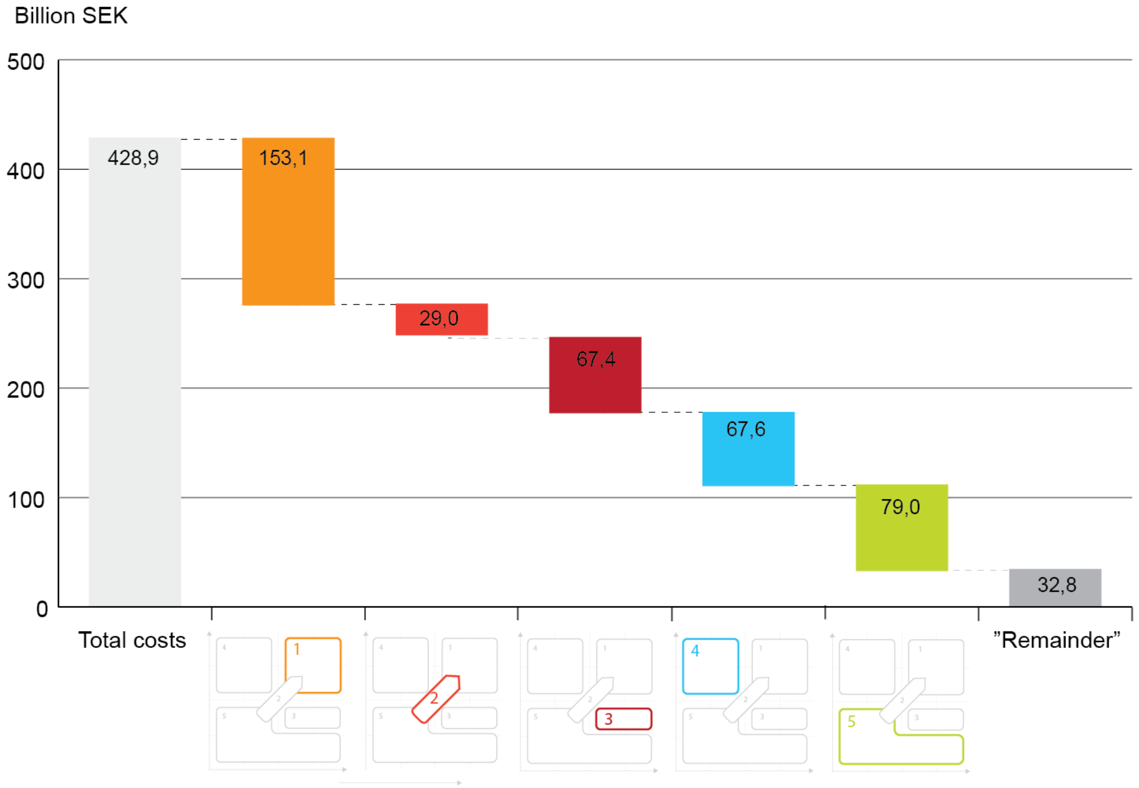


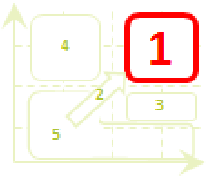
Figure 16d. The total costs of health and care services for groups 1-5.

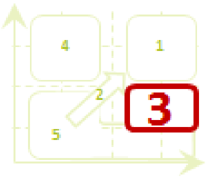


5.2 IN-DEPTH EXAMPLES OF GROUPS WITH LARGE COORDINATION NEEDS

This section presents some in-depth examples of groups with large coordination needs. The selection is based on those groups that the people interviewed have emphasized in the question about what groups they consider to have the largest coordination needs. The majority of those individuals concerned are also included in group 1 that was described earlier.

5.2.1 Individuals with mental health problems





Mental health problems constitute a public health problem that is estimated to affect 20 per cent of the working population at some point in their lives and which continues to increase at both the national and the international level (Socialstyrelsen 2015c). There has been an increase in disorders such as anxiety and sleeping problems in both the twentieth century and the beginning of the twenty-first century, and the increase is the largest among young women (Folkhälsomyndigheten 2014).

In this section, we make an in-depth study of the problems that surround people with mental health problems. Individuals with mental health problems do, for several reasons, have a reduced ability to coordinate the different contacts with the health and care services that they might need themselves. While diagnoses such as ADHD lead to concentration problems and difficulties in coping with daily life, depressions make the individual dispirited and she might lose her energy (Arbetsförmedlingen et al. 2011). The interviewed individuals say that there is insufficient knowledge among medical staff about mental health problems which might lead to these patients getting worse treatment or getting the wrong treatment. The Swedish Agency for Health and Care Services Analysis (Vårdanalys 2014d) has previously shown that there is insufficient competency about mental health problems in somatic care, which contribute to different health care services for patients with and without mental illness.

What agents are involved in the health and care services for the individuals?

Figure 17. Examples of agents that an individual with mental health problems normally encounters in the health and care services.

The individuals that we have interviewed emphasize that mental health problems might be long term or even chronic and might entail difficulties in coping with daily life. Thus, coordinated services from different agents within the whole welfare sector might be needed in order to create a well-functioning daily life for these individuals. A long-term contact is also necessary for many of these individuals, since there is no natural end date. Depending on what is the diagnosis and its degree of seriousness, the individuals might be treated within in-patient psychiatric care, specialist psychiatric out-patient care or within primary care. For children and young people, there are special medical centres such as psychiatric units for children and youths but also health centres for young people. Those who suffer from a milder version of mental health problems might only be in contact with their care centre and all threads have to be winded up from their care centre.

Those contacts that the group is in need of thus include everything from psychiatric care for medical or psychological treatment to help from the social services with housing and other kinds of social support, for example social skills training. For those suffering from comorbidity in the case of addiction, there are addiction treatments in the county councils and the municipalities. When so needed, they get sickness benefits or activity grants from Försäkringskassan (the national social insurance office) or support from the social services. When so needed, Arbetsförmedlningen (the employment agency) will also offer support through specially adjusted work tasks or work places.

How does the coordination work today?

According to the legislation, an individual plan (a so-called SIP, coordinated individual plan) should be drawn up between the municipality and the county council when a person is in need of support from both medical care and the social services (3 f § The Health and Medical Services Act 1982:763 and 2 ch. 7 § Social Services Act 2001:453). The individual plan should favour increased cooperation so that the individual does not need to take any responsibility for the coordination of the services she needs. Within the PRIO-venture, a number of objectives have been set up for increased cooperation and coordination between different principals (Vårdanalys 2014a). When the venture was evaluated in 2014, 97 per cent of the municipalities and all county councils had drawn up cooperation agreements. Many did also report the number of SIP:s that had been drawn up, but we know very little about how the actual coordination worked for the individual.

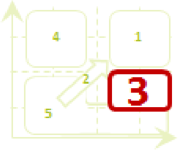
Since the psychiatric reform in 1995, cooperation has been a recurring theme in those ventures that the government has implemented within the area of mental health problems. Within the latest government venture, PRIO, remuneration based on achievement has been paid out to municipalities and county councils that have drawn up cooperation agreements and reported the number of SIP:s that have been created. Despite recurring cooperation ventures, there is, however, a need for continued development work within this area (Vårdanalys 2014a).

”We have put too much focus on actual cooperation but have forgotten why we do this. We must do things differently in our work and this must lead to better results for the individual.” (Project leader SKL).

A problem that has been given much attention as concerns individuals with mental health problems is that they are treated differently when it comes to somatic care. For example, people with mental health problems are treated differently in case of a heart attack and run a larger risk of dying six months after a heart attack as compared to individuals who do not suffer from mental health problems (Socialstyrelsen 2011c). These are examples of these individuals not being considered from an overall perspective when they get in contact with the care services. In our interviews, it also emerged that individuals with mental health problems are sometimes not trusted in somatic care but are instead referred to psychiatric care when they seek care.

