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Social Welfare and Health Care

Data and Information Reform 2005 – Working Group Report, English summary



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Report of the Working Group on Social Welfare and Health Care Data and Information Reform 2005

Summary

The Ministry of Social Affairs and Health set up on 24 April 2002 a Working Group to prepare a proposal for a national social welfare and health care data and information system to be introduced at the beginning of 2005 comprising the corporate data and information of statistics, registers, regularly repeated studies and separate surveys. The system should take into account new data and information needs, the possibilities entailed by data technology, information service, and data security provisions. The system is meant to present the achievement of the objectives set for social and health policy and support the related decision-making. The Working Group was assigned to look at those issues from the point of view of the citizens and clients, municipalities, joint municipal boards and other service providers. Changes in international data needs should also be taken into account. The Working Group had a steering group that co-ordinated the work of the four sub-groups and prepared the proposal for the information and data service system on the basis of the sub-groups' proposals. The sub-groups focused on the service system and its effectiveness, income security, the well-being of the population, and the health of the population. Their reports have been published separately.

In the opinion of the Working Group the present data and information production in the sector and its labour division is mostly workable. In some respects the Working Group suggests changes in the data production. The use of data can be promoted by increasing co-operation, establishing a specific data portal for in social welfare and health care, producing easy-to-use compiled statistics and publications on different themes and by enhancing instruction in the use of data. By the year 2010 the data production within social welfare and health care will be based on electronic data collection from the patient and client records. They enable production of data on non-residential social and health care, service chains and a more rapid and easy data production in particular regarding the activities of the local authorities. The use of electronic documents and production of comparable data presupposes definition of the central terms. The sector needs at regular intervals population surveys; part of the data is produced through health examinations. The sector has inadequate data of children and young people, out-patient primary health care, in some respects of non-residential social welfare services and services for older people. All data in social welfare and health care should be provided by gender, as far as possible. The Working Group considers that the data needed in decision-making by the Ministry of Social Affairs and Health, other related authorities and local authorities and in performance of their duties that is produced by public funds must be available free of charge to the relevant authorities. The data needed in steering by information and making of surveys must be, as a rule, available free of charge. The most important data must also be accessible free of charge to citizens, professionals and the media. A charge corresponding to the amount of work can be collected for additional expenses caused by transfer and working up of data or other measures. According to the Working Group more attention must be paid to data needs at the stage of preparing the legislation, budget and other documents used as tools of guidance so as to enable the assessment of their impact and implementation. Part of the proposals of the Working Group can be implemented by the resources provided under the action and economic plans by prioritising and targeting actions. Several significant objects of development in data and information production however require additional resources.

Key words

data, information, statistics, compilation of statistics, registers, research, social welfare, health care, well-being, health, cash benefits, income security

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Task of the Working Group

On 24 April 2002, the Ministry of Social Affairs and Health appointed a working group to prepare a proposal for a national social welfare and health care data and information system, to be introduced at the beginning of 2005. The system would comprise the data resources of the institutions and agencies under the Ministry of Social Affairs and Health, and would take into account new requirements for data, the opportunities provided by data technology, an information service, and data security regulations. The system would implement the objectives set for social and health policy and support policymaking.

The working group's tasks were:

- 1. To make a summary of the statistics, registers, regularly repeated surveys, and separate studies concerning social welfare and health, and their utilization.
- 2. To assess the data and information requirements concerning the well-being, health, and income of the population. The requirements concern data required in, for instance, policymaking, research, steering by information, legislation drafting, and in monitoring their effects.
- 3. To make proposals concerning the common concepts, classifications, and definitions required in the national provision of data for social welfare and health care, while also taking into account international concepts and definitions.
- 4. To make a proposal for an information and data-service system for social welfare and health care. The system would comprise statistics and registers, as well as regularly repeated surveys and separate studies. The system should encompass all social welfare and health care: public, private, and activities of non-governmental organization. The system should utilize as effectively as possible the data resources of various institutions and organizations, and should permit measurement of the availability, effectiveness, and quality of services.
- 5. To estimate the costs of the system and propose ways to finance it.

The working group should examine the above matters from the points of view of citizens and clients, municipalities, municipal federations, and other service producers. In addition, the working group should take into account the requirements of the managements of organizations and of various professional groups. The development of international data requirements should also be taken into account.

A steering group was appointed to co-ordinate the work of the working group and make a proposal for an information and data-service system for the entire sector based on the proposals of the four sub-groups.

