Social Insurance in Sweden 2002

The Swedish social insurance administration is a natural part of virtually every citizen’s life. It is of considerable importance, not only in terms of people’s security and welfare, but also in terms of the national economy, with a current total expenditure per annum of approximately SEK 380 billion.

The National Social Insurance Board continues with this book the recurring publication Social Insurance in Sweden, designed both to discuss and to provide an overall account of important and topical issues relating to social insurance in Sweden.

ISSN 1404 – 1650
Social Insurance in Sweden 2002 can be ordered through the RfV homepage at www.rfv.se, or by phone: +46 8 556 799 29, or by fax: +46 8 718 29 90, and costs SEK 195 excluding VAT and postage and packing.
The theme of this fourth volume is *Ideals and Reality in Disability Policy*. The aim of disability policy has long been to enable people with disabilities to be an integral part of society, enjoying the same living conditions as those of other citizens. However, much remains to be done before parity in living conditions between people with disabilities and the population in general becomes a reality. Levels of education are lower for persons with disabilities, as is their position within the labour market. Moreover, many of those receiving social insurance support aimed at people with disabilities feel a sense of financial insecurity. This means that the people with disabilities as a group are excluded from many aspects of life which encourage independence in an individual.

Support from society for persons with disabilities is only given in response to the individual’s own initiatives, the aim being to protect the individual’s right to autonomy. This principle is healthy and attractive in regard to the relationship between an individual citizen and the authorities, but one that in practice seems to require a great deal from the individual. To push the argument, it might be said that people with disabilities need advanced skills in the art of being a citizen.

Disability policy applies important principles which are subject to prerequisites for successful implementation. These are not supported by the real environment, thus proving to be a source of problems. This said, the fundamental principles of disability policy should remain as a template, even for the future. Integration and individual autonomy must be guiding principles and it is clear that measures of some kind must be taken. However, for ideological aspirations to become a reality, attitudes will have to change and efforts put in.

It is clear that our society is not pre-fabricated and that simplicity is not always a primary focus. Further work is required to achieve the same conditions and opportunities for social inclusion for all people - disabled or not. Vision, commitment and knowledge are required to facilitate a process of change, which must take place within a framework of open dialogue, one that involves and engages many in order to implement the necessary adjustments. *The Social Insurance Book 2002* is part of the contribution made by RFV towards this important dialogue.
Many members of staff at RAV have been involved in the work behind The Social Insurance Book, notably, Britt-Marie Anderson, as editor. The various sections have their own principal authors: Cecilia Eek and Lars Grönvik on Ideals and Reality in Disability Policy and Lena Ericson on Social Insurance in Figures.

The following people have been involved in the preparation of the first section: Stina Berggren, Parviz Ghaemian, Zabrina Leung and Ulrik Lidwall. Among all of those who have contributed their valuable opinions of the draft text, I would make particular mention of Carina Burguete, Christina Janzon, Anna Karlsson, Inger Marklund and Tomas Sundberg. A special thank you also to Kristina Malm, who produced the master copy and diagrams.

I am grateful that the manuscript has been examined and commented upon by Marta Szebehely, Associate Professor in social work at the Department of Social Work, Stockholm University; Barbro Lewin, Doctor of Medicine and Director of the Centre for Disability Research, University of Uppsala; and Rafael Lindqvist, Professor of Social Work, University of Umeå.

Stockholm, November 2002

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Aims and Achievements

This first chapter of Social Insurance Insurance in Sweden 2002 describes how Sweden’s national policy for people with disabilities has evolved from the beginning of the twentieth century to the present. In addition, the current goals of Swedish disability policy are described and an attempt is made to see whether these are being achieved.

Disability and Handicap – The Terms Explained

Two terms that recur throughout this book are “disability” and “handicap”. Neither is easy to define. What normally springs to mind first is people with physical and apparent disabilities, for example someone in a wheelchair or finding his way about with a white stick. In what follows, the notions of disability and handicap are described in more detail, as is the connection between them.

Disability

Opinions differ about what constitutes a disability and how the category “disabled persons” should be defined. In research and in policymaking, different types of delimitation are employed, depending, for example, on the information required and what it is to be used for (Szebehely, Fritzell & Lundberg, 2001).

In its simplest form, disability may be expressed as the consequences of an illness or an injury, and for general purposes this may perhaps suffice as a definition. In other contexts, such as when studying disabled people’s living conditions or when determining who is to receive support from the community, more exact definitions are needed. However, it is almost always hard to draw the line between who is disabled and who is not: it is often a matter of degree. For example, many people have a visual impairment and need glasses, but are not usually regarded as disabled. On the other hand, if the visual impairment is severe, “disability” may seem the more appropriate term. Consequently, what counts as a disability must depend partly on some delimitation from what does not.
Two common ways of establishing this delimitation are presented here. The first approach is based on the functional ability of the individual and the second on an administrative definition of disability.

**Definitions Based on Functional Ability**

In surveys of living conditions, a common approach is to define disability as the impairment of various functional abilities. This may refer to walking, carrying, reading, writing or hearing. With this method, the category “disabled persons” is created by concentrating on certain characteristics. For example, in the Statistics Sweden (scn) national survey of living conditions (utl), the category “physically disabled persons” is created by asking questions such as: “Can you run a fairly short distance, say 100 metres, if you are in a hurry?”

Several problems are associated with this way of defining disability. One criterion does not necessarily exclude another. A person may have both a physical and a visual impairment; a combination that probably gives rise to an entirely different situation unfamiliar both to physically disabled people and to those with visual impairments.

Some people maintain that a definition based on this view focuses too much on the individual, laying at his door the difficulties that the disability involves. The community’s responsibility for ensuring that its organs are accessible is completely overlooked when the problem is ascribed to the individual.

**Administrative Definitions**

The second way of defining disability is based on the social support afforded to people with disabilities. For example, after an investigation by the social insurance office, a person who satisfies the criteria established under one of the laws determining the right to disability support will be regarded as having a disability on this definition. Administratively, then, a person is considered to be disabled if she or he is granted a certain type of support and hence comes under a certain category. Thus an administrative definition can be narrower than a functional one, depending on the type of support granted.

Given the ways they are created, administrative delimitations are common ways of defining disability in the support system; so it is not unusual for an administrative definition to be used
when evaluating reforms in the area of disability (e.g. Socialstyrelsen, 1997b; RfV, 2001). One limitation of this kind of definition, especially in the context of evaluation, is that there may well be people who in fact satisfy the requirements for receiving support but who for various reasons do not get it.

In practice, administrative definitions too are often based on criteria, for example, by considering a person’s functional ability. This is because much of the legislation governing entitlements defines its target categories with an array of individual criteria to be met before support can be given.

How Many People are Disabled?
The choice of definition affects the size of the group considered to have a disability, so there is no definite answer to the question of how many people with disabilities there are in Sweden. In their national surveys of living conditions, Statistics Sweden employs a definition based on functional ability. According to their criteria, around 1.3 million people aged from 16–85 are disabled, of whom 700,000 are of working age (16–64). Consequently, a large proportion of disabled people are aged 65 or older (Szebehely, Fritzell & Lundberg, 2001).

If instead we use one of the administrative definitions underlying the entitlement to special benefits from the community, the numbers turn out to be lower. In December 2001, just over 100,000 people received disability support from the social insurance system. Another example, from the municipal services, estimates that over 47,000 people receive support under the provisions of the Act on Support and Services for Certain Disabled Persons (Socialstyrelsen, 2002a). In practice, these two categories overlap. People who receive social insurance benefits may receive support under the Support and Services Act at the same time.

One reason why these categories are smaller than those identified according to a definition based on functional ability is that the right to these supportive measures is often based on age. Several forms of support are given only to people whose disability arose before they were 65. This means that many people classified as having a disability according to a criterion-based definition fall outside the scope of an administrative one.

Handicap
The term handicap is used to describe the loss or limitation of opportunities to take part in the life of the community on an equal footing with others. Hence, a handicap is viewed as the effect of an encounter between a person with a disability and an environment that is inaccessible.
A person with a disability can thus be “handicapped” in one environment but not in another. The concept is thus related to the environment.

Some examples may serve to illustrate the spirit of this definition. Imagine a person disabled in a traffic accident, whose impairment consists of a difficulty or inability to walk. A handicap is manifest in, for example, a building where there are no lifts between floors. Another example is a person with an intellectual disability where a handicap may arise if information from the community is too abstract, or presented in language that is too complicated, for the person to understand.

On this view, handicap is not an individual characteristic but a description of the encounter between an unsatisfactory environment and a person with a disability. Handicap then becomes “an abstract category which actual individuals move in and out of depending on situations and circumstances” (Barron, Michailakis and Söder, 2000, p. 139).

This explanatory model invites reflection on how our society is organised, both in its physical aspects and in its social and cultural. In so doing, it stresses the fact that issues concerning people with disabilities are not confined to a small specialist area but should permeate the whole of our society.

From an Institution to a Flat of One’s Own

Before we look more closely at the current aims of Swedish disability policy, we need some understanding of how the ideas leading up to today’s disability policy have developed.

For this, we have sought help from Olof. He is a boy with a physical disability who, at the beginning of the twentieth century, comes to Eugeniahemmet, one of the large institutions on which activity for people with disabilities was centred. The inspiration for Olof-in-1900 is drawn chiefly from Eugeniahemmet records and from an interview with a man who grew up in that institution. The quotations used in this section are authentic, but the persons’ names are fictitious.

Olof is also a young boy struggling at the beginning of the twenty-first century to get on with his life and to live like others. This Olof is fictitious but the tale is based on facts gathered by the National Social Insurance Board (rfr) in earlier studies (rfr, 2002a). First we get to know Olof-in-1900 and Olof-in-2000, and then provide a background of social policy for the support Olof receives in each period.
**Olof-in-1900**

In the late summer of 1913 Karl Gustafsson visits the vicar in Dunkers parish. It’s about Karl’s son Olof. When Olof was only ten months old he lost the ability to move his legs and also had slightly reduced arm function. Olof is now seven, but still needs to be looked after like a little child.

Karl explains to the vicar that the situation is becoming impossible for the family. There are three children apart from Olof, and providing for them is hard. Karl’s only income is a low wage from his work as extra station hand at Stålboga railway station. Olof’s mother, Anna Karlsdotter, works at home on the farm. They are poor, but not poor enough for poor relief.

Karl tells the vicar that apart from the difficulties in providing for the family Olof takes up too much of their time. His wife cannot give the farm the time it needs. And over and above all this, Karl says, Olof will never be able to help with the work. Karl therefore wishes the vicar to help him find a home where Olof can be looked after.

The vicar remembers when Olof became paralysed. “He became as lame as was possible”, the vicar had noted. He thinks over what Karl has told him and realises how serious the family’s problem is. He has been in contact with a family in similar circumstances before, and that child was able to get a place at Eugeniahemmet in Stockholm. The vicar writes off for the necessary documents and late in the autumn of 1913 he helps Karl to write to the institution in Stockholm. Karl writes:

*Enclosing the documents required, I herewith most humbly apply for a free place at Eugeniahemmet for my son Erik Olof. Unfortunately my circumstances are such that I am quite unable to pay for my son’s care and upkeep in our home. I have no other income but my wage as extra station hand at Stålboga station.*

The vicar attaches a certificate to the effect that Erik Olof has been christened and vaccinated. Karl and his wife also have to fill in a form with questions about “the child for whom admission to Eugeniahemmet is being applied”. Karl pauses at the question “Under what economic circumstances has the child been living?” He considers, and then writes in the small box as the vicar advises: “As in a simple home of workers”. Another question concerns the hygienic condition of the child. On the advice of the vicar, Karl writes: “As a rule, clean. Makes his needs known – needs to be fed”. 
Olof comes to Eugeniahemmet shortly before Christmas. He has been admitted to a place which the poor relief organisation has guaranteed to finance. At Eugeniahemmet Olof starts an entirely new life. He spends the first period in the sick bay since he is judged to be much too thin. After a few weeks he has gained what the doctors consider to be an acceptable weight and is moved to the boys’ department. He is given a bed in a dormitory with seven other boys, most somewhat younger than he is. He soon settles down and the department becomes a secure home.

The years go by and Olof gets on better and better. Eugeniahemmet becomes his world. The home is mainly self-supporting, with large kitchen gardens worked by its farm-hands and also by the somewhat older children. The staff, the nurses and the boys living with Olof become his new family.

Olof gets some education during his time at Eugeniahemmet. At eleven, it is time to start learning a trade. Shoemaking is judged to be suitable for Olof since his arms and hands have regained much of their function. So he starts in the cobblers’ shop, where he masters increasingly difficult jobs.

When Olof is eighteen he is considered an adult and fully trained as a shoemaker. Although he has learned shoemaking and is doing very well in other respects, it is feared that he will find things difficult outside the home and at worst may end up in the workhouse. Accordingly, he is allowed to stay at Eugeniahemmet but to live in the building that has been erected for the “over-aged”. He continues to work in the cobblers’ shop as an extra hand.

**Olof-in-2000**

Olof was born in 1975. Before he is one year, his doctors suspect that he has cerebral palsy. An injury to the brain during either pregnancy or delivery has caused paralysis of both his legs. A time of strain begins for Olof and his family. His parents and the hospital staff alike are determined that he should of course stay at home with his parents and siblings.

The doctors wish to start habilitative training immediately so that Olof can retain and develop as much mobility as possible. A large part of the training is at a habilitation clinic, but Olof’s parents are also taught how to do daily training with him. However, Olof does not develop like other children and still needs help and nursing from his parents when he is older. Since the need for parental care is great, Olof’s mother stays at home half the day to look after him. A 50-percent care allowance makes this economically possible. She manages to arrange for Olof to...
be at a child care centre for a few hours every day so that she can continue working half-time. She thinks it important for Olof to meet other children and spend time in the same surroundings as they do.

Soon before Olof is seven, preparations for his education start. The local school proves largely able to cater for children with disabilities, but a small ramp up to the entrance door is needed. Not without trouble, Olof’s mother manages to get a ramp built. The school management and the municipal officials think the ramp costs too much when it will be used only by one pupil. Late one evening when she has just finished a long discussion with a local politician, she takes out her diary and writes:

*I know that Olof can and wants to do so much. But how can he develop and how can he show his ability if everyone spikes his guns? A tiny little ramp, a bit of metal, and Olof gets his education. Surely this isn’t too much to ask?*

After upper-secondary school Olof wants to leave home. He is sick of his parents’ nagging and mollycoddling and he has to move on. Yet it is not quite as easy as he had hoped. The number of hours for which he has a personal assistant is not nearly enough for living in a flat of his own and anyway the municipality has no vacant flats adapted for a physical disability like Olof’s. However, he has the law on his side and together with his mother he goes to court to get the municipality to arrange an accessible home and the social insurance office to give him enough personal assistance hours. The struggle drags on and Olof has to continue living at home.

When the legal machinery has ground for some time Olof wins his case against both the municipality and the social insurance office, and a year almost to the day after the struggle began he can move into his first flat. It is in a new block and the rent is really very high for a flat of that size.

Spurred by success, Olof arranges for personal assistance from a different provider. He goes from the municipality to a cooperative where the majority of members are younger. He is trying in this way to gain more control over how his assistance hours are planned, but he also wants more say in who his assistant will be. “I am tired of the home help ladies. I want someone who more lives the kind of life I live”, he explains.

