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Disability Welfare Justice
[Report]

43pgs

DISABILITY WELFARE JUSTICE

Summary

SOU 1991:49

Report of the 1989 Disability Commission

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A Society For All [Report] 52pgs

A SOCIETY FOR ALL

Summary

SOU 1992:52

Final report of the 1989 Commission on Policies for the Disabled

not cited in study

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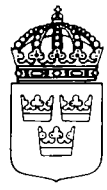

S T A T E M E N T

BY

H.E. MR BENGT WESTERBERG
DEPUTY PRIME MINISTER AND
MINISTER OF HEALTH AND SOCIAL AFFAIRS

IN THE GENERAL DEBATE OF THE 47TH SESSION OF THE GENERAL ASSEMBLY

IN OBSERVANCE OF THE CONCLUSION OF THE UNITED NATIONS
DECADE OF DISABLED PERSONS

12 October 1992

PERMANENT MISSION OF SWEDEN TO THE UNITED NATIONS
885 SECOND AVENUE • NEW YORK, NY 10017 • TEL (212) 751-5900 • FAX (212) 832-0389

CHECK AGAINST DELIVERY

Mr President,

Allow me first of all to congratulate you and your colleagues in the Bureau on your election. I feel confident that we may look forward to a constructive and fruitful Assembly discussion.

Mr President, The United Nations Decade of Persons with Disabilities has led to increasing international awareness of the needs and capacities of persons with disabilities. It has stimulated activities throughout the world.

To a very high degree they are the product of longstanding, persistent and arduous work of people with disabilities themselves and their organizations.

Sweden was one of the countries playing a very active role in the preparation of the Decade. We were most satisfied to see important elements of our own outlook on policies for people with disabilities reflected in the World Programme of Action, in particular the notion of equalization of opportunity: our societies have to be planned and adapted to respond to the special needs of people with disabilities. This is a tremendous challenge since it involves such a wide range of policies: education, employment, social services, city planning, transportation, just to mention a few. It requires resources. But it has to be done.

To read the Secretary-General's report is sobering. Much of the World Programme still awaits its realization. We have to use this opportunity to move forward, and the time is right: we meet just a few months after the Rio Conference which focused attention

Our deliberations here should result in the establishment of a realistic basis for a long term strategy for action in the field of disability by the international community. Anything less than that would mean letting people with disabilities down at the very moment when they have their highest hopes pinned on us. It is certainly incumbent upon us to move beyond the rhetoric which has so often beclouded our vision to a plan for concrete and practical action.

Mr President, in several countries, national programmes of action have been formulated on the basis of the World Programme to promote their implementation.

Thus, there is no lack of recommendations and declarations regarding the rights and needs of various groups of people with disabilities. But unfortunately many share - at least in my opinion - a basic shortcoming, namely a virtual absence of effective mechanisms for monitoring their implementation by the international community and by Member States. Therefore, Member States have been prone to look upon the precepts they contain in rather a non-committal fashion, rather than seeing them as a set of rules to guide conduct.

Mr President, precisely to improve upon the implementation of the World Programme, and its monitoring, and following a Swedish initiative at the first regular session in 1990 of ECOSOC, the Commission for Social Development in 1991 established an ad hoc open-ended working group to elaborate standard rules on the equalization of opportunities for people with disabilities.

A large number of member states have taken part in the work of the group, and the international organizations of people with disabilities have contributed actively to its deliberations and to the good result of its efforts.

The Standard Rules form in our view an integral and central part of a longterm strategy of international action. While they are not legally binding they will provide an important yardstick by which each of us may measure progress.

I should like to underline that we view the integration of disability matters into the general context of social planning as fundamental to the process of realizing the human rights of people with disabilities.

Mr President, I should now like to turn to what I believe should be some of the basic tenets underlying our long-term strategy for international action.

First, we need to be clear in our minds as to what we regard as the very concept of disability. What constitutes disability and how does it manifest itself socially, economically, culturally, politically?

Second, do we have the requisite tools for getting our facts straight, so as to be reasonably assured that the various measures we undertake reflect real conditions and problems?

As regards the first item, I share the view that disability ought to be looked upon as one of several natural and inevitable differences between people. Society must be designed for and adapt to all of us. Or expressed in different words: A disability is not a characteristic of the individual, but a relationship between the individual and her or his environment. This attitude to disabilities entails political consequences as regards social planning. It challenges us to design society so that we may all participate in it. My basic assumption is that people with disabilities should not be regarded as a <u>problem</u>, but that society should be adapted to suit everybody.

Let me now come to my second question. It emphasizes that our views and measures must reflect actual conditions and thorough comprehension of facts.Sweden has recently completed a major governmental survey of conditions for people with disabilities. It indicates clearly that, in spite of general improvements in their life conditions, people with disabilities still lag behind others in a number of respects. This is especially true of people with severe or multiple disabilities.

Without doubt, the right to decide for ourselves in matters concerning our own situation is central to the quality of life. The Swedish survey shows, however, that dependency on others is a frequent fact of life for many persons with disabilities. In fact, only a very small proportion of interviewees with severe disabilities considered themselves in a position to determine who should provide them with requisite support services.

Mr President, this survey forms the basis for a very far reaching reform. I am pleased to have this opportunity to tell you something about the Swedish Government's disability policy.

I should like to point out that, despite the severest and longest recession that Sweden has experienced in the last sixty years, we are not only implementing a costly reformn, but we are also doing so on the basis of a fundamental approach to disabilities that is very much inspired and supported by the organizations of people with disabilities involved in this field.

About two weeks ago The Swedish Government decided to propose new legislation to Parliament.

The legislation will apply to about one hundred thousand Swedes, in particular:

* people with mental retardation and autism;
* people with considerable brain injuries;
* people who, due to other serious and permanent functional disabilities, encounter substantial difficulty in their daily lives and are in need of extensive support. These people will have a statutory right to

* personal assistance
* counselling and expert help
* a contact person
* various kinds of respite care
* apartments with special services or group homes
* an individual support plan

The most important of these rights is the right to personal assistance.

Personal assistance will enable the individual to decide in what way and in what situations assistance is given. In some cases this may make all the difference as far as job or study opportunities are concerned.

Others need a small number of attendants whom they know well so as to make themselves understood and be able to obtain information.

For many, this provision of flexible assistance help them to avoid isolation and passivity by limiting their dependence on pre-planned activities.

Mr President,

I have outlined here the broad lines of a far-reaching reform which we are undertaking. It illustrates the commitment of the Swedish Government to pursue policies which are in line with the objectives of the United Nations Decade. But we certainly realise that conditions and opportunities vary from country to country.

In designing and implementing strategies and programmes for international cooperation we must understand and respect national differences with regard to the cultural, social and economic background. Rather than just assessing country positions we must seek to build our policies upon the common understanding that all people are fundamentally equal and are all entitled to the same rights.

Thank you, Mr President

DISABILITY WELFARE JUSTICE

Summary

SOU

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 conclude 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 fines 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 depravation 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

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 opportunities 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 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

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 disadvantages 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 (± 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 with in 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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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 Administra-tion), Chap. 11 (Transport Assistance). Extensive documentation was also supplied by Dick Jonsson, B.Sc. (Econ.), Linköping University, for the economic calculations in Chapter 18.

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