Steering group

Chair:

Deputy Director-General Rolf Myhrman, Ministry of Social Affairs and Health

Members:

Director-General Kimmo Leppo, Deputy Director-General Marjatta Blanco Sequeiros, Deputy Director-General, (from 1 June 2003, Director-General) Aino-Inkeri Hansson, Ministerial Adviser Carin Lindqvist-Virtanen, Director of development Lars-Mikael Bjurström, and Chief Data Officer Johanna Hartman, Ministry of Social Affairs and Health

Deputy Director-General Matti Heikkilä and Director of Division Hannu Hämäläinen, National Research and Development Centre for Welfare and Health (STAKES)

Research Professor Arpo Aromaa, National Public Health Institute

Professor Matti S. Huuskonen, Finnish Institute of Occupational Health

Deputy Director Tarja Holi, National Authority for Medicolegal Affairs

Head of development Rolf Eriksson, Association of Finnish Local and Regional Authorities

Head of statistics Kari Lindroos, Social Insurance Institution

Director Jussi Simpura, Statistics Finland

General Secretary Jouko Vasama, Social and Health Organizations Co-operation Association YTY r.y.

Senior Financial Officer Tiina Heino of the Ministry of Social Affairs and Health was appointed secretary.

The sub-groups and their chairs and secretaries were:

1. The service system and its effectiveness

Chair: Director of Division Hannu Hämäläinen, National Research and Development Centre for Welfare and Health (STAKES)

Secretaries: Development Manager Mika Gissler and Development Manager Anu Muuri, National Research and Development Centre for Welfare (STAKES).

2. Income security

Chair: Head of statistics Kari Lindroos, Social Insurance Institution

Secretaries: Researcher Kati Ahonen, Finnish Centre for Pensions, Planner Pirjo Ylöstalo and Researcher Sari Kehusmaa, Social Insurance Institution.

3. The well-being of the population

Chair: Deputy Director-General Matti Heikkilä, National Research and Development Centre for Welfare and Health (STAKES)

Secretaries: Senior Researcher Sakari Karvonen and Senior Planning Officer Ari Virtanen, National Research and Development Centre for Welfare and Health (STAKES)

4. The health of the population

Chair: Research professor Arpo Aromaa, National Public Health Institute Secretaries: Development Manager Mika Gissler National Research and Development Centre for Welfare and Health (STAKES) and Researcher Sami Heistaro, National Publish Health Institute.

There was extensive participation over the entire administrative sector in the work of the Working Group and its sub-groups. The Working Group and its sub-groups had a total of eighty members. In addition, the groups took evidence from nearly sixty experts in the sector.

The proposals of the Working Group are based on the work and proposals of the sub-groups. The Working Group decided that data and information required for control and permit matters lay outside of its remit. In addition, the Working Group started from the premise that the necessary changes would be taken into account in activity and financial planning mainly through prioritization and rearrangements. The Working Group suggests that means for financing its main proposals should be investigated later by the parties concerned.

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1. Proposals of the Working Group

Basis and background

The data and information needed in the Ministry of Social Affairs and Health and the institutions and agencies under the ministry is extensive and diverse. It ranges from individual and family-level data to the monitoring of overall national effects. The investigation of dependencies between matters and phenomena requires several different data sources and methods, as well as combinations of them. The data sources of social welfare and health care are basic registers and statistics, supplemented by regular population studies (questionnaires, interviews, and health examinations). Using these data resources together one can meet most information requirements. The regular production of data can be supplemented with separate studies, though these should be chosen carefully.

The present production of data and information and the related division of work in the institutions and agencies under the Ministry of Social Affairs and Health is, in the main, efficient. The institutes of the sector should network and increase co-operation to increase data and information utilization. They should also arrange regular management meetings. National Research and Development Centre for Welfare and Health's (STAKES) statistics co-operation group includes representatives of Statistics Finland, STAKES, the Ministry of Social Affairs and Health, the Association of Finnish Local and Regional Authorities, the National Public Health Institute, and the Finnish Institute of Occupational Health. STAKES will continue to develop statistical co-operation in the sector and investigate its extension to the Social Insurance Institution and the Finnish Centre for Pensions.

Increasing use of data and information and avoiding overlapping data collection will improve utilization of the research, statistics, and register material. Co-operation between institutes can improve the utilization and further processing of existing data and information, as well as fill in gaps and improve the preconditions for steering by information. In some areas, there is justification for complementing for making changes and additions to the current production of data and information. Data and information production in social welfare and health sector is also linked to the data and information produced by other sectors.

The differences between municipalities should be taken more into account in data collection, services, and products. There is established co-operation between large towns and this should be exploited. Development should particularly target municipalities with electronic client and patient systems available. Co-operation should take place with municipalities and the suppliers of data systems. In data collection and information services in small municipalities, attention should be paid to their special position and their possibilities to produce and use data and information.

