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DISABILITY WELFARE JUSTICE

Summary

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Report of the 1989 Disability Commission

Introduction

A special parliamentary commission appointed by the Government is investigating the situation for children, young persons and adults in Sweden with severe functional impairments. The committee has taken the name of the 1989 Disability Commission.

The broad-based membership of the Commission includes representatives of all the parliamentary political parties, the entire disabled movement, the national associations of county councils and municipalities, national authorities and other bodies. Altogether it has 11 members, 14 special advisers and 3 expert advisers. (Further membership details are appended to this report.)

A whole variety of aspects of the living conditions of several disabled members of the community are to be investigated. Where improvements are needed, the Commission is to put forward proposals which will assure persons with functional impairments of effective support enabling them to become full participants in the life of the community.

The Commission has conducted and reported on surveys of the views of both users and mandators of the support and service available to persons with severe functional impairments. The results of ~~questionnaires, interviews, hearings etc.~~ point to critical shortcomings in several respects, not least with regard to the self-determination of individuals, opportunities of occupation and employment, and access to leisure and recreational activities.

In May 1991 the Commission presented its main report, which is entitled Disability, Welfare, Justice (SOU 1991:46). This is the Commission's fourth report summarising a number of interim reports on various subjects. Two further reports are in preparation, one dealing with interpreting services for the deaf, the deaf and blind, the speech-impaired and the hearing impaired, and another dealing with such general issues as the accessibility of media, transport systems etc. The Commission plans to complete its investigations in 1992.

The main report, a summary of which is presented here,

contains specific proposals aimed at eliminating deficiencies revealed by the Commission's various surveys.

The proposals are intended to assure persons with severe functional impairments of individualised support and good service in the community. This means habilitation, rehabilitation, expert measures and technical aids. Proposals are also put forward concerning personal support and better access to occupation, employment, transport assistance, housing etc. The proposals underline respect for the self-determination of the individual and user participation. The proposals are to be put into effect by means of new legislation, changes of mandatorship and financial support.

The following summary gives the main outlines of the proposals.

After the proposals have been circulated for comment, the Riksdag (parliament) is expected to make them a basis of legislation in 1992, after which the new Support and Services (Persons with Certain Functional Impairments) Act proposed by the Commission should be able to enter into force in 1993, together with various other statutory instruments etc.

It should be emphasised in this connection that the Commission is unanimous on all the main issues dealt with in the present report.

For further information, we may add that the Commission, which stresses the openness of its work, presents its reports in several different forms, so as to make them more readily accessible to different groups. This, in addition to the English summary presented here, cassette, Braille and (e.g. for the intellectually handicapped) easy reader versions of the report are also available.

Summary

The remit

The 1989 Disability Commission has had the task of investigating certain aspects of community support for persons with functional impairments. Its main concern has been to chart and analyse measures taken in social services, together with habilitation and rehabilitation. The inquiry has taken as its starting point the situation of children, young persons and adults with extensive functional impairments, and of the small, less-known groups of disabled. The remit stated that, if there were shortcomings in the measures taken by social services and in habilitation/rehabilitation inputs, the Commission should put forward proposals conducive to improvements, so as to assure persons with extensive functional impairments of adequate support. Differences in standards as charges payable between individual persons and groups of persons, and also between different parts of Sweden, were to be observed. Furthermore, among other things, the remit includes access to employment and to leisure and recreational amenities. General access to environments and activities and the need for anti-discriminatory legislation were further questions to be investigated.

The Government's remit to us in these matters was conveyed in a directive (1988:53) and in supplementary directives (dir 1988:65 and 1990:24). In addition, the Commission has received certain letters and Riksdag statements.

Three interim reports and a number of reports on special subjects have already been presented by the Commission. These are presented in greater detail in other sections of the present report.

The Commission intends to discharge its remit by presenting a special report on interpreting and other services for the deaf/deaf-blind, hearing impaired and speech impaired, and also a final report during the second half of 1991.

The basic approach of our report

It is above dispute that the emergence of the environmentally related concept of disability has profoundly affected Swedish policy for the disabled and continues to do so. The interest-related work of the organisations of the disabled has established the concept in a way which is reflected in many different contexts. Describing disability as a relationship between the injury or disease and the person's surroundings (as in Government Bill prop. 1979/80:1, enacted as the Social Services Act) is important for two reasons. It stresses that disability or handicap is not a property of the individual, and it creates possibilities of change.

We have been able to observe, however (in our interim report SOU 1990:19), that, where many people with extensive functional impairments are concerned, the potentialities of the concept have not been utilised. On the contrary, we have been able to see how certain social changes maintain and even create new and important obstacles, i.e. compound disability.

We have also been able to see how individual persons and groups with serious functional impairments have living conditions which reveal persistent gaps in the development of welfare. Well-known targets concerning full participation and equality have not been achieved.

Great expectations were attached to the national programme of action on matters concerning the disabled (1982), widely endorsed as it was by all political parties at that time represented in the Riksdag, by both the national associations of local authorities and by the disabled movement. Both the follow-up carried out on the Government's behalf by the National Council for the Disabled and our own surveys have made it clear that, while reforms have been introduced which in several respects have improved the situation of persons with functional impairments, at the same time considerable inequalities have also been developed between persons with different functional impairments, between different parts of the country and within different sectors of the community, e.g. in working life, the leisure sector, the recreational sector and the cultural sector respectively. In a word, those who, on account of extensive functional impairments, encounter very great difficulties in their everyday life, are most deprived in terms of

housing, employment and occupation, leisure and recreation, health care and medical attention, public communications, information etc. This in turn excludes them from opportunities of exerting influence. Very often these deficiencies remain invisible, and a state of exclusion is established. In this circular process, those attitudes on the part of the surrounding community are consolidated which can be manifested by individual self-determination in the private situation being disregarded and taken away from those who are entirely or greatly dependent on support and assistance in their daily lives.

This is alarming and challenging, as regards both the conditions of individuals and the development of society. It has led us to undertake a deeper analysis of various ways of looking at the situation of persons with functional impairments and at structural changes in society. All in all, this has provided a basis for our recommendations and for the qualitative demands, fundamental principles, which we have defined.

To overcome the state of exclusion to which we refer, and to assure individual persons with extensive functional impairments of secure, good living conditions, we have a starting point in the approach formulated by the united disabled movement in a document addressed to the Disability Commission (1991). We agree with the disabled movement that functional impairments are to be regarded as one of several natural and inevitable variations in a population. People with functional impairments and their needs are not ever-new "problems" to be solved by a special process. Diversity – and people's functional impairments – can always be expected. This knowledge must be a starting point for general welfare policy and social development. Everybody must be given equal rights and opportunities of leading a good life.

We maintain that this perspective sets an obvious course for necessary and vigorous reforms. In the present situation we believe that both general and individualised measures are called for. The recommendations which we put forward in this report, and the inquiry which will be completed in a final report during the second half of 1991, include measures to bring about:

- ✓ changes in personal conditions through habilitation, rehabilitation, health care and medical services etc.,
- ✓ changes in the structure of society, through measures creating accessibility in the broad sense,

- ✓ - support and service aimed specially at catering to the needs of individual persons with functional impairments.

As we see it, basic values and economic considerations require changes in the general accessibility of society to be made an emphatic strategy. At the same time we wish to emphasise that the need for individualised measures must be provided for. Special and individualised measures, however, will not replace the great and general changes that are needed in order to make schools, housing environments, workplaces, clubs and societies, media, cultural life, public transport etc. accessible.

Every day, individual persons within the sector of the population with which we are concerned are confronted by inequality and deficiencies with regard both to general access and to the special support which is made available. The insecurity arising for the individual (and his or her next-of-kin) causes mental and physical wear and tear, the costs of which in all respects are difficult to calculate. We have therefore judged it necessary to guarantee individual persons good living conditions and necessary support through special legislation. This may seem inconsistent with our view that people with functional impairments are not to be treated as "problems" to be solved by special means. But, in our opinion, it is consistent, in the light of experience derived from our surveys of the present situation for the persons with whom we are concerned.

These needs are accentuated by aspects of current social development, e.g. explicit emphasis on the independence of the individual, the growing use of management by objectives, decentralisation, the growth of international dependence and certain changes in the public sector, all of which are creating more competition between different input sectors, at a time when common economic resources are overstretched.

We believe that legislation is needed as part of the process of asserting the position of the individual in society and giving him/her (and his or her next-of-kin) a means of influencing their situation. But also in order for him/her to be able to take part in the development of society and to fashion the society in which children, young children, young persons and adults with extensive functional impairments are automatically included and respected in the general diversity.

Looking further ahead, into the next century, however, we

feel that it is a natural objective for the needs of the persons we are referring to here to be provided for through the provisions of legislation which all members of the community will find adequate.

Brief digest of the report

Structural changes (Chap. 3)

This chapter analyses the consequences of increased international integration and of the new administrative policy with its aims of decentralisation and management by objectives. The point of departure is opportunities for individuals with extensive functional impairments to assert their civic rights and to influence such things as support and service. We discuss management by instruction and management by objectives with reference to various activities.

Critics of management by instruction have often overlooked differences between external and internal regulations.

External regulations refer to the citizen in relation to authorities/the state. The more exact those regulations are, the stronger will be the position of the citizen and the greater his or her civic rights.

Internal regulations refer to the concerns of an administrative organisation (budgeting rules, personnel matters etc.). Organisational efficiency apart, the manner of internal management is of no consequence to the individual citizen.

Management by instruction presupposes legal controls, for example through a faculty of judicial appeal against administrative decisions. In certain respects this can lead to a problematic relationship between policy-making and the administration of justice. But at the same time, a judicial authority is independent and can safeguard the legal security of the individual in the event of conflict between citizens and the authority on which they depend.

There is a current trend in favour of substituting management by objectives, as a means of achieving flexibility. To the individual, goal descriptions are serviceable mainly as a definite norm against which an activity can be assessed publicly. Management by objectives can serve as an internal steering instrument, e.g. for an administration. On the other hand, it is

unclear whether it can serve in the citizen's relation to the administration, i.e. in the context of external control. What is more, it has proved difficult to carry out the evaluation which the idea of management by objectives incorporates. Vague objectives are one of several obstacles.

There may be advantages in a combination of management by instruction and management by objectives, in the sense of the internal conditions of authorities/administrations being subjected to a greater element of management by objectives and relations between the citizen and the administration being more exactly governed by instructions.

Privatisation is another topical line of development, above all in the sense of privatising the production of public services. The competitive situation which this can result in presents advantages and disadvantages to people with functional impairments. One possible disadvantage, for example, is the risk of segregation, i.e. of the public sector having to take care of complicated sides of an activity at the same time as qualified personnel move to other producers. An advantage to individual persons with functional impairments may take the form of greater freedom of choice and closer adjustment to individual service needs.

Other aspects of current structural changes are concerned with decentralisation. For persons with functional impairments, decentralisation in the form of municipalisation means closer proximity to decision-makers. At the same time this means greater differences between municipalities, resulting in different conditions for individual persons in need of support and service. Individuals may find themselves entirely at the mercy of local political majorities and have difficulty, due to their situation, in playing an active part in the local political process – which in turn may be further accentuated by decentralisation through sub-municipal or local committees.

We also raise certain questions of user influence which, up to now, have been fairly unexplored, e.g. as regards their distributive consequences. In our inquiry, we have primarily described self-determination, influence and priority measures to strengthen the opportunities of the individual, e.g. through personal assistance.

From this analysis of various structural changes, we con-

clude that the process of reform will require two, mutually complementary emphases:

- The position of the individual in society, his or her legal security and political power must be strengthened.
- General social planning must be aimed at preventing the exclusion of citizens with functional impairments from the basic opportunities of exercising their civic rights.

In the work of the Commission, these emphases have prompted special concern with the following questions:

- the necessity and design of a law on civic rights,
- the necessity of wider support for individual persons through the legal aid system,
- contingent funds for mandators not complying with the law,
- freedom of choice through a multiplicity of producers of activities, but with public funding and regulation,
- measures to strengthen self-determination and influence, e.g. through personal assistance,
- the relationship between the rights of individuals and the duties of the community, i.e. opportunities of strengthening the position of individuals by means of exactly framed rules (external rules), and liberty for mandators to design local activities in response to individual needs (internal rules).

Welfare in a society for all – an ethical perspective (Chap. 4)

This chapter describes the basic values concretised in our qualitative demands and basic principles. Their purpose is to lead to the achievement of the aims of full participation and equality.

We present our considered choice of the humanist view of mankind as the basis of our proposals, thereby rejecting the idea of people as objects and subjects of administrative measures.

All people are of equal worth, all have the same human rights and the same right to have those rights respected. Regardless of deprivation of or access to one or other individual capacity.

Autonomy means defending the right to integrity and privacy. Certain individuals are dependent on that right being de-

fensible by proxies; this applies, for example, to persons with severe intellectual handicaps. We point out that situations of this kind require great vigilance if they are not to be abused. The more impaired a person's autonomy, the more vulnerable his or her integrity will be. And, accordingly, the greater will be his or her dependence on the solidarity of others.

We have observed gaps in welfare between people with and without functional impairments, and have seen that these gaps cause considerable difficulties of everyday living to individual persons in the population with which we are concerned. Furthermore, we have asked what values result in persons with severe functional impairments obtaining a smaller share in the development of welfare.

The "just right for the functionally impaired" mentality (W. Ekensteen 1989) is a ballast expressing negative values and a position of social exclusion. One of its results is the neglect of accessibility, in the general sense, in urban planning.

We note that a society for all cannot delimit certain fields as accessible to or "permissible" for people with functional impairments. The community as a whole must be prepared for children, young persons and adults with functional impairments. This is a duty of solidarity which has to be translated into action.

In our opinion, inputs must be framed with these qualitative requirements, to assert:

- Self-determination and influence
- Accessibility
- Participation
- Continuity and a holistic approach

These concepts are our fundamental principles.

Our proposals are not concerned with benefits or charity. Instead they describe necessary and obvious tools for making the goals of full participation and equality attainable.

The survey population (Chap. 5)

The Disability Commission has a remit referring to children, young persons and adults with functional impairments. This remit includes various problem fields concerning various numbers of persons. This has resulted in our recommendations being geared to a target group which varies in size, depending

on the focus of each recommendation and its relation to a particular field.

After a brief review of the concept of disability and of an approach which we share with the disabled movement, we present our deliberations concerning the survey population.

We assume that the approach formulated by the disabled movement, to the effect that welfare and social development must be based on knowledge of the host of variations naturally and inevitably occurring in a population.

This approach implies that vigorous efforts must be made to augment the general accessibility of society, something which refers to a very wide population. But there is also a need for individualised, special measures. These again must be provided through qualified measures in keeping with individual needs.

We describe the population for

- individualised measures under the Support and Services Act (LSS)
- other individualised measures.

In keeping with our remit, we also consider the concepts of "small and less well-known groups of the disabled" and "immigrant background". Measures relating to these concepts are described, respectively, in a special chapter of this report and in our final report.

Furthermore, we make certain delimitations relating, for example, to the terms of reference and responsibilities of other official inquiries and sectors of the community, e.g. the tasks of caring services for the elderly. Briefly, we find that general aspects of conditions affecting the elderly are beyond the scope of our remit, as are questions referring to individuals and groups of persons with drink and drug problems. Delimitation is also effected in certain respects in relation to the remit and target group of the so-called Psychiatry Commission.