”There exists an attitude problem in the care services. There is a fear of mental ill health.” (Analyst, patient organisation)

5.2.2 Individuals with disabilities for whom different kinds of services have been approved according to the Law Regulating Support and Service to Persons with Certain Functional Disabilities (LSS)



The group that is described in this section has such extensive and permanent functional disabilities that it has difficulties dealing with daily life. What individuals that fall into this group is largely regulated by the legislation. Due to the Law (1993:387) Regulating Support and Service to Persons with Certain Functional Disabilities (LSS) that came into force in 1994, individuals with extensive and permanent functional disabilities have the right to services in order to deal with difficulties in daily life (Government Bill 1992/93:159 p. 45). Those who belong to this group according to 1 § LSS have the right to services in the form of special support and special services if they need such help in their daily life and this need is not fulfilled in any other way.

For an individual to obtain services within LSS, the individual must be considered to be in any of the following conditions:

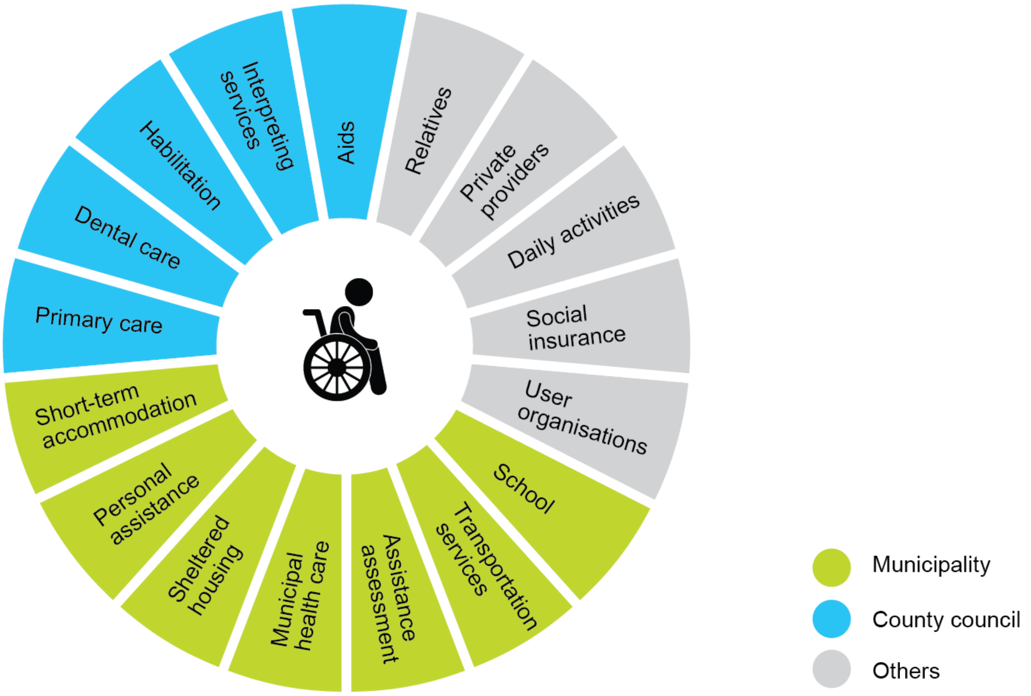
- Retardation, autism or a condition that is similar to autism.
- Considerable and permanent mental disability after brain damage in adult age caused by external violence or bodily illness.
- Other permanent physical or psychological disabilities that are apparently not due to normal ageing, if they are large and create considerable difficulties in daily life and thus an extensive need for support or services.

Individuals within LSS do generally have a very low ability to participate in coordinating their health and care services. An individual within LSS has been estimated to have such an extensive and durable functional disability that she cannot cope with her daily life. Many individuals within LSS with autism and conditions similar to autism do also have profound disorders as concerns social skills, communication and behaviour (Autism- och Aspergerförbundet 2015).

What agents are involved in the health and care services for the individual?

Individuals with functional disabilities are in need of support from many different agents in the state, the municipality and the county council. The government objective when designing this support was that individuals with a functional disability and their families should, to the largest possible extent, be able to live a life like ”anyone else”. The group can receive government support from, for example, Försäkringskassan (the national social insurance office). The group receives support from the county councils in the form of different kinds of aids, certain medical care, advice and support, habilitation and rehabilitation. For example, the municipalities offer personal assistance, companions, home adjustments, contact persons and transportation services for the disabled. The municipality also offers support through schools and, under certain conditions, access to compulsory school for pupils with learning disabilities and training school.

Figure 18. Examples of agents that an individual with assistance within LSS will normally encounter within the health and care services.



How does the coordination work today?

Since individuals with functional disabilities have many different contacts with health care and medical care as well as the municipal health and care services, it is important that these agents coordinate their services. There are few studies on how the coordination actually works in this group, but in our interviews, it appears that it very often has shortcomings. In many cases, the coordination seems to work better for children and young people than for adults. Also the Swedish National Audit Office (Riksrevisionen 2011), which has made the most thorough evaluation of the coordination of services for this group, shows that the coordination is often insufficient. According to the evaluation, relatives get to carry a large part of the responsibility for the coordination. It is then crucial that there exists a strong relative with a driving force for the coordination to work. There also seem to be problems as concerns the total division of responsibility for the services, which has, among other things, emerged in our interviews. No agent considers that she has a clear authority to be the driving force for cooperation and nobody considers herself to have the main responsibility for the coordination. This might lead to no agent having an overall picture of the individual’s situation.

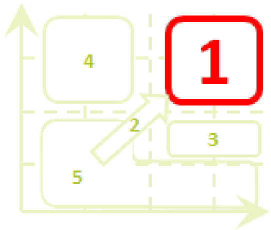
Several of the people interviewed also describe that children’s habilitation and medical care for children take a large role in coordinating services but that this support disappears when the individual becomes an adult and is transferred to adult habilitation and the general care centre. Here, there is a risk that there will be a clash between, on the one hand, an individual who is to live like anyone else and, on the other hand, that this is an individual with an extensive functional disability who has completely different abilities than a normal visitor to the care centre. Some of those doctors that we interviewed said that it is a great challenge for the care centre to meet and deal with these groups in an appropriate way when the knowledge about this group is low among general practitioners and nurses.

"When children turn 18, they are all of a sudden supposed go to a clinic for adults and it is not certain that they will get the help that they need from parents or some other relative. This group needs to be coordinated with compulsory school for pupils with learning disabilities and adult health and care services when the transfer is being made. It is different to meet someone with diabetes than to meet someone with a mental disorder. This is a very vulnerable group." (Doctor in primary care)

"Already at the age of 16, things are beginning to pile up, the individual is getting closer to the border of adult life and might have developed different needs – maybe you need to get out in the world, have other needs for assistance, other medicines. Then you enter organisations with a tunnel vision– one speech therapist, one neurologist etc. As long as you are a child, you are cared for in paediatric care. As a child, you are always surrounded by a team, and also have a special contact nurse. But once you become an adult, you are one among lots of people suffering from a stroke, Parkinson, MS etc when you meet the neurologist." (Head of care centre)

A large part of the municipality health and care services for people with a functional disability is carried out by private providers, for example personal assistance and sheltered housing. Our interviews and the evaluation made by the Swedish National Audit Office (Riksrevisionen 2011) point to the fact that contracts with the municipalities often lack the requirement that it is part of the private provider's task to cooperate with other agents. When there is no formal requirement, the provider also lacks incentives and legitimacy to coordinate with other agents.

5.2.3 People with addiction problems who also suffer from a mental disorder (comorbidity).



Addiction problems can take many different shapes, for example overconsumption of alcohol, tobacco, narcotics and gambling. Moreover, different forms of risk behaviour are related: an individual with risky alcohol habits also runs a larger risk of having risky gambling habits, a larger risk of smoking or snuffing on a daily basis and to have used cannabis in the last twelve months. Moreover, there is a relationship between educational level and risky use in all of the previously mentioned areas of addiction (Folkhälsomyndigheten 2015b).

The use of and the addiction to narcotics are, in turn, related to several other factors that concern health and social situation (Folkhälsomyndigheten 2015a). There is a strong relationship between the use of narcotics and mental health problems; when an individual has a diagnosed addiction or dependence and some other mental disorder, this is usually called *comorbidity* (Socialstyrelsen 2014b). The use of narcotics is more common among those groups that are mentally vulnerable (Folkhälsmyndigheten 2015a) and unemployment, homelessness and criminality are common among individuals with addiction problems. People who use narcotics do also run a larger risk of having worse health and more than one individual dies every day in Sweden due to diagnoses that are related to narcotics. The national guidelines of The National Board of Health and Welfare recommend that the treatment be integrated since individuals with comorbidity run the risk of a worse course of events during the treatment and both illnesses should be treated simultaneously. It is estimated that about 4-5 per cent of all children aged below 18, about 100 000 children, live in a home where there is a parent with addiction or dependence problems (Socialstyrelsen 2015b).