Statistics production of social welfare and health care follows Finland's official statistics quality criteria: data should be useful, valid, up-to-date, easily available, comparable, clear, and the data should be documented and defined. In all data production in the sector, good data protection and security must be ensured. It is also important to ensure that an unreasonable data burden is not placed on the respondent. Data should be produced differentiated by sex/gender whenever possible.

Some of the Working Group's proposals can be implemented by the prioritization and allocation of resources already available by taking the needs into account in plans of action and budgets. Several important data and information production development objectives will, however, demand additional resources.

During the work of the Working Group, a need has arisen to pay increased attention to data and information requirements already when drafting legislation, financial estimates, and other documents used as steering devices for in social welfare and health care, to permit assessment of their effects and implementation.

On the basis of proposals by its sub-groups, the Working Group has assembled ten core proposals. In addition, there are many significant proposals in the reports of the sub-groups, affecting data and information production and the utilization of data and information in various sub-sectors, which should be used as a basis when developing data and information systems. The Working Group has not dealt with them in detail, but has instead left them in the form presented by the sub-groups, for use in future development.

Core proposals by the Working Group

1. The data and information system of social welfare and health

Statistics Finland produces a significant proportion of the data relating to social welfare and health. An important part of the sector's own regular data and information is based on the existing statistics, registers, and population surveys of National Research and Development Centre for Welfare and Health (STAKES), the National Public Health Institute, the Finnish Institute of Occupational Health, the Social Insurance Institution, and the Finnish Centre for Pensions. The institutions in the sector and Statistics Finland should continue to jointly construct a unified base to data, which will enable them to produce data sets and publications covering entire fields.

The task of the Ministry of Social Affairs and Health is to develop data and information system in social welfare and health sector as a whole and pay particular attention to the report and monitoring system required for national policy making and strategic planning. In addition, it is the ministry's task to ensure the provision and sensible use of sufficient resources for

the data and information system of the entire group, as well as to promote co-operation. The ministry should support the development of expertise on data and information resources.

1.1. Social welfare and health care statistics and registers

The Working Group proposes that in data providers in the institutions and agencies under the Ministry of Social Affairs and Health and Statistics Finland continue and further develop the existing central statistics and registers, which are:

- Statistics Finland: Municipal economics and activity statistics, population statistics, employment statistics, statistics on income and property, statistics on income distribution, cause of death statistics, and municipal personnel register.
- STAKES: Alcohol and drugs statistics, register of induced abortions and sterilisations, medical birth register, register of congenital malformations, register of visual impairment, cancer register, statistics on maintenance of children, register on child welfare, care register on institutionalised care in social welfare and health care facilities, statistics on out-patient services in public health care, health care producer statistics, register of institutions, statistics on private providers (social welfare, health care), statistics on social welfare and health care in municipalities, register on social assistance, statistics on social protection expenditure and statistics on health care expenditure and financing.
- National Public Health Institute: Infectious diseases register, national registers of sample surveys (Adult Population and Pensioned Population Health Behaviour and Health surveys, Finrisk -survey, Mini-Finland, and Health 2000 health examination surveys), foodstuffs composition database.
- Finnish Institute of Occupational Health: Work-related diseases register, exposure registers.
- Social Insurance Institution: Benefits registers
- Finnish Centre for Pensions: Employment and pension registers

The data content of the municipalities' financial and activity statistics will be examined concerning the data for 2006 and there after. Attention will then be paid to the needs for changes relating to social welfare and health care proposed by the sub-group of the Working Group especially on children's day-care, and services for the elderly and disabled people.

To correct the lack of data on out-patient primary health care, STAKES will develop a new statistics system together with the expert organizations in the sector, starting in 2005. Data production is based on the available electronic client and patient data systems, which permit monitoring of the care and service chains. The new system will produce, among other things, data on the health of children and young people, on occupational health care, and on mental health. At the same time, the separate survey on infant feeding, conducted every fifth year by the Ministry of Social Affairs and Health and the biannual separate survey on children's vaccinations made by the National Public Health Institute will be discontinued. The development of statistics was started in 2003 with a separate allocation of funds. After the development

stage, STAKES will maintain the data system, together with the other organizations, using annual budgets.

In co-operation with the Ministry of Social Affairs and Health and the Association of Finnish Local and Regional Authorities, STAKES will initiate the continuous, electronic, secure collection of data from the electronic patient and client systems of social welfare and health care facilities. By 2010, the production of social welfare and health care statistics will be based on electronic data collection, including the introduction of electronic signatures. The task of the Ministry of Social Affairs and Health will be to bring legislation concerning social welfare client and patient data up to date by 2007.