The population for individualised measures, under the new legislation which we propose, viz the Support and Services (certain functionally impaired categories) Act (LSS), comprises persons who, as a result of

1. serious functional impairments, have
2. great difficulty in their everyday living and, accordingly,
3. an extensive need of support.

These criteria imply that inputs are to be concentrated on persons with permanent or increasing functional impairments. The cause or nature of functional impairment, on the other hand, is not decisive, nor is the medical diagnosis.

The extent of the functional impairment has to be balanced against difficulties in everyday living and the need for special support.

Our population cannot be statistically delimited to a certain number of persons.

All in all, we assume a population of some 100,000 persons (children and adults) for individualised inputs under LSS.

We recommend necessary reinforcement of several *other individualised measures*, e.g. habilitation/rehabilitation, technical aids and transport services. In these fields, the population cannot be delimited in the same way. Activities for habilitation, rehabilitation and technical aids, for example, are conducted for our population in the same forms as for others with functional impairments, and in certain respects for senior citizens in caring services for the elderly. We also take the view that habilitation and rehabilitation, as well as technical aids, can, at a generous assessment, reduce the need for special, individualised inputs. Transport assistance services are discussed in similar terms in Chapter 11. This wider population has been taken into account in our financial assessments (Chap. 18).

Special support and service for children and the family (Chap. 6–6.1)

The aim of the measures we propose is for children and young persons with extensive functional impairments to have the same access as others to childhood and adolescence with good formative conditions, giving them at the same time an individually shaped preparation for a good life as adult citizens.

The special inputs we propose are not ends in themselves but necessary means of well-being and participation in the life content, activities, environments etc. of other children and young persons. This also implies that the content and quality of inputs must be continuously scrutinised and amended. The possibilities of children and young persons (and their next-of-kin) taking part in and influencing this development work,

concretising their qualitative demands and obtaining provision for their viewpoints must be reinforced.

Our population also includes children and young persons in a particularly vulnerable position. Their injuries/diseases/functional impairments create impediments which today cannot be remedied in all contexts by adapting and supplementing the environment by means of technical aids, personal support etc.

In situations of this kind, we believe that vigorous efforts are highly essential in order to devise ways and means of giving individual children and young persons a positive quality of life. This can require compensatory measures.

We go on to describe a family perspective in our inquiry: we emphasise the responsibilities and influence of parents, we take into consideration the wellbeing of the entire family and also the various roles which each member of the family has or wants to have outside it.

Basically, children and young persons with extensive functional impairments must have access to a stable family life. This requires the social support addressed to all children and families with children to be supplemented in a manner corresponding to individual needs and preferences.

One "benchmark" for calculating the number of children and young persons aged up to 20 who may need expert inputs in the form of habilitation (a combination of medical, psychological, educational and social resources) has often been put at some 1.5 per cent of the total number of children/young persons in this age group.

Despite manifest endorsement, in various contexts, of the needs of the individual child, young person and family as the starting point for obtaining support and service, legislation, organisational models, resource expansion etc. have come to be preoccupied with diagnoses or group designations. In certain contexts, this has resulted in a necessary concentration of forces and measures to deal with very palpable shortcomings. At the same time, it has created inequalities in the availability of support and service in situations where individual persons with similar great difficulties have been described by means of various diagnostic or group-related designations.

As we see it, vigorous action will now have to be taken to create good and equal conditions for children and young per-

sons in our population in this respect. The work of change must proceed in a way which, at one and the same time, utilises positive achievements hitherto and augments the possibilities of developing new knowledge and forms of action.

Individual children and young persons (and their families) must be given access to all-round, qualified examination, diagnosis, functional assessment, treatment, technical aids and counselling, as well as other supportive inputs. More fields of competence must be involved. The emphasis of inputs – medical, educational, psychological and social – varies, but the need for co-operation between different fields of competence remains. Today the county councils are mandators for most of the inputs referred to and, for certain groups, have established activities in a special organisation for child and youth habilitation. These habilitation inputs do not replace the advanced knowledge and inputs, essential to children and the family, provided by others, e.g. in child care, schools, social services and child health care. In these and several other activities, there must be a basic knowledge of disabling situations and of measures which can be taken to alleviate the consequences of a functional impairment.

The School Boarding Houses Act (1965:136) and the Care of the Mentally Retarded Act (1985:568) constitute a starting point for the framing of our recommendations. Both these Acts supplement inputs under the Social Services Act (SoL) and the Health and Medical Care Act (HSL).

We have found that statutory regulation will in future be needed to supplement the statutory support otherwise existing for our population. The strongest reason for this, in our opinion, is the vulnerable nature of this population and the unequal conditions of different groups, in different input fields and in different parts of the country.

Through additions to the Health and Medical Care Act (HSL), we recommend that medical mandators be required to organise and finance habilitation for children and young persons with functional impairments, whatever the nature of those impairments may be. The availability of resources is to be made clear in a special organisational plan drawn up by the mandator. That plan must include activities within the county council area concerned, but also inputs existing, for example, at centres of knowledge concerning small, less well-known disabled categories.

The organisation of habilitation must be made clear by an individual plan. This is also prescribed through an addition to the Health and Medical Care Act (HSL). We propose that certain supplementary expert inputs be made available through a provision in LSS.

What is more, children and families need to be assured of a number of other inputs which we find it natural to include in municipal mandatorship.

In our draft version of a new enactment, LSS, we describe inputs to which children and the family are to be entitled and which are aimed at facilitating a good life.

We refer for example, to the assistance of a personal contact, to the right to a co-ordinated individual plan of various supportive measures and to various forms of relief service, both in the home and in short-term homes. Furthermore, we recommend rights referring to supplementary formative environments such as school boarding houses and foster-homes, as well as entitlement to special supervision for children over 12 before and after the school day, during school holidays etc. Special attention is paid to children and young persons with very complicated functional impairments.

In the draft version of the new legislation, LSS, we have included several provisions augmenting opportunities for assistance geared to the individual child or young person in connection with various activities. We believe that these various measures can improve the child's access to leisure activities, for example.

Parental participation in treatment and education facilitated (Chap. 6.2)

To improve the measures taken on behalf of children and young persons with extensive functional impairments, we also need a family perspective. This refers, among other things, to economic opportunities for parents to take part in the treatment of their child and to receive education concerning their child's functional impairments, as well as measures for promoting the child's all-round development. To make this possible, we recommend that the system of contact days under parental insurance be augmented for the benefit of parents coming with the ambit of our proposed legislation (1992:000)

on support and services for certain functionally impaired persons.

We recommend that a parent should be ~~entitled to claim contact days from the child's second birthday and until the child is 16~~. It is proposed that 10 days be made available per child annually. For parents with children in the 4-12 age group, this will mean an 8-day increase, from 2 to 10 days per child annually. For parents with children aged 2-4 and 12-16, our proposal will mean an additional 10 days per annum.

This proposal will increase the possibilities of both parents taking part, individually or together, ~~in parental education~~ organised, for example, by organisations of the disabled. It should also imply some ~~improvement in the possibilities of both parents obtaining compensation for taking part in the treatment of their child when they simultaneously visit a~~ caring institution etc.

In addition, we recommend that parent's allowance in connection with childbirth be made applicable to the same kind of parental education as temporary parent's allowance, contact days included, can be used for, e.g. for parental education, provided by an organisation of the disabled.

Other proposals include wider availability of parent's allowance to a parent taking part in the treatment of the child. Under the existing rules, the child normally has to accompany the parents in order for parent's allowance to be payable. Under our proposal, the child's presence will no longer be a necessary condition for the payment.

We estimate the total parental insurance cost of our proposals at some MSEK 85 per annum.

In our review we have observed inequalities between different aspects of parental insurance, as regards target groups and forms of compensation. These differences affect the prospects of creating universal, uniform solutions by adding to the existing rules. Moreover, an important question regarding parental insurance benefits in relation to functionally impaired and sick children is the upper limit, 16 years, for entitlement to temporary parent's allowance. We find it essential that the improvement we propose to parental insurance should be introduced as part of our reform package. As a second stage, we feel that the rules of parental insurance concerning children with functional

impairments need to be reviewed and more uniformly framed. We are prepared to consider this point in our further deliberations.

Special support and service for adults and their next-of-kin (Chap. 7-7.2)

First of all we describe general principles of habilitation, rehabilitation and continuous support and service for adults. On the strength of viewpoints received during the consultation process, we state the importance of adults with extensive functional impairments having access to support and service which will enable them to become established in and retain various roles in adult life.

In the part of this chapter dealing with habilitation and rehabilitation, we define terms such as processes requiring comprehensive and synchronised inputs to support the development, training etc. of individual persons. We emphasise the influence to be wielded by the individual, and we affirm that he or she must not be "an object of habilitation and rehabilitation".

We quote examples of shortcomings in the present availability of inputs, and we lay down guidelines for the vigorous expansion of activities. In our opinion, active inputs must also reach those who have hitherto been excluded from working life. We know that knowledge and experience exist - e.g. concerning rehabilitation after brain injury - but that resources have not been expanded in step with these advances.

The expansion must be comprehensive, taking in several fields, such as medical rehabilitation and vision and hearing rehabilitation. The form of expansion also needs to be characterised by diversity (e.g. knowledge centres, individual facilities for rehabilitation).

To make this expansion of both habilitation and rehabilitation possible, we recommend compensatory payments out of social insurance to the county councils equalling MSEK 400.

We indicate lines of development for adult habilitation and we point to the necessity of early planning for young person's transition to adult life.

We recommend that one mandator, the medical mandator, be required to organise and finance all-round habilitation and

rehabilitation for adults. These activities can be conducted by others or, in certain cases, be based on co-operation between several medical mandators. The medical mandator in an individual person's county council area of residence must, as being responsible for a special organisational plan, be able to indicate habilitation and rehabilitation routes in connection with different functional impairments. This duty is made clear by an addition to the Health and Medical Care Act.

We recommend that the individual be entitled to an individualised habilitation and rehabilitation plan, setting out needs, inputs, responsibilities etc. This too is expressed in a supplementary provision of the Health and Medical Care Act.

In addition, the individual may, in this as in other connections, derive benefit from a special personal contact, an assistant, who can be appointed in accordance with our proposed LSS (Section 6).

Housing and services (Chap. 7.3)

The overriding aim of housing policy is for everyone to have access to a good home. This chapter describes general demands concerning the design of a good home and the personal support and service which persons with functional impairments require in the domestic situation.

We have chosen to describe forms of housing classified as follows: an independent, detached home, a service flat, collective forms of housing and institutional accommodation. In various ways, these different forms of housing and service have been subjected to a number of official inquiries, projects, legislative enactments etc. in recent years. Several initiatives have been aimed at improving the situation of people with functional impairments.

Despite various positive approaches, we have found that people with extensive functional impairments have difficulty in obtaining provision for their housing and service needs. Many of them are still living in institutions and do not have homes of their own. Others are still living, as adults, in their parental homes, even though they would like to have homes of their own. Others again, for several reasons, do not have the form of housing or service they desire – for example, due to a shortage of space, personal support etc. Many are unable to

move to the locality of their preference, due to uncertainty as to whether necessary provision can be made for their service requirements.

For this reason, and in spite of existing legislation in this field, we have found that there is a need for stronger and wider statutory safeguards for our population. We recommend that individuals be entitled, through their municipality of residence, to obtain suitable housing with special services. This entitlement, in our opinion, must be expressed through a provision in the new enactment, LSS. Municipal responsibility for catering to the needs of individual persons in this respect is in line with the obligation incurred by municipal authorities under the so-called "elderly reform".

We see no reason to single out the intellectually handicapped as a group in our proposals; instead we feel that the municipal obligation must apply to all persons with serious functional impairments.

We go on to describe how individual needs for support and service in the home can be provided for, and we indicate opportunities of greater autonomy and better continuity through our proposal concerning the appointment of a personal assistant (cf. Chap. 9).

Attention ~~is paid to the phasing-out of institutions and also~~ to forms of housing accommodation ~~which must be made available~~, for example, to those who have spent a long time living in institutions. We affirm that nursing homes for the intellectually handicapped are to be abolished, and we set a deadline for this being accomplished throughout the country. That deadline, according to our recommendation, should be 1st January, 1998.

The phase-out calls for joint planning by county councils and municipalities. We find it justified to make the municipalities financially responsible for nursing home accommodation as long as nursing homes continue to exist.

Special support and service for small and less well-known groups of disabled persons (Chap. 8)

In recent years, attention has come to focus on the difficult circumstances which can arise when an individual person suffers from an unusual disease/injury/functional impairment.

These difficulties are concerned, briefly, with access to specialist expertise and with opportunities of comparing notes with other persons in the same position. The starting point for our deliberations and recommendations is the unusual diseases/injuries which lead to extensive functional impairments and occur in 100 persons (children and adults) or less per 1 million inhabitants. This, however, is not a hard and fast limit.

To supplement the other inputs we recommend for our population, we feel that the situation of the small disabled groups must be made the subject of a national, continuous follow-up study, for which we recommend that the National Board of Health and Welfare be made responsible. On this basis we propose the establishment of certain knowledge centres at regional and national levels, as a development of the duty of medical mandators to organise and finance habilitation and rehabilitation. Knowledge centres must offer all-round specialist expertise and training and must assume responsibility for various tasks serving to improve the conditions of small groups of the disabled. The working approach must be characterised by close co-operation with the support, services and competence available within a municipality or county.

In view of the additional expense in which this proposal will involve the mandators, we recommend reimbursement out of insurance, for each knowledge centre, by agreement between the National Social Insurance Board and the county councils, represented by the Federation of County Councils.

Knowledge concerning the needs of small groups should be disseminated more effectively. We recommend state funding to support the information activities of the organisations of the disabled, through publications about small and less well-known groups of the disabled, and for the establishment of a data bank. The latter will be co-ordinated with the technical aids data bank which we also propose.

To facilitate exchanges of experience between individual persons, we recommend that the follow-up undertaken by the National Board of Health and Welfare should also include the access of different groups to activities which provide opportunities for meeting others, obtaining information and so on. An annual list of amenities is to be compiled by the Federation of County Councils in association with the organisations of the

disabled and other parties. If necessary, amenities must be supplemented so as to provide for various groups.

Parental opportunities of taking part in activities at knowledge centres and elsewhere will be facilitated by the amendments we propose with regard to temporary parent's allowance (Chap. 6.2).

Personal assistant – financial support (Chap. 9)

In many municipalities, personal assistance has emerged as a social service input. This form of personalised support, however, is not available everywhere, and so there are geographical inequalities in the support given to persons with equivalent needs resulting from extensive functional impairments. We feel that the availability of such assistance must be reinforced, so as to improve freedom of choice, autonomy and continuity in the personal living situation.

We therefore recommend that LSS be made to include entitlement to a personal assistant for everybody who can be deemed to need such a measure and who is included in the population to which LSS refers. The individual must be able to turn to the municipality for this type of support. Furthermore, we recommend that the individual personally be able to act as employer or to engage, say, a co-operative as employer.

The municipality should have a basic duty of supplying and financing the personal assistant input. This financing includes a duty of providing, as an option, a direct financial grant for the individual.

The term "personal assistant input" implies that the support and assistance needed by the individual in all situations are provided by a limited number of persons. These persons are attached to the individual and not to any particular activity.