The National Board of Institutional Care shows, by making interviews with users who have been admitted to health and care housing for addicts (so-called LVM-homes), that this is a group that does often have other problems besides the addiction (Statens institutionsstyrelse SiS 2015).

Table 1. Share of individuals with addiction problems who also..:

30 per cent	have been in foster care
	have early retirement pension or temporary disability pension
	have tried to commit suicide
40 per cent	have only completed comprehensive school
	have had suicidal thoughts at some point in time
	have at some point in time been treated in psychiatric care
50 per cent	have no home of their own
	have serious problems with their physical health

What agents are involved in the health and care services for the individual?

An individual or a family with addiction problems is in need of meeting a doctor, nurses, psychologists, trained social workers, behavioural scientists, psychotherapists etc. There is treatment for addiction and dependence within the social services, there exist psychiatric care, primary care and also care in case of dependence within the county councils. According to the Social Services Act (3 ch. 7 § and 5 ch 1 and 9 §§), there is a responsibility to help individuals get rid of the addiction. The need for contacts with health and care services is long term – of those who try to become sober, at least 90 per cent have a relapse at least once before they remain sober and of those who succeed in completing a whole treatment, 40-80 per cent run an increased risk of a relapse within twelve months (Socialstyrelsen 2014b). Those who have used narcotics might be in need of psychiatric care and care for detoxation and other injuries (Folkhälsomyndigheten 2015a).

How does the coordination work for this group today?

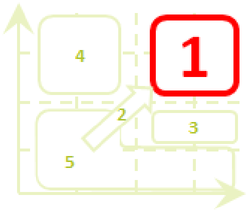
In our interviews, it is emphasized that the group is very vulnerable as concerns the need for support and coordination. Both the report from the National Board of Health and Welfare on the current situation as well as our results emphasize the need for a family perspective in addiction care services. If there is a family perspective, there is a reduced risk of a relapse, the children are doing better and the communication within the family is improved (Socialstyrelsen 2015b). However, this requires coordination between different units since adults with an addiction and children of addicts are often handled by different organisations.

"Addiction does often lead to mental problems among relatives. Having a family perspective, considering the needs of each individual and coordinating the services is often more efficient than pure treatment of the addiction." (Analyst at the National Board of Health and Welfare)

There is an increase in the share of municipalities that have routines for how to coordinate the addiction and dependence activities with other activities within the social services (Socialstyrelsen 2015c). In 2014, 77 per cent of the municipalities had routines for coordinating the addiction and dependence unit with the unit that is responsible for financial support. About half of the municipalities have routines for coordinating the activities of the municipalities and the county councils for individuals with a mental disability. Elderly people with addiction problems run a larger risk of not getting any help, however. A reason for this that has been identified is that there are no routines for internal coordination between elderly care and addition care within the social services. One third of the municipalities state that they have routines for this. Alcohol addiction is more common among the elderly today that what was the case in the past. Despite this, the municipalities have insufficient routines for discovering alcohol addiction and how to act if this is discovered. There is no decrease in the mortality in this group either, as is the case in other age groups with the same problems (Socialstyrelsen 2015e).

5.2.4 Individuals who are subject to abuse in close relationships

Figure 18c. The main location of the group in the framework.



Violence can be divided into four main types: physical abuse, sexual abuse, psychological abuse and neglect (NCK 2014). Neglect is about failing to give someone care, for example failing to help an elderly person who cannot take care of herself with her personal care.

Every fifth person states that at some point in their lives, they have been subject to abuse from a current or previous partner, every fourth woman and every sixth man (BRÅ 2014). On average, 17 women and four men are killed each year by a current or previous partner. Many perpetrators in severe violent crimes suffer from a mental illness (SOU 2014:49). According to the Swedish National Council for Crime Prevention (BRÅ) Swedish Crime Survey (NTU) from 2014, 7 per cent of all women and 6.7 per cent of all men were subject to crime within a close relationship at some point in the year 2012 (BRÅ 2014). Crime covers all kinds of systematic emotional and physical abuse. About two per cent have been subject to physical abuse. Of those who were subject to physical abuse, 85 per cent claim that they were also subject to emotional abuse. Women were to a larger extent than men subject to threats and sexual abuse and also to recurring abuse. Moreover, women were subject to more severe violence than men and have a larger need for medical care due to violence than men. About one third of those women who are subject to severe violence seek some kind of medical care. Most likely, more people are in need of care but might not take the contact that is needed since this situation is associated with shame. The group of women who are subject to violence also differs in several respects: young adults are more subject to violence than the elderly, the same applies for women with a lower level of education and also for women with worse economic conditions. The same differences do not exist among those men who have been subject to severe violence.

Violence in close relationships is a national health issue that can be prevented and health care and medical care can play an important role in this work (SOU 2014:49). A survey carried out by The National Centre for Knowledge on Men's Violence against Women in 2014 illustrates that different kinds of ill health are more common among individuals who have been or are subject to any kind of violence (NCK 2014). It should be emphasized that the study has not tested any causal relationships. For example, the study shows that men and women who have been subject to different kinds of violence in childhood or in adult life ran an increased risk of mental and certain somatic health problems, for example to suffer from a depression, self-harm behaviour, addiction and heart attack. The relationship between violence and health problems is strong, both in the short and the long run.

One third of the women and one fourth of the men who had been subject to any of the above crimes in 2012 claimed that there were children living with them at home. BRÅ (2014) scales this up to the population and estimates that at least 150 000 children live in households where there is violence.

Several studies of violence in close relationships emphasize certain groups as particularly vulnerable and running a larger risk of being subject to violence, where the consequences might be worse. These individuals are often also less able to use economic, political and social resources. The groups consist of individuals with a functional disability, individuals with addiction problems, elderly people, LGBT-individuals and foreign women who have come to Sweden for a relationship with a Swedish man.

”Violence affects the whole life situation. That is, the possibility of leaving a violent man might depend on whether you have money, food for the day, for example, thus you need economic support, then you need support and advice and then a women's line or the social services are needed, then you might need sheltered housing, and that is another unit within the social services. Then you might have physical injuries from the violence and then you need to visit the health and medical care services. And if this chain does not work, the health and care services do not work and then lives are at risk, the ultimate consequence.” (National experts, violence in close relationships)

What agents are involved?

An individual who is subject to violence in a close relationship might need support from a network of different agents: police, prosecutor, care services, family law, children's care, women's care, women's line/men's line/victim support, individual and family care, school etc. Many people who have lived in isolated relationships might also need help with simple daily activities such as opening a bank account, but for many people sheltered housing or even a new place of residence might also be relevant. Only a few of these individuals get in touch with the authorities, however, and where such contacts exist, it is not always evident that the problem (for example physical injury) has been caused by another person. "Being hit by or hitting a close relative is connected with a lot of shame and guilt for most people. The authorities still only learn about a very small share of all cases of violence." (SOU 2014:49).

The perpetrator in these relationships is usually a man but, as shown in the above section, men are also subject to violence in close relationships. They might need special contacts and treatments since they have a problem that differs from those of women and children, i.e. that weakness and vulnerability are not accepted within the norms for masculinity (SOU 2014:49).