The contents of the electronic patient and client records will be based on central core data defined and harmonized in the National Health Project and on development in the social services of electronic data systems to be initiated in the National Development Programme on Social Welfare. The electronic patient and client data systems will be based on the electronic documents used by municipal service providers, so that they will support the policymaking of municipalities and accelerate information production. The development was started in 2003 using separate funding, as part of the National Health Project. In regards of social welfare development it is intended to start in 2005 as part of the National Development Programme on Social Welfare.

1.2. Surveys of the population's living conditions, working conditions, well-being, and health

The Working Group proposes that, in the future, the monitoring system based on population surveys describing the population's living conditions, working conditions, well-being, and health will be as follows:

The basic monitoring system will produce the following data:

- Statistics Finland will monitor the general development of living conditions using two large annual questionnaires. These are the income and living conditions survey EU-SILC¹ and a Labour Force Survey monitoring the population's labour market situation (monthly). An annual income distribution survey will be carried out in connection with EU-SILC. Basic monitoring will also be supported by register-based statistics on income and property and by statistics on income distribution.
- *STAKES* will initiate a new, biannual Welfare and service use questionnaire survey. The survey will combine the population's use of services with questions relating to well-being and health. Alternating surveys (i.e. at 4-year intervals) will have separate themes of children and young people and the elderly. The National Public Health Institute will cooperate in carrying out the research.
- The National Public Health Institute's annual Health behaviour and health among adult population survey will be reduced to a biannual survey and will also be altered to include data on

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¹ EU-SILC = Community Statistics on Income and Living Conditions

the state of well-being and the use of health services. In the future, the present Health behaviour and health among pensioned population -survey will be amalgamated with the adult population survey. Part of the research will be implemented in co-operation with STAKES.

By alternating STAKES's Welfare and service survey and the National Public Health Institute's Health behaviour and health -survey, a unified, up-to-date, rapid, and lightweight monitoring system will be created for the population's well-being and health and for the overall use of services.

In addition, more detailed data, in which methods other than questionnaires are also applied, will be required at regular intervals. The following more detailed data is produced at regular intervals:

- Statistics Finland produces data on consumption by the population about every six years, on wealth every few years, on use of time about every ten years, on leisure also about every ten years, and on working conditions about every six years, depending on the cooperation arrangements.
- *The Finnish Institute of Occupational Health* produces a work and health interview survey every three years, as well as a work capacity barometer and an occupational health care questionnaire survey. From 2006, the work and health interview will also include young people (15 -29-years).
- *STAKES* produces data on substance use and on the well-being and health of school children. Substance use surveys will be co-ordinated and rationalized by alternating the various questionnaires and using them to complement each other more appropriately than at present.
- The National Public Health Institute carries out a Finnrisk -survey on the population's risk factors, every five years, which includes a brief health examination and question-naires and interviews. Furthermore, every ten to fifteen years, new rounds of the Health 2000 survey, including a health examination, are made instead of Finrisk -survey. Other institutes in the sector participate in the implementation. The institute will begin a children's risk factor survey every five years, which will be supported by maternity welfare clinics and school health care. The data will be collected in co-operation with STAKES as part of the new out-patient primary health care data system.
- The Social Insurance Institution, the National Public Health Institute, STAKES, and Statistics Finland are planning a joint interview survey of households (and the institutionalized population) to be carried out every five years, which will be a follow-up of the traditional health security interview surveys of the Social Insurance Institution (so-called TERVA surveys). This will provide detailed data on the needs and use of social welfare and health care services by all ages, and on the subsequent costs, as well as on health, functional limitations, and well-being. The survey will include the interview data required by the Health Interview Surveys (HIS) and of the EU's planned health monitoring system. These surveys will require financing arrangements, to be negotiated separately.

In addition, other studies, surveys, and barometers will be carried out jointly with other sectors.

Table 1 shows the planned timing and order of the surveys to be carried out regularly. Most of the new population surveys can be implemented by co-ordinating the resources of each entity. The data collection and analysis of results of extensive population surveys carried out less frequently will require additional resources in the relevant years and this should be agreed separately.

2. Joint data portal for the sector

Together with STAKES, the National Public Health Institute, the Finnish Institute of Occupational Health, the Social Insurance Institution, and the Finnish Centre for Pensions and other institutes in the field of social welfare and health care, as well as Statistics Finland, the Ministry of Social Affairs and Health will develop a common data portal (similar user interface) relating to the most important data produced by these institutes on health, well-being, services, and social protection. The Ministry of Social Affairs and Health will start preparations for the portal and investigate its costs and funding in 2004. The work must take into consideration the construction of the planned Finnish official statistics portal.