The personal assistant input also implies that the individual decides or does a great deal to influence who is employed as an assistant, and also that the individual must exert a great deal of influence on the timing of help. Improved availability of personal assistance will also augment the possibilities of co-ordinating the personal support now provided in homes, at work and in schools. We also take the view that the introduction of entitlement to a personal assistant will facilitate the

14/11/82
 resettlement of intellectually handicapped persons and long-term mental patients, for example, away from institutions.

We also feel that the financial support for personal assistance must be strengthened. This should be done through social insurance. In this way, expensive supportive arrangements needed in the municipalities can be financed on a basis of solidarity. Social insurance already includes a great deal of financial responsibility for the functionally handicapped through various kinds of support, such as permanent disability pensions and disability benefit.

A basic measure of responsibility, however, must always rest with the municipalities. That is, even if a great deal of support is needed in the individual case, not all support must be financed through social insurance; instead a certain portion must remain with the municipality. Responsibility should not be incurred by the Social Insurance Service until the help needed exceeds 20 hours per week.

The support from the Social Insurance Service is termed "assistance compensation". This compensation is compensation for additional expense, in common for example with disability benefit under the National Insurance Act (1962:381). It is intended primarily for those included in the LSS population, aged 16 or over and living independently, in service accommodation or with families/next-of-kin. Assistance compensation is not payable for daily rest.

If the Social Insurance Service does not award assistance compensation, the individual can request the municipality to do so. Thus the municipality has a subsidiary financial responsibility in cases where assistance compensation can be provided but the Social Insurance Service feels that there is no entitlement to it.

The additional expense entailed by the determination of assistance compensation consists mainly of wage costs for the assistance or of the charges – in principle corresponding to wage costs – made by the municipality or some other agency responsible for the input. Compensation is payable per hour and week and at the present time can be estimated at some SEK 6,240.

If the individual wishes to arrange the assistant input in some other way than through a personal assistant from the municipality, he or she still ought to approach the municipality

first for a grant, which as a rule will cover up to 20 hours per week. The individual can then turn, with or without administrative assistance from the municipality, to the Social Insurance Service for compensation for inputs covering excess supportive needs.

We estimate that the right to a personal assistant with assistance compensation from the Social Insurance Service will initially affect some 8,000 persons. Furthermore, we estimate the net additional expenditure incurred by the municipalities at some MSEK 500 per annum. At the same time, social insurance will take over expenditure totalling some MSEK 1,100, thus relieving the municipalities of expenditure totalling some MSEK 600 annually. As a result of the closure of institutions, 3,000–4,000 persons will eventually become entitled to assistance compensation.

Occupation and employment (Chap. 10)

The survey which we presented in an earlier report (SOU 1990:19) showed lack of employment and occupation to be one of the most difficult problems affecting our population. Paths to occupation and employment must be strengthened considerably. Inputs for employment and occupation must be co-ordinated and must have the clear objective of strengthening the employment prospects of persons with extensive functional impairments.

We recommend that municipal responsibility for occupational arrangements for our population be articulated through the introduction of a municipal occupational guarantee in the Support and Services (certain functionally impaired categories) Act (Section 6 of LSS). At present, 17,000 intellectually handicapped adults take part in activities of this kind at county council day centres. We recommend that these day centres be transferred to the municipalities. The same degree of expansion is needed for other persons with severe functional impairments, which means a gradual expansion requirement for 17,000 persons. We point out that municipal responsibility for arranging occupation can be discharged in various ways.

The municipalities should also be responsible for compiling individual plans in dealing, for example, with paths to occupation and employment. We recommend that the social insurance

offices be given the duty of following up these plans and, if necessary, calling for discussions with the relevant public agencies, labour market authorities included.

As a further means of strengthening paths to occupation and employment, we recommend that the Employment Service have special personal contacts in relation to habilitation and rehabilitation activities, and also that municipal job adjustment appointments be established.

It is vital to avoid the early retirement (on permanent disability pensions) of young disabled persons. On the whole, we endorse the Rehabilitation Commission's recommendation of compensation for handicapped youngsters. In our view, an absolute minimum age limit for permanent/temporary disability pensions should be put at 25.

There is now a distinct threat scenario in the development of working life, despite very positive inputs in the fields of the work environment and rehabilitation, for example. There are obvious risks of increased employer responsibility for rehabilitation measures on behalf of employees, possible systems of differentiated employers' contributions, the introduction of sick-pay periods etc. leading to new exclusion effects for severely handicapped persons outside the employment sector. At the same time, sweeping structural changes are taking place in working life, resulting among other things in jobs being rationalised out of existence. Continuing great efforts will therefore be needed to develop and open up new paths into working life for the disabled. We observe the importance of certain labour market policy resources/instruments being reserved for persons with severe functional impairments. This applies above all to such inputs as wage subsidies, special employability institutes, the Samhall enterprises and special induction opportunities (together with inputs corresponding to such induction opportunities).

We recommend an expansion of the number of job opportunities for our population within Samhall at a rate of about 600 annually over a period of more than 10 years. A certain proportion of Samhall's job opportunities should then, by agreement, be placed directly at the disposal of the municipal mandator for those persons in the population concerned who are prepared to proceed from occupation to employment.

The Commission notes that the special induction opportuni-

ties have proved a good way of introducing the population concerned into working life. We therefore recommend an expansion of opportunities for the entire survey population, to provide an input corresponding to special induction opportunities. In our final report we intend returning to consider questions concerning paths to employment and the feasibility of earmarking job opportunities for our population.

Transport assistance (Chap. 11)

Public transport, as we see it, is the foundation of traffic supply for all people. Considerable changes are needed in order to improve availability, despite certain inputs in recent years. We regard the responsibility and funding principle as a point of departure for such changes. We will be returning to this point in our final report.

Here we will mainly consider specially adapted public transport (service lines) and transport assistance as a supplement to modify public transport.

Individual persons who have appreciable difficulty in getting about on their own or in using public transport must, in our opinion, be able to experience greater independence than is the case under the present system of transport assistance. To this end we have defined targets for the development of transport assistance. These include the following:

- Transport assistance as a form of transport is, for example, to supplement public transport.
- County transport assistance is to be introduced in all counties, on an inter-municipal basis.
- In principle, there is to be no ceiling on the number of journeys.
- In principle there are to be no restrictions on the timing of journeys during the day.
- The direct charge payable by the passenger is not to exceed public transport fares for local and county services. No charges are to be made for escorts or for children accompanying a passenger entitled to transport assistance.

To achieve these aims, we recommend amendments to the Social Services Act (Sections 10 and 35).

We also recommend that an incentive grant of MSEK

50–100 annually (new money) be distributed to municipalities and transport mandators over a period of 4–5 years to hasten the development of, above all, service lines.

Furthermore, we recommend a follow-up of the reform by means of research inputs.

Technical aids (Chap. 12)

In this chapter we chart and define responsibilities and make recommendations aimed at strengthening the security of the individual as regards the supply of technical aids.

An addition to the Health and Medical Care Act will make it the duty of county councils to provide and finance technical aids for everyday living and self-care and treatment, for all persons with functional impairments. This is to be done on an individual and equivalent basis. This can be supplemented by an undertaking on the part of the county councils, "guaranteeing" that the individual will not need to wait more than a certain length of time for the right technical aid.

It will also be the duty of county councils to maintain an organisation for charting and fitting aids for everyday living and for self-care and treatment, but also for aids of other kinds.

The county councils will be at liberty to use different producers for fitting etc. The identities and locations of the producers will be made clear to the individual user and otherwise by an organisational plan, in keeping with the availability requirement. Together with the individual habilitation and rehabilitation plan and the possibility of obtaining assistance from a personal contact, this will also strengthen the security of the individual.

Furthermore, we recommend a special allocation (MSEK 100/year) for technical aids for leisure and recreation and for technical aids for groups requiring special competence in connection with the testing and fitting of aids and training in their use. The Swedish Institute for Disabled Persons is to be a national centre of knowledge and development for technical aids.

We also put forward recommendations concerning competence development and the distribution of information.

Individual persons with functional impairments are not to pay for the aids and service which those impairments necessitate.

In our final report we will be dealing with further aspects of technical aids, e.g. technical aids at work and consideration of the possible need for a revision of financial responsibility for the total supply of technical aids.

Freely chosen leisure and recreation (Chap. 13)

This chapter describes the very severe shortage prevailing with regard to different aspects of availability in the leisure, recreation and cultural sectors.

We show that, despite a great deal of knowledge and experience concerning necessary and possible changes, this situation has not developed appreciably where our population is concerned. A situation of inequality is compounded by several circumstances. We mention, for example, the fragile socio-economic position of individual persons, which often fails to provide scope for leisure activities either in the everyday context or during holiday time. Furthermore, there are many impediments caused by restricted access to transport assistance, escort services etc.

In our opinion, measures to improve general accessibility in the community must be a strongly asserted strategy, above all together with more consistent implementation of the responsibility and funding principle. This question covers a very wide range, and we therefore propose returning to it in our final report.

Here we present our recommendations concerning individual inputs which can strengthen the ability of individuals to take part in leisure and recreational activities. We refer, for example, to support by means of a personal assistant, improved supply of technical aids, assistance from a personal contact, free escort services and directional measures. We also recommend changes in transport assistance with a view to greater independence and freedom of choice (e.g. opportunities for travel outside the municipality of residence and charges corresponding to public transport fares). Proposals concerning leisure-time interpreting services for the deaf etc. will be put forward in a future interim report.

The proposals put forward here imply a funding reinforcement of MSEK 200–300 for the leisure sector.

Legal aid (Chap. 14)

This chapter describes various ways of supporting and safeguarding the interests of individuals:

- The Administrative Procedure Act (1986:223).
- The Administrative Litigation Act (1971:293).
- Support under the Care of the Mentally Retarded Act (1985:568)
- Support under the Social Services Act (1980:620).
- Supervision by the National Board of Health and Welfare of activities coming under the Social Services Act and the Care of the Mentally Retarded Act.
- General legal aid under the Legal Aid Act (1972:429), subject to the amendments enacted on 1st July, 1988.
- Measures by the organisations of the disabled.

We also describe our proposal concerning assistance from a personal contact (Section 6, LSS).

The Commission finds that the Legal Aid Act should be amended so as to make it easier for persons with functional impairments to obtain legal assistance in proceedings before administrative tribunals relating to social insurance benefits, assistance under the Social Services Act or special support and services under the proposed Support and Services (certain functionally impaired categories) Act (LSS).

We believe that changes can be made in the form of additions to Section 8a of the Legal Aid Act.

Ways of demanding social rights (Chap. 15)

In recent years, with an increasingly adverse economic climate, there has been a growth of discussion concerning the ability of individuals to insist on their social rights. Publicity has been given to appeal cases relating, for example, to assistance under Section 6 of the Social Services Act and special caring services under Section 4 of the Care of the Mentally Retarded Act.

This chapter describes the possibilities of exaction afforded by administrative appeal.

The chapter also describes the new rules governing the criminal offences of dereliction of duty and gross dereliction of duty and the penal liability which can be imposed. It is made

clear, for example, that members of municipal social welfare committees and county council mental welfare boards are not exempt from liability.

In the case of public activities involving the exercise of authority, liability in damages is governed by Section 2 of the Damages Act. The liability of the public sector in damages, however, is so limited that it is seldom possible for the individual to base any claim in damages on, say, failure to provide measures of support or assistance (under, respectively, the Social Services Act and the Care of the Mentally Retarded Act).

Another possibility may be to employ provisions concerning contingent fines. Under the Execution Code, a judgement has to be enforced by the enforcement authority issuing the respondent with an injunction to comply with the judgement. This injunction can be combined with a contingent fine. Following this review, we conclude that the Execution Code makes it possible for an enforcement authority, by means of a contingent fine, to compel a county council or municipality to comply with a judgement handed down by an administrative tribunal. This question, however, has not been put to the test. If this is a viable expedient, we feel that consideration should be given to a statutory amendment whereby contingent fines can be imposed on county councils and municipalities.

Follow-up, evaluation and supervision (Chap. 16)

With reference to current development tendencies (management by objectives, decentralisation, the transformation of the public sector), we describe how evaluation and follow-up are replacing other forms of supervision (such as inspection activities).

As stated in Chap. 3, this implies both advantages and disadvantages where our population is concerned.

We go on to describe how supervisory activities are regulated in various enactments such as the Care of the Mentally Retarded Act and the Health and Medical Care Act, with the National Board of Health and Welfare as the supervisory authority, and the professional supervision of health and medical personnel under the Insurance (Control) Act (1980:11).

In our discussion concerning future forms of evaluation,

follow-up and supervision, we take as our starting point the proposed new enactment, LSS.

We note that the proposed LSS amounts to a codification of rights, enabling individual persons to contest decisions going against them. To make it easier for individuals to exercise their right of appeal, we recommend wider entitlement to legal assistance, by proposing an amendment to the Legal Aid Act (Chap. 14). We also believe that our recommendation that individual persons be entitled to an individual plan of habilitation/rehabilitation, specifying inputs, responsibilities, follow-up etc., will provide greater security and safety. The same applies to our proposal concerning assistance by a personal contact. At the same time as the new enactment (LSS) as proposed by us strengthens the position of the individual, it affirms the responsibilities of municipalities and county councils (organisationally and financially speaking) for inputs which it prescribes.

We feel that it should be the duty of a central authority to maintain coherent supervision of practical compliance with the intentions of the legislation. Any shortcomings should be reported to the Government and necessary changes suggested.

Within the scope of its responsibilities, each national authority must supervise the activities intended to serve individuals in the respects described by the proposed enactment. The authorities must also disseminate knowledge. In their discharge of these duties, the central authorities will be entitled to full insight into all activities of public and private agencies within the purview of the enactment.

In our opinion, the supervisory duties of the County Administrative Board should be confined to activities under private auspices. The County Administrative Board will retain its task of co-ordinating regional planning in the urban planning context. This is also of vital importance in matters concerning the disabled.

In addition, we feel there is already justification for establishing an office of the Ombudsman for the Disabled, charged among other things with supervising compliance with the legislation. We intend to give special consideration to this question and will be returning to it in our final report.

Legal aspects (Chap. 17)

The new legislation, as well as amendments and additions to various existing enactments, which we propose are set out (together with special reasons for the same) in other parts of this report.

In this chapter on legal aspects we describe current legislation and experience of the same, and also various deliberations leading to the recommendations which we now put forward.

The enactments described here are the Social Services Act (1980:620), the Care of the Mentally Retarded Act (1985:568), the Health and Medical Care Act (1982:763) and the School Boarding Houses Act (1965:136).

Our standpoints of principle are based on the manifest shortcomings and inequalities confronting individual persons in our population and revealed, for example, by replies to the various questionnaires we have distributed to individuals and mandators. Employment and leisure aspects provide some very conspicuous examples.

Shortcomings cannot be eliminated by legislation alone, but legislation can be calculated to channel public resources into neglected fields. Legislation can also underline the intention of the community to improve conditions for disadvantaged groups. We have seen that the Health and Medical Care Act, the Social Services Act and the Care of the Mentally Retarded Act in their present form have not been sufficient to avert deficiencies.

What is more, this legislation has among other things resulted in inequalities between different groups of disabled persons, even groups with equivalent supportive needs.

We have found that many individual persons with severe functional impairments are living in great insecurity.