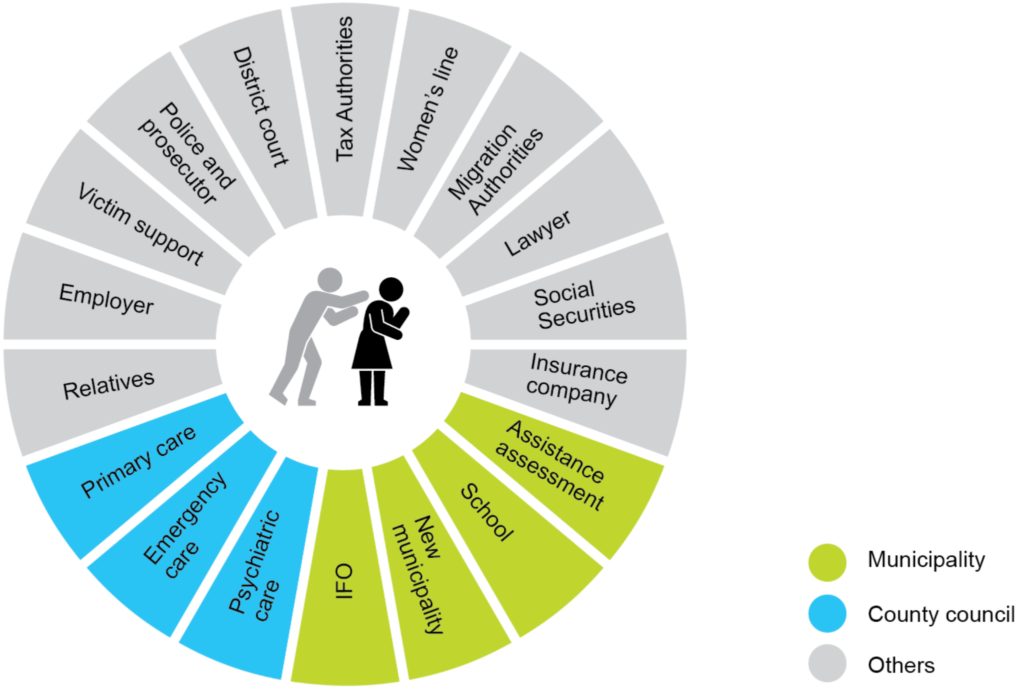
Out of those who were subject to violence in a close relationship in 2012, 11.7 per cent of the women and 2.7 per cent of the men had been in contact with medical care due to the incident. When this is broken down into what kind of crime this is, it is shown that 29.1 per cent of the women and 2.4 per cent of the men that have been subject to violence have needed to seek medical care. BRÅ (2014) draws the conclusion that women are more subject to more severe crime. 7 per cent of the women and 2.3 per cent of the men had been in contact with the social services and 5.6 and 0.6 per cent, respectively, had been in contact with some kind of emergency line. The service that gets most contacts with individuals who have been subject to domestic violence is thus medical care.

"The care centres have a very large possibility of discovering violence in close relationships and of carrying out further preventative work. I think that they are quite anonymous here. It would mean a great deal if a larger number of care centres were more attentive when it comes to discovering and preventing crime. This is, for example, about observing certain patients that return with diffuse symptoms and similar things. This is definitely an area that has potential for development."
(National expert, violence in close relations)

How does the coordination currently work for this group?

The 2014 report from the coordinator for violence in close relationships did, in particular, point to the need for a better coordination by the agents involved: "Those who seek help from society to leave a relationship that involves violence can today easily get the feeling of being in a labyrinth of authorities and different professions. It is obvious that the services provided by society need to be better coordinated for those who are subject to violence" (SOU 2014:49).

Figure 19. Examples of agents that an individual who has been subject to violence in a close relationship does normally encounter in the health and care services.



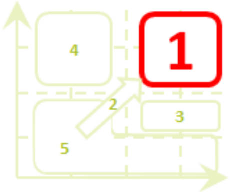
Our interviews with representatives for the operations and representatives for women's lines confirm this picture and the fact that the course of events is often very swift creates an additional challenge for creating a good coordination. ”*Women must often take the coordination responsibility themselves. When one is in the middle of a crisis, it is hard to even remember who one has met. A coordinated plan must be drawn up so that they do not have to run around to everyone themselves.*” (Operations manager of individual and family care)

Coordination is also made more difficult due to the fact that those involved have different commissions, objectives and principals and due to the fact that the operations are partly subject to different legislations. ”Many people with own experience of violence in close relationships that the national coordinator has met talk about powerlessness and disappointment when it comes to the authorities' ability to coordinate and cooperate on their services” (SOU 2014:49).

The figures in the previous section also show that very few of those who have been subject to violence actually get in contact with any authority at all. The most common contact is health and medical care. The coordinator for violence in close relationships did thus suggest that the National Board of Health and Welfare were to design questions about exposure to abuse for patient meetings. This would lead to more proactive actions from the health and care services. Those operations where these questions would mainly be used are emergency care, addiction care and psychiatric care for children and young people. (SOU 2014:49). A better coordination might contribute to those individuals getting all contacts and the assistance that they actually need.

5.2.5 The most ill elderly people

Figure 19b. Main location of the group in the framework.



Currently, the population in Sweden has an increasing life expectancy. A contributing factor is reduced mortality in many of the most common national diseases, for example vascular diseases (SKL och Socialstyrelsen 2015). Nowadays, the elderly also have a higher education and have lived under better conditions with a higher material standard than previous generations. There has also been an increase in the share of the elderly who do physical exercise which might have led to a better overall functional ability. The trend has also lead to an increasing number of people reaching a higher age. High age also entails an increased risk of developing several simultaneous chronic diseases. Many elderly people also have a reduced cognitive ability due to different kinds of dementia.

This chapter describes the coordination need for the group that is usually called *the most ill elderly people*. This group has been defined by The National Board of Health and Welfare (Socialstyrelsen 2011a) as a basis in the state venture that The National Board of Health and Welfare and SKL worked on in 2010-2014. The starting point is that the most ill elderly people are individuals aged 65 or older who have a considerably reduced functional ability due to age, injury or illness. The definition covers those individuals who have "extensive care services" or "extensive medical care". Extensive care services refer to individuals who either live in sheltered housing or for whom there exists a decision about 25 or more hours of home care per month. Extensive medical care means more than 19 bed-days in in-patient care, more than three admissions to in-patient care or more than seven admissions to out-patient specialist care. In 2008, the group of most ill elderly people amounts to about 300 000 individuals.

This group does often have a considerably reduced ability to coordinate its health and care services. Forgetfulness that is related to age and in certain cases to different kinds of dementia makes it difficult to remember time and what contacts one has had with the health and care services. The body does also become more fragile with age and elderly people often have a reduced functional ability. Many elderly people also suffer from general tiredness and low-spiritedness which make it more difficult to have the strength to take those contacts that are needed for coordination. Some elderly people might feel that they do not contribute to society and might thus feel that they do not have the right to require anything from it.

What agents are involved in the health and care services for the individual?

The most ill elderly people have a great need for both health and care services. Thus, they do almost always have regular and several on-going contacts with both the health and medical care services of the county council and the municipal social services (for examples, see figure 1 in chapter 2). Many people in the group are also in contact with the health and medical home care services that are supplied by the municipality, in those counties where the municipality has taken over the responsibility for these services (in 2015, this applied to all counties except Stockholm county). Among other things, the municipalities offer home care services, sheltered housing and medical home care. In the county council, the group is often in contact with primary care, specialist care and rehabilitation. Many elderly people also get aids in order to cope with daily life. Aids can be prescribed by both principals, depending on the division of responsibility and the individual needs.

How does the coordination currently work?

There are many studies that indicate that there is insufficient coordination for the most ill elderly people. This problem is also emphasized by almost all our interview people. In the report from the National Board of Health and Welfare (Socialstyrelsen 2013b) on waiting times and the patient's path through care, where the most elderly are used as an example, it is found that it is not the waiting times that constitute the large problem for this group – it is insufficient coordination. SKL's (2012) analytical report for the most ill elderly people shows that there is a lack of coordination both between principals and between primary and specialist care. The same picture emerges in the final report by IVO (2013) on the national supervision of the health and care services for the elderly. IVO's study shows that there is no overall perspective for the elderly.

Between the years 2011 and 2014, the government invested in improving the health and care services for the elderly who are most ill. The objective was, among other things, to make home care, elderly care, care centres and hospital care cooperate better on fragile elderly people. SKL has coordinated the services, which have covered health and care services to the elderly in all municipalities, county councils and regions. The evaluation by the National Board of Health and Welfare (Socialstyrelsen 2014c) of the venture shows that there are certain positive effects, for example working procedures that are based on themes. But overall, a large part of the coordination problems for this group remains.