Institutions and agencies under the Ministry of Social Affairs and Health, and Statistics Finland have already, or are developing their own databanks and indicators in their respective areas of responsibility. From the point of view of users, the data is, however, widely scattered and one must know the sector in order to find the right data and information. The data and information sources of the sector and connections to them should be collected in an easy-to-use data portal open to all, which has a similar user interface in all organizations.

3. Well-being and health indicators

The well-being and health indicator databank, which STAKES is continuing to develop together with the Ministry of Social Affairs and Health, the National Public Health Institute, the Finnish Institute of Occupational Health, the Social Insurance Institution, the Finnish Centre for Pensions, and Statistics Finland, will be integrated as part of data portal for the sector of social welfare and health care. The databank, which will be on the Internet, will provide, free of charge, the most important municipal, regional, national, and international basic indicators of well-being, health, use of services and benefits, as well as the most important monitoring indicators in the sector, from 2005.

Responsibility for the development, maintenance, and interpretation of the various indicators will be divided between the institutes, according to their areas of responsibility. STAKES, together with the National Public Health Institute, the Finnish Institute of Occupational Health, the Social Insurance Institution, the Finnish Centre for Pensions, and Statistics Finland, will be responsible for maintaining the databank, in a manner to be agreed separately. The technical development stage of the indicator bank will be funded separately. Maintenance of the databank will be funded from the regular budgetary funds of each organization.

4. Refined publications and statistics

The institutions and agencies under the Ministry of Social Affairs and Health will produce, at regular intervals, easy-to-use publications, in which data from different sources is analysed and interpreted. The institutions and agencies and Statistics Finland will continue to develop the following comprehensive publications describing social protection and the well-being and health of the population:

• Ministry of Social Affairs and Health:

Trends in Social Protection, an annual evaluation by the Ministry of the challenges and future of social protection.

Social and health report, assessment made every fourth year of the implementation of the administration programme. To be made next in 2006.

• STAKES:

Social Welfare and Health Care Service review, a comprehensive publication made every second year on the state of social and health services.

Finnish well-being, a review made every second year on the well-being and living conditions of the population.

Statistical Yearbook on Social Welfare and Health Care, annual review of the most important statistics in social welfare and health care.

Social Protection and Health Care Expenditure, annual statistics on total expenditure on social protection and health care.

• Finnish Centre for Pensions and Social Insurance Institution:

Statistical Yearbook of the Social Insurance Institution, Finland (collection).

Statistical Yearbook of Pensioners in Finland and Statistical Yearbook of Pensioners in Finland by municipality.

• National Public Health Institute:

Health in Finland, the most important data on the health of Finns, at two to four-year intervals.

Various basic reports on population surveys.

• Finnish Institute of Occupational Health:

Work and health in Finland, data every three years on work conditions, the health and well-being of those of working age, and the use of health services.

Work capacity-barometer, data every three years on workplace activities to maintain and promote working capacity.

Occupational health in Finland, data every three years on the national development of the occupational health services system.

• Statistics Finland:

Statistical yearbook

The Working Group proposes that new publications/statistics be produced in the sector:

- Child-care arrangements (Social Insurance Institution and STAKES)
- Cash benefits during rehabilitation (Social Insurance Institution, Finnish Centre for Pensions and Ministry of Labour)
- Cash benefits and rehabilitation services (Rehabilitation Foundation, Rehabilitation Affairs Negotiating Committee, Social Insurance Institution, Finnish Centre for Pensions, Finnish Institute of Occupational Health, National Public Health Institute, and STAKES)

In addition, the Working Group proposes the following publications/statistics:

- Comprehensive data of various daily allowances paid during periods of sickness (Social Insurance Institution)
- Comprehensive publication of cash benefits for the unemployed and those participating in labour-policy measures (Social Insurance Institution, Insurance Supervisory Authority, and Ministry of Labour). Production possibilities to be investigated in negotiations between the above entities.

The construction, procedures, and scheduling of the comprehensive publications will be included in the information production of the actors in the sector, by prioritization and rearranging tasks.

Publications meeting the criteria for Finland's official statistics, will be published in its series.

5. Increasing the utilization of data in and information

Special attention will be paid to the possibilities to use the comprehensive data. The most important statistics, reviews, and reports will be prepared in both printed versions and in versions that can be viewed on websites and electronic versions of them will be made, which will permit further processing of the data. The institutes and agencies of the sector will continue together to construct a database, which will permit complete sets of data and information to be compiled.

The utilization of register data will be increased in the social welfare and health care sector, in research into and monitoring of income security, services, health, and well-being. The Finnish Data Centre for Register Research established by STAKES in 2003 will promote research use.