We have therefore found that legislation is needed, assuring them of fundamental supportive inputs.

This legislation must refer to children, young persons and adults and among other things must be capable of eliminating geographical differences in the availability of support.

We have also attached very great importance to strengthening individual opportunities of autonomy and influence with regard to measures of personal support and service. Several draft regulations concern matters of influence, e.g. the right of

125. personally employing or choosing a personal assistant and entitlement to assistance from a personal contact.

One of our fundamental concerns has been for individual persons with functional impairments to be provided for primarily through existing laws and regulations. In certain respects this has called for reinforcements of existing legislation, so as to expressly indicate measures of great importance to our population as a whole and for the security of individual persons in exposed situations.

An amendment to the Health and Medical Care Act makes it clear that county council duties also include habilitation, rehabilitation and the provision of technical aids for daily living, self-care and treatment. These inputs are equivalent to other inputs under the same Act. In our opinion, the incorporation of this express provision in the Act will help to give individual persons access to advanced resources at an early stage.

In our survey we have noted considerable difficulties and inequalities with regard to the availability of public transport to persons with extensive functional impairments. Through an amendment to the Social Services Act we propose certain reinforcements of transport assistance services. (Further deliberations concerning access to public transport will be presented in our final report.)

In these connections, the relevant population cannot be strictly delimited according to the degree of functional impairment, partly because this can be hard to establish at the beginning of a habilitation or rehabilitation process.

We have found that, in addition to support from existing enactments (and the additions which we propose to them), our population also needs stronger statutory controls in order to assert its rights and to obtain the support which can eliminate difficulties of everyday living. In our draft legislation, these statutory provisions take the form of a special enactment, LSS. Our proposed new enactment is to be regarded as the adjunct to the Social Services Act and the Health and Medical Care Act, providing additional protection through rights in complicated living situations. This does not imply any curtailment of the rights which may accrue to the individual under the Social Services Act, the Health and Medical Care Act and other enactments.

In our inquiry we have analysed advantages and disad-

vantages of an enactments on rights (see also Chap. 3). We have found that there is a great need to strengthen legal safeguards for the individual, not least because persons with severe functional impairments constitute a minority and for several reasons are very liable to find themselves at the mercy of stronger majority groups. Through the Care of the Mentally Retarded Act, there are examples showing that certain groups have been deemed to require this additional legal security which, in our opinion, must also include other groups with equally great impediments and difficulties.

In order for statutory rights to have the intended effect, one has to define the circle of persons entitled and also the services to which they are entitled. This has permeated our deliberations concerning proposed new legislation.

The enactment which we propose and which among other things is to supersede the existing Care of the Mentally Retarded Act refers to a population including that to which the Care of the Mentally Retarded Act now applies. In a special chapter (Chap. 5) we present deliberations concerning the population and observe that, as regards general measures proposed, it is a wide one. For individualised inputs such as habilitation, rehabilitation, technical aids and transport assistance, there is a population which, in our view, must be assessed generously. Inputs in these respects are provided for persons with extensive functional impairments on the same organisational basis as for other persons with functional impairments and for persons using caring services for the elderly, and so a distinct delimitation does not seem really appropriate.

Concerning our proposed new enactment, LSS, we have pointed to exact inputs which persons with extensive functional impairments may need when they encounter great difficulties in their everyday living and require special support. In the light of experience concerning the Social Services Act, which defines the entitlement of the individual to assistance in general terms and does not explicitly indicate the full extent of the assistance which a municipality can be called upon to provide, we find it necessary, as a matter of justice and security, to define certain basic rights of persons who, on account of severe functional impairments, are in a very exposed situation. Those rights must be unaffected by residential locality.

LSS is aimed at strengthening the position of the relevant

population in a short-term perspective. In the longer term – extending into the next century – legislation referring to all citizens should be revised and reinforced in such a way that the measures which it is here proposed to regulate through LSS can be included in those enactments. Our survey and analysis have shown that the protection and support offered today are not sufficient.

The proposed new LSS is intended to supersede the Care of the Mentally Retarded and Others (special measures) Act (1985:568) and the School Boarding Houses (certain physically disabled children and others) Act (1965:136). Coercive measures which at present, under certain circumstances, can be taken against persons with intellectual handicaps will be abolished at the same time. It is proposed that LSS, together with the proposed amendments to the Health and Medical Care Act and the Social Services Act, enter into force on 1st January, 1993.

Consequences of our proposals: economics, mandatorship, finance and implementation time (Chap. 18)

In this chapter it is observed that, altogether, our proposals will entail an estimated additional expenditure of MSEK 2,400 ($\pm 20\%$). This, however, is spread out over several years from the entry into force on 1st January, 1993.

The Riksdag has stated that it is necessary for the disabled sector to be given sufficient resources for necessary measures to be put into effect. Accordingly, through supplementary directives, the Government has exempted the Disability Commission from the so-called zero directives of 1984.

We divide ultimate mandatorship responsibility for various supportive and service-related inputs for persons with severe functional impairments between county councils and municipalities, while at the same time indicating that the mandators may agree between themselves on a different apportionment in response to local conditions. Labour market policy programmes and financial support, including a personal assistant under our reform, will be the responsibility of the State. In our draft legislation we make it possible for the mandator to utilise co-operatives, companies and organisations as producers of

various inputs. The mandator is to show, in an organisational plan, how and where inputs are arranged and can be offered to individual persons with functional impairments.

Our proposals also mean that mandatorship under the Care of the Mentally Retarded Act and School Boarding Houses Act now in force will be transferred to the municipalities within a three-year period. This will affect nearly 40,000 persons with functional impairments and about 30,000 employees. It presupposes a gradual tax transfer between the two mandators corresponding to present-day expenditure of MSEK 9,000.

Our proposals will have to be financed by several alternative means. Above all, we recommend funding through social insurance and, to some extent, through the national budget, as well as through municipalities and county councils. With regard to municipalities and county councils, the reference is to funding requirements occurring successively. We assume that these will be included in the annual deliberations on municipal and county council finance.

It is important in our view to follow up the consequences of our proposals. Among other things we therefore recommend a data bank organisation for the continuous follow-up of expenditure, among other things. An initial evaluation should take place after three years.

Questions concerning charges and individual finance (Chap. 19)

As a general rule, the disabling situation of individual persons includes additional expenditure resulting from functional impairment. This expenditure can comprise the cost of services essentially provided by the public sector, such as care, other services, medicines and so on or goods/services purchased commercially, such as frequent hairdressing services and special diet.

Additional expenditure is incurred by individual persons with otherwise differing private economic circumstances (income, dependants, pensions). In addition, there are differences between certain public compensatory transfer systems (e.g. varying rates of municipal housing supplement).

There are also differences in the charges made for identical

services provided by municipalities and county councils respectively.

In its survey, the Disability Commission showed that this, among other things, could cause substantial differences of available income, depending on the individual locality (municipality) of residence.

In our final report we will be presenting a deeper analysis and putting forward recommendations aimed at equalising differences in the charges paid for identical services by individuals living in different municipalities, and also at influencing the effects of individual persons in our population incurring heavy expenditure for services across sectorial boundaries in the community. Taken together, these two things amount to a considerable burden. The possibility will be investigated of relating these costs to each other and of creating some form of high-cost protection.

In this chapter we also present a summary of a study undertaken on our behalf by the University of Linköping (CMT, U. Hass, 1991). Among other things, that study shows that certain households have permanent deficits which are attributable to various factors related to the functional impairment. As we observe in Chapter 13, most of the households in this study had no scope at all for hobbies, entertainment, holiday activities etc.

Finally we review tendencies in the structures of municipal and county council charges for services to individuals.

The Commission puts forward proposals which are now capable of positively influencing the economic situation of individuals.

The main rule of the proposed enactment on support and service for certain functionally impaired persons (LSS) is for inputs to be free of charge.

Our proposals concerning transport assistance imply a reduction of the high charges now being made in several quarters to levels corresponding to ordinary public transport fares.

Summing up, we state that, before compiling our final report, we intend to explore the following ways of saving the individual from incurring extra expense on account of his or her disability:

- measures to influence, for example, the degree of direct finance and a ceiling on charges or exemption from them,

- a high-cost safeguard co-ordinated across mandatorship boundaries,
- income reinforcement, e.g. through disability benefit.

Relation to the EC (Chap. 20)

Developments within the EC have a bearing on Swedish policy for the disabled, regardless of whether or not Sweden becomes a member. In this chapter, therefore, we have prepared a brief description of the feasibility of co-operation in various respects, in terms of basic facts, and we have described the position of disability questions through the Social Charter and in EC programmes for the disabled (e.g. Helios 1 and 2).

Finally, against this background, we present a very brief, general analysis of our proposals in relation to the working methods and rules of the EC. We conclude that our recommendations of certain inputs under a new enactment (LSS) are concerned with internal, Swedish conditions and are not to be regarded as social security benefits coming under the EC social security regulatory system.

In our final report we propose returning to questions relating to various forms of international co-operation, including the role of the organisations of the disabled.

Scope for future statutory regulation of the responsibility and funding principle (Chap. 21)

This principle implies that environments and activities are to be designed and conducted so as to make them available to everybody. The cost of adjustment measures is viewed as a self-evident part of the total expenditure entailed by the activity and, accordingly, is financed like the rest of the activity itself. This principle was formulated in the mid-1970s by the then Disability Commission.

To assess the feasibility of applying the responsibility and funding principle more consistently, we have input documentation which includes a questionnaire study of our own and international material, above all from the USA. New anti-discriminatory legislation (the Americans with Disabilities Act, ADA) was adopted in the USA in 1989. ADA's discrimination concept implies that impediments to access, for example,

to certain kinds of transport, facilities, telecommunications etc. are deemed discriminatory.

In our analysis of the responsibility and funding principle (which, basically, includes all activities addressed to the general public), we have found a need to strengthen its implementation by means of

- information and opinion formation
- compensatory measures by the State (during a transitional phase)
- legislation (combined with sanctions).

In our continuing work we intend to deepen our analysis and to consider proposed regulations in certain fields, viz planning and building, the media, telecommunications and transport.

Consistent implementation of the responsibility and funding principle ought in the long term to mean cost-saving to the community, over and above the value of expanding opportunities for citizens to take part in activities of different kinds.

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- Arne Edström, Deputy Social Insurance Court Judge
- Allan Everitt, former Union Legal Adviser

In its compilation of this report, the Secretariat was also assisted by a number of researchers and special advisers, viz Bo Rothstein, Ph. D., Uppsala University, Structural Changes (Chap. 11), and Bernt Lundgren, B. Sc. (Local Government Administration), Chap. 11 (Transport Assistance). Extensive documentation was also supplied by Dick Jonsson, B.Sc. (Econ.), Linköping University, for the economic calculations in Chapter 18.

A SOCIETY FOR ALL

Summary

SOU

Final Report of the 1989 Commission on Policies
for the Disabled

Introduction

The following is a summary of the final report, "A Society for All", of the parliamentary 1989 Commission on Policies for the Disabled, appointed by the Government of Sweden.

The Commission received its remit from a Social Democratic government and has continued its work under an non-socialist government.

The Commission is made up of representatives of all parliamentary parties and is chaired by Gerhard Larsson, Group President of Samhall. It has been assisted by expert and political advisors representing, for example, the organisations of the disabled, national authorities, government departments, the national organisations of local and regional authorities, and the scientific community (see App. 1).

The Commission's terms of reference outline a number of tasks, all of them prompted by the necessity of improving the position of children, young persons and adults with extensive functional impairments.

The Commission has previously submitted five reports to the Government and has published several other reports on such topics as self-determination and participation, the socio-economic situation for the severely disabled, and statutory provisions.

In a special survey report (1990), the Commission showed that severely disabled persons were disadvantaged in many respects and had not been able to share, on the same terms as other members of the community, in the growth of national prosperity.

With this background in mind, the Commission has made a number of recommendations aimed at strengthening the position of individual persons with extensive functional impairments. Prominent among these recommendations is a special "Bill of Rights" which, when necessary, will supplement other legislation concerning expert support, services, personal assistance, employment etc.

We have found, however, that individualised measures are not enough. Those measures have to interact with general inputs aimed at making society accessible in the broad sense. We have affirmed that every sector of society, with its particular actors, must accept its share of responsibility for enabling persons with functional impairments to avail themselves, in a manner equivalent to the opportunities enjoyed by other members of the community, of the goods, services etc. which that sector affords.

The task of achieving this is primarily to be accomplished on a basis of integration with other sectorial tasks. Accessibility-creating measures, insofar as they are needed, are to be financed in the same way as other sectorial commitments.

We have also found cause for specially recommending measures in eight priority sectors of society which mean a great deal to the functionally impaired. Those sectors are presented in the course of this summary.

As a means of ensuring, throughout the fabric of society, that persons with functional impairments are not prejudicially treated, we have recommended the establishment of a special office, that of a Commissioner for the Disabled.

This is one of several vital measures which we recommend in order to assert the parity status of the functionally impaired, their self-determination, influence and participation.

The final report of the Commission on Policies for the Disabled was presented to the Minister of Health and Social affairs in June 1992. In keeping with our principles, cassette, Braille and easy reader versions of the report have also been produced.

Stockholm, June 1992

Gerhard Larsson
Chairman

/Tore Karlsson

The remit and the basic principles of our deliberations

“A Society for All” (SOU 1992:52) is the sixth and final report of the 1989 Commission on Policies for the Disabled. The focus of the Commission’s deliberations has been on the situation for children, young persons and adults with extensive functional impairments and on the small, less well-known categories of disabled persons. The content of our five previous reports is summarised in a special section.

The Commission’s remit included both general measures to give persons with functional impairments parity of status with other members of the community, and individual measures to improve personal capabilities and achieve greater independence.

The Government’s remit was conveyed in terms of reference (Dir. 1988:53) and supplementary terms of reference (Dir. 1988:65 and 1990:24), in addition to which the Commission has received various letters and Riksdag (parliamentary) statements.

In our survey report (SOU 1990:19) we noted considerable inequalities of welfare between the disabled and others, and also between different categories of disabled persons, between different parts of the country, between different input fields and so on. Throughout our inquiry, one of our main concerns has been to devise measures for bridging and reducing these gaps. We have been guided by our fundamental principles, which express qualitative demands and stand for self-determination and influence, participation, availability, a holistic perspective and continuity.

One of our main themes has been the strengthening by various means of self-determination and influence. This has applied to the everyday lives of individuals – e.g. through our proposal concerning entitlement to personal assistance – and

in society at large, through the monitoring activities of a special Commissioner for the Disabled.

We have affirmed that every sector of society must assume its share of responsibility for enabling persons with functional impairments to participate in sectorial services on a basis of parity with others. This task is primarily to be accomplished on a basis of integration with the other tasks of each actor in the social sector concerned, and is to be financed in the same way as other sectorial activities.

Establishment of the principle of responsibility and funding is one means of achieving this kind of development. In eight vital sectors of society we have made recommendations to strengthen the impact of that principle and to point the way to further developments. In several cases, accordingly, we have recommended supplementary legislation. In other cases, e.g. as regards access to working life, we have proposed new legislation altogether.

In short, the recommendations made by the Commission have all been concerned with achieving parity of status for persons with functional impairments.

In the following pages we describe, chapter by chapter, the main substance of our final report. For detailed particulars concerning expenditure etc., the reader is referred to the original chapter concerned.