At upper-secondary school Olof took an IT-oriented programme and he now tries for a job as a webmaster. He discusses this with the
official at the social insurance office who deals with his temporary disability pension and with the official at the job centre. They are both keen for him to work in web production and ask whether he has any contacts in the disability movement where a webmaster might be needed. Olof explains that his having a disability does not mean he is interested in disability issues. He is not interested in work in the disability movement: “I want an ordinary job at an ordinary workplace”, he says.

Even though there are vacant web jobs in the municipality it is hard for Olof to get work. Instead, with the help of the job centre official he manages to arrange a work experience placement with a computer company. The salary is nothing special but with a little help from his parents he is able to make ends meet despite his expensive flat. After a few years of practical work, sandwiched with educational courses, Olof gets the opportunity of a wage-subsidy job as webmaster of the municipal home page. The subsidy is for one year only, and the employers already seem doubtful whether they can afford to continue the position unless the subsidy is extended. “My life never seems quite for real”, Olof thinks.

Olof Then and Now – Similarities and Differences
What both accounts have in common is that Olof’s lives turn out fairly well even if the paths he takes are different. Remember, the two boys grew up in different worlds, and perceptions of what constitutes a good life have altered over the past century. The period represented by Olof-in-1900 depicts Sweden before the growth of the welfare state. Help when things were bad was by no means to be taken for granted.

Institutions such as Eugeniahemmet where Olof-in-1900 grew up long played a central part in disability care. For people with intellectual impairments, what were termed asylums or institutional schools were built, while for those with chiefly physical impairments institutions such as Eugeniahemmet were built. Actually, the underlying idea was twofold. One purpose was protective; that people with disabilities could avoid being subjected to a hard and unsympathetic society but could instead remain secure within the walls of the institution. The other purpose, referring chiefly to people with mental disabilities, was to protect society from these (Söder, 1984; Qyarsell, 1991).

As early as the nineteenth century this type of institution started being built throughout Sweden and contemporary support was based
predominantly on charity. Voluntary movements espoused groups of people considered to need everyday help. The purpose of the help could be pure compassion but there was often a focus on helping people to provide for themselves in some way. Many institutions explicitly purposed to make those they admitted self-supporting. Thus Olof learned to be a shoemaker while at Eugeniahemmet.

For people with intellectual disabilities, too, the idea of using the institutions to provide conditions for the inmates to be able to work in due course, developed early. Söder (1984, p. 8) quotes an article from 1857 in which a psychiatrist maintains that by taking care of children with intellectual impairments one can change them “from useless members who only consume to active and productive ones”.

Olof-in-1900 was lucky to get in to Eugeniahemmet. Charity was the only real alternative to poor relief for many people with disabilities during the period he represents. Accepting children from the whole of Sweden, Eugeniahemmet could accommodate at most 200. For this reason, a placement at Eugeniahemmet, which long operated entirely without state funds, was granted to few.

Even though Olof-in-1900 was lucky to get any support at all, his life was clearly limited to the institution. Eugeniahemmet was a world of its own where you lived, got your training and had your social life. People often left after their training but our Olof stayed and was provided for in the institution.

For Olof-in-2000 on the other hand, it was taken for granted that he would grow up with his family. During the 1960s, discussion on support to people with disabilities grew intense. The general struggle for equality of opportunity marking Swedish social debate at the time had its effects on disability policy as well. Criticism of institutional thinking and segregation waxed strong and assumed central significance in the new principles of disability policy then developing (prop. 1999/2000:79).

At the core was the endeavour for people with disabilities to live like other people. The institutions were to be torn down and, instead, ordinary homes were to be made accessible. Integration and normalisation became the watchwords. People with disabilities were not to live segregated in institutions but to live integrated in the community. People who earlier
occupied the country’s institutions and asylums could successively move out to ordinary residential areas, either to flats of their own or together with others in special accommodation. The process has not been rapid, however, and it was not until the 1990s that the institutions were finally closed down.

That people with disabilities should have opportunities of living like other people concerns not only the kind of homes they live in. As early as 1964, the report “Social care of the handicapped” (Social omvårdnad av handikappade) (soU 1964:43) made it clear that education, the labour market and cultural life were to be adapted so as to enable people with disabilities to participate. Yet much still remains to be done for this to be achieved in practice.

Another important change is that while Olof-in-1900 depended on the goodwill of others, Olof-in-2000 has certain rights. Despite certain shortcomings in present-day support to people with disabilities, opportunities for claiming support have clearly improved. Since a large part of the support to disabled people is formulated in terms of rights, Olof-in-2000 can go to court to have his case examined. Olof-in-1900 could only note with gratitude that he had avoided poor relief.

In addition, the Disability Reform has been significant for Olof-in-2000. The reform came into force on 1 January 1994, prompted by the welfare gaps noted during the 1980s between people with disabilities and the rest of the population. These gaps concerned primarily people with severe disabilities, whose welfare standard had not kept pace with general development.

The 1994 reform introduced a number of new measures including personal assistance which is practical support given by a person paid by the municipality to assist the disabled person in everyday life. The purpose of the new measures was that people with extensive disabilities should be able to create decent lives for themselves, resembling other people’s as far as possible. The support was to be designed to strengthen the individual’s ability to live an independent life and to participate actively in social life (prop. 1992/1993:159).

The reform has meant much for the development of support for people with disabilities. The new forms of support, particularly personal assistance, have allowed many people with disabilities to live a more independent life directed by their own wishes instead of by the authorities’ (RFV, 2002a).
Under this reform, Olof-in-2000 was enabled to have personal assistants, in all probability increasing his potential to make himself an independent life and to move away from his parents.

Improving both support and society is a continual process. During spring 2000 the Government presented its new plan for the disability policy, with goals and guidelines for continued work. The ideology that is to infuse today's work to improve society for people with disabilities was developed under the slogan “From patient to citizen” (prop. 1999/2000:79). In the main, today's disability policy is about implementing and extending the principles developed during the 1960s. But the view that the situation of people with disabilities is a matter of human rights is also very clearly emphasised. It is the right of every human being to be able to express his views, live a free and active social life. Making society available, helping with economic and practical resources, is thus bound up with the right to be a citizen. What this involves will be described in more detail in the following section.

**Policy Goals and their Achievement**

Sweden has since 2000 a national plan for disability policy (prop. 1999/2000:79). The plan stresses that disability policy is about citizenship rather than merely care and nursing. Not everyone with a disability needs this help. Yet all citizens have certain rights. The policy may be illustrated briefly in the goals agreed by the Government and Parliament. They are:

- social community based on diversity
- full participation in community life for people with disabilities
- equality of living conditions.

In the bill, passed by Parliament in May 2000, disability policy is viewed as a matter of supporting individuals in their role as citizens:

> Disability policy is ultimately a question of democracy – society must rest on the understanding that people are of equal worth, have the same fundamental needs and should be treated with the same respect; that diversity enriches, and that every person's knowledge and experience represent an asset for society. In concrete terms, it follows that everyone must have equal rights.
and equal opportunities to decide on their own lives and to have their wishes respected. People with disabilities must have the same right to move about, both geographically and socially, as others. Everybody must have the same right to receive information and to be heard. All must have equal opportunities and obligations to contribute to the development of society (op. cit. p. 24).

Much can be done to create opportunities and rules that do not discriminate against people with disabilities. As already mentioned, accessibility is an important issue. Further, social support to level out the differences between persons with disabilities and others has its effects. For example, the car allowance enables the individual to get to work or follow a course of training.

Sweden is striving to enable people with disabilities to participate fully in society. For this reason, according to the Bill, disability policy must operate largely from the perspective of citizenship. Herein lies an important shift governed largely by the political endeavours of the past few decades and the UN work on standard rules (see fact box). From earlier operations based on a care perspective, it is now clear that Sweden is now tending to stress equality of opportunities for people with disabilities to play a full part in community life.

### United Nations Standard Rules

In 1989 the Swedish Government initiated work in the United Nations to bring about international rules safeguarding the right to participation and equal opportunity for people with disabilities. This led in 1993 to adoption by the General Assembly of the document “Standard Rules on the equalisation of opportunities for people with disabilities”. The document comprises 22 rules covering among other things the right to work and an accessible society.

The rules are not binding upon member-states but have significantly influenced the design of many nations’ disability policies.

There has been little controversy over this stress on the citizenship perspective as a principle. It is attractive to view disability policy as a matter of democracy requiring the same human rights and opportunities as all others enjoy. There is political unity regarding these goals and that they represent a good foundation for continued development towards a better and increasingly accessible society.

However, from the viewpoint of research and evaluation these goals are not without problems. One overshadowing problem is what the specialists term “operationalisation”. Operationalisation means making a concept measurable. What do living conditions mean? – How are they
to be measured? – What areas of life should be included? – What does social participation mean? – Participation in what parts of community life? The texts formulated over the years to describe these goals of disability policy are often couched in sweeping terms (e.g. prop 1999/2000:79; rskr. 1996/97:120; sou 1990:19). The descriptions have therefore become unassailable as guidelines for policy work, gaining a hearing among officials and the disability movement. But the lack of concretisation of what measurable goal achievement signifies in practice means that disability policy most resembles spun sugar: sweet but lacking in substance. The goals are beautiful but hollow, and a number of risks are associated with this. Over and above the difficulties of evaluation, it is also hard for a country’s citizens to judge the value of the policy followed if achievement of its goals cannot be measured. And if the goals are unclear it is hard to insist on changes.

Despite the problems of measuring the effects of the policy, there are reasons to try. It can generate impulses to furnish the concept with measurable significance but, further, it affords important knowledge of the situation of people with disabilities.

The RFV Study of Living Conditions
To evaluate whether the goals of disability policy are being reached for recipients of disability support from the social insurance, during spring 2002 RFV conducted a study of this group’s living conditions. The RFV study concerns a certain group of people with disabilities, namely those in receipt of assistance allowance, car allowance or disability allowance. Hence, in the present study, an administrative definition is employed to delimit the group “people with disabilities”.

Since the political aims are hard to define and measure, the point of departure is the aim of equality in living conditions. Studying the living conditions of people with disabilities is nothing new. Statistics Sweden has, since 1984, fairly regularly published material on the subject. This is based largely on the data collected for their Surveys of Living Conditions. In connection with the 1994 Disability Reform and the trials preceding it, universities also followed developments in welfare for people with disabilities (e.g. Åkerström, 1993; Hedquist,
1997, and Tideman, 2000). In addition, the disability movement sometimes carry out measurements of living standards among their memberships (e.g. Handikappolitiska utredningsinstitutet 1996; Paulsson & Fasth, 1999).

The RFV Study of Living Conditions
In spring 2002 the National Social Insurance Board (RFV) carried out a questionnaire survey among people receiving one or more of the following benefits: disability allowance, assistance allowance or car allowance. These benefits are described in the chapter on Authorities and Individuals.

From a population of about 50,000 people, 6,800 aged between 23 and 64 were selected. Of those who received the questionnaire, nearly 5,000 answered, the exact response rate being 73.6%. Statistics Sweden assisted with the design of the questions and was responsible for collecting the answers.

The survey included questions about living conditions relating to, inter alia, education, work and finances. Other areas were also included but Social Insurance in Sweden 2002 presents only a selection of the results. Many of the questions are the same as those in the Statistics Sweden Survey of Living Conditions (ULF) directed annually to a population sample. This has permitted comparisons between people with disabilities and the total population in the present study. The ULF material used is from 2000 and was the latest available at the time of the statistical analyses.

Categories of Disability
Earlier studies have shown that different disabilities can affect the outcome of various measures concerned with living conditions. Szebehely, Fritzell and Lundberg (2001) demonstrated large differences in work and finances between people with different types of disability. It may therefore be useful to report separately on different groups of disability. The approach of the present study differs, however, from that of earlier studies, and this may need explaining.

One common way of grouping disabilities in investigations of living conditions is to start with the following categories: impaired mobility, reduced function of the arms/hands, impaired vision, impaired hearing, intellectual impairment and psychological impairment (e.g. Szebehely, Fritzell and Lundberg, 2001). One problem of grouping in this way is that a person can have more than one disability and hence be included in several categories. For example, a person can have reduced mobility in the legs as well as in the arms and hands.

To create categories that overlap less, the statistical method termed factor analysis is employed. With this method it is possible to study how a fairly large number of variables are linked with each other. In this
way, important patterns may be discovered in the material and this may help in creating categories that differ essentially from one another. Using factor analysis, three main categories were created:

- **Physical disability**: people who use some form of technical aid to move about, or cannot, or can only with difficulty, turn a tap on and off.
- **Sensory disability**: people who, even though they may have a hearing aid, wholly or partially lack the ability to hear what is being said in conversation among several people, or people who, even though they may wear spectacles, have impaired vision or no vision at all.
- **Intellectual disability**: people with intellectual impairments or autism.

**Congenital Disability or Acquired Disability**

Yet another aspect affected the way in which the categories were created. This is whether a person has had a disability since birth or acquired one later in life. Whether the disability is congenital or acquired may be very significant for the person’s living conditions. Nevertheless, the differences in living conditions between these two groups are seldom studied.

Important differences exist in the preconditions for the two groups. A person who has acquired a disability later in life has not been affected in the choice of education and occupation. For a person with a congenital or an early-acquired disability, the choice of education may have been affected by expectations concerning a future job.

In addition, a person with an acquired disability may have gained a foothold in the labour market before the disability arose. This may have provided experience and qualifications that enhance his or her chances of getting a new job or continuing in the old one. And should it prove impossible to continue working, a person with an acquired disability will probably get better support from the social insurance office since these measures are essentially income-related. On the other hand, someone with an acquired disability has grown accustomed to a more expensive level of existence and may therefore get into financial difficulties when acquiring a disability. House loans or similar may become hard to repay out of a reduced income.

Due to the potential effects of these differences on education, work and economy it may be fruitful to present the material consistently by congenital or acquired disability. The final categories are as in the following table.
Disability            | Women, nos. | Average age | Men, nos. | Average age |
---------------------|-------------|-------------|-----------|-------------|
**Physical disability** |             |             |           |             |
Congenital or acquired before age 16 | 339         | 43          | 347       | 40          |
Acquired after age 16 | 905         | 53          | 672       | 51          |
**Sensory disability** |             |             |           |             |
Congenital or acquired before age 16 | 520         | 43          | 555       | 42          |
Acquired after age 16 | 786         | 52          | 635       | 52          |
**Intellectual disability** |             |             |           |             |
Congenital or acquired before age 16 | 314         | 36          | 417       | 36          |
Acquired after age 16 | (38)        | 49          | (71)      | 51          |


Basic facts on the participants in the RFv Study of Living Conditions.

The group with intellectual disabilities acquired after age 16 is too small for our analyses. The same applies to people with psychological disabilities, for which reason they are not reported in a group of their own. This is unfortunate since, in earlier studies, this group has proved to have poorer living conditions than others. The reasons are that this group is hard to identify with a questionnaire, and that few people with psychological disabilities receive disability support from the social insurance. Where people with psychological disabilities do appear in the selection group, they often have a further disability entitling them to compensation.

The present categories gather 2,242 of the women and 2,055 of the men: close to 4,300 people. Thus not all those who participated in the study were grouped. However, those not included had such diverse disabilities that it was not meaningful to create another category.

The sum of the categories exceeds the total number of people, for both sexes. This is because the groups overlap, i.e. a person can have both a sensory disability and a physical one and hence belong to both groups.

The reported results contain the terms “congenital physical disability” and “acquired physical disability”. The questionnaire data show what kind of disability (or disabilities) a person has and whether the person has a congenital or an acquired disability. However, the questionnaire does not show which disability is congenital and which is acquired. It is quite possible that a person with a congenital physical disability later acquires a further disability. It is assumed for present purposes that if a person reported a physical disability and a congenital disability, this involved congenital physical disability. Strictly speaking, however, it is
more correct to maintain that the person had a congenital disability and a physical one.