To increase expertise in the utilization of data and information, training relating to these should be included in basic, post-graduate and further training in the social affairs and health sector. The Ministry of Social Affairs and Health will start negotiations on this with the Ministry of Education. Arrangements are also needed to support the regional and local utilization

of data and information. The Ministry of Social Affairs and Health and the institutes in the sector will develop procedures supporting this objective.

6. Measurement of the population's work capacity and functioning

The most important objectives of social and health policy include the improvement of work capacity and functioning, the extension of the duration of working life, and the improvement of the preconditions for the elderly to look after themselves. Work capacity, functional ability, limitations and disabilities are important indicators when monitoring the health of the population. They are essential data in rehabilitation and pensions solutions at an individual level. In addition, functioning is an important indicator of the need for treatment and care. Improved measurements of work capacity and functioning are needed for health monitoring.

The National Public Health Institute develops and co-ordinates the measurement of the population's functioning while the Finnish Institute of Occupational Health does the same for the measurement of work capacity and the development of indicators. They co-operate with STAKES and other institutes and organizations activity in the sector.

STAKES is responsible for developing the classification of functioning and continues the development and introduction in Finland of the WHO's classification of functioning (ICF²), together with other operators (National Public Health Institute, Finnish Institute of Occupational Health, Social Insurance Institution, professional organizations). STAKES also continues to develop the classification of the functioning and need of care of the elderly (RUG³ and RAI⁴) and the assessment of its development, together with research institutes, municipalities, and institutions involved in the care of the elderly.

The measurement of work capacity and functioning of the population will be developed using existing resources, taking into account international classifications.

7. Policy on payments for the delivery of data and information

Data and information produced with public funds and used in decision-making and in performing official tasks by the Ministry of Social Affairs and Health, other public authorities in the field of social welfare and health care, and by municipalities, will always be available to the appropriate officials free of charge. Data required in activities in the sector, such as in information steering or studies, should as a rule be available free of charge. The most important data and information should also be available for use by citizens, professionals, and the media free of charge. A charge corresponding to the amount of work involved may be levied for the transfer and processing of data and for other operations incurring additional costs.

² ICF = International Classification of Functioning, Disability and Health

³ RUG = Resource Utilization Groups

⁴ RAI = Resident Assessment Instrument

The aim is that all pricing for delivering administrative data should be changed to conform to principles according to the proposals of the Ministry of Finance's working group on interadministrative data supply pricing, as soon as the legislative amendments required by the proposal have been made. The Ministry of Social Affairs and Health has requested the Ministry of Finance to expedite the implementation of the proposals of its working group.

8. Reviewing legislation and procedures

The relevant legislation and procedures should be reviewed, to determine the possibilities of enhancing the possibilities of using person-level statistical and register data required in health monitoring, particularly in the National Public Health Institute and the Finnish Institute of Occupational Health.

9. The concepts, definitions, and classifications of social welfare and health care

STAKES is responsible for defining the concepts of social welfare and health care. As part of the National Health Project, STAKES will develop, together with other operators, an data directory (codes server), containing not only the classifications and nomenclatures in health care, but also the concepts of statistics and register operations in social welfare and health care. The codes server will serve all those requiring common concepts and classifications.

When defining concepts, particular attention will be paid to the concepts needed to classify services for the elderly and disabled and of housing services.

More precise definitions of cash benefits and services are needed to construct comprehensive data. The Social Insurance Institution, the Finnish Centre for Pensions, STAKES, and other data producer organizations unify their definitions to support comprehensive reviews.

Concepts, definitions, and classifications should be based on international concepts, definitions, and classifications, whenever this is possible and sensible.

10. Provision of resources for the proposals of the Working Group

STAKES, The National Public Health Institute and Finnish Institute of Occupational Health will have provided, by 31 January 2004, the Ministry of Social Affairs and Health with justified estimates of the additional funding they will need to implement the proposals of the Working Group. The Ministry of Social Affairs and Health will then prioritize the proposals and decide to what extent they can be included in the activity and financial plans for 2005 and subsequent years.

 Table 1. Plan for alternation of main welfare and health surveys

Institu- tion	Research/ theme	2004	2005	2006	2007	2008	2009	2010
STA- KES	Alcohol & drugs	Alcohol		Drugs	ESPAD ⁵	Alcohol		Drugs
	School health survey (every 2 nd year same munici- palities)	School health survey (½ of Finnish munici- palities)	School health survey (½ of Finnish munici- palities)	School health survey (½ of Finnish munici- palities)	School health survey (½ of Finnish munici- palities)	School health survey (½ of Finnish munici- palities)	School health survey (½ of Finnish munici- palities)	School health survey (½ of Finnish munici- palities)
	Welfare and ser- vices	Welfare and ser- vices ques- tionnaire survey		Welfare and ser- vices ques- tionnaire survey		Welfare and ser- vices ques- tionnaire survey		Welfare and ser- vices ques- tionnaire survey
	Children and young people/ elderly – part	Children and young people		Elderly		Children and young people		Elderly
National Pubic Health Institute	Health behaviour and health		Health behaviour and health among adult and pensioned population		Health behaviour and health among adult and pensioned population		Health behaviour and health among adult and pensioned population	
	Finrisk- survey (5 y)				Finrisk- survey			
	Children's risk factors survey (5 y)		Children's risk factors survey? (time un- certain)					Children's risk factors survey? (time un- certain)
	Health 2000- health examina- tion survey (10-15 y)							2012