Insufficient coordination between the health and care services does, in many cases, have serious consequences for the elderly person. Elderly people do currently often get too many different pharmaceutical drugs – many of which are very unsuitable to combine – due to insufficient coordination in the health and care services (SKL and Socialstyrelsen 2014). Other consequences might be that the elderly person feels insecure, has an increased risk for fall-related injuries and that there is insufficient preventative and rehabilitating work.

The large coordination problems seem to appear in the intersection between the principals. The problems emerge due to an unclear division of who should do and be responsible for what and who should pay, respectively. In particular, it appears that the division of responsibility is often unclear between municipal health- and medical services and county council primary care. Another question that is often subject to discussion is the responsibility between municipalities and county councils for those elderly who are ready to be discharged from the hospital and need housing in the municipality. These kinds of discussions about who is responsible for what might take a lot of time and energy in individual care plans and coordination meetings at the management level between municipalities and county councils. Some of the people that were interviewed stated that the strong willingness to split all responsibility among each other runs the risk of creating "grey zones" where nobody takes responsibility in the end. Certain areas might, in fact, simply need common responsibility.

Several of those interviewed also emphasized that primary care has difficulties in taking the coordinating role for the elderly that it is expected to have. This was partly about insufficient resources, partly about insufficient total competence as concerns the illnesses of the elderly, *geriatrics*. There is also a feeling that there is not sufficient information from other care providers when the elderly person has been to emergency care or visited specialist care. Primary care does not always participate in the planning of the care for the elderly person, something that also appears in the IVO (2013) report.

”When the care centres have many patients, the elderly disappear. They would have needed the same structures as in child health care, they should for example check their kidneys after the age of 70, brittleness of the bones at a certain age and so on. Primary care needs to become the conductor of elderly care.” (Head of care centre)

Rare diagnoses

Another large group that is also in great need of coordination but that has not been as clearly identified is individuals with a rare diagnosis. This group consists of 2 to 5 per cent of the population, where most people have had large and complex needs since their childhood (NFSD, 2014). Many of these individuals are probably part of those groups that have already been described, but besides common challenges, there are also additional challenges that make the coordination even more complex. The diagnoses are characterized by a broad spectrum of symptoms and diseases that do not only vary between diagnoses, but also between patients with the same diagnosis. Moreover, the diagnoses are often life-long, incurable, extremely complex and entail severe functional disabilities.

The complexity is due to the fact that :

- most diagnoses are syndromes that affect many of the bodily systems.
- each different symptom is in itself unusual.
- Rarity does also affect (and sometimes makes impossible) normal medical examinations and treatments.

Individuals with rare diagnoses often have multi-faceted needs that might change over their life span. Health and care services are thus needed from many different specialists in the health and care services. For daily life to work, different support measures are also needed from the rest of society (NFSD, 2015). In many cases, the coordination from the health and care services is insufficient for this group. The specific reasons for this might be:

- There is unclear or non-existent information about where in the health care services that diagnostics or treatment should take place. An adult with a rare disease describes her situation in the following way: *(NFSD 2014)*:

  -"Who is your doctor?"

  This is what all staff in the health and care services always ask. I usually also wonder about this, since they refer to each other all the time. In primary care they say that you belong to the hospital now, we do not have any knowledge of these diseases. At the hospital, they say:

  -"..but should this not be coordinated by primary care?"
- Insufficient knowledge about the diagnosis and possible treatments, since the research about each individual diagnosis is very limited (EURORDIS 2014)
- The competency on rare diagnoses is in general low within health care and medical care and in the rest of society. There is also a lack of structures for how both individuals with rare diagnoses and their relatives are to find the right competence (NFSD 2014). Patients and relatives encounter both lack of knowledge and distrust from care providers, Försäkringskassan and the municipality, due to the fact that the diagnosis is rare (Wallenius 2008).
- Refusal from medical care, 18 per cent of the patients with rare diagnoses have been refused medical care. In 85 per cent of the cases, the complexity of/around the diagnosis was stated as the reason (EURORDIS 2009).

6 What are the challenges for creating more coordinated health and care services?

This chapter describes the main challenges that we have identified in the Swedish health and care services system when it comes to creating more coordinated health and care services. The chapter starts with a general description of the demographic challenges related to a growing population. Then, a framework consisting of seven general coordination challenges is described. This might be considered as our general conclusions about the conditions that we find to be essential in order to promote more coordinated health and care services. The chapter is concluded by a presentation of the respective challenge.

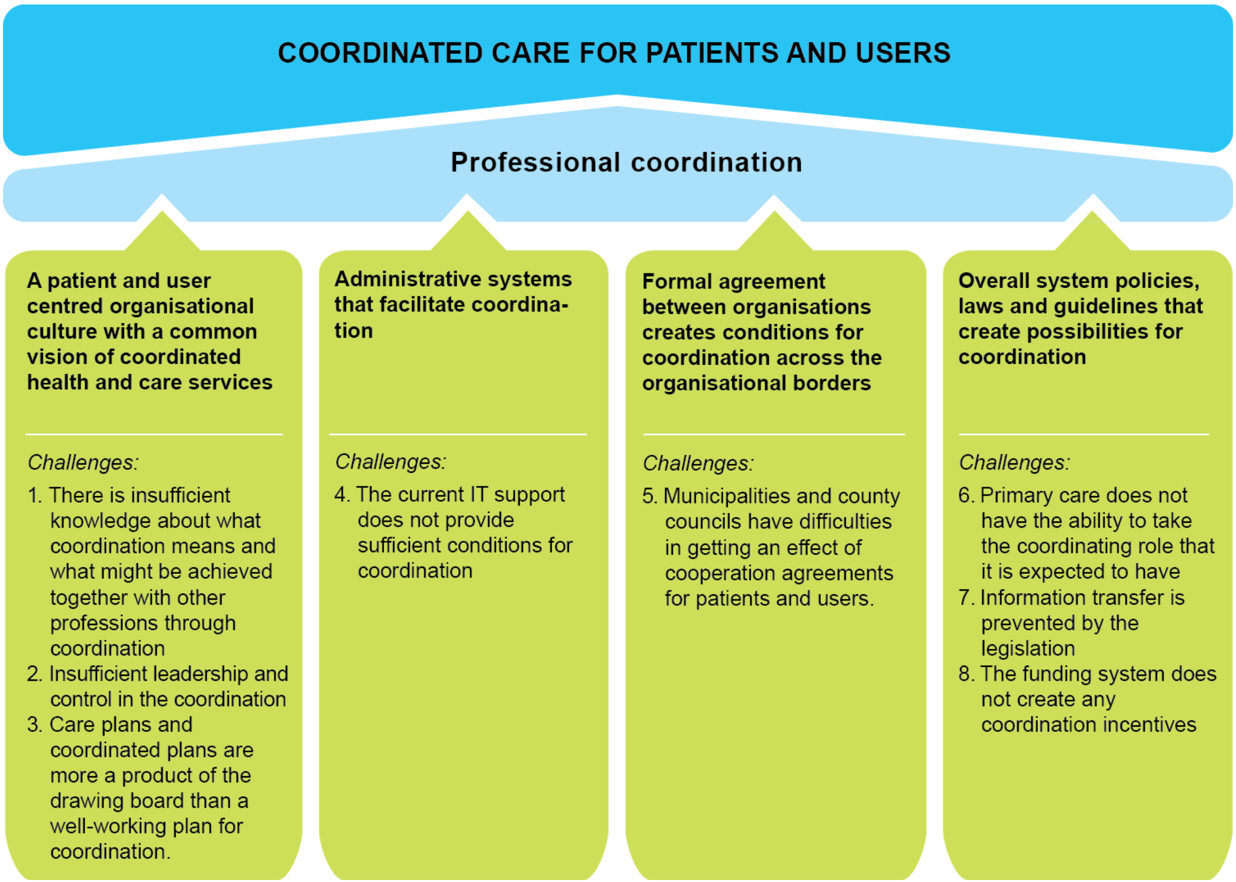
6.1 INSUFFICIENT COORDINATION – A GROWING PROBLEM?