**Some Were Helped to Answer**
The majority of those who completed the questionnaire did so on their own or together with another person. In some cases, though, somebody else, most often a relative (parent, brother or sister or partner) answered the questions on the respondent’s behalf.

To a greater extent than the other categories, people with intellectual disabilities did not answer the questionnaire themselves, either completely or partially. There is here a direct link between the abilities required to answer the questionnaire and the form the disability takes. Just under six percent of those with an intellectual disability answered the questionnaire on their own. In the main, the respondent did not take part in answering the questionnaire at all.

There is always a problem if a person cannot take part in a study that directly concerns him or her. If somebody else answers on their behalf there is a risk that the answers are influenced by this. However, it may sometimes be difficult to obtain information directly from the person to whom a questionnaire is addressed, in the present case people with intellectual disabilities. One way would be to exclude this group from the investigation. This would minimise the proportion who did not themselves participate in the answering but would also, which is probably worse, exclude a large proportion of the people with intellectual disabilities now included, thus missing vital information.

**Education**
The need for a good educational background is increasing in our society. People need to be able to compete on the labour market, to participate actively in community life and to stand up for their rights ([SOU 1998:106](#)). Only when everyone is able to obtain the best possible education can the goal of equal living conditions be reached.

The community must support people with disabilities so that they can take advantage of what education has to offer. School buildings can be adapted and classrooms can be pro-
vided with technical aids. More individually-adapted support can be made available in the form of e.g. an assistant.

There are however differences in educational level between people with disabilities and the population at large.

<table>
<thead>
<tr>
<th></th>
<th>Comprehensive School</th>
<th>Upper-secondary or Equivalent</th>
<th>Higher Education</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Women</td>
<td>Men</td>
<td>Women</td>
</tr>
<tr>
<td>Congenital disability</td>
<td>38.4</td>
<td>49.6</td>
<td>47.7</td>
</tr>
<tr>
<td>Acquired disability</td>
<td>44.4</td>
<td>43.3</td>
<td>36.2</td>
</tr>
<tr>
<td>Whole population</td>
<td>14.9</td>
<td>16.8</td>
<td>49.3</td>
</tr>
</tbody>
</table>


**Highest completed education.** Percent.

People with disabilities generally have a lower educational level than the total population. We see throughout that people with acquired disabilities have a higher level than those with congenital. This difference was expected since people who acquired their disability after age 16 may have completed their education before the disability arose. For people with congenital disabilities, it may be that certain problems have affected the possibility of studying to a greater extent, but it may equally well be a matter of poor accessibility and adaptation.

Particularly among persons with congenital disabilities, there are large gender differences. This is either because women are more inclined to study than men are, or that men have a different type of disability that more strongly affects the inclination to study or the possibility of doing so.

However, the table above does not explain the differences noted. For studying differences in outcome between different groups and what can cause these, several statistical methods may be used, of which logistic regression (see fact box) is one. The table below shows the effects of the various kinds of disability on the probability of having higher education.
Logistic regression and interpreting odds ratios

With logistic regression it is possible to analyse the probability that an event, or an outcome, will occur. The probability of the outcome is measured using odds ratios. An odds ratio states whether a certain group has a higher or a lower probability of that outcome than the reference alternative selected, which is given odds of 1. For other alternatives if an odds ratio is greater than 1 the probability of that outcome is greater than for the reference group, while an odds ratio lower than 1 means that the probability of the outcome occurring is lower than for the reference group. For example, according to the following table the probability that a person with acquired physical disability has a university degree as the highest completed education is half that for a person in the total population.

Logistic regression can also be used to test how some factors affect the outcome being studied while keeping other factors under control. This means that the effect of these factors does not influence the result.

The table shows that people with disabilities have a lower probability of having a university degree than the total population has. This applies regardless of whether the disability is congenital or acquired in adulthood. However the probability is somewhat lower with people whose disabilities are congenital. The difference is probably explained by the likelihood that people who acquired their disability after age 16 had managed to complete their education before the disability arose.

<table>
<thead>
<tr>
<th>Disability</th>
<th>Odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical disability</td>
<td></td>
</tr>
<tr>
<td>Congenital or acquired before age 16</td>
<td>0.37</td>
</tr>
<tr>
<td>Acquired after age 16</td>
<td>0.52</td>
</tr>
<tr>
<td>Total population</td>
<td>1</td>
</tr>
<tr>
<td>Sensory disability</td>
<td></td>
</tr>
<tr>
<td>Congenital or acquired before age 16</td>
<td>0.29</td>
</tr>
<tr>
<td>Acquired after age 16</td>
<td>0.49</td>
</tr>
<tr>
<td>Total population</td>
<td>1</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td></td>
</tr>
<tr>
<td>Congenital or acquired before age 16</td>
<td>0.01</td>
</tr>
<tr>
<td>Total population</td>
<td>1</td>
</tr>
</tbody>
</table>

Separate regressions were made for each group. The reference group is the total population, i.e. the result of the Statistics Sweden Ulf survey of 2000. The model has been controlled for the possibility of the same individual belonging to more than one category. The effects of gender, age, country of birth and regional differences (H region) have also been removed. All differences from the rest of the population are significant at the 95% confidence level (p<.05).


Probability for a person with a disability to have completed a course of higher education. Comparison with total population.
The generally lower probability of people with disabilities to have a university degree or equivalent can be interpreted in several ways. As mentioned earlier, the disability itself may affect the person’s ability to follow a course of study. But it is also likely that part of the difference may express the limited ability of society to make education accessible for people with disabilities. A handicap arises in the encounter between a student with an impaired function and an environment that in the broad sense is not adapted.

Somewhat over half the participants in the RFV study stated that their possibility of choosing subjects for study had been affected by their disability. This applies more to people with congenital disabilities, where about 60 percent considered that the disability had affected their choice, than to people with acquired disabilities. Just over 30 percent of the latter considered that their opportunities of choosing what subjects to study had been affected by the disability. There may be several reasons why people with disabilities are affected in their choices of education. Some of the respondents described in their own words how they have been affected:

- Chose an occupation where I could continue even if my disability should get worse.
- Retraining after the accident.
- When I was 18 the authorities wanted to put me in an old people’s home. Then I went to a school for the deaf with no info. on what this entailed. There I was told I’d never manage a course of study, never be able to support myself.
- The schools were not equipped for disabled people, so I had quit my studies.
- Because of personal assistance that didn’t work I have not been able to finish my civil engineering education.
- Shortage of technical aids and information on what possibilities there are.
- Don’t dare join a study programme involving loans since I don’t know if I can manage the programme because of my MS.

Several main themes can be discerned in the respondents’ comments. First, many stated that the disability prevented them from choosing certain types of occupation, however attractive. Another clear theme is the lack of adaptation or help in the study situation. This may involve physical adaptation of the school environment, but also social adaptation:
it is not unusual that large classes, noisy school surroundings etcetera cause problems. A third theme, though not as frequent as the first two, is the lack of information on what support is available for students with disabilities. Some respondents also feared that they may not be able to finish a course of study, or that it would not result in a job anyway. Borrowing money and perhaps not getting a job appears to worry some of those who answered the question.

There is little research on the link between disability and the possibility of acquiring a good education. A number of studies, however, indicate that it is hard for people with disabilities to acquire an education because of poor physical accessibility. The Swedish Disability Ombudsman showed in 2000 that about 40 percent of the country’s upper-secondary schools were not adapted for people with physical disabilities (Handikappombudsmannen, 2000).

The National Agency for Higher Education (Högskoleverket) was commissioned by the Government in 1998 to examine the circumstances of university students with disabilities. The Agency reported that their circumstances varied. One key issue was that information to disabled students on the various technical aids and forms of support was poor. Some students testified that they had studied for several terms before receiving information on the support they were entitled to in their studies. In the Agency for Higher Education survey (635 respondents) of students with disabilities and receiving some form of study support, about half stated that their disability had a great or a very great negative effect. The chief reason given was that the disability had rendered their studies more time-consuming and tiring. The students’ comments also showed that some of these problems could have been avoided with better technical equipment and fairly simple adjustments in lecturing methods (Högskoleverket, 2000).

On 1 March 2000 Sweden introduced a new law intended to protect, among other people, students with disabilities against discrimination in higher education. Under this law, the Equal Treatment of Students at Universities Act (2001:1286), unsatisfactory accessibility can in individual cases be equated with discrimination. It is hoped that the law will support many students with disabilities, increasing their potential for following higher education.

In summary, people receiving some form of social insurance benefit intended for the disabled generally have lower levels of education than the population at large. The reason for this can lie in the disability itself, in unsatisfactory accessibility and in poor incentives to study.
**Work and Occupation**

The Swedish welfare model is based on the *work line*. Active measures receive priority so that unemployed people may go to work rather than being passive recipients of cash benefits. The work line means that employment always takes precedence over the payment of cash benefits. If there is no work to be had, the unemployed person is offered suitable education or training which may in turn lead to a job.

The work line also applies to people with disabilities. In their case, the work line means that habilitation, rehabilitation and measures to strengthen their ability to compete for jobs should take precedence over unemployment benefit and disability pension. Other possibilities include employment with wage subsidy, work support measures, work at Samhall sheltered employment and economic assistance for disabled people who wish to start their own businesses. The Act on the Prohibition of Discrimination in Working Life of People with Disability (1999:132) may also be viewed as an instrument for supporting the individual on the labour market.

The SHF Study of Living Conditions shows that, despite various efforts by the Government, people with disabilities often lack a foothold in the labour market.

<table>
<thead>
<tr>
<th>Disability*</th>
<th>Working on the open labour market</th>
<th>Employed through work-support measures*</th>
<th>Entirely employed or occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Women</td>
<td>Men</td>
<td>Women</td>
</tr>
<tr>
<td><strong>Physical disability</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital or acquired before age 16</td>
<td>24.2</td>
<td>23.9</td>
<td>21.9</td>
</tr>
<tr>
<td>Acquired after age 16</td>
<td>10.4</td>
<td>14.0</td>
<td>5.8</td>
</tr>
<tr>
<td><strong>Sensory disability</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital or acquired before age 16</td>
<td>32.7</td>
<td>34.7</td>
<td>26.3</td>
</tr>
<tr>
<td>Acquired after age 16</td>
<td>16.0</td>
<td>17.9</td>
<td>5.3</td>
</tr>
<tr>
<td><strong>Intellectual disability</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital or acquired before age 16</td>
<td>1.0</td>
<td>1.5</td>
<td>82.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>22.2</td>
<td>22.5</td>
<td>21.0</td>
</tr>
</tbody>
</table>

* The categories Physical disability and Sensory disability do not include people who also have an intellectual disability.

2 By work support measures is meant work with wage subsidy, organised daily activity, sheltered employment or work experience placement.

Of the people who answered the questionnaire, just over 22 percent of both sexes were employed on the open market. The proportion of persons employed through work support measures was 21 percent for women and just over 31 percent for men.

More women than men were entirely without paid work, even though the proportions on the open labour market were equal. The proportion without work was close to 57 percent for women and just over 46 percent for men. As the table indicates, this is because more men than women have access to other forms of work and occupation than those available on the open labour market. This applies both to people with physical and sensory disabilities, irrespective of whether congenital or acquired. The fact that more men than women had access to work-support measures is hard to explain. Earlier studies of rehabilitation show, however, that the ambition to channel people back into the labour market is higher for men than for women. Here one discerns a social norm by which men are expected to be in work more than women are (RFV, 1997; RFV, 1999). Possibly the same phenomenon is reflected in the table above.

Another finding is that people with acquired disabilities to a larger extent than people with congenital disabilities are entirely without work or occupation. This is true both for physical and sensory disabilities. The result is somewhat surprising as some of those who acquired their disability probably already had a foothold in the labour market when the disability arose.

That people with intellectual disabilities are so strongly represented in the work-support group is explained by the fact that this group is, via the Act on Support and Services for Certain Disabled Persons (1993:387), entitled to organised daily activity scheme.

The consistently low proportion of disabled people on the open labour market may have several causes. A majority of the respondents stated that their opportunities of choosing occupation had been affected by their disability. Among people with congenital disabilities, about 65 percent stated that this was the case, while the proportion among those with acquired disabilities was just over 45 percent. Some people described how their opportunities of choosing occupation had been affected. Here a few examples capture the main themes:
Can’t manage work because of aches and painful joints.

Jobs that need a good constitution are not suitable. White-collar jobs are perfect.

I must get to my workplace, lunch-room and toilet must be suitable for wheelchairs.

My disability makes great demands on flexibility as to work hours and how the workplace is laid out.

I am disabled and I spend my time in a wheelchair. You just look around society, you can’t get in, up, down or out.

Employers’ attitudes to my ability to work despite the fact that I have a degree. Prejudices about cerebral palsy.

My employer considers me a “burden” rather than a resource.

Three main themes emerge from the above comments. The first concerns the disability, some stating that the disability itself either makes work impossible or means one must choose an occupation that is suitable despite the disability.

Another recurring theme is inaccessible work environments. The questionnaire answers indicate that certain occupations are not accessible because of poor adaptation. Adaptation can also refer to work tempo or flexi-time. Workplace accessibility is an important issue. In the Government’s Diversity Project on University Graduates with Disabilities almost 40 percent stated that they did not get the workplace modifications they needed. Only one-third stated that they had received the technical aids they needed (Ds 2000:69).

The third theme in the questionnaire survey was employer attitudes. Many described these as hampering their chances of getting jobs. In their study of employers’ attitudes to people with disabilities, Knutsson and Persson (2001) showed that employers initially underestimated applicants’ work potential. Thirty-four percent of the employers included in the study, and who had employed a person with a disability, felt that the appointment had gone better than expected. Just under nine percent considered the appointment had gone worse than expected.

About half the participants in the SRFV Study of Living Conditions entirely lacked jobs. Of these, somewhat under 79 percent had full disability pensions. The proportion was higher for those with disabilities acquired in adulthood than for those who were born disabled or became so before age 16.

There is no information on how many of those in the SRFV investigation had a disability entirely precluding any form of work. However,
earlier investigations show that some disability pensioners themselves considered they would be able to work. A joint project by fifteen disability organisations showed that 64 percent of people on disability pensions aged 16–35 considered that they could take a job if offered one (Olsson, 1999).

In 1992 the National Board of Health and Welfare evaluated the living conditions of 1,200 young disability pensioners aged 20–44. It emerged that over a third would like to work if offered suitable employment. Poor health was the reason given by an overwhelming majority (two-thirds) for not doing so. Other reasons in which some concurred were lack of suitable job opportunities in the district, employers’ reluctance to employ people with disabilities or inadequate education or training (Socialstyrelsen, 1992).

Having a disability pension does not mean however, that one is entirely without work or occupation. A disability pension can be combined with various forms of occupation. The rfv study shows that almost all of those working in the organised daily activity scheme are on disability pension. Of those in wage-subsidised employment, over 40 percent are on half disability pension. However, the fact that some people are able to work through work-support measures implies that they actually represent a potential asset on the open labour market.

The fact that some studies indicate that some disability pensioners consider they could work, but do not do so, signifies doubt as to whether the work line (see above) is being upheld for people with disabilities. For many of them, the disability itself represents obstacles to gainful employment, but the question is whether this applies to all or whether other aspects may have led to the low proportion gainfully employed. Important but forgotten labour potential may well be lying hidden behind the large proportion of disability pensioners.