⁵ The European School Survey Project on Alcohol and Other Drugs

Institu- tion	Research/ theme	2004	2005	2006	2007	2008	2009	2010
Social Insur- ance Institu- tion / National Public Health Institute	Health monitoring (5 y, incl. EU health monitor- ing)			Health monitor- ing? (year uncertain)				
Finnish Institute of Occu- pational Health	Work and health question-naire (3 y) Work capacity barometer (3 y.) Occupational health care question-naire(3 y)	Work capacity barometer	Occupational health care question-naire	Work and health	Work capacity barometer	Occupational health care questionnaire	Work and health	Work capacity barometer
Statistics Finland	Income and living conditions survey (incl. EU- SILC)	Income and living conditions survey	Income and living conditions survey	Income and living conditions survey	Income and living conditions survey	Income and living conditions survey	Income and living conditions survey	Income and living conditions survey
	Labour Force Survey (every mo.)	Labour Force Survey (LFS)	Labour Force Survey (LFS)	Labour Force Survey (LFS)	Labour Force Survey (LFS)	Labour Force Survey (LFS)	Labour Force Survey (LFS)	Labour Force Survey (LFS)
	Repeated surveys (according to separately confirmed annual programme: consumption, use of time, work conditions, leisure etc., in one year)	Repeated survey	Repeated survey	Repeated survey	Repeated survey	Repeated survey	Repeated survey	Repeated survey

2. Basis and background for the work of the Working Group

Ministry of Social Affairs and Health and institutions and agencies under the ministry require data and information on the general conditions in which policies and actions take place (the *contexts* of action: general living conditions, economic and political conditions) as well as data and information on the *states* of the matters on which a policy is wished to have an impact (the state of the well-being and health of the population). In addition, the activities and systems, which are expected to have an impact on the state of matters, must be described (*interventions*; the social welfare and health service system and cash benefits). Finally, the most demanding need for data and information, relates to the *effects* of policy: how to distinguish between the changes in conditions that are probably a result of interventions and those that are not, and how to assess whether the effects are in the desired direction and of the desired magnitude.

The institutions and agencies under the Ministry of Social Affairs and Health itself produces most of the data and information on its own actions (interventions). It also produces a significant proportion of the data and information concerning the state of the matters. A great deal of data and information production outside of the sector is also available for use in descriptions of the states and especially in descriptions of general conditions. Data of efficacy is produced by the sector itself, for example, by developing indicators, producing comprehensive evaluative reviews, and by carrying out separate studies and research. Such data is also obtained from the products of institutes outside the sector. In addition to up-to-date data, predictive data and assessments concerning the future are also required. Increasingly often, it is also desired to compare the situation in Finland with that in other countries.

Challenges and opportunities

Data and information requirements must be met in a world in which the demand for data in social welfare and health questions appears to be diversifying and the phenomena targeted by data and information production are becoming increasingly varied, but in which data and information production resources remain the same. New data production is, however, needed and existing gaps in data must be filled. In such a situation, data production can be reformed by improving the efficiency of present actions, reducing overlapping, and eliminating production of less needed data and information. In addition to improving the efficiency of actions and activities, information technology will help: a detailed investigation must be made as to how new technical solutions can help in the reforms.

Technology development allows data and information to be provided more comprehensively for the use of different persons requiring data. The interpretation of the data and information then would then increasingly remain the responsibility of each user. This leads to the danger that the diversity of interpretations may increase to such an extent as to impede common discussion. In this new situation, particular care must therefore be taken to ensure that comprehensive reviews with unified interpretation of the data, are produced sufficiently frequently.

Data and information production and evidence-based policy-making

One objective of the data and information reform is to improve the possibilities to practice evidence based policy making. The database must provide all parties (politicians, administrators, social welfare and health experts and personnel, citizens, the media, and business) the opportunity to be informed on the basis of social policy and health policy. Evidence based policy on social welfare and health aims to understand how the actions of government affect living conditions and the state of the well-being and health of the population. It must also be possible to evaluate whether the changes are in line with policy goals and to what extent the changes have taken place as a result of policy measures. For this purpose, the data and information system must produce data and information of the inputs regulated by policy, which are assumed to be connected to the outcomes.