Swedish health and care services face a great challenge since patients and users with several simultaneous needs for health and care services constitute a growing group. Due to the medical trend, individuals with chronic diseases live increasingly longer and have the time to develop more diseases (Vårdanalys 2014b). Currently, chronic diseases among elderly people might be considered as a normal condition. In the county council that has been studied by The Swedish Agency for Health and Care Services Analysis, 85 per cent of the population had at least one chronic disease and 66 per cent had two chronic diseases or more, for example. Of all those elderly people who have home services or live in sheltered housing, the majority has one or several chronic diseases. The larger the number of chronic diseases, the larger is the need for contacts with both health care and the care services. In medical care, for example, contacts with several different specialists are often required besides the care centre where the individual is registered.

The growing group of patients and users with several complex and interrelated needs makes new and large demands on the health and care services. The overall picture of our interview survey is that the health and care services are currently organised to meet a completely different kind of patients and users, with less complex needs, where it is clear what services are needed and where it is clear when the need has been fulfilled

6.2 CONDITIONS FOR STAFF WITHIN THE HEALTH AND CARE SERVICES TO WORK IN A MORE COORDINATED WAY

Figure 19d. A framework for conditions and challenges to create more coordinated health and care services.



A patient and user centred organisational culture with a common vision of coordinated health and care services

Challenges:

1. There is insufficient knowledge about what coordination means and what might be achieved together with other professions through coordination
2. Insufficient leadership and control in the coordination
3. Care plans and coordinated plans are more a product of the drawing board than a well-working plan for coordination.

Administrative systems that facilitate coordination

Challenges:

4. The current IT support does not provide sufficient conditions for coordination

Formal agreement between organisations creates conditions for coordination across the organisational borders

Challenges:

5. Municipalities and county councils have difficulties in getting an effect of cooperation agreements for patients and users.

Overall system policies, laws and guidelines that create possibilities for coordination

Challenges:

6. Primary care does not have the ability to take the coordinating role that it is expected to have
7. Information transfer is prevented by the legislation
8. The funding system does not create any coordination incentives

The above figure presents a framework for the current conditions and the ensuing challenges for creating more coordinated health and care services. The framework is based on international research (for example Ködner 2002, Suter et al 2007) together with the total experience from the work on this report. This framework starts by emphasizing the need for professional coordination. This might concern information sharing or actual cooperation on a patient or user. The professions do, in turn, work and act within a system with, for example, different organisations, logistics for control and a number of multi-faceted demands from legislations, regulations and guidelines. Their possibilities to coordinate their services might thus depend on the possibilities and incentives that they are given by the overall system. The next part of the framework bears these particular aspects in mind. In order to support professional coordination, we here identify four main conditions that need to be fulfilled by the overall system for health and care services. Each condition has then been connected to those challenges that the interview people have emphasized in each respective area. Each challenge is presented in more detail in the remainder of the chapter. The four conditions consist of:

- *A patient and user-centred organisational culture with a common vision of coordinated health and care services*

One condition for organisations to be able to succeed with their coordination is that those people who work in the operation understand and share the value of working with other professions/agents outside the organisation. In order to achieve this, a leadership is needed where the patient and user constitutes the focus of the operation and its development.

- *Overall system policies, laws and guidelines that create possibilities for coordination*

Those laws and regulations that regulate how the health and care services are to be controlled and funded need to be designed in such a way that they create conditions for coordination and do not contribute to create new or reinforce existing barriers. The same applies for targeted state subsidies and knowledge control and follow-up at the national level.

- *Formal cooperation between organisations that creates conditions for coordination over the organisational borders*

In order to cooperate across organisational borders, contracts and agreements between the organisations that have been approved at the management level are required for how the cooperation is to be implemented. These contracts do, for example, regulate areas of responsibility and the related funding. The rules of the game are clarified in clear and formal contracts which create conditions for the staff to focus on the individual patient and/or user meeting.

- *Administrative systems that facilitate the coordination*

Most individuals who work in the health and care services use some kind of administrative support system in their daily work. Doctors and nurses do, for example, need to document their work in an electronic journal and operational mangers need access to statistics and follow-up. All this information is currently stored and dealt with by large IT-systems. A condition for a well-working coordination is that the IT systems both link information about the individual throughout the entire health and care services process and that they link the information between different agents. This makes it possible for all agents that the individual meets in the health and care services to have access to the correct information at the right point in time. For this to work, a technical solution is required that can handle this, together with a joint information structure and legislation that make it possible to share information across organisational borders

6.2 CHALLENGES FOR CREATING MORE COORDINATED HEALTH AND CARE SERVICES

1. There is a lack of knowledge of what coordination means and what can be achieved by coordination together with other professions

The culture and values in an organisation are of great importance for how people choose to prioritize and carry out their work. Several of the interviewed people say that it is often cultures and values that create coordination obstacles. For those patients and users who have a great need for coordination, there are many organisations and professions involved which need to coordinate. The interviewed people state that it is often the case that the different professions do not understand the perspective of the other agents; what they might contribute and what can be achieved together. There might also be unreasonable or erroneous expectations as concerns each other's areas of responsibility or competency.

One explanation that emerges in the interviews is that there is not enough time to create a joint picture of the needs of the patient or user when meeting other professions. There are often no fora or contact areas for sharing experience or perspectives between professions. Different organisations do also have different languages, values and views which make it easy to not understand or misunderstand each other. One interview person considered it to be a shortcoming that during the education/training, one does not get to know what other professions one should coordinate with and how coordination can be implemented.

"In order to make coordination work, a certain approach is required. This is a process that one must know about. But such a culture does not currently really exist. Has coordination been made sufficiently clear to me if I am a doctor, a nurse or an assistant nurse, for example? Have we taken coordination for granted and not problematized it sufficiently?" (Development manager in a municipality)

2. Insufficient management and control of the coordination

Patients and users with complex needs are characterized by the fact that their total problems require services from a larger number of different people and organisations. These needs are often combined in such a way that there is no standardised solution for how to coordinate around the individual. In this context, the task for the health and care services is to identify and implement uniquely adapted services that meet current needs – it is about being a problem solver. Solving or dealing with complex or combined problems thus requires that several different competencies are collected and that they coordinate their work. This might be about creating an organisation around the patient and user in interprofessional teams. The team's problem solving task can thus here be compared to the work of a handyman, which is, for example, described in the research programme Leading Health Care's report (Uppdrag Välfärd 2014) on organisational interspace. The report states that an insufficient understanding of the craftsmanship characteristics of the health and care services has led to organisations not having created sufficient conditions for their employees to able to work in a problem-solving and team-based way for these patients and users.

From those operations managers that we have interviewed, it appears that many find it difficult to manage and control coordination services. They claim that they lack knowledge of what coordination is, i.e. how as a manager one can create conditions for coordination and what the result of this might be. Insufficient knowledge – when one does not know whether it will pay off – also makes it difficult for an operations manager to allocate resources and time to coordination. When there is a lack of knowledge among both employees and managers, it also becomes unclear who should take the initiative and the managing role in the coordination.

It also appears from the interviews that there is very seldom any joint follow-up at the management level of those patients and users where several different agents have a responsibility. When this is not the case, the managements do not get any joint picture of whether the coordination and the services that are provided today are sufficient either.

▶ *3. Care plans and coordinated plans are more like products of the drawing board than a well-working coordination plan*

A so-called *coordinated* (or *individual*) *plan* is to be drawn up when a patient or user is in need of services from both health care and medical care and from the social services. There are different laws regulating this, for example the Health and Medical Services Act (3 f §). The objective of the plan is to create better coordination between those agents who are responsible for the health and care services for the patient and user.

In our interviews, it emerges that the planning of care is often initiated by in-patient care and that primary care is not always involved in the planning for various reasons. In our interviews with doctors in primary care, it is, among other things, pointed out that they are often not even invited. Other professions are also sometimes missing in the planning of care, for example assistance officers, dental care staff and rehabilitation staff.

"Primary care should participate in the planning of care but this is not the case in practice." (Care centre manager)

The same picture is confirmed by a research study that has been carried out by FoU Senorium (2011). This study does, among other things, emphasize that there are often practical problems that do, for example, prevent primary care from participating in the coordination. One example is that the patient has been discharged from the hospital at short notice and it is urgent to draw up a care plan. Primary care has then often had difficulties in finding a time when it can participate in the planning at such short notice.