**Financial Security**

Having a secure financial situation is an important precondition for being able to live like other people. In this section, two measures of financial security are studied: the risk of being afflicted by a financial crisis and the risk of lacking a cash margin. We do not study income,
which is sometimes used as a measure of economic resources. Income is hard to use as a measure since an individual’s income is often less important than the household’s total income. Moreover, a measure of income need not directly reflect financial difficulties.

The first measure of financial security relates to lack of cash margin and is measured with the question “If you unexpectedly found yourself in a situation where you have to get hold of SEK 14,000 in a week, could you do so?” Another measure of financial security often used in standard-of-living surveys is financial crisis. This is measured using the question “Has it happened during the past 12 months that you have had difficulties in managing current expenses for food, rent and so on?”

As opposed to cash margin – which measures the availability of a financial buffer – this question probes a more direct experience of financial crisis.

The answers showed that the group studied was in financial difficulties more often than were others. The following table compares the two measures between the people included in the RFV study and the total population.

<table>
<thead>
<tr>
<th></th>
<th>Lack of cash margin</th>
<th></th>
<th>Financial crisis</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Women</td>
<td>Men</td>
<td></td>
<td>Women</td>
</tr>
<tr>
<td>Congenital disability</td>
<td>40.4</td>
<td>29.9</td>
<td></td>
<td>24.0</td>
</tr>
<tr>
<td>Acquired disability</td>
<td>42.1</td>
<td>34.2</td>
<td></td>
<td>31.2</td>
</tr>
<tr>
<td>Total population</td>
<td>16.4</td>
<td>12.2</td>
<td></td>
<td>17.2</td>
</tr>
</tbody>
</table>


Financial difficulties. Percent.

The result is unambiguous for both measures: having a disability, whether congenital or acquired, involves greater financial difficulties than those besetting the rest of the population.

Whether congenital or acquired, the disability does not create especially large differences regarding cash margin. If instead one considers those who have experienced a financial crisis, one finds that more people with acquired disabilities have suffered such a crisis than have people with congenital ones.

However, in this analysis differences between types of disability are not visible; nor do we know how much other factors influence the situation. For this reason it is interesting to know how great the influence of the disability is if one controls for other factors believed to affect a
person’s financial position. Once again, logistic regression is used (see fact box on page 29). The results are presented in the following table.

<table>
<thead>
<tr>
<th>Disability</th>
<th>No cash margin</th>
<th>Financial crisis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital or acquired before age 16</td>
<td>4.31</td>
<td>1.90</td>
</tr>
<tr>
<td>Acquired after age 16</td>
<td>4.67</td>
<td>2.88</td>
</tr>
<tr>
<td>Total population</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Sensory disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital or acquired before age 16</td>
<td>3.81</td>
<td>2.25</td>
</tr>
<tr>
<td>Acquired after age 16</td>
<td>4.47</td>
<td>3.30</td>
</tr>
<tr>
<td>Total population</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Intellectual disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital or acquired before age 16</td>
<td>2.57</td>
<td>0.29</td>
</tr>
<tr>
<td>Total population</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Separate regressions were made for each category. The reference group is the total population, i.e., the result of the Statistics Sweden ULF survey of 2000. The model has been controlled for the possibility that the same individual belongs to more than one category. The effects of gender, age, country of birth and regional differences (H region) have been removed. For people with intellectual disabilities we have also controlled for whether they are living at home with their parents or have homes of their own. All differences from the rest of the population are significant at the 95% confidence level ($p < 0.05$).


**Probability of lacking a cash margin and of experiencing a financial crisis.**
Comparison with total population.

The probability of lacking a cash margin is considerably greater for disabled people than for the total population, and greatest for those with an acquired disability – more than fourfold. For people with an intellectual disability, the probability of lacking a cash margin is just over double that of the total population.

Regarding the risk of recent financial crisis, people with intellectual disabilities stand out in this analysis, with a risk that is only one-third of that of the total population. One important explanation of this may be that the majority of them have a trustee or administrator whose job it is to manage their money so as to prevent a financial crisis from arising.

People with sensory and physical disabilities have a considerably greater probability of being afflicted by financial crises than does the total population. The risk is greatest for people with acquired physical disabilities. Among these it is almost three times greater than in the total population, while among people with acquired sensory disabilities it is more than three times greater. That people with acquired disabilities have greater financial problems than those with congenital disabilities may be explained by the fact that someone who becomes disabled as an adult may have attained a more expensive life (house loans, etc) which
can be hard to keep up given the economic setback a loss of salary involves.

However, financial difficulties do not only beset people with acquired disabilities. All the categories studied, except those with congenital intellectual disabilities, run a greater risk of encountering financial problems. Szebehely, Fritzell and Lundberg (2001) show that people with disabilities, even those with income levels similar to the total population’s, find it harder to make ends meet. The authors conclude that, because of the extra costs entailed by the disability, people with disabilities would need higher incomes than the total population to have the same financial resources.

Additional costs can arise for special diets, modification of a car, or high costs for clothing and footwear because of more wear. The individual is partially compensated for such extra costs. Car allowance and disability allowance are two forms of social insurance support designed to compensate the individual for this type of cost. The idea is that certain economic differences between disabled people and others should be evened out in this way.

Commonly, however, not all additional costs are reimbursed. The Report of the Committee on Additional Costs (sou 1995:35) shows that for six people in ten, the additional costs exceed the benefits and allowances intended to compensate for them. Forty percent of the respondents in one of the Committee’s surveys stated that additional costs represented moderate financial problems for them, while over 20 percent stated that the additional costs represented great or very great financial problems. Later studies also show that additional costs are not fully covered (Paulsson and Fasth 1999; Socialstyrelsen, 2002b).

**Education and Training, Work and Finances – a Circle of Exclusion**

Above we outlined the situation as regards education and training, work and finances for people with disabilities. Three important conclusions may be drawn. First, people with disabilities have on average a lower educational level than others. Secondly, their foothold in the labour market is as a rule but poor. Thirdly, the risk of financial problems is greater for them than for other people.
It is reasonable to assume that these three indicators of living conditions are connected. A higher level of education makes people more competitive in the labour market and an established position there enhances their finances. The assumed connection would look like this:

![Diagram showing the connection between education and training, work, and finances.]

**Assumed connection between different indicators of living conditions.**

Below we examine briefly whether there is empirical support for this model. The previous section showed that people with intellectual disabilities differ much from people with other disabilities in terms of education and training, work and finances. For this reason they are excluded from the analyses now presented.

We start with the first step, that between education and work. The calculated probability that people with disabilities will have a foothold in the open labour market is shown in the following table:

<table>
<thead>
<tr>
<th>Educational level</th>
<th>Odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comprehensive school</td>
<td>1</td>
</tr>
<tr>
<td>Upper-secondary school</td>
<td>1.39</td>
</tr>
<tr>
<td>Higher education</td>
<td>4.32</td>
</tr>
</tbody>
</table>

People with intellectual disabilities are not included in the regression model. The model controls for effects of gender, age class, country of birth, regional differences (H region) and for whether the disability is congenital or acquired. Odds ratios given are significant at the 95% confidence level.

**Effect of educational level on probability of working in the open labour market.**

The table shows that the probability of being established in the open labour market increases if one’s education is above comprehensive school level. For people with upper-secondary education or equivalent the probability increases by about 40 percent, while those with higher education have a more-than-fourfold greater probability of being established in the open labour market.

Hence higher education improves the opportunities for people with disabilities to get jobs on the open labour market. This tallies with the conclusions of the Government’s Diversity Project. This study shows that graduates with disabilities get the type of work for which they have trained and that their salaries largely follow those of other graduates.
On the other hand it takes longer for them to get jobs and they also spend longer periods unemployed (Ds 2000:69).

Following the model on page 39 the next stage is to investigate the link between establishment on the labour market and financial situation. This is described in the following table:

<table>
<thead>
<tr>
<th>Establishment on the labour market</th>
<th>No cash margin</th>
<th>Financial crisis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work on the open market</td>
<td>0.31</td>
<td>0.45</td>
</tr>
<tr>
<td>No work on the open market</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

People with intellectual disabilities are not included in the regression model. The model controls for effects of gender, age class, country of birth and regional differences (H region) and for whether the disability is congenital or acquired.


**Effect of establishment in the labour market on risk of lacking a cash margin and of having a financial crisis.**

People working in the open labour market have a greater probability of enjoying a secure financial situation. This applies both to the probability of having a cash margin, which is over three times greater for those working in the open labour market and to the risk of being beset by a financial crisis, which is about half as great. Thus there seems to be a clear link between work in the open labour market and secure economic circumstances.

However, the gap between disabled people and the rest of the population starts in school. Active participation in society is making increasing demands on education, and the importance of education in order to compete on the labour market is evident. Therefore, an important prerequisite for achieving equal living conditions is for people with disabilities to have equal opportunities to good education.

As a group, people with disabilities are shut out from many of the sectors of human life that generate independence. By analogy, the people who are excluded from education and the labour market will not be able to live as others do in any full sense.

This calls for action.
Authorities and Individuals

This chapter is about the system of support for people with disabilities. It starts with a description of the system and the people who operate it and then, using the RFF Study of Living Conditions, goes on to examine how the system is functioning for the people for whom it is intended.

The Authorities of the Support System

Many people with disabilities need no special support. A well-functioning community with good accessibility to the physical and social environment may be all that is needed. For people who do need support in consequence of their disability, various kinds are available. The responsibility for the support is divided among the municipality, the county council and the state. Different laws and ordinances regulate each authority’s responsibility.

<table>
<thead>
<tr>
<th>Authority</th>
<th>Main responsibility</th>
<th>Important laws/ordinances</th>
</tr>
</thead>
<tbody>
<tr>
<td>Municipality</td>
<td>Basic responsibility for all citizens and their living conditions</td>
<td>Social Services Act (SoL, 2001:453)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Act on Support and Services for Certain Disabled Persons (Iss 1993:387)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Act on Municipal Transport Services for Elderly and Disabled Persons (1997:736)</td>
</tr>
<tr>
<td>County Council</td>
<td>Certain special (expert) measures</td>
<td>Health Services Act (1982:763)</td>
</tr>
<tr>
<td>State/social insurance</td>
<td>Financial support and compensation for additional costs</td>
<td>National Insurance Act (1962:381)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Act on Disability Allowance and Care Allowance (1998:703)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Assistance Allowance Act (1993:389)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ordinance regarding Car Allowance for Persons with Disabilities (1998:890)</td>
</tr>
<tr>
<td>State/labour market authorities</td>
<td>Assist people with disabilities to obtain or to keep a job</td>
<td>Ordinance regarding Special Measures for People with Occupational Disabilities (2000:630)</td>
</tr>
</tbody>
</table>
It is not self-evident that the measures of support should be distributed between different authorities. Before the disability reforms of the 1960s, the institutions, as showed in the story of Olof, supplied all the support the individual could be thought to need: living quarters, education and training, occupation and care.

As mentioned in the previous chapter, asylums and institutions were abolished with the aim of integrating disabled people into the community. This also affected the ways in which support for this group was to be administered. In 1964, the ideologically significant report “Social omvårdnad om handikappade” (Social Care of the Handicapped) presented a proposal for how responsibility should be apportioned among the different authorities. This proposal tallies fairly well with the present-day appearance of the support system. The Committee on Social Policy, which wrote the report, laid down that several ministries and government agencies should be responsible for the welfare of people with disabilities, and that this was a natural part of the integration then in progress:

*It is probably natural for this to be so. The idea that people with disabilities should be included in community life to the greatest extent possible implies that their education should be catered for by ordinary educational organs, their homes provided by the housing organs, their care under the auspices of the ordinary health services and so on (SOU 1964:43, p. 116).*

Thus the division of responsibility among different authorities can be viewed as a way of realising the idea of integrating people with disabilities into the community.

This is nowadays termed the *principle of responsibility and financing*. The principle implies that all social sectors should design and conduct their activities so that they are accessible to all citizens, irrespective of whether they have a disability. The underlying notion is that each area of society should take its responsibility for issues concerning people with disabilities. In other words, there are tools in all sectors of the community for harmonising the living conditions of people with disabilities (prop. 1999/2000:79).

The principle also implies that the support given to people with disabilities should be integrated with general services rather than being administered by a special “disability authority”. This is an important notion. People with disabilities should not be separated from the rest of the population but should go to the same authorities as all others do to
have their needs for support and service met. The principle of responsibility and financing has another side to it, though, as will be shown later in this book. For people needing much support, it may be complicated to keep track of the various authorities involved.

What follows is an overall description of the work and responsibility of the local authorities – municipalities and county councils – and the state. State responsibility for making it easier for people with disabilities to enter and remain in the labour market, is also touched on.

**Municipalities**
The municipalities – corresponding to town or city councils – have the ultimate responsibility for ensuring that citizens living within their borders obtain the support and help they need. The municipality represents the basis of the support offered by the community to people with disabilities. For example, it is here that the responsibility lies for seeing that people with disabilities obtain housing that is adapted to the disability. For some people, this may involve fairly simple adaptation of an existing home while others may need some special residential form. The municipality is also responsible for ensuring that people with disabilities receive the personal support they need, round the clock. This may be anything from getting in and out of bed to following one’s leisure interests.

Two important laws govern the municipality’s work in this field. The first is the Social Services Act (2001:453) which regulates large parts of the municipal social services, including the care of the elderly and of people with disabilities. Through the Social Services Act, many people in the autumn of their lives can get help in the home or the opportunity of moving to a service flat. Some people with disabilities receive all or part of their support under this legislation. In autumn 2001, just over 14,100 people under 65 were receiving home help granted under the Social Services Act. About 5,500 people lived in some form of special accommodation under the same law (Socialstyrelsen, 2002a).
The Social Services Act is a “basic act”, meaning that with a few exceptions it contains no specific descriptions of measures that the municipality must offer its residents. Hence the municipality has great latitude to implement the provisions of the law according to local conditions. This mode of legislation is largely compatible with the principle of local self-government: that is to say, the state should not interfere in local affairs but should leave the municipality to manage its own business.

The Social Services Act obliges the municipality to ensure that people with disabilities can live as others do: the municipality should facilitate their participation on equal terms and provide the support they need. To do this, the local authorities should also actively seek to identify people who may need support, to give information on what help can be offered and to assess the need for support among local residents. This “outreaching” can be done in different ways. Placing brochures in health centres and habilitation units, for example, represents one way. Another is to spread information through various forms of cooperation with local disability organisations.

The other important law in the municipal area is the Lss Act (Act on Support and Services for Certain Disabled Persons, 1993:387). This law was introduced in 1994 and may be seen as a supplement to the Social Services Act. While measures under the Social Services Act should in principle be available to all who need them, the Lss Act – see the fact box on page 45 – follows a narrower definition of who should be eligible for these measures. A further important difference between the Social Services Act and the Lss Act is that the latter has considerably stronger elements of rights legislation. A law of rights guarantees a citizen specific benefits, given that he or she meets certain criteria. Critics consider this to be in conflict with municipal self-government since the local authorities are required to carry out an activity but have no say in what it involves (see Svenska kommunförbundet, 1998).

The municipal responsibility applies equally to all its residents, meaning that all who need support in their daily lives should obtain this via the municipality. However, the starting point for this work may vary. Further, the Lss Act and the Social Services Act also differ in what they seek to achieve. While the goal of Lss is for people with disabilities to enjoy good conditions of life, support under the Social Services Act is intended to ensure a reasonable level of existence.