Content of the report in brief

Social development and persons with functional impairments (Chap. 2)

In this chapter we described how the growth of international dependence and the increasingly prominent role of municipalities and regions are leaving the State less room for manoeuvre in controlling the course of social developments.

In addition to changing economic and material conditions, we note value shifts of a more elusive nature which, among other things, have made mutual dependence on collective amenities a less pronounced social objective.

Growing importance attaches to the role of local government, with municipalities and county councils accounting for over 70 per cent of public spending on consumption and investments.

The new Local Government Act (1992) has given the municipalities a freer hand in deciding their political and administrative organisation. State grants to local government are being generalised, at the same time as restrictions have been imposed on municipal powers of taxation.

Structural changes in local government and elsewhere are leading to greater decentralisation, management by objectives and market thinking. The public economy is making ever-more rigorous demands for greater efficiency, rationalisation and, in certain cases, cutbacks.

Persons with functional impairments are highly dependent on public services. Several of the changes which have now been mentioned are tending to aggravate difficulties and deficiencies in the daily lives of the disabled. We have also seen that this has implications for their prospects of exercising their rights as citizens.

To illuminate various ways of strengthening the position of the disabled, an analysis is made of the possibilities and problems of general welfare policy, especially in a free-choice perspective.

Among other things, the analysis shows that there is much greater public support for the general policy of welfare (i.e. welfare policy referring to "everybody" and not combined with a needs test) than for a selective, directional policy. In fact, the general policy of welfare has various advantages, such as simplicity and greater administrative flexibility.

But the general policy of welfare entails certain problems, e.g. concerning the economic feasibility of keeping promises (e.g. concerning medical care and pensions). In addition, the ongoing decentralisation of public sector activities is tending to increase the differences between individual communities.

Disabled members of society and their living conditions are affected by the changes occurring in general welfare. In our recommendations we seek to strengthen the position of the individual by means of both general and individualised measures and by affirming that responsibility for matters relating to the disabled must lie with the social sector concerned. That responsibility must be administered on a basis of integration with other tasks of the field or sector concerned. This, as we see it, is a necessary guiding principle for continuing development.

Basic viewpoint (Chap. 3)

Democracy in greater depth

The Commission on Policies for the Disabled regards its deliberations and recommendations as a critical stage of the process of deepening democracy.

Facilitating and realising participation and equality for persons with functional impairments must, in the full sense of these terms, involve the whole of society, including those who have no personal experience of functional impairments (but who may incur them at some stage of life).

The process of reform is guided by our fundamental principles of self-determination and influence, availability, participation, holistic perspective and continuity. Those principles emanate from the thesis of universal human equality.

The direction to be taken

Up till now, it is only to a minor extent that general aspects of availability have been a subject of deliberations and positive action.

The Commission has been able to see that this has resulted in a "patchwork quilt" of individualised and directional measures to offset the shortcomings of general planning. The result has been to reduce opportunities of independence and free choice for persons with functional impairments. Makeshift repairs of this kind are also a very expensive way of doing things. The available resources should be differently targeted, on more lasting and effective inputs.

The Commission believes that simultaneous, concerted efforts must be made

- *to assure disabled persons of basic opportunities of social participation.* We refer here to the rights which, in our main report, we defined in a special Act on support and services for persons with certain disabilities (LSS) and to the obligations of mandators, which we augmented in our proposed additions to the Social Services Act (SoL) and the Health and Medical Services Act (HSL).
- *to develop and guarantee general accessibility and distinct assumption of responsibility in every social sector, with regard to matters affecting the disabled.* Our recommendations in the present report are designed to achieve this and they also express statutory obligations on the part of mandators and others.

Further development

The work of the Commission must be viewed as a single entity. The recommendations previously made concerning individualised measures interact with the recommendations concerning general measures which form the principal theme of this, our final report. Parallel to the implementation of our proposals, regular evaluations – with user participation – will be essential, in order to find out whether the current balance between individualised and generalised measures reflects a holistic view and is appropriate to the needs of the users.

Summing up, the Commission seeks, through its recom-

mendations, to strengthen the position of disabled persons in the community by means of

- a distinct indication of responsibility, in each sector of society, for questions relating to the disabled,
- legislation and monitoring/evaluation of its effects
- economic steering instruments
- attitude-conditioning measures
- knowledge development – knowledge dissemination – knowledge banks.

These measures will bring us closer to a society for all. A firmer foundation will be created for the further development of individual self-determination and of the solidarity which must exist in a democratic society.

The role of the organisations of the disabled (Chap. 4)

The organisations of the disabled constitute one of the popular movements of Sweden, and their history goes back a hundred years or more. Today these organisations have a combined membership of some 450,000.

The disabled movement has been and remains a very important factor of active reforming policy in our country. The organisations act, for example, by taking part in consultation processes connected with official inquiries, by supplying expert and political advisors for those inquiries, and by lobbying representatives of policy-making bodies.

The Commission feels that consumer interests/user influence must be reinforced. To reduce the risk of persons with functional impairments being placed at a disadvantage and incurring discriminatory treatment in the local government context, we recommend that a provision be added to the Local Government Act making it the duty of municipalities to assert, in all their activities, the parity status of the disabled. For the purpose of keeping developments under observation, we also recommend that the municipalities, as part of their obligatory annual reporting (under the Local Government Act), be required to show what provision has been made for parity of status in all their various activities.

The organisational changes which are now taking place in local government are transforming the conditions in which the

disabled movement conducts its policy-conditioning activities. This, we have stressed, means additional demands on the organisations of the disabled. It is also our opinion that society stands to benefit considerably from a well-informed, knowledgeable disabled movement. In order for that movement to be capable, among other things, of acting in the planning and programming context at, say, municipal level, we have recommended a more extensive right of basic public information. Furthermore, we have assumed that the organisations of the disabled will continue to receive wide-ranging support from the community.

International development trends (Chap. 5)

The internationalisation by which developments in Sweden are increasingly dominated, are of great moment to persons with functional impairments. Co-operation within the EC is one such example, but developments outside the EC are also important.

Where the EC is concerned, we may note that the structure of social security systems in the member countries will continue to be of national concern, concurrently with certain uniform principles.

We have not been able to find any conflicts between our proposals and current or impending EC conventions.

Sweden should act through various international agencies to disseminate the attitudes, working procedures etc. established within Swedish policy for the disabled. It is especially important that these tasks should be accomplished in the holistic perspective which is presented in our report and which implies that every sector of society has a responsibility for access-creating measures and that disabled members of the community must have access, on the same terms as others, to the goods, services etc. which each sector affords.

The EEA agreement raises new questions which can have far-reaching implications for our country. We have found cause to strengthen the monitoring of questions concerning the disabled through Sweden's delegation to the EC in Brussels. We believe that a council, specially charged with observing questions of concern to the disabled, should be added to the Swedish delegation.

In this chapter we describe certain international initiatives concerning legislation, the development of standards etc. We go on to describe the position and working methods of organisations of the disabled in various countries. In doing so we note the importance of creating opportunities for co-operation between Swedish organisations of the disabled and their counterparts in other countries. Initiatives in this direction ought, in our opinion, to be supported, partly as a means of encouraging the development of organisations by disabled persons themselves as a means of exerting influence. In our country, organisations and their working methods are permeated by this view. In many other countries, organisations of the disabled are run by professional groups in a manner which prevents the disabled themselves from gaining a hearing for their viewpoints, experience and knowledge.

Equality and participation of the disabled (Chap. 6)

One consistent theme of our report is ways in which society can be opened up and made accessible to people with functional impairments.

As a means to this end we wish to apply the principle of responsibility and funding, which means that environments and activities must be designed and conducted so as to make them accessible to everybody. The cost of creating accessibility is viewed as a natural part of total expenditure on the activity concerned and, accordingly, is to be financed like the rest of the activity.

To strengthen this principle in practice, we have given priority to eight fields which, according to our investigations and in the experience of the organisations of the disabled, present risks of discrimination and many great impediments to the disabled. Often those impediments also give rise to expensive and restrictive separate solutions.

The eight sectors of society to which we have given priority and which we describe here in separate chapters are basic public information (Chap. 7), local government activities (Chap. 8), the accessibility of buildings and environments (Chap. 9), the fields of culture, media and teaching materials (Chap. 10), travel facilities (Chap. 11), telecommunications (Chap. 12), the employment sector (Chap. 13) and economic activity (Chap. 14).

We analyse the possibilities of introducing legislation on the responsibility and funding principle (abbreviated "the AF principle" in Swedish), partly through programme enactments or constitutional prohibitions of discrimination. In addition, we analyse the effects of a possible discrimination ban through other legislation.

We opt for the inclusion in the Constitution Act of a ban on discrimination, by law or statutory instrument, on grounds of functional impairment, and also for an exploration of the possibility of introducing prohibitions with penal provisions in central areas of the law, based on our fundamental principles.

This chapter contains a review of American legislation, including the Americans with Disabilities Act (ADA, passed in 1990), which prohibits discrimination of disabled persons in both the public and private sectors. The ADA includes sanctions to secure compliance with its stipulations in various fields.

Up till now, Swedish law has included no provisions of the kind to be found in the ADA. However, the regulations we propose in the social sectors to which we have given priority are based on that legislation.

In the eight sectors mentioned previously, we recommend measures to make sectorial amenities available and in this way to strengthen individual prospects of equality and participation. We recommend various sanctions, e.g. contingent fines, for non-fulfilment of the stipulations.

The right to basic public information (Chap. 7)

Freedom of information and the right to inspect public domain documents are cornerstones of our democratic society. These rights apply to all citizens and are protected by the constitution.

Even so, disabled persons often experience great difficulty in procuring information. This can be because a wheelchair-bound person is unable to enter the premises where a public domain document is kept. It can also be due to a lack of interpreting services for the deaf, deaf-blind and hearing-impaired, or to lack of opportunity for visually handicapped persons to study a document in an available medium, such as cassette recording or Braille. We also note that negative response and challenging of the disabled individual's claims are

not uncommon and compound the obstacles encountered by disabled persons when requesting information.

Although existing legislation could be a sufficient guarantee of opportunities for disabled persons to obtain basic public information, experience, in our view, clearly indicates a need for stronger legal safeguards. It must be made clear that the service obligations of public authorities (at national, local and regional levels) include access-creating measures for persons with functional impairments. To this end we propose that the Administrative Procedure Act be made to include a revision entitling disabled persons to basic public information in a suitable medium for the individual concerned.

This recommendation also includes individual entitlement, on request, to a modified form of the information widely distributed to the general public (e.g. election information, notice of alterations to municipal charges). Furthermore, we note that information in emergencies (alarms) must be able to reach the deaf, deaf-blind, severely hearing impaired and intellectually handicapped in a manner which they can comprehend.

Municipalities for all (Chap. 8)

The new Local Government Act guarantees members of the community opportunities of participation and influence where municipal and county council activities are concerned, but there is nothing in the new Act to strengthen the equality of treatment for the disabled.

Knowledge and experience accumulated in the course of the Commission's work have shown, however, that, in a time of extensive structural changes, it is very important that legislation should be passed requiring local authorities, in all their activities, to ensure parity of status for the disabled in relation to other members of the community.

To make this clear, we propose that the following provision be added to the new Local Government Act: "Municipalities and county councils shall in all their activities assure disabled persons of parity of status with other members of the community." This makes clear the duty of municipalities and their various sectors to offer the disabled a quality of services equalling that received by other residents. It will then also be the duty of local authorities to take necessary measures of access

creation. These are to be financed like any other local government activity, in keeping with the AF principle.

The municipalities are required to present annual reports on their activities, including activities conducted under the aegis of a different legal corporation, such as a foundation or a municipally owned company.

Our investigations have shown that measures to create access for the disabled in the community have fallen behind in many respects. We underscore the responsibilities of municipalities and county councils by proposing a special provision in the Local Government Act to the effect that municipal annual reports are to specify the disabled access measures taken during the year.

An account of this kind will make it possible for the organisations of the disabled, for example, to see at a glance what has been achieved. It will also be possible in this way to procure information on the effects of policy decisions made and on the extent to which the fundamental principles defined by ourselves have been put into practice.

A purpose-oriented build-up of knowledge is also needed within the municipalities. Outreach activities are an important means to this end. In several proposals we have underlined their significance and the importance of these measures being taken regularly and in such a way as to convey an accurate picture of environmental and psycho-social conditions and structural aspects. Needless to say, the methodology employed must comply with the provisions of the Secrecy Act.

Municipal plans and programmes on the subject of access must reflect the line of policy adopted and at the same time be practical and concrete. They must also be amenable to monitoring and evaluation in the short and long term. The organisations of the disabled, if they are to make their influence felt, must be enabled to enter the policy-making process at an early stage. The organisational side of co-operation must be worked out according to local conditions. It is important that the participation of the organisations of the disabled should be made to focus on points where they are possessed of special competence.

Disabled persons and the design of housing and the environment (Chap. 9)

Public environments and housing of recent date afford relatively good basic access, above all to the physically disabled, but new premises are still being built with separate levels/stairs which have to be negotiated. As a general rule, poor provision is made concerning access and serviceability to persons with impaired orientation capacity. Street and other outdoor environments often display great deficiencies (kerbs, steps, steep gradients and poor orientation qualities).

The really serious problems affecting the disabled occur in older environments, housing etc. Conditions there are often of such a kind that convenient individual modifications are hard to achieve.

The effects of these deficiencies on the individual include greater dependence on personal assistance, less freedom of choice and, in certain cases, very great isolation.

In this chapter we emphasise that the concepts of "accessibility" and "serviceability" must be amalgamated into *one* qualitative requirement. Acceptable access is not enough if it does not at the same time enable individuals to make independent use of the environment, activity etc. concerned. In this chapter we discuss attitudes and approaches in the planning and building process, implementation of the Planning and Building Act (and user influence) and the level of stipulations concerning access and serviceability. Against this background, the Commission presents a number of recommendations designed, in the short and long term, to improve qualities of access and serviceability for persons with functional impairments. We believe that attitude conditioning is needed in order to guarantee disabled persons the right and opportunity of participation and influence. We recommend a broad-based information campaign addressed to elected representatives, public servants and the general public. We estimate the cost of this campaign at about MSEK 5.

A deeper knowledge concerning the needs of the disabled is also called for in various training and educational programmes, and we therefore recommend the arrangement of subsequent training for active planners, architects and design consultants on aspects of accessibility.

We believe that the national-municipal housing adjustment grant must be guaranteed by law, so as to improve housing conditions for the disabled. We recommend that disabled tenants be entitled to carry out housing adjustments under the Housing Adjustment Grants Ordinance.

As we see it, everybody actively involved in the planning and building process must comply with the provisions of the Planning and Building Act on structure plans. To underline this point, we recommend a stronger role for the county administration in the planning process. We propose that, in addition to supervising the suitability of environments from the viewpoints of health hazards and accident risks, the county administration should also be empowered to test the accessibility and serviceability of environments. In this way the county administration will be able to overturn decisions contrary to access requirements. The National Board of Housing and Physical Planning will be able to take part in the process by observing, evaluating and publicising good examples of modifications for the disabled.