There is also a great deal to indicate that it is difficult to make the coordinated plan actually be a well-working plan for coordination. The fact that all important agents who are needed for the coordination do not participate in the planning of care constitutes a large obstacle to this. For the care plan to have any real effect, it is, for example, required that it constitutes a natural part of the daily work of the staff, which is often not the case today.

”There is a formal requirement for care plans. But it takes time to change the working procedures, time to get the staff to learn the new IT systems that are required. They prefer to work in the way they have always done. The care plan is created in its own system, thus there is a great risk that for example doctors in emergency care do not enter the system and might miss the care plan and what has been decided there.” (Chairman, The Swedish College of General Practice)

▶ *4 and 7. The current information structure of the IT-support does not provide sufficient conditions for coordination and the legislation prevents information sharing*

Individuals who suffer from comorbidity or need help from the social services do often have several contacts with the health and care services. One of the conditions for creating coordinated health and care services is that the information about the patient or user is easily available at the right point in time for the person who needs it. Since this information also needs to be protected against unauthorized access, this is a complex issue. Currently, the information mainly exists within the organisation that the individual has been in contact with. Normally, it is, for example, difficult for another organisation to obtain the information in any other way than by calling or sending it by fax since the information is not always documented in a joint IT system or based on a joint information structure. In some county councils, there are, however, joint operational systems so that the information can be shared electronically within the county council. But this requires the permission of the patient or user.

Based on the current legislation, it is not possible to share information electronically between municipalities and county councils. The Swedish Data Protection Authority (Datainspektionen 2015) confirms in a supervision case that, according to the Patient Data Act and the Personal Data Act, there are currently no legal possibilities for municipalities and county councils to make joint follow-ups of the operations. This makes the coordination for patients and users with complex needs who need support from both principals more difficult. An example that was described in our interviews is a nurse within the municipality home care services who must currently choose whether she will document her services to an elderly person with home care according to The Health and Medical Services Act (HSL) or The Social Services Act (SoL). If the information is documented according to

SoL, the elderly person’s doctor will not be able to see it, if she instead documents it according to HSL, the home care staff will not be able to see it. This information is often relevant for both parties.

Once the information has been saved, it is not saved in such a way that the relationship to other information about the patient or user appears. Even if a provider of care gets permission to access other information from another provider of care, it does not mean that the information is supplied in the required way. The only thing that is constant in the system is the individual’s civic registration number. The National Board of Health and Welfare (Socialstyrelsen 2015a) points out that there is no joint information structure which makes it difficult to make an efficient reuse of information even if access is allowed.

The current operational systems in the health and care services do thus overall have shortcomings when it comes to support a health or care services process that focuses on the individual in a logical way. There is a large number of difficulties as concerns how measures and needs for a patient or user are interrelated over time. Even if a provider of care would be able to see information from all previous contacts, it is difficult for it to see how the information is interrelated. The National Board of Health and Welfare (Socialstyrelsen 2015a) emphasizes that the existing legislation makes it possible to adapt the systems so that it is possible to follow processes, but in order to do this, it is required that all providers of care make their documentation in a structured and uniform way.

”Even if the legislation between municipalities and county councils were to open up, one would not see how all services are interrelated. There is still no structure for coordinated information.” (Analyst, The National Board of Health and Welfare)

5. Municipalities and county councils have difficulties in making cooperation contracts have an effect on patients and users

Within several areas where both municipalities and county councils have a joint responsibility for a patient and user group, the municipalities and county councils often draw up so-called *cooperation contracts*. For certain target groups, the municipalities and county councils are legally obliged to make agreements. The objective of the cooperation contracts is to ensure that the principals coordinate their operations. From our interviews with cooperation managers, it emerges that it is very challenging to make the cooperation contracts have a positive effect and keep them alive.

In order to create an agreement that both parties can support, it is required that the conditions and needs of other organisations are being taken into consideration and understood. The answers in our interviews indicate that this is seldom the case. This means that the cooperation agreements might instead lead to deteriorated coordination since both parties consider that they have been ”fooled”. The interviewed people also emphasize that there is often also no joint view of what coordination means. There is a feeling that the cooperation agreements do make the division of responsibility clearer but that “grey zones” are instead created for which nobody takes responsibility. The interviewed people consider that the cooperation agreements are often more about division of responsibility than about coordination so that there is actually an improvement for the patient and user. It is also stated that there is seldom any representative present for patients and users when the agreements are made.

Those interviewed did often mention a special agreement which seems to create conflicts in several places in the country. The agreement concerns medical services in those counties where the municipalities have taken over home medical care. From the point of view of the county council, there is, for example, insufficient knowledge among the municipality politicians about what the responsibility of the municipality actually is for the health and care services. From the point of view of the municipality, there is instead frustration that the county council does often discharge patients too early from the hospitals and thus, burden the municipalities with extra costs. Another source of frustration is that the county council in itself is not coordinated and that the municipalities feel that they must coordinate with several organisations within the county council, for example both in-patient care and out-patient care.

▶ *6. Primary care does not have the conditions for taking the coordinating role of health and care services that it is expected to have*

Primary care, with its general commission to deal with out-patient care, its large competence in general medicine and multi-professional care centres, does have good conditions for being a coordinating function of the care services. In our interviews, it also emerges that primary care would very much like to have such a coordinating role, but that, for various reasons, there are not sufficient conditions for completely fulfilling that role. This picture is confirmed by the 2015 questionnaire to doctors in primary care; virtually all doctors claim that they do not have the authority, the time or the correct IT-support to coordinate patient care (Vårdanalys 2015).

”Elderly people who are ill do often go straight to emergency care, home care calls them directly. They get pharmaceutical drugs very quickly and are sometimes admitted. Primary care loses its coordinating role.” (Head of care centre)

On July 1 2010, a new regulation was introduced in 29 a § in the Health and Medical Care Services Act. According to this regulation, the operations manager is to ensure that the health and care services fulfil the patient’s need for security, continuity, coordination and safety. The operation’s manager should also assign a permanent contact in the health and care services for the patient if necessary, or if required by the patient herself. For many patients, primary care is the natural place for a permanent contact in health care. The care centre is usually closest to the patient and it has a broad competence with the possibility of getting an overview of the patient’s total needs. Patients with a permanent contact in the health and care services do also to a larger extent consider that the coordination is better than patients who do not have any such contact (Vårdanalys 2014). Doctors in primary care also state that health care becomes more coordinated for patients with a permanent contact in the health and care services (Vårdanalys 2015).

”The feeling of being part of a context increases when meeting one’s doctor over a longer time period, there is somebody you know and have confidence in. It is important to be able to follow the same patient.” (Head of care centre)

On basis of a number of evaluations made by The National Board of Health and Welfare (Socialstyrelsen 2015b), it can, however, be found that few patients in primary care are offered such a contact in the health and care services. The National Board of Health and Welfare thus emphasizes that a great deal remains in order to clarify how a permanent contact in the health and care services should work in practice, in particular when it comes to cooperation with other operations. In primary care, it is not uncommon with temporary employment contracts, and so-called “relay race”-doctors. This might lead to less good continuity for those patients who visit the care centres – for example, it is not unusual that you meet a new doctor at every visit – but it is also difficult to have a permanent contact with a doctor or the health and care services when such a large part of the staff is temporary.

If primary care is to have a coordinating function, it also needs a clear such mandate and the commission to actually take on this function. According to The National Board of Health and Welfare, there is currently no sufficient such description of this commission, neither in the legislation nor when the county councils give authorization to care centres (Socialstyrelsen 2015d). In an international perspective, Sweden also has a small share of general practitioners (Anell 2015), which might mean that the resources for taking on an extended role might be limited. The unclear commission together with the current economic control might make it difficult for the care centres to give priority to coordination, even for those groups who might need this the most. A coordinating role does also stipulate that primary care is an obvious participant in those care plans that are drawn up for patients and users. As we have described, primary care is not always included when such a plan is drawn up.

▶ *8. The funding system does not create any coordination incentives*

A number of different remuneration systems are currently used within the health and care services. The foundation Leading Health Care (LHC 2014) points out that in a traditional perspective, remuneration models where the operations get a fixed remuneration have been used in the public sector, but that so-called variable remuneration for, for example, patient and user visits that have taken place has lately become increasingly common. The objective of the remuneration is often to remunerate measures that are taken at the unit level. Each unit is in both cases remunerated in relation to a limited task and the objective of the remuneration is to reflect what has been produced within the specific unit. LHC also describes that this might result in operation-specific objectives being given priority at the cost of measures that are taken outside or as an extension of the own commission.