The Lss Act provides a number of measures ranging from different types of accommodation to expert measures, for example counselling and support, personal assistance, and
organised daily activities. Today just over 47,000 people are receiving support under the LSS Act. The most common measures are organised daily activities and accommodation for adults (Socialstyrelsen, 2002a).

<table>
<thead>
<tr>
<th>Entitlements under LSS</th>
</tr>
</thead>
<tbody>
<tr>
<td>The following three groups are entitled to support under the LSS Act:</td>
</tr>
<tr>
<td>1. People with congenital intellectual disabilities, autism or autism-like conditions</td>
</tr>
<tr>
<td>2. People acquiring, in adulthood, permanent and significant intellectual disabilities in consequence of external violence or somatic disease</td>
</tr>
<tr>
<td>3. People with other permanent disabilities clearly not related to normal aging, if the disabilities are extensive and cause major difficulties in daily life and hence a comprehensive need for support or service.</td>
</tr>
</tbody>
</table>

A municipality also has obligations under the Health Services Act (HSL, 1982:763). The Health Services Act lays down that the municipality is responsible for seeing that people living in special accommodation get the habilitation, rehabilitation and technical aids they need.

Support to people with disabilities may be dispersed over several municipal sectors or units. The work may sometimes be integrated with care of the elderly or with school health services and child care. Other municipalities have chosen to create special units for issues concerning people with disabilities. Alternatively, the choice of organisation may lie between having a centralised operation for the whole municipality or a decentralised organisation, for example under the responsibility of urban district councils (Puide, 1999).

**County Councils**

The role of the Swedish county councils in the support system surrounding people with disabilities includes the provision of health care, habilitation, technical aids and interpreters. The county council is also responsible under the LSS Act for the measure termed counselling and support. Basically, this measure consists of providing expert support for disabled people. The support may be given by e.g. hospital social workers, occupational therapists or psychologists.

<table>
<thead>
<tr>
<th>Examples of support available from the county council</th>
</tr>
</thead>
<tbody>
<tr>
<td>– Habilitation</td>
</tr>
<tr>
<td>– Technical aids</td>
</tr>
<tr>
<td>– Interpreter services</td>
</tr>
<tr>
<td>– Counselling and support</td>
</tr>
</tbody>
</table>
County council work is often divided into various administrative units and clinics. Clinics are most often organised on the basis of the medical speciality for which they are responsible. Other county council operations may be organised on the basis of the groups they serve. The youth clinic is one example of this, habilitation another.

Most county council activity is regulated by the Health Services Act. This act provides that the county council must offer good health services for residents in its area. The goal of Swedish health care according to the Health Services Act is “good health and care on equal terms for the whole population” (sec. 2). More specifically, this means for the county council that, as well as offering medical care, it must meet the need for habilitation and rehabilitation, technical aids for disabled people and interpreter services for people with sensory disabilities. This makes the county council a further important actor in the support system for people with disabilities, providing support with relatively well-defined measures.

Unlike the lss Act, the Health Services Act is not a rights law but an obligations law. An obligations law regulates chiefly an authority’s obligations vis-à-vis another party, most frequently a citizen of a country. Regarding health and medical care, this means that the community has an obligation to guarantee citizens good care, but that the individual has no exactable right to care. Thus an individual cannot appeal against a decision by a medical care provider.

**Authorities can Transfer their Responsibility and the Provision of Support**

The fact that the municipality or the county council is responsible for a support measure does not necessarily mean that it needs to perform it itself. Hence a municipality or a county council can employ an external provider e.g. to run residential homes, organise the daily activities scheme, arrange home help services and so on. These types of commission can be contracted out according to the Social Services Act, the Health Services Act and the lss Act. However, local government is always responsible for ensuring that the support is actually supplied, that the quality is good and that the intentions of the law are realised. In addition, local government cannot make over the actual exercise of authority, i.e. assessing the need for and entitlement to support and reaching decisions about these.

To some extent, the authorities can also conclude agreements with each other, hence shifting the main responsibility for various forms of support from one to the other. One example is the counselling and support measure under the lss Act. The county council is the principal authority for this since when the measure was introduced it was con-
sidered to fit in well with core county council activity. However, this does not prevent a municipality and a county council from concluding a contract under which the municipality administers this form of support. The same goes for other measures under the same legislation (sec. 17 lss). Similarly, municipalities and county councils can reach agreements on the provision of certain support measures under the Health Services Act (sec. 18b HSL).

The Labour Market Authorities
Among the bodies responsible for the state’s share in support to people with disabilities are the labour market authorities.

The labour market authorities are responsible for ensuring that disabled people with limited working ability gain entry to the labour market and that, where necessary, the actual working environment is adapted so the person can continue in work. The National Labour Market Board (AMS) is the central authority. It lays down guidelines and outlines tasks for the local Public Employment Services, which allocate the resources in their own counties.

Various forms of labour market support are intended to increase the opportunities for people with disabilities to be gainfully employed. Of these forms, wage subsidies and the operations of the Samhall sheltered employment organisation are perhaps the best known. In addition, employers can obtain financial assistance with various costs for e.g. the purchase, rent or repair of technical work aids, or the costs of audirotaped or braille literature for employees with visual or hearing impairments (Ordinance on Special Interventions for Persons with Work Disabilities, 2000:630).

Social Insurance Support to People with Disabilities
Social insurance is a part of the lives of practically all citizens. It is of great importance for people’s social security and welfare. Every citizen is legally entitled to insurance benefits and allowances in various situations of life.

Social insurance is administered by the National Social Insurance Board (RFV) and the Social Insurance Offices for which RFV is the supervisory authority. In addition, through general advice and guidance, RFV tries to harmonise the application of the regulations throughout the country. Another of RFV’s tasks is to evaluate the effects of social insurance for people and for the community. The insurance offices manage the
direct handling of social insurance support by investigating and assessing their clients’ right to the various forms of benefit.

The social insurance system administers one part of the support the community offers people with disabilities. For actual upkeep, measures such as temporary or permanent disability pension may be appropriate. Starting in 2003 these measures are being replaced with income-related sickness compensation and income-related activity compensation.

Apart from the maintenance support, four benefits are earmarked for people with disabilities. Their chief purpose is to cover various forms of additional expense the disability may entail. These are disability allowance, care allowance, car allowance and assistance allowance. They have become part of the social insurance at various times and have special purposes. Social insurance support for people with disabilities will be described in more detail below.

Although the various earmarked benefits differ in many ways, they have a common denominator. All four include large elements of interpretation, so that investigations often involve searching questions into the applicant’s conditions and need for support.

For this type of case, which involves a high degree of means testing, the formal decision is made by a special body whose members are laymen and represent the public. They decide about the proposed decision written by the official at the social insurance office. This body decides on the right to such support as is intended directly for people with disabilities.

Temporary and Permanent Disability Pension (Sjukbidrag och förtidspension)
Disability pension and its time-limited form temporary disability pension have long been granted to people who, for medical reasons (mental or somatic) are incapable of work. Disability pension has therefore been an important source of upkeep for people with impaired working ability. The benefit has four levels: full benefit, three-quarters benefit, half and quarter. In this way, people with some working ability can partly retain their foothold in the labour market and still receive compensation from the social insurance system for their partial inability. Disability pension has been granted if the impaired working ability is expected to be permanent, while the temporary form has been granted if there is reason to believe that working ability can be regained or gained.

The system of disability pension and temporary disability pension has been an important element in the Swedish welfare system, covering the whole population from youth to pensionable age (16–64 years). The rules have remained essentially the same since they were introduced in the early 1960s. However, society has undergone great changes during
the past forty years. For this reason, starting in 2003, a new system more in keeping with the times is being introduced, which involves income-related sickness compensation and income-related activity compensation. Sickness compensation is taking over from the disability pensions but cannot be granted until the person has reached thirty. Activity compensation has been introduced for young people entering the social insurance system, so as to diminish as far as possible any passive dependence on benefits and to increase the individual’s own ability to provide for himself or herself.

**Income-Related Activity Compensation (Aktivitetsersättning)**

Since their inception, temporary and permanent disability pension have had as their primary purpose to ensure financial security for people who, after becoming established on the labour market, have been forced for medical reasons to leave it prematurely. The system has not encouraged activity, and the need for rehabilitation or habilitation often prevalent among people entering the system at young ages has thus remained largely unmet. For these groups, disability pension has become a passive receipt of support without opportunities to develop and improve functional and working ability. When at the end of the 1990s and beginning of the 2000s the Government investigated the disability pension system and proposed reforms, one starting point was that the new system should enable and encourage young people with disabilities or diseases to develop full or partial self-sufficiency and to develop an independent lifestyle as similar to others’ as possible. The investigator assumed a perspective that was clearly grounded in modern disability policy:

*The disability policy goals of equal opportunity and participation for people with disabilities have involved integration of groups who earlier lived a large part of their lives in institutions and who in practice were seldom considered for or by the labour market. [The new] insurance must now, in a competent manner, handle the need for habilitation, rehabilitation and contact with working life for groups who, formerly, were in many cases granted disability pensions fairly routinely and who then did not become the objects of any genuine work rehabilitation (SOU 1998:106, p. 25).*

Income-related activity compensation was introduced on 1 January 2003 for people aged 19 to 29. It is intended to encourage the recipient to become and remain active
without affecting financial security. The aim is for people who enter the social insurance system at young ages to be given the opportunity to increase their independence and create active lives for themselves. It can also lead to increased self-sufficiency.

The activity compensation scheme, then, encourages the individual to participate in activities during the period for which compensation is payable. The activities may be of varying kinds but have in common that they should have a beneficial effect on the disease or impaired working ability. Examples are courses, hobby activities and sports. The individual should govern the choice of activities. The Social Insurance Office should act to support the individual by e.g. planning and coordinating activities.

Activity compensation is time-limited and can be granted for at most three years at a time. The Social Insurance Office must follow the individual during this period to form an opinion on how things are developing for him or her and in this way gain information on suitable activities.

While activity compensation is available for many different types of activity, there are certain restrictions. An important one is that it may not be used during post-upper-secondary studies. Hence it is not possible to study at a university with activity compensation.

Disability Allowance (Handikappersättnings)
Disability allowance is given to people with impaired functional ability who need practical help to manage their daily lives or who, due to the disability, incur large extra expense. The allowance comes in three fixed levels: 36 percent, 53 percent or 69 percent of the price base amount (see fact box on page 51). In practice the allowance in 2002 varied between SEK 1,137 and SEK 2,179 per month. The allowance is age-limited, being granted at age 19 at the earliest; and the disability must have arisen before the person reaches 65.
Disability allowance in its present form has existed since 1975, but its history really begins in 1934 with the introduction of the blindness allowance. It no longer exists in its previous form, having been transformed through a number of social-political reforms into today's allowance. Yet people with severely impaired vision are still guaranteed disability allowance, as are, since 1975, people with severely impaired hearing. In other cases, the right to disability allowance is examined in the light of the need and the cost of additional help. Apart from the groups mentioned above, there has been an explicit intention not to specify more closely what disabilities should entitle people to this allowance (prop. 1962:90, prop. 1974:129). Instead, each case is examined on its merits.

The legislative preparatory materials describe the allowance as compensation for costs. Early on in the drafting the term “care costs” was used, while in the later preparatory materials the more general phrase “additional costs” was used. Since the allowance was first introduced, therefore, the idea has been to compensate the disabled person for additional costs entailed by the disability, e.g. for drugs, wear and tear on clothing, and journeys (prop. 1962:90, prop. 1974:129).

The price base amount

The price base amount is a sum of money fixed annually by the Government. It is adjusted to be of the same value despite price increases. Many social insurance benefits are linked to the price base amount, allowing them to retain their value even if general price levels change. Sometimes the Government may decide that the amount should not be entirely geared to price changes. This may be done, e.g. to facilitate the management of state finances.

In 2003 the price base amount is SEK 38,600.

Care Allowance (Vårbidrag)

Care allowances are granted to parents caring for a seriously ill or disabled child. The care allowance has two purposes: payment towards the care and supervision exercised by a parent and compensation for the additional costs entailed by the child’s illness or disability. The care allowance may also represent compensation for part of the loss of income the child’s need of care and supervision may entail if a parent must stay away from paid employment partly or entirely.

Like the disability allowance, the care allowance has existed for a fair number of years. It was introduced in 1964 to improve conditions for families with disabled children. Especially noted was that:
...families with handicapped children incur additional costs and have a greater workload than those with healthy children. The load can become unreasonably large and there may be a risk that, for financial reasons, the child does not get the care it needs. [—]. Economic support from the community can enable the parents to use extra help from time to time so that the child’s mother, in particular, may be afforded some relief and relaxation [—] (prop. 1964:94, p. 13).

The purpose of introducing the care allowance was to ensure that the child was really cared for, and also to lighten the care-giving parents’ burden.

The care allowance is one of the benefits calculated using the price base amount (see fact box on page 51). A full allowance is 250 percent of the base amount, amounting in 2002 to SEK 94,750 a year, or SEK 7,896 a month.

The allowance can be combined on the basis of various benefit levels to compensate for care given and for additional costs. There is no lower age limit. From 2003 it is payable until June of the year the child reaches 19.

**Car Allowance (Bilstöd)**

The purpose of the car allowance is to help with the purchase of a car or other motor vehicle for people with disabilities who cannot use public transport. The car allowance can thus be seen partly as compensation for shortcomings in the accessibility of today’s transport services.

The allowance consists of three components: the basic allowance of maximum SEK 60,000, the means-tested purchase allowance, to assist in the financing of car purchase up to SEK 40,000 and the modification allowance to cover the costs of modifying the vehicle to suit the person’s disability. In certain cases, allowance is also paid for the costs of driving lessons. The car allowance is age-limited, partly depending on whether the person is in work.

The car allowance became part of social insurance in 1988. Previously it consisted of two support forms, a tax relief system administered by the inland revenue and a system of assisted car purchase for which the public employment services were responsible. These two forms were intended only for disabled people who were, or who after training/rehabilitation could be expected to be, established in the labour market. This was criticised, chiefly by the disability movement where it was considered that car allowance should be available not only for the gainfully employed but for other groups of disabled people as well (prop. 1987/88: 99).
Combined with a desire for a simplified organisational structure, this led to presentation by the Government, in February 1988, of a new car allowance scheme. The purpose was partly to give more people the right to car allowance and partly to improve the actual support by simplifying it through increased coordination. The latter was achieved chiefly by gathering the components of the allowance under the social insurance system, in practice the social insurance offices. The decision for the allowance to be handled by social insurance was not self-evident, several of the instances consulted making suggestions as to which authority it should come under. Some saw the allowance as closely connected to the transport service, at least in its intentions, so that the municipality should be responsible. Others considered that the social insurance offices should handle it, as finally became the case.

There were two reasons for placing the administration of the car allowance with the social insurance offices. First, the Government considered that the social insurance offices had good knowledge and experience of the type of assessment the car allowance could involve, and secondly it was assumed that the majority of the groups to be considered for the new support were already known at the insurance offices, e.g. through the administration of disability allowances, disability pensions and care allowances.

In connection with this reform the national authorities stated that “A well-functioning car support system is of great importance in disability policy. Access to a vehicle not only improves disabled people’s opportunities to take their place in working life. The car can also contribute in other respects to disabled people living active, self-sufficient and independent lives” (prop. 1987/88:99, p. 13). Thus the purpose of the car allowance is fully in line with the endeavours of disability policy.