The existing environment is today the paramount difficulty in the way of access and serviceability for the disabled. This applies both to buildings and to street environments. We therefore recommend that premises to which the general public are admitted be made accessible and serviceable to the disabled. This applies to both private premises and publicly financed premises. We propose an implementation period of 15 years. The stipulation of disabled access, however, should not be altogether absolute. We describe certain cases in which it must be termed manifestly oppressive to stipulate adjustment within a period of 15 years, for example in the case of the person responsible risking insolvency if the modification is made.

We take the street environment to include terminals and stopping points. Our aim is to make it possible for a wheelchair user to get about in the street environment and for persons with reduced orientation capacity to find their way. A 10-year implementation period should apply to the modification of the street environment.

Stipulations concerning the modification of non-housing premises and the street environment are to be given statutory codification through additions to the Planning and Building Act.

Given our proposed implementation periods of 15 and 10 years, the annual cost of modifications is estimated at some MSEK 133 for publicly financed facilities and about MSEK 100 for the street environment. We estimate the cost of modifications to private non-housing premises to be of the same magnitude as for the modification of publicly financed premises, namely MSEK 133 per annum.

The annual cost of modifications to non-housing premises and the street environment will, in our belief, be greatest during the early years, after which it will level out. Thus the amount stated are to be viewed as average costs after aggregation of the varying levels for successive years.

Culture, media and teaching materials – important paths to participation and equality (Chap. 10)

Culture

Cultural institutions (both facilities and activities) must be modified to enable persons with functional impairment to share in cultural amenities generally. Certain cultural activities must also, by way of supplementation and compensation, be designed with special consideration for the needs of, for example, the deaf, deaf-blind, very hard of hearing, visually handicapped and intellectually handicapped. In our view, directional measures should be introduced for these categories and supported by means of non-recurrent State grants of the order of MSEK 2.

Radio and television

A growing proportion of news and information is being conveyed by way of radio and television. Functionally impaired persons are being excluded, owing to severe defects in the accessibility of media. Future agreements between the State and the self-financing enterprises must therefore be made to include exact stipulations concerning measures to provide for the needs of different target groups. Access-creating measures need to be formulated in concrete terms, e.g. as regards timing and type of input. In our opinion, a minimum level for an accessible programme output should be for 50 per cent of daily news transmissions and 10 per cent of activities produced

in-house to be accessible before the end of 1996. The cost of various accessibility creation measures – approximately MSEK 4.5 annually – can be recouped by means of direct charges (previously known as licence fees).

Stipulations concerning access-creating measures should also be laid down by contract in the case of the new television channel (TV 4) and any additional independent channels. The Commission therefore recommends that future concession agreements between the State and independent television companies be made to specify, in transmission hours etc., each company's undertaking, with the same stipulations concerning modification of output as applied to the licence-funded enterprises. The expenditure thus involved in the case of the independent television channels can be financed out of advertising revenues.

Newspapers

Newspapers which are cassette-recorded for the visually handicapped should be made more numerous. We do not believe the newspaper industry to be in a position at present to cope with this by raising prices (in keeping with the AF principle). State support will therefore be needed for five years, after which the possibility should be considered of implementing the AF principle without reducing the selection available to the target group. Modified, easy reading information is needed to reach, for example, the intellectually handicapped and persons with other reading disabilities (e.g. dyslexia). Processed information of this kind is furnished by the newspaper 8 SIDOR, but the Commission believes that further resources are needed in order to enlarge the distribution of this newspaper, so that its circulation and earnings can be augmented. We recommend State support totalling MSEK 2.5, spread out over five years, for the development and marketing of this newspaper.

Books

At present the State provides upwards of MSEK 60 towards publication of talking books.

We believe that publication of talking and LL books (easy readers) needs to be augmented. This support should be funded through the national budget for the coming 5-year period as well. Grants, however, should be written up by MSEK 25 over a five-year period so as to reach larger numbers of disabled persons and to finance a diversification of these publishing activities.

Teaching materials

For the achievement of an equivalent teaching and teaching materials situation for pupils with functional impairments, we recommend that the Education Act be elucidated on the subject of appropriately modified teaching materials, that the supply of talking books for visually handicapped compulsory school and upper secondary school pupils be augmented, that new technology be more efficiently utilised, and that the supply of teaching materials be augmented for the deaf and hearing impaired and for certain physically disabled pupils. In our belief, the need for teaching materials for severely dyslexic pupils calls for a special remit to the National Institute for Questions Concerning the Disabled in the Education Sector (SIH).

With this background in mind, we recommend a non-recurrent allocation of MSEK 5 for upgrading of teaching materials units etc. With effect from 1st January 1995, we recommend that the municipalities be made fully responsible for the requisite modification of teaching materials for pupils with functional impairments.

Travel facilities (Chap. 7)

It is our opinion that, for the disabled as for other people, public transport must be the basis of transport supply. The aim must be for people with functional impairments to be assured of the same travel conditions and opportunities as other members of the community. The individual must be able to travel independently, even by public transport.

We describe in detail two models for establishing concerted responsibility for transport assistance services and public transport. One model is for the county transport administration to be made responsible by law both for mass transit and for transport assistant services.

Another model is for municipalities and the transport administration in each county to conclude a formal agreement whereby the transport administration is to procure and coordinate transport assistance services (including the authorisation of transport assistance operators).

As things now stand, we advocate consistent implementation of a contractual model under the existing regulatory system for public transport, transport assistance services and medical transport.

It is our opinion that experience of the contractual model must be followed up. A statutory model is to be assessed not later than 1996.

Other contents of this chapter include a description of shortcomings in the adjustment of vehicles etc., terminals and environments to the needs posed by various functional impairments (also with reference to "medical disabilities" and to the needs entailed by mental disturbances).

From the viewpoint of the disabled, public transport constitutes a single entity. Adjustment is needed at every stage of the travel process, and we therefore believe that the Mass Transit (modifications for the disabled) Act (1979:558, "HAKO") needs to be supplemented with a provision referring to our proposed provisions in the Planning and Building Act concerning the disabled adjustment, over a ten-year period, of street environments, stopping places and terminals.

Furthermore, in keeping with our basic approach, we feel that the term "passengers with functional impairments" should consistently be substituted for "disabled" in the Mass Transit (modifications for the disabled) Act.

Different types of transport and the need for access-creation measures are considered at length (buses, trackbound vehicles, suburban trains, regional train services, air transport etc.) and stipulations defined concerning time frames and scope for the implementation of various measures. For regular and chartered bus services, a period of about 15 years between 1995 and 2010 is proposed for access adjustment. The additional cost is

estimated at MSEK 130 per annum. For railway carriages we assume an implementation period of 1-15 years, giving an annual expenditure of MSEK 9 for the first five years and MSEK 1.5 for the last five years.

The cost of modifications to suburban trains is estimated at MSEK 3 annually between 1997 and 2002 and MSEK 1.5 up to and including 2012, while for trams it is estimated at MSEK 9 annually between 1997 and 2002. Between 2002 and 2012, the additional cost for trams is estimated at not quite MSEK 10 per annum. As regards airport lift devices, a non-recurrent investment of MSEK 3 is recommended, which would mean all airports in Sweden without nose bridges having lifts installed not more than two years after our recommendations on this subject came into force. All in all, the additional expenditure entailed by the measures outlined comes to MSEK 150 per annum for the first five years and MSEK 140 per annum between 2002 and 2012.

It is proposed that the Commissioner for the Disabled be given the task of monitoring compliance in these connections and be empowered to draw attention, for example, to any failure to meet modification deadlines.

The right to basic telecommunications (Chap. 12)

The development of telecommunications technology represents great, in some cases unique, opportunities of increased participation for persons with functional impairments. We emphasise that basic telecommunications for the disabled mean much more than viable telephone services. The concept should also include ways in which telecommunications, combined with information technology, can facilitate everyday tasks, social contacts etc. and also be a very important factor of security for individual persons (and their next-of-kin). Even when making purely traditional use of telephone services, disabled persons incur additional expenditure compared with other members of the community. To quote one of several possible examples, text telephone calls take 3-10 times longer than the corresponding conventional calls, which makes a big difference to phone bills.

We make recommendations aimed at utilising new advances in technology and at making it economically more feasible for persons with functional impairments to have access to basic

telecommunications on similar terms to other people. Disabled persons must not have to pay more than others for telecommunications services.

We find that ordinary telephone services will predominate throughout the foreseeable future, but that there are several ways in which equipment could be made more easily available and serviceable.

Computer conferencing has proved to open up many new opportunities of contact for persons with extensive functional impairments. We also describe a number of new services (Tele-Guide, telephone reading services, digital transmission of speech, images and text (ISDN), mobile telephony etc.) which have great development potential and can make all the difference to individual persons' everyday lives (and in some cases to those of their next-of-kin).

Companies in the telecommunications sector have paid far too little attention to the needs of the disabled. In our opinion both legislation and incentive measures are needed to bring about changes.

We recommend that the Telecommunications Act which is now being drafted clearly affirm the equal entitlement of all members of the community to basic telecommunications. The tasks of the special telecommunications authority to be set up with effect from 1st July 1992 must, in our view, include the scrutiny and monitoring of provision for the telecommunications needs of the disabled.

We recommend that the AF principle be applied both individually and collectively to the telecommunications sector.

By individual application of the AF principle we mean that the activities of each telecommunications operator must as far as possible be adapted to suit the needs of the disabled. This is to be done subject to normal commercial considerations, and access-creating measures are to be paid for by the operators.

By a collective AF principle we mean that operators together must be responsible for each other's expenditure, and for public and private expenditure, within this sector. This will be accomplished through our proposed establishment of a special Telecommunications Fund.

The Telecommunications Fund will be able to give financial support to:

- private individuals, for the acquisition of expensive telecommunications equipment
- private individuals, for additional daily expenditure on telecommunications
- research and development in this field, with special reference to the needs of the disabled
- operators and companies offering services for the disabled (e.g. intermediary services).

The Telecommunications Fund will be built up by all telephone operators paying an annual charge in proportion to turnover.

The provision of telecommunications aids for private individuals is to be facilitated by making it the duty of the county council rehabilitation and technical aids services to investigate needs and, if necessary, to make requisitions enabling the individual to obtain compensation out of the Telecommunications Fund for the purchase of equipment. If necessary, it is proposed that county councils should help to finance the acquisition and installation of telecommunications aids, and that their additional expenditure on this account be met from the Telecommunications Fund.

For greater lucidity concerning an extensive and complicated output of products, we recommend the introduction of voluntary informative labelling of telecommunications terminals (possibly on a Nordic basis). All in all, we estimate the cost of various measures relating to basic telecommunications for private individuals at MSEK 58 per annum. Together with estimated expenditure on R&D (MSEK 15), text telephones (MSEK 61) and telecommunications aids (MSEK 22), this gives a funding requirement for the Telecommunications Fund of MSEK 156 per annum for the next few years.

Access to the employment sector for persons with functional impairments (Chap. 13)

Individual employers have a very extensive freedom of choice when hiring personnel. Labour legislation contains only a small number of rules aimed at promoting job opportunities for persons with functional impairments. Besides, those rules are generally concerned with safeguards for established employees.

In certain other countries, quota systems are used, to various extents, as a means of giving disabled persons access to the employment sector. Sweden does not have any such systems. On the other hand we have a broad arsenal of labour market policy programmes (counselling, Employability Institutes, Samhall, wage subsidies etc.) designed to improve the job prospects of individual persons.

In Chapter 3 we analyse three alternative forms of steering measures or incentives for job promotion which can also be variously combined with each other:

- (a) wage subsidies
- (b) quota systems
- (c) other economic incentives for employers.

Wage subsidies now take the form of a new, flexible payment at a rate decided through negotiations between employment office and employer. Subsidy rates are based on the jobseeker's capacity and degree of functional impairment.

When the employment situation deteriorates, there is a grave risk of employment offices having to offer higher subsidisation rates in order for hirings to materialise, and also having to pay wage subsidies for persons who would otherwise have obtained work in the regular labour market without any such support.

The Commission strongly underlines the need for following up the new, flexible wage subsidies and their effects on the employment prospects of the disabled.

Quota systems would mean compelling employers to hire a certain proportion of employees with functional impairments. Experience of this type of arrangement in other countries has not been altogether encouraging, partly because it is difficult for small employers to be included in the system, with the result that many suitable job opportunities are lost. It is also the risk of negative attitudes towards persons obtaining jobs through a quota procedure.

The Commission therefore believes that the introduction of quota systems must only be considered as a secondary recourse. We are not completely foreign, however, to a renewed assessment of this possibility, adapted to Swedish conditions.

Other economic incentives would mean employers experiencing palpable consequences of their recruitment policies. For

example, employers hiring persons with functional impairments could be allowed payroll tax reductions, while others not doing so would have to pay higher charges.

The Commission is in favour of developing economic incentives and steering instruments, but great care will have to be taken to develop systems with distinct, simple rules concerning levels of charges etc.

The Commission recommends that no time be lost in developing the following fields, as an overall reinforcement for job promotion measures for persons with functional impairments:

- preparatory measures
- parity of status at work
- measures to strengthen individual capabilities
- economic incentives.

Preparatory measures and measures to strengthen individual capabilities

The Commission proposes a statutory obligation on the part of employers with a certain minimum number of employees (we suggest 25) to make work experience opportunities available for persons referred to by the proposed new enactment, LSS. It is proposed that this duty on the part of employers be defined in a new Access to Employment Act (see below).

In the event of the monopoly of placement services being abolished, the Commission finds that new, non-public employment agencies must also incur a statutory obligation to assist persons with functional impairments.

Employability institutes with special resources (AMI-s institutes) must be able, in a holistic perspective, to offer elements of basic rehabilitation to persons with extensive functional impairments.

Parity of status at work

To safeguard the position of the disabled in working life, we recommend new legislation on access to employment for persons with functional impairments. This proposed legislation requires employers to take both general and individualised measures to promote recruitment and employment opportunities for persons with functional impairments. It also lays down

that employers must not subject an employee or jobseeker to unfavourable treatment on account of his or her functional impairment. This enactment is to be viewed as an upgrading of existing labour law, and a practical implementation of the AF principle.

Economic compensation for additional expenditure connected with access creation measures should eventually be financed within the sector as a whole, e.g. out of payroll tax, but for the time being through the national budget. The stipulations mean among other things that the individual must have access to technical aids or a personal assistant at the workplace if necessary. The proposed legislation also requires the employer, for example, to adjust introduction, training and other suchlike measures within the framework of personnel development.

The proposed legislation includes a system of sanctions against employers discriminating against a jobseeker or employee on account of his or her functional impairment. This means that a previous agreement can be invalidated and/or damages awarded.

It is proposed that the new legislation should replace the existing Promotion of Employment Act.

In addition to the measures which have now been mentioned, we also wish to strengthen start-up opportunities by means of increased economic support. We recommend an experimental scheme of "supported employment", and also an evaluation, in 1993 of the implications for the severely handicapped of the 1992 sick pay reform.

Economic incentives

Economic incentives for employers are vitally important, not only with reference to the occupational environment and rehabilitation, but also as regards job promotion measures for persons with functional impairments. The Commission feels that consideration should be given to developing a system of differentiated payroll taxes. It is suggested that the system could provide for a payroll tax reduction in the case of an employer taking measures to facilitate the hiring and employment of persons with functional impairments.

We also observe in this chapter that research and devel-

opment focusing on the working conditions of the disabled needs to be intensified. Among other things, we recommend the endowment of a special professorial chair in methods development for making the employment sector accessible to the disabled.