The remuneration system does thus play an important role in making it easier to give full priority to coordination with external agents. Coordination measures are thus both often time and resource consuming. However, most remuneration systems do not specifically reimburse different coordination services, this is often something that is to be done within the regular activities. A condition for remuneration according to coordination services is that there is a system that can follow up how well the coordination works; there is largely no such system for the health and care services today. If coordination is not remunerated, there is a risk that those resources that are being allocated to this instead become a cost for the operation. Several of those individuals who have been interviewed do here point out that the funding systems do, in many cases, run the risk of counteracting a patient and user-centred way of working, which is a condition for coordination to work:

”The funding system is a big dilemma and thus also how it is controlled. Budget and funding are put before the individual person.” (Director of Development in a county council)

Appendix

DESCRIPTION OF METHODS WHEN MAKING THE EMPIRICAL ESTIMATION OF THE FRAMEWORK

When estimating the size of the general groups (the number of individuals) and the costs, we have taken as the starting point an analysis of the different specific patient- and user groups (*subgroups*) that are considered to be part of the general groups. In a first stage, 28 subgroups were identified (*subgroups 1-28*) within the five general groups (*groups 1-5*).[1] The sub groups were selected so that they would together cover the majority of the individuals in each respective general group. For each subgroup, a survey was then made of the number of individuals that were included, and the related costs (per year) for health and care services in the county council district. The results of the subgroup analysis were then summed up in order to estimate the size and costs for the general groups. When summarising, the overlap between subgroups as well as between general groups was taken into consideration. The number of individuals and the related costs for the different subgroups will also be reported separately.

Mainly secondary sources have been used to estimate size and costs. These do, among other things, include published reports from The National Board of Health and Welfare, The Swedish Agency for Health and Care Services Analysis, Stockholm Gerontology Research Center, different quality registers, interest groups etc. In order to increase the validity of our estimates we have, to the largest possible extent, used several sources and methods.

Depending on the data availability, The Swedish Agency for Health and Care Services Analysis has used different methods in estimating the size of the subgroups and the costs (listed according to the level of priority below):

1. Published estimates of the size and costs of the specific patient- and user groups from different data sources have been used in the first place.
2. In those cases where there are no direct estimates of specific patient- or user groups, The Swedish Agency for Health and Care Services Analysis has summarized estimates of different smaller subgroups or has combined estimates of broader patient/user groups with, for example, population statistics in order to estimate the subgroup's share of the broader patient or user group. One example of the first is the estimate of the number of individuals in the subgroup Serious Mental Illness. The results for this subgroup are based on a summary

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[1] There are local variations in how the health and care services for specific patient- and user groups are organised and thus how complex is the coordination of these individuals. For this reason, a specific patient- or user group might belong to different general groups in different parts of the country. In the estimates made in this report, we have chosen to allocate the specific patient and user groups on basis of what the organisation of the health and care services is considered to look like in general in Sweden.

of existing information as concerns the existence of and costs for schizophrenia, bipolar disorder, and delusional disorder.

3. In certain cases, where relevant information is missing for a specific patient or user group, The Swedish Agency for Health and Care Services Analysis has made the necessary assumptions and simplifications in the calculations. If, for example, if there are no costs for municipal care for a certain subgroup, a stereotyped cost from other comparable subgroups has been used.
4. Due to the lack of national data sources, The Swedish Agency for Health and Care Services Analysis has in some cases based its estimates on extrapolation of information from a county council or a municipality. For example, The Swedish Agency for Health and Care Services Analysis has analysed data from a medium-size county council in Central Sweden in order to make estimates for certain of the subgroups within the group: This mainly concerns individuals with good mental and somatic health (group 5).
5. Cost estimates for the municipality (costs for care) do, in this analysis, include costs for elderly care, functional disabilities and individual and family care, but do not include costs for education, child care, school and economic support. The costs for county councils/regions (medical costs) do, with a few exceptions, include costs for health- and medical care, dental care[2] and medicine, but do not include costs for local transports and regional development. The costs for principals (total cost) include the total costs for municipalities and county councils, and do not include costs for the government or indirect costs (for example costs for production loss, social insurance or care to relatives).

Main group	Group	Approx number of individuals
Main group 1	Individuals aged below 65 with addiction/dependence	400000
Main group 1	The most ill elderly	350000
Main group 1	Elderly people with mental problems	190000
Main group 1	Serious mental problems	180000
Main group 1	Dementia	160000
Main group 1	Individuals aged below 65 with mild mental problems and chronic somatic illness	80 000
Main group 1	Elderly with addiction/dependence	50000
Main group 1	Violence in close relationships	40000
Main group 1	Late palliative stage	40000
Main group 1	Comorbidity (addiction and schizophrenia)	20000

[2] The cost estimates for dental care only include support for dental care from the county council that is given to patients with special needs for dental care and to children and young people, and do not include government support for dental care. Government support for dental care has been estimated for the following subgroups: *The most ill elderly people; Elderly with addiction/dependence; Early palliative stage; Adults with an intellectual disability, Serious mental disorder; Dementia; and* subgroups that include children and young people (*Children with intellectual/neuropsychiatric disabilities; Children with mental disorders; Children in care without addiction or mental problems; Healthy>15 years; Mild somatic disease >15 years; Largely healthy children(4-15 years) in normal homes*).

Main group 1	Serious self-harm behaviour	10000
Main group 2	Falling accidents (elderly)	50000
Main group 2	Stroke	30000
Main group 3	Self-harm behaviour (without in-patient care)	500000
Main group 3	Number of adults with intellectual/neuropsychiatric disability	150000
Main group 3	Number of children with intellectual/neuropsychiatric disability	160000
Main group 3	Children with mental problems	70 000
Main group 3	Children in care without addiction or mental problems	20 000
Main group 4	Individuals with comorbidity aged below 65 without simultaneous mental problems	1050000
Main group 4	Early palliative stage	40000
Main group 4	Homeless without addiction/mental problems	10000
Main group 5	Healthy >15 years	2340000
Main group 5	Mild somatic disease >15 years	1530000
Main group 5	Mild mental problems >15 years	1060000
Main group 5	Individuals who are largely healthy with a functional disability	930000
Main group 5	Largely healthy children (4-15 years) in normal homes	81000
Main group 5	Largely healthy younger children (0-3 years) in normal homes	180000
Main group 5	Largely healthy individuals (>15) with insufficient relevant language skills	100000

After our estimates of the size of the general groups, there remain about 8 per cent (730 000 individuals) of the general population, ten per cent (SEK 18 billion) of the total costs for care services and six per cent (SEK 14 billion) of the total costs for medical care. There might be several reasons for this:

- It is possible that the subgroups do not cover everything.
- We have made assumptions that might have underestimated the number of individuals and the costs. For example, we might have overestimated the overlap between subgroups when summing up into general groups.
- We assume that several subgroups have negligible costs for care and that we have thus not made any estimates for the costs for care services for these sub groups. This simplification might contribute to a certain underestimate of the costs for care services.
- In the cost estimates, we have sometimes used estimates that are a few years old. There is thus a risk that the costs are underestimated due to the general cost increase that has taken place in both health and medical care and the care services.

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Coordinated health and care Services

An analysis of the coordination challenges in a fragmented system for health and care services

It has been a well-known problem for a long period of time that patients and users perceive the health and care services as being fragmented. The objective of this memorandum is to provide a patient- and user perspective of coordination, a perspective that emphasizes the fact that patients and users are participating and contributing agents in the coordination process. The memorandum does thus contribute to provide a broader perspective of the coordination problem in the health and care services and the social services.

The task of the **Swedish Agency for Health and Care Services Analysis** (Vårdanalys) is to follow up and analyze health care, dental care, and the interface between health and social services from the perspective of patients and citizens. Vårdanalys takes the needs of the patients and the users as the starting-point in the investigations. The mission of Vårdanalys is to contribute to quality and efficiency improvements that benefit patients and citizens.

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