**Assistance Allowance (Assistansersättning)**

Introduced in 1994, the assistance allowance is the youngest of the four special support types. Its purpose is to make it financially possible for people with severe disabilities to appoint, themselves or through a provider, a personal assistant. The idea of personal assistance is to create support as far as possible adapted to the individual and to optimise the person’s influence over how the support is arranged. This is often achieved by, for example, the person himself or herself being the assistant’s “supervisor”. The target group for the assistance allowance is the same as that for measures under the LS Act (see fact box, page 51).

The allowance is granted in the form of a number of assistance hours which the person may use within a certain period. In 2002 an hour was worth SEK 191. There is no ceiling, i.e. the number of hours can theoreti-
cally be unlimited where people with severe injuries or diseases may need several assistants at the same time.

The personal assistance measure was created following models from the Independent Living Movement, which started in the USA during the 1970s as a popular movement for people who needed help from others every day. The purpose was to struggle against what was experienced as over-protectiveness and paternalism. In Sweden the movement started in 1984 with the formation of the Stockholm Cooperative for Independent Living (STIL). This movement, among others, started the first experiments with personal assistance, seeking to show that assistance users as a group can be employers and achieve better quality for the same cost as do the home help services (prop. 1992/93:159; STIL, 2002).

The municipality pays for the first twenty assistance hours per week, while the state, i.e. the social insurance system, pays for assistance hours exceeding twenty hours per week. The fact that the responsibility is divided between municipality and state (via social insurance) was naturally a subject for discussion when the measure was introduced. Many of the bodies that were consulted observed that the dual responsibility, with two deciding authorities and two routes of appeal, constituted a risk of complicating the measure (prop. 1992/93:159).

The reason for personal assistance coming under dual responsibility is in fact purely administrative; so that state and municipality shall share the costs. The legislator feared that the scheme would involve very high costs and it was therefore considered important for the state to assume the peak costs of the allowance. Under these circumstances it appeared reasonable for the state portion to be administered through the social insurance offices since it was assumed that they already possessed the knowledge and experience of individual needs assessments through their work with, among other things, the allowances described above (prop. 1992/93:159).

A Logical System?
In the introduction to this chapter the principle of responsibility and financing was presented as the principle underlying the idea that different authorities administer different parts of the support to people with disabilities. The purpose is that people with disabilities should apply to the
same authorities as everyone else in the different contexts, instead of their needs being separated from other people’s.

The emerging picture is one of a support system that appears relatively clear and logically arranged. The municipality, which is closest to the citizen, should be responsible for the citizen’s basic security in the form of support and service. The county council should supplement this by providing expert competence through medical care and habilitation/rehabilitation. In addition, the labour market authorities should employ their competence to make it easier for disabled people to go out to work. Lastly, the social insurance system should provide compensation for the costs that a disability can entail.

But how the system works in practice must be judged in terms of how it helps the people for whom it is intended. Not until this organisational structure is shifted down to the lives of real and actual people can the working of the system as a whole be analysed. In the next section, therefore, the support system will be considered from the perspective of the individual.

The System Seen from the Perspective of the Individual

In the figure below, the operations of the various authorities have been arranged in the actual life of our more recent Olof. What seemed in the previous section to be fairly clear and logical now appears considerably more complicated.

As we have seen, the system consists not only of three responsible authorities; each authority is divided into various sectors. Moreover, certain operations have been added that are outside the respective authorities yet are linked to their support measures. Examples are providers of personal assistance or companies that carry out special modifications to vehicles.
Municipality

Home Adaptations Unit
Occupational therapist
Engineer

Social Services/Disability Care
LSS officials
SoL officials
Transport service officials

Technical Aids
Occupational therapist

Municipal providers
Manager
Staff

External providers
(of e.g. municipal activity)
Manager
Staff

Car adaption firm
Mechanics

Arranger of assistance
Personal assistant
Supervisor

Job Centre
Job centre official
Consultants

Social Insurance Office
Officials (one for each benefit)
Lay board

State

Olof, aged 27, and disabled

County Council

Primary Care
District Medical Officer
District nurse
Physiotherapist

County health services
Specialist physician
Experts
Care staff

Adult habilitation
Doctor
Occupational therapist
Physiotherapist

Technical Aids Centre
Technicians
Advisory officer

LSS officials
SoL officials

Transport service officials

Social Services/Disability Care
LSS officials
SoL officials
Transport service officials

Technical Aids
Occupational therapist

Municipal providers
Manager
Staff

External providers
(of e.g. municipal activity)
Manager
Staff

Car adaption firm
Mechanics

Arranger of assistance
Personal assistant
Supervisor

Job Centre
Job centre official
Consultants

Social Insurance Office
Officials (one for each benefit)
Lay board

State

Olof, aged 27, and disabled

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Primary Care
District Medical Officer
District nurse
Physiotherapist

County health services
Specialist physician
Experts
Care staff

Adult habilitation
Doctor
Occupational therapist
Physiotherapist

Technical Aids Centre
Technicians
Advisory officer
The experience that will be presented here is based on the RfV Study of Living Conditions. One question in the questionnaire ran: “The lines below are for you to describe in your own words what you think is best and worst about present-day support for people with disabilities. What do you consider should be improved?” Of the almost 5,000 who completed the questionnaire, about 2,000 answered this open question. One-fifth chose to describe their contacts with the support system and its officials. The answers included both negative and positive comments, but the negative ones were in a clear majority. The most common comments were that it is hard to find information and that one has to fight for one’s rights. Using comments that refer to people’s experience of contact with the system and its officials, this section will address the following problems:

- It is hard to find relevant information.
- You have to be able to take the initiative and formulate your needs.
- You have to be able to appeal and fight for your rights.
- The system is complicated and bureaucratic.
- Coordination among different authorities is poor.

No attempt has been made to quantify these comments: the material has only been treated qualitatively. Patterns have been distinguished among the comments, and the quotations chosen to illustrate our reasoning are representative of a fair number of people. While the selection was made among the population of people with disability support from the social insurance system, the findings confirm the conclusions of other studies in the area (e.g. Paulsson & Fasth, 1999; Lewin, 1998 and 1999; Brodin et al., 1998).

**A Question of Information**

One condition for being able to apply for support is knowledge that it exists. The ability to find relevant information is therefore an important quality for being able to share in what the community has to offer.

The Administrative Procedure Act (1986:223) lays down that the public authorities shall provide enquirers with information, guidance, advice and other help regarding the authority’s sphere of activity. Officials of that authority are obliged to help people by informing them of what support the authority can give, and also to assist with application procedures and other matters. This duty to provide service applies only within the particular authority and involves no co-ordinating obligation or more general support.
The municipalities have a more explicit duty to actively inform residents about the support that they provide. However, evaluations indicate that this is not being carried out to the extent laid down in the legislation (Socialstyrelsen, 1997b; Länsstyrelsen Gotlands län, 2001; Länsstyrelsen Jönköpings län, 2000; Länsstyrelsen Skåne län, 1998).

The social insurance system boasts no statutory obligation to provide information unless asked to do so. However a number of social insurance offices run local programmes to spread information on social insurance benefits.

Despite the information available (via the Internet, brochures, visits and telephone calls) many studies show that people with disabilities often lack knowledge of their own rights, and that it may be hard to find one’s way among the various authorities (RFV, 2002a; Lewin, 1998). A study of the circumstances of families with disabled children shows that many parents are unaware of their legal rights (Lärka Paulin et al., 2001; also Brodin et al., 1998).

The difficulty of getting information about the various support measures for which people with disabilities can apply is confirmed by the participants in the RFV Study of Living Conditions. The same goes for people who considered they have satisfactory support from the community. People feel they cannot rely on the authorities to volunteer relevant information; they must themselves actively seek information the whole time:

I’ve had to ferret out my better technical aids myself, and nag until I got a modified shower, for example. Nobody automatically tells you what’s actually available. If you suddenly get disabled […] like I did, it’s a whole new world you’re chucked into.

I’m afraid you have to find out everything yourself and keep at it. You haven’t always the strength for this, so your everyday life gets worse.

The dispersal of support among the different responsible authorities is reflected in the information they put out. It is obviously more complicated to find information about what support may be available in a particular case when different authorities are responsible for different measures,
and hence for information about these. This dispersal also makes it hard to gain an overview of the system. One person expressed it like this:

... for us the social apparatus is a maze we mostly get lost in and give up. Perhaps that's the purpose?

Since knowledge of what is available is a precondition for being able to apply for support, it is important that the information is disseminated effectively. Otherwise there is a risk that people who are good at finding information get more satisfactory support than others. People's opportunities for seeking information and easily grasping how the support system works must therefore increase.

**Getting Information – a Matter of Luck**

Information on the various forms of support reaches people in a fairly random manner. Pure coincidence may be what causes a person to find out about an allowance he or she can apply for. Information is most often passed on by the disability movement or spread among people who are in similar situations. This phenomenon has been noted in research and investigations (e.g. sou 1998:48; Paulsson & Fasth, 1999). RFV has noted this, too, both through its contacts with the disability movement and through comments in the questionnaire study:

*I had my disease for five years before I found out (from an acquaintance) that you can get compensation for the special diet and car allowance.*

*I honestly had no idea what the community does for us who have various types of disability, and what kind of support. I was nearly thirty before I was told by my oculist that I could go on a course for people with poor sight, that there was a transport service. [...] You have no idea of what support is available when nobody tells you anything.*

*I hardly know what is available apart from the car allowance I got (not without discussion, last time). Have never got any information from anywhere about this (or other possible support).*

An RFV interview study of parents of children with disabilities confirms this picture. Many parents tell of the difficulties of finding information on support measures for their children. It emerges from the material that it is common for parents to get the information by hearsay, or that other parents tell them what support one can apply for (RFV, 2002b).

Chance is not a reliable bearer of information, and it is therefore disquieting that chance should decide whether a person may get to know
about a benefit. This may entail some people not getting the support they need.

**Is the Information Available to the Target Group?**

Obtaining effective support often requires both good access to information and opportunities to assimilate it.

Getting information from different authorities has become easier in one way. Using new technology, many authorities today have their own home page where citizens can get information, download a form and e-mail the authority. To some extent one can now conduct one’s affairs with some authorities directly through the authority’s home page. For example, many people can now file their income tax returns entirely electronically. In the social insurance system, too, a number of electronic services have been developed and more are on the way. In addition, various forms of voice-activated talking-telephone system are making it easier to exchange information with the authorities.

The new information technology is normally viewed as both an opportunity and an obstacle for disabled people. Interactive computer services have had positive consequences for many groups of disabled people but at the same time brought new obstacles for others. One example is the design of web sites which, if incorrectly designed, can cause much trouble for visitors with impaired vision. People with visual disabilities can use special aids to have the home page text read out using synthetic speech. However, since this applies only to text, all pictorial information is lost. It is therefore important that home pages are so designed that everyone, whether disabled or not, can take in the information and use all the interactive services.

It is possible that information about social support is already sufficient, but since the people for whom it is intended feel otherwise, there is reason to wonder whether the form of the information is right. First, the issue of accessibility in the new information technology must be solved. Here among other things,
the Swedish Disability Institute (Hjälpmedelsinstitutet) has produced guidelines and advice on how to develop accessible home pages. Secondly, the majority of today’s information operations presuppose that interested parties themselves take the initiative and contact the authorities. This is an important precondition for individual self-determination, and one that probably works for most people. But there’s also a catch: not everybody has the necessary initiative.

**Taking the Initiative and Formulating One’s Needs**

Contacting the authorities is seldom an attractive pastime. Much paperwork, complicated rules and difficult questions are to be expected. The majority of us have dealings with officials from time to time. It may be about a building permit or other less weighty matters. The contacts are often fairly brief and about a specific issue. For many people with disabilities, however, contact with the authorities can involve a long-term relationship and be of great importance to the person involved. The number of contacts also distinguishes disabled people from other citizens.

The goal of disability policy is for the individual to be supported as a citizen, i.e. afforded the same conditions as everybody else. The notion of citizenship infuses the whole application process: all support should be given and planned on the basis of the applicant’s wishes, and the community should not make a contribution until the applicant requests one. This is one theme of disability policy in its endeavour to strengthen the individual. Hence, the community should not step in until the applicant has taken the initiative. In this way, individual integrity is reinforced as well as self-determination. This focus on individual initiative is sometimes termed *individualisation*.

Similarly, official dissemination of information presupposes personal initiative. This is by no means unintentional since, when it works, it means that the person contacts the authority when he or she needs help, rather than the authority intervening when someone is considered to need assistance.

The 1994 disability reform, in particular, is often held up as an example of how in recent years disability policy has stressed individual initiative as the deciding factor in whether support should be granted (Barron, Michailakis & Söder, 2000; RFV, 2002a).

However, Lewin (1998) considers that people with disabilities are not always as forceful about applying for support as the legislation assumes. There is a lack of knowledge of one’s legal rights and it is hard to find one’s way about in the bureaucratic jungle. An important conclusion of Lewin’s doctoral dissertation is that people who can handle
the encounter with authorities – or those whose representatives can – have better chances of getting support.

The **rfv** Study of Living Conditions shows that many people feel that the ability to initiate contacts with the authorities, and to use the right language, are valuable qualities for getting the support one needs.

> You have to be very pushy. Nothing happens unless you find out yourself what you’re entitled to.

> If you yourself can manage to contact the authorities and can find out what your rights as a disabled person are, I reckon that on the whole today’s support functions pretty well.

> I’m verbal, thank goodness. But what about all the people who aren’t? It must be terrifically difficult.

**Appealing and Fighting for One’s Rights**

The Report on Service to People with Disabilities (**sou** 1998:48) is the result of a Government study of how people with disabilities experience attitudes among and treatment by the local government employees they encounter. The report noted that people with disabilities, or their relatives, often feel they are being checked up on and doubted in their contacts with the system. One has to argue and appeal to get the support one needs. This conclusion has been confirmed in several reports (e.g. Paulsson & Fasth 1999; **rfv**, 2002a; **rfv**, 2002b; Tideman, 2000).

According to some people, it has become harder to obtain support measures as a result of the lean years of the 1990s (e.g. **sou** 1998:48).

This is confirmed in **rfv** contacts with representatives of the disability movement, who discern a tendency for officials to make more restrictive appraisals, even though neither legislation nor practice has changed.

In an attempt to quantify whether one has to fight for the right to help, the **rfv** Study of Living Conditions included the following statement: “Disabled people must struggle to get the support they need”. Answer alternative 1 signified “Do not agree at all” and 5 “Agree entirely”. As many as 85 percent marked 4 or 5, thus agreeing with the statement. This signifies a striking conviction that a person’s ability
to fight for his or her needs is a condition for obtaining sufficient support. As the following table shows, the result was about the same regardless of sex or disability.

<table>
<thead>
<tr>
<th>Disability</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital or acquired before age 16</td>
<td>83.7</td>
<td>82.2</td>
</tr>
<tr>
<td>Acquired after age 16</td>
<td>82.9</td>
<td>83.7</td>
</tr>
<tr>
<td><strong>Sensory disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital or acquired before age 16</td>
<td>81.9</td>
<td>87.1</td>
</tr>
<tr>
<td>Acquired after age 16</td>
<td>85.2</td>
<td>84.0</td>
</tr>
<tr>
<td><strong>Intellectual disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital or acquired before age 16</td>
<td>84.2</td>
<td>84.8</td>
</tr>
</tbody>
</table>


The figures in the table also find expression in the respondents’ comments:

*The way things are today it’s always the people that shout loudest that get help and support.*

*Sometimes you just want to give up [...] instead of bashing your head on the social insurance office door till you bleed.*

The questionnaire material does include people who report that they have never experienced problems of getting support. However, there are strikingly many stories about the struggles people have to get the support they need and are entitled to. Even people who say they have good help tell of the arduous path they had to follow to get it.