The expenditure entailed by our recommendations refers mainly to the State allocations for labour market policy measures. Most of the persons affected by these proposals are receiving temporary or permanent disability pensions and, through the realisation of our proposals, will gain access to active rehabilitation measures. The latter entail costs corresponding to present-day expenditure on the municipal housing supplement and social insurance systems. The expenditure entailed by implementation of other measures we propose is MSEK 30 annually over a three-year period for increased start-up support and an experimental scheme of "supported employment", plus MSEK 1.5 annually for research.

Discrimination in the enterprise sector (Chap. 14)

Through news media and the experience transmitted by individuals and organisations of the disabled, the Commission has been able to study many examples of discriminatory response to persons with functional impairments. Examples include the non-admission of intellectually handicapped persons to a restaurant, exclusion of a wheelchair-bound person from a certain form of transport, and the non-availability of public premises to persons with functional impairments. There are at present no statutory provisions to protect disabled persons against discrimination in the enterprise sector.

In our view, society must emphatically reject different forms of prejudiced behaviour towards the disabled. As a matter of principle, it is important that society should actively support persons who are disfavoured on account of functional impairments.

We therefore recommend a safeguard against discrimination of the disabled, through the establishment of a faculty of common prosecution in cases where a person is subjected to discrimination on account of functional impairment. This provision should be made to supplement the existing provision of

the Penal Code (Chap. 16, Section 9) on the subject of unlawful discrimination.

This proposal of ours has far-reaching implications. It can come into play, for example, when a disabled person is refused admission to a restaurant on account of his or her functional impairment and when a disabled person is denied the opportunity of using a form of public transport on the same terms as other people. Unlawful discrimination can also occur when a tradesman has not modified a technically controlled service (e.g. a cash dispenser or telephone booth) so that it can be used by a disabled person.

A discriminatory act can also take the form of a remark, gesture or act of violence etc. The provision in the Penal Code applies only to situations where a person intentionally disfavours another person by treating him less beneficially than others. The penalty for such unlawful discrimination is a fine or up to one year's imprisonment.

As regards access to premises to which the general public are admitted, amendments have been proposed to the Planning and Building Act. Failure to modify premises or the street environment so as to make them accessible to a person with a functional impairment cannot be deemed criminal discrimination. The Commission proposes that, in situations of this kind, the Commissioner for the Disabled should be empowered, under the Planning and Building Act, to issue an injunction and to set a contingent fine as a means of securing accessibility.

The ban on discrimination also applies to a person employed in a business activity and to national or local government servants.

We feel it is important that, within the scope of his remit, the Commissioner for the Disabled should keep developments under observation and should be empowered, on behalf of the individual, to file criminal proceedings for unlawful discrimination in cases where the prosecutor does not do so.

Monitoring of parity of status for the disabled (Chap. 15)

As we see it, monitoring of the parity of status of the disabled with other members of the community must be conducted in a variety of ways.

In all their activities, municipalities and county councils must assure disabled persons of parity of status with others. We have recommended that an addition to this effect be made to the Local Government Act.

Every sector of society has a duty of monitoring questions relating to the disabled and their conditions. These matters must be administered and developed on a basis of integration with other sectorial tasks. We feel it is insufficient for observation, development etc. to be carried out solely by authorities specialising in matters of concern to the disabled. These authorities have an advantage in their ability to maintain a high level of overall competence in practical issues, but there is a serious risk of others in each sector "passing the buck", thereby giving rise to undesirable special solutions.

For this reason, we also see a need for a vigorous function which, acting throughout the length and breadth of society, can monitor compliance with legislation etc. and take special care to ensure that disabled persons are not unfavourably treated. We have recommended the appointment, with effect from 1st July 1993, of a special ombudsman, the Commissioner for the Disabled, who will have advisory and informative duties and at the same time will have the task of scrutinising and evaluating current legislation in this field.

In addition, the Commissioner for the disabled will guarantee the rights of the disabled in the community and will be able to act throughout the length and breadth of society. To be capable of discharging this duty, the Commissioner, acting in partnership with organisations and national authorities, should endeavour to create a better insight into current rules and their underlying values, and to initiate processes of change to assert the interests of the disabled.

The tasks of the Commissioner are both general and individual.

General tasks include deliberations with national and municipal authorities, companies and organisations etc., to pro-

mote opportunities for the disabled to utilise public and private activities in a manner conducive to participation and parity of status. Deliberations of this kind can be partly based on the welfare studies which we propose should be carried out by SCB (Statistics Sweden) with special reference to the living conditions of severely disabled persons (see below).

Individual tasks include giving advice and information to individual persons on how to exercise their rights, whom they should turn to and so on.

In certain respects we recommend powers of litigation for the Commissioner, though he is not to act as the individual person's "advocate". As we see it, the Commissioner must be authorised, on his own initiative, to represent the individual in matters involving important legal precedence. This will equip the Commissioner with a further means of monitoring the practical workings of the law.

This will require close deliberations in every sector of society. Following such deliberations, we have recommended solutions which in certain cases differ from each other with regard to the eight sectors to which we have given priority. In two of those sectors – employment and business enterprise – we recommend, in detailed provisions, a ban on the discrimination of disabled persons. We also recommend legal sanctions in this connection. In these sectors the Commissioner for the Disabled will have the task of instigating proceedings in cases and matters involving significant legal precedents. Where the employment sector is concerned, we recommend that the Commissioner for the Disabled be authorised to represent the individual if there are otherwise special reasons for doing so.

In certain other sectors we recommend that the Commissioner be given the task of monitoring compliance with, for example, deadlines for the implementation of access creation measures which we have proposed. In these connections we recommend that the Commissioner be able to exercise coercive powers by setting contingent fines.

We have indicated the responsibilities and powers of the Commissioner in a draft Commissioner for the Disabled Act.

In this chapter we also put forward other proposals for monitoring the parity of status of the disabled.

We recommend that SCB be especially instructed to maintain continuous observation of welfare developments among

the severely disabled and that this material be placed at the disposal of mandators, user organisations, the Commissioner for the Disabled and others.

Management of State grants to the organisations of the disabled is geared to the National Board of Health and Welfare and to the Board's existing administrative responsibilities for these grants.

A revised allocation of tasks with distinct responsibilities for each sector of society leads the Commission to recommend that the National Council for the Disabled (SHR) be abolished with effect from 1st July 1993.

We estimate that the new expenditure entailed by setting up the office of the Commissioner for the Disabled, about MSEK 5 annually, will be covered by the funds at present paid to SHR.

Leisure, recreation and holidays (Chap. 16)

The Commission's deliberations and recommendations concerning leisure, recreation and holidays for persons with extensive functional impairments are presented in this and three of the Commission's previous reports. Together these various proposals make up a single entity. Different individuals have different ideas on the content of rewarding leisure, recreation and holidays. Accordingly, the Commission has seen as its main task an effort to achieve fair opportunities for freedom of choice and scope for catering to various interests. Leisure, recreation and holidays in the individual situation are more important to many severely disabled persons than to others in the context of wellbeing, health and quality of life.

As we see it, the most important stages in improving leisure, recreation and holiday opportunities for the severely disabled are

- firm establishment and realisation of the AF principle as applied to access creation measures,
- introduction of individualised recommendations from our main report (SOU 1991:46), and especially measures under the proposed Support and Services (certain functionally impaired categories) Act, LSS.
- certain supplementary measures which we recommend in this chapter, e.g. concerning facilities for recreation, holidays and travel services.

- follow-up and monitoring of the planning and implementation of measures promoting parity of status for the disabled, viz through the monitoring responsibilities of various authorities and through the proposed appointment of a special Commissioner for the Disabled.

Furthermore, we refer to the need, greatly emphasised by ourselves, for continuous and efficient outreach activities.

We recommend national financial support for recreation and holiday facilities, having the whole of Sweden as their catchment area. We believe, however, that this question should be reconsidered during the second half of the 1990s. The aim should be to devise forms of municipal support for these activities.

We recommend certain guidelines for the State operating budget for recreational facilities as they now stand. The general principle is for disabled persons to pay the same boarding house charges as other guests, at the same time as compensation is paid for the additional cost entailed by extra equipment and service within the facility or establishment. In this chapter we put forward detailed proposals concerning the basis for calculating this grant, which is made up of various components.

Travel services need to be reinforced at several stages. In this chapter we observe, among other things, that, under the AF principle, travel arrangers should be obliged to provide information about their activities in a manner which is accessible to persons with various functional impairments. One of the first steps must be to draw the attention of the interest organisation of the travel sector to this need. In addition, we recommend that the Swedish Institute for disabled persons and the National Board for Consumer Policies be given the special assignment of developing this proposal into a formal obligation.

We also take the view that informative labelling of journeys (especially to foreign destinations) must be conducted in a manner clearly indicating the degree and nature of modification for the disabled. The National Board for Consumer Policies should be given the task of studying this question further, together with the Swedish Institute for Disabled Persons, representatives of the travel sector and the organisations of the

disabled. Special attention should be paid to the needs of persons with severe functional impairments.

Furthermore, we find that existing travel opportunities need to be supplemented with journeys whose tempo, activities etc. are adapted to the needs entailed by various functional impairments. In this connection, close attention must also be paid to the development of "technology-controlled" services, to ensure that these do not create new impediments. The National Board for Consumer Policies and the Swedish Institute for Disabled persons should be given the task of campaigning in the travel sector for the supplementation of travel opportunities.

The additional expense entailed by travel arrangers through adjustment measures should, in keeping with the AF principle, be jointly borne by all travellers.

Individual persons incur expenditure on account, for example, of personal assistance. To enable people receiving personal assistance under LSS to go on holiday journeys, there must be special compensatory arrangements for extra expenditure in this connection. A first step in this direction must be for the individual to be entitled to at least one week's holiday a year with full personal assistance. We recommend support of the order of MSEK 55.

Our proposal concerning financial support for recreation and holiday facilities will entail raising the annual State grant concerned by MSEK 4.5.

Technical aids at work (Chap. 18)

No regulations exist today on the subject of technical aids in the employment sector. Employers, it is true, are responsible for the occupational environment and workplace adjustments, and are also primarily responsible for vocational rehabilitation, but their explicit responsibilities do not include the provision of technical aids at the workplace. On the other hand, employers do incur primary responsibility for the vocational rehabilitation of established employees.

Labour market authorities are primarily required to pay grants for workplace aids for unemployed persons with functional impairments, and for workplace aids during the first six months of employment. Social insurance offices can award grants towards the cost of workplace aids for employees.

The individual can encounter difficulties due to responsibility for different kinds of technical aids being divided between several agencies, and due to the poor availability of lucid, up-to-date information on technical aids and other matters. To the employer, the recruitment of persons requiring technical aids means additional expenditure and a need to acquire new knowledge of fields with which he or she is not immediately familiar.

From the viewpoint of society, the fragmentation of responsibility for technical and working aids respectively makes it difficult to derive full benefit from opportunities of co-ordination between different sectors (medical care, the labour market). In addition, decentralisation can mean a risk of specialised knowledge being undermined. Economic pressure also creates uncertainty concerning the possibilities of providing advanced technical aids etc. when they are needed. Thus there are several reasons for underscoring the necessity of stronger co-operation.

Given this background, we define the following overriding demands where workplace aids are concerned:

- better access to adequate, modern and efficient working aids, as a means of asserting the work strategy for our target group
- stronger stipulations/incentives for employers to ensure that working aids are available
- a distinct allocation of responsibilities between public authorities and a small number of uniform interfaces, for rational processing of individual cases etc.
- hotline support for users and employers
- stronger motive forces for research and development concerning technical aids.

To these ends, we recommend that the supply of working aids be regulated by the legislation we have proposed on access to working life. We recommend that employers be obliged to ensure that there are working aids to enable employees with functional impairments to carry out their work. The Commissioner for the Disabled is to safeguard the right of individuals to working aids and will be empowered, in cases of prejudice involving important questions of precedent or when there are

otherwise special reasons for doing so, to bring individual cases before the Labour Court.

The current allocation of responsibilities for grants etc. towards working aids is to be retained but refined. Opportunities of co-operation should be utilised, in order among other things to establish a policy consensus between agencies concerned with these questions. We see an appropriate forum for the treatment of such matters in the local joint groups set up by the social insurance services.

We have devoted special attention to the situation posed by progressive conditions, i.e. illnesses involving successive impairments. Technical aids may become more necessary as time goes on. The social insurance offices should be given more scope for awarding grants to employers in connection with progressive diseases/impairments, on the same lines as with grants for the hiring of new employees. We estimate the additional expenditure thus involved at MSEK 15-20.

It is also our opinion that persons with extensive functional impairments should be assisted, free of charge, by employability institutes with special resources (AMI-S institutes), even in situations where they are not unemployed. We estimate the additional cost of this input at MSEK 2-3.

We believe that a strengthening and distribution of modern technology for the development of new working aids would enable larger numbers of disabled persons to find employment. We therefore recommend a vigorous development input with the aid of the Work Environment Fund and centre formations/knowledge centres. For this purpose, MSEK 75 will be allocated annually over a five-year period from the Working Life Fund.

Within the employment sector, the Work Environment Fund should be allocated moneys for creating an integrated programme of workplace aids, workplace design and work environment for the disabled etc. As part of this programme, for example, the National Institute of Occupational Health should strengthen its research in this field.

The activities of occupational health services as an expert resource should be promoted and deeper competence established in the disabled sector.

General and individual measures for immigrants with extensive functional impairments (Chap. 18)

Impediments affecting persons with extensive functional impairments and immigrant backgrounds can be eliminated by the same fundamental approach and essentially the same procedures, and also with supplementary measures, in the manner already indicated in the course of our inquiry. "Immigrant background" is a concept which lacks a general definition. It is not to be regarded as a disability in itself.

In our view, responsibilities and duties entailed by activities concerned, for example, with habilitation, rehabilitation, support and service must be discharged with the degree of individualisation which is always needed, regardless of whether or not the individual has a so-called immigrant background. Manners of response, knowledge and experience must be developed so as to ensure that responsibilities and duties are not shirked when individual persons need linguistic or other assistance in order to obtain necessary support.

In this chapter we review changes which have occurred with regard to questions raised in our survey report (SOU 1990:19), e.g. new forms of State compensation for municipal refugee reception, the situation for quota refugees, projects for refugee children.

We go on to observe that persons with immigrant backgrounds are included in the target group for previous proposals in our main report, by virtue of their needs as entailed by extensive functional impairments. This means that their situation can be improved through development of outreach activities, planning and information in keeping with our proposed additions to the Social Services Act. Habilitation and rehabilitation, as strengthened by us through additions to the Health and Medical Services Act, will also provide improvements, as will the special rights which can be offered under the new LSS enactment. In all these connections we note the need for measures to facilitate communication between individual persons and representatives of various supportive and service activities, e.g. interpreting services, multilingual services, Swedish language instruction which allows for the necessity of access-creating measures, personal contacts, personal assistance.

The Commission assumes that the National Board of Health and Welfare, as part of its task of monitoring implementation of the new LSS enactment, will also monitor questions relating to supplementary measures (language services, cultural understanding etc.) for persons with immigrant backgrounds.

Furthermore, we recommend that a knowledge centre be given special tasks of collecting knowledge and developing methodology in fields relating to individuals of dual minority status.