*Things are mostly fine now in our case. But we’ve had a hard fight to get here. The social insurance office was a real brake pad when it came to applying for personal assistance. The worst thing about support today is that you have to fight to get it. Once you’ve got it, you’re laughing.*

Leaving aside the fact that the need to fight and appeal was a strain, many people stated that it was hard to be a burden on the community by receiving support. This may be because we live in a society that honours self-sufficiency and independence; but it can also be a consequence of the feeling people have of being mistrusted. Nagging to get help is felt as demeaning. Many respondents wrote that they feel they were being
called into question when they keep having to appeal against an official’s
decision and fight for their rights.

I think it’s a pity you have to NAG your way to get any help. Fill in
thousands of forms lots of times and explain and apologise for wanting
this help even though I really need it. You feel you’re a sponger and it’s
as if society assumes you want to con them into giving you stuff.

In a questionnaire survey of disabled children’s parents, the Swedish
National Association for Disabled Children and Young People (SBU)
showed that 50 percent of the families had appealed at least once against
an official decision. Of these, 60 percent stated that the decision was
altered partly or entirely according to their wishes (Paulsson & Fasth
1999). That people in fact get their way after an appeal risks implying
that the officials are ignorant and unsympathetic. It may also confirm
the view that people have to struggle to get the help they need but are
also entitled to. In the SBU Study of Living Conditions, too, some stated
that the road to support often runs via a court of law:

I didn’t give up, I appealed several times and the social office finally
had to give in.

All authorities assume you’re trying to wangle help for yourself. Often
have to appeal to get car allowance, parking permit and things like
that. What’s the point of this for people who’re never going to get
better?

Equal Opportunities to Apply for Support and Fight for One’s
Rights?
Looking for information, taking the initiative and fighting for one’s
right to support makes great demands on personal resourcefulness. This
quality will be required even in an accessible and adapted community. If
the availability of support is conditional upon personal resourcefulness,
it is important to ask whether everybody in fact has equal opportunities
of applying for support and arguing for their rights.

One way of measuring this resourcefulness more quantitatively was
to ask the following question: “Would you yourself be able to write a
letter appealing against a decision by an authority?” Statistics Sweden
has used this question in its ULR survey among the population since the
beginning of the 1970s. The same question was asked in the SBU Study
of Living Conditions. The table on page 65 shows a comparison between
the respondents’ potential to write the letter required to appeal against a
decision and the potential of the total population. Once again logistic
regression, the method presented on page 29, is used.
The table above shows that the people with disabilities judged their ability to appeal against decisions to be less than that of the total population. This was true irrespectively of kind of disability and of whether the disability was congenital or acquired. Since the probability is extremely low for persons with intellectual disabilities, it is important that there is a relative or a trustee who can appeal against possible refusals to grant support.

Thus disabled people, who one would think have the greatest need for this potential, clearly have less access to it than the population at large. At first sight the survey question perhaps seems to measure mainly a personal quality, but environmental factors may also be involved. For example, a person who cannot see cannot assimilate decisions and written communications produced by the authorities in ordinary print on paper.

Possession of this quality of resourcefulness may also be affected by other factors. Level of education and country of birth are two factors worth mentioning. Education increases the ability to express oneself and to benefit from information. The RFV study notes that possession of this quality is clearly influenced by educational level. For people with higher education, 82 percent stated that they could appeal against an official decision, compared with 34 percent for people with comprehensive-school education or equivalent.

Being born in a different country may occasion language problems and difficulties in handling the Swedish administrative structure. In the RFV study, country of birth also had an effect. Twenty-nine percent of...
people born outside Europe stated that they could manage to appeal against decisions letters, while for those born in Sweden the corresponding proportion was 45 percent. Thus education and country of birth can both act to widen the differences indicated in the table above.

**Do Personal Qualities Influence the Support Given?**

In the previous section we saw that a person must possess certain qualities and resources to manage an application for support. The question is whether this really matters. It is in fact possible that personal qualities do not affect the support granted; that people who lack the necessary qualities themselves have relatives or a trustee who can assume the active role the person is expected to play.

Some of the participants in the *RFV* Study of Living Conditions stated that their ability to find information and to stand up for their rights affected the benefits they have today. This connection can be tested statistically. In the following table the proportion who could write the letter necessary for appealing against a decision is compared with the proportion who stated that they were satisfied with the support given them by the community.

<table>
<thead>
<tr>
<th>Sufficient support?</th>
<th>Can you appeal against a decision</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Women</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>64.4</td>
<td>35.6</td>
</tr>
<tr>
<td>No</td>
<td>50.3</td>
<td>49.7</td>
</tr>
<tr>
<td><strong>Men</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>57.3</td>
<td>42.7</td>
</tr>
<tr>
<td>No</td>
<td>44.5</td>
<td>55.5</td>
</tr>
</tbody>
</table>

Differences tested with Chi² test. Confidence level 95% (p<.05).


**Connection between considering one has sufficient support and the ability to appeal against decisions.** Percent.

The table above shows a significant connection between the ability to appeal against a decision and the feeling that one has sufficient support. Proportionally more people able to appeal against a decision were satisfied with the support they got than were people who were unable to appeal.

The purpose of the support for people with disabilities is to strengthen them in their role as citizens, to give them the same potential for self-determination, the same conditions of life and participation as all others have. But the path to these support measures appears to require
that applicants be familiar with what support is available; they must know which authority to apply to, be able to formulate their needs, to argue and to appeal when support has been refused.

Possession of these qualities varies, among disabled people and the general population alike. For people with disabilities, however, the problem may be more serious since the support is important for their ability to live like other people. Thus there is a great risk that the fine idea of shifting the perspective from care of a patient to support of a citizen will not be realised for everybody if even the application process demands the very resources the support is intended to provide.

**Complicated and Bureaucratic**

Part of the problems described may be linked with the complicated and impenetrable regulations. The feeling of having to fight for one’s rights also appears to relate to difficult rules and a bureaucracy whose workings are unfathomable.

If one doesn't fit into the “patterns” they use in their work, then it’s very hard to get their support and also at the same time to understand their odd reasons for the decisions they make.

The actual needs of people with disabilities should be what counts, not the rigid rules created by “healthy” people.

Benefits a person is already receiving must be reviewed at regular intervals. For personal assistance allowance the review is statutory, but RfV also recommends that the social insurance offices follow up certain other benefits regularly. The reason is that the recipient’s medical and functional state may have altered for the better or for the worse, and also that his or her situation in general may have changed in ways that affect the entitlement. Every time a benefit is reviewed, a medical certificate is required. People whose impairment is irreversible experience this as extremely frustrating.

Now they require medical certificates and they always have to be on special forms = lots and lots of visits to the doctor and they all take time.

If you do finally get a benefit, the procedure has to be repeated at regular intervals to prove that a “medically irreversible” condition hasn’t gone and got better.
Many of the authorities that handle support for people with disabilities collect respectable amounts of information about their clients. Not infrequently, the same type of information – e.g. medical opinions, particulars of help required – is collected independently by the different authorities. One way of simplifying matters for the individual would be for the authorities, with the individual’s consent, to make better use, both internally and between them, of existing information rather than burdening him or her by repeating questions already asked somewhere else.

**Lack of Coordination among Authorities**

Bureaucratic organisations handle large numbers of applications. Each case has to take the shortest possible time. Hence, each authority is interested only in the information relevant to the case in question. But people are complex beings made up of personality, experience of life and a social context. Before an authority can help, an individual has to be transformed into a client. This is done by seeking only the information needed for solving the task at hand. The tax authorities create taxpayers with their forms, hospitals create patients with their questions about symptoms and their examinations, and in the social insurance office, “the insured” is created by asking for certain information relevant to the handling of a particular allowance (Lipsky, 1980; Johansson, 1992).

In other words, efficiency and specialisation rule. While dispersal of support among different authorities may find some confirmation in these theories, this dispersal means in practice that each authority is interested in a small piece of a person. Nobody has an overall view of the person’s total circumstances.

*I lack for example an overall view in the care services. Now you have to run around from place to place and be "a gastric case", "toothless", "stiff in the joints", "depressed", "lonely" and "poor" at the different care providers’ instead of being a whole person.*

If the system is to work for the individual, the various authorities have to cooperate. If they do not, there is a serious risk that the individual will fall between two stools. Many of those in the RFV Study of Living Conditions expressed this.

*The authorities pass the buck to each other, hoping if possible to shift the responsibility onto someone else.*

*I’ve got stuck between the various authorities [...]. They’ve sent me back and forth between the different authorities.*

*Nobody has any responsibility for me, they all send me on to someone else.*
The problem of “buck-passing” was also touched upon in the questionnaire underlying the **RV** study. Respondents were asked to react to the following statement: “Authorities try to shift their responsibility onto somebody else”. Just over 68 percent of the respondents (71 percent of the women, 65 percent of the men) agreed. Thus this view is evidently fairly widespread among the study participants.

The need for coordination is by no means new. As early as in 1964, the Social Policy Committee noted that:

*There is an evident need for better coordination [...]. Not least, it is urgent to arrange simple contact with the organs of the community for those who specially often have great need for support from society in various situations* (SOU 1964:43, p. 116)

Much of welfare legislation, including the National Insurance Act, the Social Services Act, the Health Services Act and the Act on Support and Services for Certain Disabled Persons (the **LS** Act) provides that the different authorities should collaborate over support for people with disabilities. However, there is a risk that the talk of collaboration remains a paper tiger. Good cooperation leads to a smoothly-working solution both for the individual and for the authorities, while poor cooperation places the individual in unnecessarily difficult situations.

*I have no problems in finding out what my rights are, but can sometimes get tired of all the different authorities responsible for different benefits. It takes a deal of time and energy to get things working normally.*

*Coordinate all different types of contribution [...] The least little change in my simple finances and all the authorities must be contacted, new forms filled in ad absurdum.*

The dispersal of support among different authorities means that many different contacts must be established and maintained with officials at the different offices. This section opened with a figure illustrating the contacts a person with a disability may need to make with various authorities. The figure indicates the extent of the coordination the individual may have to undertake.

It may sometimes be good for the individual to coordinate a complex support apparatus. This may give a feeling of control and an overview of the situation, avoiding entire absorption by the interventions and authorities. But most people would probably prefer a less complicated coordination process, and some might be quite happy without the responsibility that coordinating their benefits involves.
There exists today an important tool for coordination. This is the individual plan to which people in the LSS target group are entitled. The plan is a method of planning the measures the individual needs irrespective of which authority is responsible. It enables the authorities to collaborate so as to achieve the best possible result. According to the LSS Act (prop. 1992/93:159), the person should, via the individual plan, be given influence and an overview of the different benefits. The plan should be designed to permit follow-up and alteration and, if the user so wishes, should serve to combine the various areas of competence and activity. Thus both county council and social insurance office can participate when the applicant wishes to draw up an individual plan. But the municipality is the responsible body for coordination of measures by the various authorities.

The recent evaluation by the National Board of Health and Welfare suggests that an individual plan, correctly used, is a useful instrument for guaranteeing the individual’s influence on the various measures granted. The Board’s evaluation also shows, however, that the plan is by no means used to the extent desired. Only five percent of beneficiaries under the LSS Act have individual plans (Socialstyrelsen, 2002c). Yet correctly used, and for a larger group than at present, individual plans can be an important instrument for reinforcing the individual’s standing and providing an overview of the responsibilities of the authorities involved.

**Not Just Swedish Problems – an International Glimpse**

The problems described do not exist only in Sweden. Support systems are often vertical structures and do not always function so well for the individual. Many countries are struggling with the consequences of sectorised welfare systems. In the USA, people say their support system looks like “smokestacks”.

Since the problems exist in other countries, too, it is fruitful to examine how they have handled them. Presented below are some examples of solutions adopted in various countries. The presentation is a selection rather than a full description of existing measures. The measures considered here are coordination of information, service declarations, Legal Rights Centre, User Support Centre and personal representatives.

**Coordination of Information**

The previous section showed that the structure of the social support system hampers people’s opportunities of obtaining information on the support for which they may be eligible. An important method for simpli-
fying the gathering of information is therefore to coordinate its dissemination. This solution is used in many countries, often with the Internet as medium.

Examples are New Zealand, Canada and Great Britain, where the governments have collated information on support programmes in a joint home page covering both national level and local level. This makes it easier for the population to acquire information on what support may be appropriate and which authority is responsible for it. In Great Britain the government has launched a home page to offer citizens easily-accessible information and service. The home page contains information arranged by the different stages in life people may be in, e.g. if one is to leave home, apply for a job or have children (www.Ukonline.gov.uk, 2002).

Apart from the information sources intended for the whole population, many countries have collated information aimed specifically at people with disabilities. An example from Canada is the Internet page Disability Weblinks, intended for people with disabilities who need support and service. Disability Weblinks is run in cooperation among the ministries responsible for disability issues at provincial, territorial and federal levels. It is intended to act as a window outwards towards users, and to give information on subjects such as accessibility, education and training. As well as this information, the Web visitor can find out what the country’s various disability organisations are and in this way learn more about what support is on offer (dwl, 2002).

In the USA a solution called One-Stop is based on personal meetings. Instead of the person needing to contact several authorities, he or she can visit a One-Stop where a coordinator collects information on what measures can be appropriate in that person’s case. The operation is not yet fully developed but the idea is that every sizeable town and city in the USA will in the long run have this type of operation (Zeitzer, 2002).

In Sweden, several information sources coordinate the dissemination of information. At national level there is the Citizen’s Guide (Samhällsguiden), intended among other things to increase people’s knowledge of their rights. It also contains information on the support various authorities offer people with disabilities (www.samhällsguiden.riksdagen.se).

In addition there is the Disability Ombudsman, a state authority that watches over disabled people’s rights and interests. One can apply to the Ombudsman if one feels discriminated against because of one’s disability. The authority’s lawyers can, moreover, give information on rights, laws and regulations. The Disability Ombudsman can also give advice on how to appeal against an official decision.
Local initiatives also operate. Stockholm County Council operates the Disability Information Centre (Handikappupplysningen), an assembly point for information on the support administered by various authorities. The Centre disseminates information by answering telephone enquiries and also through its home page. At the home page one can also see what rights people with disabilities have and what legislation governs these (www.hu.sll.se).

**Service Declarations**

The social insurance offices in Norway have developed a “service declaration” to give better and clearer information and service. The declaration gives binding information on the insurance offices’ offering of services and on the levels of these services. A service declaration can for example contain information on processing and waiting times, whether the service can be performed via the Internet and how people can put forward complaints and views (Rikstrygdeverket, 2001).

Like Norway, Great Britain uses service declarations to show what people with disabilities can expect in their dealings with state authorities, what the national organs can do for private people and how to appeal. Jointly with disabled people, disability organisations and colleagues in the social insurance system, the British Department for Work and Pensions has also produced service declarations. It is intended that they should be reviewed annually to maintain levels and standards (Service Dialogue Project, 2002).

Work on service declarations in Norway and in Great Britain has been going on for a fairly short time, and the projects have not yet been evaluated. General advantages of the declarations worthy of note are that they give straightforward and clear information on the authorities’ service and disabled people’s rights. This more citizen-oriented organisation of the administration might entail all parties knowing what is expected of them. They can then start from a common basis of information. A person with a disability wondering about a specific issue can first gain a general picture from the service declaration before consulting an authority.