It is proposed that the State reimburse municipalities for special measures under LSS (for the same length of time as with the existing "special compensatory payments"). We estimate State expenditure on this account at MSEK 5-8 annually. Synchronisation of individual plans should take place and should be developed further after evaluations of flat-rate grants etc., now being undertaken by the Immigration Board and the Swedish Association of Local Authorities, have been completed.

Changes resulting from ongoing deliberations in the Government Chancellery on matters of asylum should be combined with special consideration for persons with extensive functional impairments. It is proposed that elucidatory programme-writing on the subject of technical aids, among other things, be jointly undertaken by the National Board of Health and Welfare, the Federation of County Councils and the Swedish Immigration Board.

A higher age limit for temporary parent's allowance, to facilitate parental care of severely ill and disabled children (Chap. 19)

With support and service of different kinds, it is possible for many children with functional impairments and their families to live like others who are unafflicted by illness or disability. Youngsters with functional impairments leave home like any others, and so on. In many families, though, public services notwithstanding, the only realistic alternative is for the young person to carry on living at home until his or her entire schooling has been completed.

We believe it is necessary to raise the age limit for entitlement to temporary parent's allowance. We believe that this

increase should apply to the same persons as entitlement to temporary parent's allowance for children between the ages of 12 and 16. The new age limit, according to our proposal, ties in with the entitlement of certain disabled persons to upper secondary schooling. Intellectually handicapped students are entitled to upper secondary schooling up to the end of the spring term of the calendar year in which they are 21. Young persons with severe physical disabilities share the same entitlement to upper secondary schooling. If necessary for the completion of their education, the upper secondary school entitlement of these student categories should be extended to the end of the spring term in the year of their twenty-third birthday.

We feel that a special solution is justified in the case of parents of intellectually handicapped and severely disabled students. Parent's allowance can then be paid until the end of the spring term of the year in which the student is 23, if he or she continues at upper secondary school.

Otherwise we feel that the rules governing temporary parent's allowance for persons between the ages of 12 and 16 must also apply to those affected by the increased age limit. This means that if the child, for example, has a personal assistant, then a parent too can occasionally fill the gap to perform what are normally the personal assistant's duties. This, however, must not result in the municipality or other mandator disclaiming responsibility for personal support which it is legally bound to provide for the parent. Entitlement to this kind of input remains even if the carer/personal assistant is taken ill.

One consequence of the expanded opportunities for compensation will be a commensurate expansion of entitlement to leave of absence from work in order to stay at home and look after the child.

We estimate the additional cost of this reform to national insurance at approximately MSEK 23 annually.

Charges (Chap. 20)

The question of charges has already been studied in the Commission's survey report (SOU 1990:19) and main report (SOU 1991:46).

In the present report we review changes undergone by charges, taxes and incomes in recent years. We note that the

charges made for public homehelp services still vary a great deal from one municipality to another. We also note that the tendency for charges for social services and medical services to increase is likely to continue as a result of increasing financial pressure on municipalities and county councils, combined with a more general policy of reducing the tax ratio. Mindful of the objectives of participation and equality for disabled persons, we counsel against increased charges for important services on which individual persons are dependent in their everyday lives.

We describe the work of related Commissions on matters concerning charges and reimbursement.

The KBT (municipal housing supplement) Commission and the Ädel Charges Commission recently presented reports on the subject of housing support for pensioners (SOU 1992:21) and charges and cost ceilings in caring services for the elderly and disabled (SOU 1992:50). The Additional Expenditure Commission, which among other things is studying questions relating to cost ceilings for medical transport services and an additional tier for the system of disability benefit, is expected to conclude its deliberations in the autumn of 1992.

The strategy presented in our main report for reducing inter-municipal differences in charges and cutting the additional expenditure incurred by individual persons is to a certain extent covered by the above-mentioned inquiries. For this reason, we find it inappropriate at the present juncture to make any separate recommendations of our own on the subject of charges. We submit, however, that when studying the reports of the above-mentioned Commissions, the Government should take into account the viewpoints we present and generally try to devise means of eliminating geographic or demographic inequalities in the levying of charges. These efforts must be based on the principle that disabled persons are not to pay extra, compared with others, for the services they need.

In view of the vulnerable position of disabled persons, we recommend an evaluation, not later than 1996, of charges for services, care and attention, technical aids and support for passengers in municipal and county council fields of responsibility, as well as medical benefits and reimbursements in the national government sector. At the same time, the feasibility and necessity of introducing an integrated cost ceiling for

municipal and county council services to the disabled should be elucidated.

Personnel development (Chap. 21)

Training – basic training, further training, in-service training – is an important foundation of professional competence. Good supervision and consultation are also needed, however, in order among other things to develop good capacity for the application of knowledge to various practical duties. This applies, not least, within the scope of our remit.

We note that the current employment situation has radically transformed the recruitment scene in many professions where there was formerly a severe shortage of personnel (physiotherapists, speech therapists, audiological assistants, psychologists etc.). It has now been possible to find qualified, permanent staff for appointments, but this is not to be taken to mean that full provision has been made for the needs of individuals or groups for the services of different professional categories.

Our recommendations stipulates both supplementary and new training for several personnel categories. This need has been underlined both by organisations of the disabled and by mandators of various activities.

It has also been pointed out that aspects concerning the disabled need to be included in the training of a large number of professionals outside the support and service sector, e.g. technicians, architects and others with vital tasks in connection with general access-creating measures.

The Commission emphasises that training, supervision and consultation have several purposes. Prominent among them is the need to develop attitudes towards persons with functional impairments and, for example, questions of social equality and participation.

The Commission therefore recommends, among other things, that outreach activities (under the Social Services Act and the proposed new LSS enactment) be used as an effective basis for the planning of training content etc.

Furthermore, aspects concerning the disabled must have their natural and prominent position in the foundation training of speech therapists, physicians, physiotherapists and others. When allocating funding for these training pro-

grammes, the Ministry of Education and Science should take special care to ensure that such additions are actually made. The National Board of Health and Welfare, within the scope of its follow-up responsibility, is also to pay special attention to educational questions relating to demands concerning the content of various activities.

It is also proposed that the National Board of Health and Welfare, acting in association with the two national organisations of local and regional authorities, be specially instructed to compile an inventory of specialist personnel demand in the habilitation/rehabilitation sector and to repeat such assessments of needs at regular (four-yearly) intervals.

The Commission recommends setting up a new regionally organised specialist/further training scheme of post-secondary level, concentrating on disability studies and habilitation. The further development of expert knowledge involved here will be accomplished by stages and, initially, will involve additional expenditure of MSEK 3. From 1996 onwards, the additional expenditure is estimated at upwards of MSEK 10 annually.

As a quality safeguard, we recommend that training be planned and organised at a number of centres for disability research or corresponding higher education units, which will be enabled to apply for State grants for a special administrative/educational resource. Expenditure under this head is estimated at MSEK 1.5 annually.

This chapter also outlines in-service training measures connected with implementation of the Commission's proposals at municipal and county council level. We stress the value of organisations of the disabled and individual persons with functional impairments taking part in such training. The expenditure involved is estimated at some MSEK 70 per annum for the municipalities and MSEK 5-6 per annum for the county councils.

Research and development (R&D) (Chap. 22)

The Commission's recommendations entail research needs and the need for systematic development. Research is needed of the kind normally regarded as specific disability research, and so is other research which has or should have disability aspects

and relevance to conditions for the disabled. Much the same applies concerning development work.

Given the focus of our inquiry, research is needed concerning both the situation and conditions of individuals and concerning general structures and changes in society.

We have stated that the parity of status of the disabled must be asserted by and be the responsibility of each sector of society and its actors. This task must be accomplished on a basis of integration with other tasks within the sector, and measures taken are to be financed in the same way as those other tasks. This principle also has a bearing on the development of research within the scope of our remit.

We find a clear necessity for supporting and promoting specific disability research.

This, however, is not sufficient. Stronger emphasis must be put on the importance of disability aspects being highlighted in research into other fields. As examples from our deliberations and recommendations, we can quote such fields as transport research, telecommunications research and socio-economic research.

In our opinion, the activities which since 1990 have been affiliated to the Social Science Research Council, and which include the encouragement of disability research, should continue. They should, however, be supplemented by an over-arching (not a parallel) agency which, through the medium of programming, can give wide-ranging expression to research needs relating to the situation of the disabled in society and in different sectors.

We recommend a national programme group for this broad-based monitoring to ensure that important research needs are articulated and expressed in long-term programmes. This will serve to strengthen "disability-relevant" research. Wider fields can then be made to include disability aspects than is possible through the Social Science Research Council.

Each individual research council will then be required to consult the programmes when defining its priorities for the funding of individual research projects.

In its over-arching capacity, the programme group should be

given an over-arching organisation and not be affiliated to research in a particular sector.

The programme group must take suitable action to ensure feedback on the development of the various programmes. This feedback material can then form the basis of future Government Bills on science policy.

Additions to the standing instructions of the research councils will make it their duty to comply with the programming group's definition of priority fields.

We also recommend stronger inputs in certain neglected fields, such as co-ordination between the national research councils and inter- and multi-disciplinary disability research at special centres.

Other neglected fields concern working aids, and we therefore recommend that the Swedish Institute for Disabled Persons be allotted a more distinct role in the projection of research and development needs for this field. Vocational R&D will be reinforced by the Work Environment Fund making an allocation for an integrated programme on workplace design and other matters.

Furthermore, it is proposed that the National Institute of Occupational Health build up a special programme field on this subject. A special professorial chair is proposed in the field of methods development concerning the accessibility of employment to persons with functional impairments.

We also recommend, in view of the importance of the subject fields concerned to the disabled, the establishment of two more professorships, one specialising in habilitation activities for children and young persons with severe functional impairments, and one on economics, with special reference to socio-economic studies of support, services etc. for the disabled.

We also instance a number of other neglected fields, including the accumulation of knowledge concerning immigrants with extensive functional impairments, psychotherapy for the disabled, and other matters. As we see it, these fields should be taken into account, in the course of its future work, by the special national programme group we have proposed.

All in all, we recommend various R&D inputs in connection with our proposals which will entail additional allocations of MSEK 5 annually through the national budget, as well as MSEK 3 annually for two professorships. In addition, we re-

commend a special allocation, through the Working Life Fund, of MSEK 75 annually over a five-year period.

Funding and prioritisation of our proposals (Chap. 23)

As we see it, the basic needs of people with functional impairments must be provided for within the scope of regular social welfare machinery. Special arrangements are only to be resorted to in exceptional cases.

We also take the view that society must eventually be constructed in such a way as to be accessible to all.

Accordingly, and as stated above, we have designated eight priority fields as having a critical bearing on the prospects of disabled persons living a full life in the company of others. We believe the feasibility of consistently applying the AF (responsibility and funding) principle to be greatest in these fields. The expense entailed by various forms of disability adjustment must in the first instance be borne by each individual actor and, in the second instance, by the sector as a whole. This means that adjustment costs are to be covered in the same way as other services/products are financed. In the ultimate analysis, this should lead to the price of the commodity/service in private activities being affected and, in the case of public activities, to priority revisions, self-financing or fiscal financing becoming applicable.

Following a resolution passed by the Riksdag at the New Year 1990, the Government exempted this Commission from the "zero expenditure growth directive". This indicates the importance attached by Government and Riksdag to the necessity of support for the most severely disabled. Despite the deliberations prompting this standpoint, the available scope for funding out of taxation revenue must be termed extremely limited in the short run. In all essential respects, therefore, our proposals will have to be financed by means of revised priorities and by recouping the costs of various inputs through the price of goods or services in each sector concerned. The funding line indicated above implies that everybody will have to share the cost of the inputs, which is fully in agreement with the Commission's own view of solidarity and responsibility.

The starting point for our deliberations has been provided by

the words of the Government Bill on local government finance (Prop. 1991/92:150), passed by the Riksdag in June 1992, to the effect that expenditure imposed on municipalities and county councils must be indicated and the scope for finance made clear at the same time (the funding principle). We believe ourselves to have made clear in this report the financial implications for mandators. We assume that the question of funding frames thus to be allocated by the State when the changes we have proposed, estimated to cost, on average, some MSEK 300 annually, expenditure to be borne by county councils and municipalities, are to be implemented will be discussed by the Government and local/regional authorities for each coming year/period. The Riksdag should then decide, in keeping with the so-called funding principle, on any additional funding frames for the municipalities (charges to be levied, State grants, funding out of taxation revenue) or reduced demands in other fields or scope for general rationalisation. This view does not imply any departure from the application of the responsibility and funding principle to municipalities and county councils.

Cost apportionment

The expenditure entailed by adjustment is primarily to be borne by each actor and, in the second instance, by the social sector as a whole. This means that adjustment costs are to be covered in the same way as the cost of other services/products. This view is reflected by the following apportionment of costs between different sectors. Thus the consumer bears upwards of 40 per cent of the costs, the municipality and county council not quite 30 per cent and the State nearly 17 per cent. Of the remainder, about 7 per cent is covered by the Working Life Fund and about 4 per cent by social insurance. In absolute figures, the apportionment of costs during the initial years will be as follows. (The sum total will then diminish, as described below.)

Sector	Annual cost (MSEK)
Municipalities and county councils	304-323
State	176-180
Social insurance sector	40-46
Working Life Fund	75
Consumers	460.5
Total	1,055.5-1,084.5

The above figures express an average cost spread out over a period of up to 15 years, and they will be at their highest during the initial years, after which they will level out.

In our belief there will be economic scope for these proposed reforms, because the implementation period is fairly long and the total annual cost only about 0.1 per cent of GDP. In each sector, therefore, expenditure will be on a very modest scale.

Priorities

In the matter of priorities, we have been guided by the following three principles:

1. Successive implementation of our recommendations through the adjustment responsibilities of each sector. For the 1990s we give priority to eight sectors of society with full responsibility by law.

2. Adjustment costs are covered by being spread out per commodity/service, which will mean a redistribution of welfare and an equitable assumption of financial responsibility for the measures taken. One consequence of this may be to slow down the implementation of other measures in the sector in favour of an equivalent standard and level of resources for all.

3. To accomplish the basic adjustment of society, we have also chosen to implement the process of change over a longer period. For adjustment of the street environment, for example, we assume an implementation period of between 1 and 10 years, and for adjustment of publicly and privately financed premises to which the general public have access, we assume 1-15 years. Implementation in the telecommunications sector

should take slightly less time, viz 5-10 years. We also expect modifications to buses and trains to take up to 15 years. On the other hand, we assume that measures in the employment, media and cultural sectors can be implemented within an appreciably shorter period, viz between 2 and 5 years. We also assume short implementation times for support in connection with travel and holidays and for implementation of the proposed higher age limit for entitlement to temporary parent's allowance. This is a matter of improvements to existing support which it should be possible to introduce fairly directly.

Apart from differences in implementation time, our recommendations also differ as regards type of input. Improvements to the street environment, the local environment and travel opportunities are investments which to a great extent will be made in connection with general maintenance and improvements. These can also be termed a part of infrastructure development which can be brought forward and undertaken in the form of labour market policy projects at times – like the present – of high unemployment.

Finally, there is cause to observe that the Commission's recommendations concerning, for example, improvements to the street environment and transport will also make things easy for large groups of non-disabled persons. Furthermore, early implementation of inputs can avert the heavy additional expenditure which can otherwise occur when measures become necessary at a later stage.

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