In Sweden, work on service declarations is still at the project
stage. Together with a number of social insurance offices, RFV has started a service dialogue project to be evaluated in December 2002. This project applies not only to people with disabilities but all consumers of social insurance. Its purpose is to examine whether service declarations are an effective way of improving the authorities’ service so that it is more in line with citizens’ needs and to increase public knowledge of and participation in how the administration works (Servicedialogprojektet, 2001).

**Legal Rights Centre**

The disability movement in Norway has drawn attention to problems and shortcomings in how the authorities handle disabled people’s rights. In 2002, to support its members in e.g. legal matters, the disability organisation Funksjonshemmedes Fellesorganisasjon (FFO), acting on a commission from the Ministry for the Social and Health Services, started Rettighetssentret (the Rights Centre), for people with disabilities. The project is to continue for three years and the centre aims to give concrete expert advice on the current legal position of disabled people and to make its knowledge available to authorities and disability organisations (FFO, 2002).

Experience of Rettighetssentret shows that the need for help and support regarding legal questions is great. The FFO considers that this is because public information is not sufficiently accessible to disabled people and that the distance between the public administration and citizens is too great. Most of those who use Rettighetssentret have disabilities themselves, or children with disabilities. Every enquiry is registered so that, in discussion with the public administration, the centre will be able to present problems relevant to the development of disabled people’s rights and disability legislation. Matters handled include social insurance, finances and work (FFO, 2002).

Sweden has some legal rights centres at local level. In Stockholm **bosse** Råd, Stöd & Kunskapscenter (**bosse** Advice, Support and Knowledge Centre) exists to give people with disabilities greater chances to run their own lives. The service is financed largely by the Stockholm County municipalities and partly by the County Council. **bosse** staff themselves have experience of disabilities and may give active support, for example when a person wishes to change his or her situation. The starting point is always the individual’s own initiative and wishes. Where needed, **bosse** can help with the contact with officials at the different authorities and appeals against a decision with which the person is not satisfied. A similar operation in Göteborg is run by the LaSSe assistance cooperative.
In addition, the Disability Ombudsman’s office gives information on disabled people’s rights and on what laws and regulations apply. The office also has lawyers who can advise on e.g. how one can appeal.

**User Support Centre**

The Commission on Service to People with Disabilities (Bemötande-utredningen) proposed in its final report (sou 1999:21) that what was to be named a User Support Centre should be established on a trial basis. User support has its base in the disability movement even though it can be financed through state funds. The Commission stressed that the support should be personally designed with a wide range of measures, from simple information to legal aid. Its purpose is to strengthen the individual’s standing in, among other things, contacts with the various authorities.

The Commission also stressed the need for those who give the support, or at least a majority of them, to have disabilities themselves.

The Government bill “From Patient to Citizen” (prop. 1999/2000:79) took up the Commission’s idea and proposed the establishment of a trial User Support Centre financed by donations from the State Inheritance Fund. To develop the idea of user support the Government decided in December 2000 to allocate SEK 30 million from the State Inheritance Fund over three years.

**Personal Representative**

A further example of an attempt to strengthen the individual in relation to the authorities is the personal representation scheme. In Sweden, this measure is only available to people with psychological disabilities, to help them to make contact with various authorities and request support, and also to achieve coordination of the various measures the authorities grant.

With the reform of the psychiatric services in 1995 it was noted that people with psychological disabilities needed this help to make contact and to achieve coordination. It was assumed that these people, often with a long stay in an institution behind them and complicated psychiatric problems, would need resources from various authorities if an integrated life outside the institution was to function. The resources had to be coordinated.

The USA was ahead of Sweden in the running-down of large mental hospitals. The Americans, too, had noted the need for coordinated measures to ensure that the former patients would be able to function outside the institution. In the USA this coordinative function was called the Case Manager. The Commission on the Reform of the Psychiatry Services...
judged that this type of measure was also needed in Sweden, for which reason it sketched a new form of support for the psychologically disabled with the same purpose as the American case management concept. This role the Commission termed personal representation.

The Government viewed the proposal favourably and introduced the measure through the “Circumstances of the Mentally Disordered” bill (prop. 1993/94:218). For the first three years (1995-1998) the personal representation scheme was experimental, but it has been permanent since the latter half of 2000. The Government earmarked SEK 90 million for the scheme for 2002.

The municipalities are responsible for the scheme. However, the individual has no legal right to a personal representative. She or he can therefore be refused the measure with no right of appeal to an administrative court. It is clear from the description that the applicant’s psychiatric problems must be extensive. Thus the scheme is not completely open to all who have psychological disabilities.
Dilemmas of Disability Policy

The overall theme of this book is the difference between ideals and reality. In the first chapter, the notions of integration, participation and equality of opportunity are set against the actual living conditions of people receiving social insurance support for disabled people. In the second chapter, notions of the individual as strong and the system as logical are set against the picture of a maze where one has to fight to get support. Clearly, there are great differences between theory and practice, where fair words do not always apply the whole way to the individual’s real situation.

Disability policy is in many ways contradictory, with many dilemmas. What marks off a dilemma, according to Jerneck, that “two or more objectives cannot be achieved simultaneously, or that available courses of action are irreconcilable. In the latter case, the strategies may counteract each other or have unintended effects” (Jerneck, 1986). Hence the problem may perhaps never be resolved satisfactorily.

Common to the problems described in the first two chapters of this book is that they lack simple solutions. In this third chapter, instead of trying to present concrete proposals for what ought to be done, the dilemmas of Swedish disability policy will be discussed further. These dilemmas represent important theoretical points of entry to any discussion of changes in the support system.

Disability Policy Addresses a Heterogeneous Group

To speak of “people with disabilities” may suggest a homogeneous group with common needs and experience. Social Insurance in Sweden 2002 has shown, however, that different disabilities give rise to different needs and different contacts with the community. In fact, recipients of social insurance support show a very great range, as do the factors that have caused their disabilities. Here it is very definitely the case that “each person is unique”.

As in all political activity, disability policy must to some extent be designed following general – and generalised – descriptions. Hence today’s disability policy and goals are inspired largely by a generalised view of disabled people. Where goal and policy formulation are con-
cerned, this is a reasonable approach: the policy goals presented in *Aims and Achievements* are valid for everyone with a disability.

And yet the methods and means for attaining the goals of disability policy must become significantly more sensitive to the heterogeneity of this target group. In some cases, it is chiefly the lack of accessibility that encroaches upon disabled people’s potential to live as others do and to share in community life. In others, the need is largely for support from another person. Ongoing work towards an accessible society and the attainment of Sweden’s disability policy goals should therefore include the search for unique solutions to unique needs rather than trying to find universal solutions. Entry to the labour market, for example, may for some people be via higher education, while for others it may involve training, or the creation of a daily occupation that resembles gainful employment.

**Principles for the Right to Benefits**

One dilemma concerns the choice of strategy for who should receive the support the community provides for people with disabilities. Even in a wealthy society such as Sweden’s, resources are limited and there are many demands on the nation’s tax revenues. In addition, the ageing population and the low birth rate are expected to place strains on the welfare state during the next few decades. This prompts discussion on how the benefits should best be distributed so that they may continue to serve their purpose and be of real help.

There are several possible strategies for designing the actual support system. One conceivable starting point for discussion is to place the extent of the support in relation to the size of the target group. These two aspects are compared in the following model.

<table>
<thead>
<tr>
<th>Limited target group</th>
<th>Broad target group</th>
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<tbody>
<tr>
<td>Restrictive support</td>
<td>Little support to few</td>
</tr>
<tr>
<td>Generous support</td>
<td>Much support to few</td>
</tr>
</tbody>
</table>

*Theoretical model of relationship between the generosity of a support system and the size of the target group.*
With limited resources, much support to a broad target group is not a realistic alternative. Nor is little support to a limited target group desirable in a relatively rich country, such as Sweden. Instead, much support to a limited target group is placed against little support to a broad target group.

The advantage of covering a broad target group is that the support benefits many people. In terms of resources, however, the danger is that such a system gives each person a small amount, there being no real effect for anyone. The purpose of giving such watered-down support may be questioned. A system of this kind also has very negative effects on the people who most need the support.

There remains generous support to a limited target group, which is probably the most practicable way in tomorrow’s welfare society. By limiting the target group to those with the greatest needs, the system is better able to give a real effect, compared with distributing scanty resources over too broad a group of people.

A system with a narrowly defined target group, however, gives marginal effects where the support to those admitted to the system is markedly greater than that to those who remain outside. Wherever – or however – the line is drawn, there will always be people who come near to it but on the other side. This requires that there be more general support, albeit less comprehensive, for people with smaller needs.

State resources, and municipal and county-council ones as well, are limited, and it is important that they be used effectively and for high-priority groups. This is indeed part of the task the Swedish people have laid upon the public authorities. There are also other reasons for contemplating a limited target group rather than a broad one: the way the group is defined may possibly be significant for the legitimacy of the system and consequently public willingness to finance it. In other words it is important to choose a strategy that gains legitimacy among a large majority of the people for them to be willing to pay for it.

**Selective Support – a Condition for Integration**

The goal of disability policy has long been that people with disabilities should be integrated in the community, on the same terms as other people. However, as the chapter *Aims and Achievements* shows, much remains to be done before equality in living conditions between disabled people and the rest of the population is a fact. People with disabilities have
lower educational levels and are less well established in the labour market. In addition, financial insecurity is fairly widespread among them.

For many people with disabilities the greatest obstacle is poor accessibility, which hinders both study and work and participation in community life in general. For this group, adaptation of the physical and social environment is a perfectly sufficient measure for achieving integration.

For others, further measures may be needed for them to achieve the same living standard as others. Selective measures aimed at a well-defined group become a condition for attaining a fully integrated society. Home adaptation, for example, is a must for people with severe disabilities to be able to live and function in their own homes. Selective measures can include certain financial maintenance and practical help with everyday life.

Integration and participation can be achieved through living and moving about in the community, but also through education, work or other meaningful occupation. The results of the RFV Study of Living Conditions 2002 shows, however, that much remains to be done to make another giant leap towards the goal – integration through work on the open labour market or with some other form of suitable occupation, preferably at an ordinary workplace.

The large numbers of people in Sweden – about 450,000 – who receive disability pension suggests that the mechanisms that eject people from the labour market, or prevent them from entering it, are themselves a problem. It is easy to think that many of these people could make valuable contributions if the working environment or working conditions in general looked a little different.

Much can be done to improve labour-market attitudes towards people with disabilities, but such change takes time and probably does not offer the straightest of paths. Economic conditions, social development and altered values can change attitudes for the better and for the worse. Yet relying on a slow change in attitudes is an unenterprising policy, and more aggressive selective measures, for example affirmative action, are probably called for. Perhaps this is a must for tackling some of the problems voiced by the respondents in the RFV study.

The issue of affirmative action is fraught with dilemmas, such action often being rejected as unfair. It is not all that simple to decide who should receive it. It can be
argued, however, that people with disabilities are suffering from discrimination and that a quota system would be one way of ensuring a fairer outcome. Current differences in living conditions between disabled people and others are hardly fair. Moreover, there are socioeconomic gains to be made, since measures to increase disabled people’s establishment in the labour market can in the long run reduce or eliminate dependence on benefits.

It is not certain, however, that affirmative action is the best way of increasing labour-market establishment. And even should this strategy be chosen, many questions remain. European Disability Year 2003 offers a golden opportunity of getting this discussion onto the political agenda.

There are obviously groups that have no possibility of working on the open labour market. Since the right to live as others do remains, these people should be entitled to meaningful occupations that resemble work as far as possible. Under various laws, a limited proportion of Sweden’s disabled people are entitled to join daily activity schemes. However, the right to a meaningful occupation ought to apply to everyone.

For yet another group, neither work nor other occupation is possible. Among the respondents in the RFV Study of Living Conditions were people whose days are spent surviving and whose diseases or injuries require continual life-supporting measures. If work is not an option, financial circumstances should be assured with a disability pension or sickness benefit. Such benefits should never be granted in a routine manner, however, but should always be the last alternative when all other avenues have been explored.

**Strong Individuals or Rule by Ombudsman?**

Under *Authorities and Individuals*, above, the notions of the individual as strong and the system as clear and logical were set against the picture of the system as a maze through which a person has to struggle to obtain support. It was also seen that the individual must possess certain qualities to obtain satisfactory help from the public support system. One needs first to be familiar with what benefits are available and which authority administers the relevant ones. In a differentiated support system it is not all that easy to know where to apply for the right information and the right help.
In practice, this sectorised support system reflects an important theme of disability policy, the principle of responsibility and financing. According to this principle, which tallies well with the concept of an integrated society, people with disabilities should apply to the same authorities as everybody else when they need help. This is an important notion but, as expressed in peoples’ daily lives, it contributes, through those who operate the system, to the creation of an almost impassable jungle.

Much, then, is required of a person who is to find his way around in the system. Here, too, an important principle of disability policy is displayed. This is individualisation, meaning among other things that support is not given until the individual has taken the initiative. This is a very sound and attractive principle for contact between individuals and the world of the authorities, but in practice it seems to demand a very great deal of the individual. From the comments presented in the previous chapter it seems that people with disabilities need to be elite practitioners of the art of citizenship. Somewhat reminds of a David-and-Goliath struggle.

Individualisation and the principle of responsibility and financing are grounded in an ideal conception of the principal operators in the support system and its users. In the best of all possible worlds all the operators would fulfil their duties and do so on grounds that the individual finds easy to understand. Similarly, in the best of all possible worlds the applicant is a knowledgeable, well-informed and energetic citizen who in the space of some few telephone conversations comes into contact with helpful and willing officials.

However, in unedited reality, report is piled on report and testimony on testimony to show that the individual is obliged to fight for the right to support. Moreover, the authorities – who are to implement the right for the disabled individual to live like others do – are not always particularly helpful and, further, seem to have enmeshed themselves in a rule system so complicated that they hardly seem to find their own way about in it. So how can Olof be expected to do so?

Important principles of disability policy have found application in a reality that does not support the conditions the policy requires if it is to succeed, and that, instead, has become a source of problems. But the leading principles of disability policy should still remain the points of departure: there is no way back to a more segregated support system. Integration and self-determination must always be the starting points. It is beyond all doubt that measures of some kind are needed. For the desired ideal to become reality – without the attendant effects described here – the system that realises the aims must be changed.
As shown earlier, a number of measures are already intended to bridge the problems people meet in contacts with the support system. Over and above the measures presented in the international review, others are discussed earlier in this book. They include demands that authorities coordinate their operations, opportunities for individual plans, the authorities’ duty to provide service and the municipal responsibility to conduct outreaching. Also discussed are personal representatives, an activity for the psychologically disabled in which a special official helps the person to find the way about the system and manages his or her contacts with the officials who run the system. Some form of strategy for other categories of disabled people is also conceivable.

Yet the question is whether the individual can be strengthened in other ways than via representatives and ombudsmen. And is it not strange that the system is so complicated that it needs a special professional group with the single task of helping citizens around in the public support system?

The answer to this question is left open. But together with the other dilemmas illustrated in this book, it is clear that our society is not yet fully fashioned, and that it is marked in places by a form of engineering that has not given pride of place to simplicity. More work is needed to ensure that everyone has the same conditions and the same opportunities for participating in community life, whether they are disabled or not. The work and the changes that will be required, however, must be set in hand, with public discussion of our society and how it may best be configured so that all may participate. With Social Insurance in Sweden 2002, RFV seeks to open this important discussion.