Data and information production should serve three separate needs: *monitoring* (mainly statistics), *evaluation* (mainly surveys, some indicator work), and *prediction* (forecasts). Data and information production for monitoring basically requires a database that is continuous, up-to-date, and understandable. Evaluation principally requires an analytical database that is relevant to policy. Prediction requires data production that is continuous and clearly reveals temporal change. The Data and Information Reform 2005 will seek to improve the data and information system in all three respects.

3. Data and information requirements

Ministry of Social Affairs and Health an the institutions and agencies under it aims to promote good health and functioning in the population and a healthy work and living environment and ensure sufficient income and social welfare and health services. To plan social welfare and health policy, and to evaluate operations, data and information is needed on the national, regional, municipal, organization, and private service-producer levels. Data and information production in the sector is also connected and linked to data and information in other sectors, such as the Ministry of Labour's registers of the unemployed, students' benefits administered by the Ministry of Education, and housing and its support administered by the Ministry of the Environment. These interfaces should be taken into account when building comprehensive data and information systems.

3.1. Basic data and information requirements

The Ministry of Social Affairs and Health, the institutes and agencies under it, other ministries, universities, municipalities, municipal federations, health care districts, research institutes, and individual data and information users all need data and statistics to carry out their tasks. The Ministry of Social Affairs and Health also needs statistics and registers to develop, control, and monitor its sector and its legislation. This data can be grouped as four major entities. Data and information is needed on the population's well-being, its state of health, its income, and social welfare and health services. The data and information should permit municipal, regional, and national social welfare and health policy to be monitored, evaluated, planned, and developed.

The data and information needs of the sector are very broad, relating to the use, coverage, and quality of services, clients' needs, the level, amount, allocation, and payment of benefits, and to the well-being and state of health of the population. Increasing interest is shown in the costs, efficiency, and effectiveness of the actions of the sector and to regional differences. The preparation of legislation needs estimates of the economic, social, and health effects of proposed regulations and of the effects of proposals on equality. Often highly detailed data is needed to make estimates. The sector also needs data for supervision.

Citizens too are entitled and need to be informed of the actions, activities and state of social welfare and health care, and of the level, amount, and allocation to various population groups of different benefits.

Municipalities are responsible for organizing social welfare and health services. The payment of cash benefits is divided among various institutions in the sector.

The Ministry of Social Affairs and Health and the institutions and agencies under it does not alone affect by its decisions the income, well-being, and health of the population, instead other sectors too have a considerable significance. Examples are housing conditions, education, and unemployment. Individuals too affect their own well-being and health by their choices, decisions, and lifestyles.

The figure below shows the framework of all data and information needs of social welfare and health. The figure is a comprehensive illustration off all data and information needs, resources, and different actors. In accordance with the figure the Working Group's sub-groups are called the social welfare and health services group (including occupational health services and rehabilitation) dealing with the means of the sector and a group dealing with cash benefits. The two other sub-groups examine the state of the well-being of the population and the state of its health. Data and information on the well-being and health of the population show the results of actions and also the basis for possible new actions and activities. Work safety and preventive actions are taken into account in the work of all sub-groups on the penetration principle.

State Conditions **Population** Well -being Needs Income Health Rest of **Organizations** the world **Systems** Social welfare Cash Resources and health benefits services Politicians **Experts** Institutions Response and Context assessment

Figure 1. Operational environment of social and health policy

Source: Jussi Simpura, Statistics Finland

3.2. Steering, evaluation and monitoring documents

The Ministry of Social Affairs and Health has published *Strategies for Social Protection 2010* (Ministry of Social Affairs and Health publication 2001:3), committed itself to the *Target and Action Plan for Social Welfare and Health Care 2004-2007* (Ministry of Social Affairs and Health publication 2003:20), and provided quality recommendations for some services. The Health 2015 public health programme has, in turn, outlined the aims of health policy. To monitor these recommendations and objectives, municipalities, the Ministry of Social Affairs and Health, and other entities in the sector require regular up-to-date statistics and data. Besides the aforementioned documents, the actions of the entire sector and its results are reported annually in statutory reports and annual reports. Every four years, the ministry gives parliament a Social welfare and Health Report on the state and development of public health and social protection. This assesses the implementation of the government's aims. The latest report is from 2002. The reports are prepared in the ministry. Data and information produced from statistics, registers, and surveys forms a substantial part of these reports.

In ratifying various international agreements, Finland has agreed to prepare monitoring reports according to the agreements. Various statistics and research data is also needed for these.

3.3. Data and information needs at and from different levels

The experts working in state administration, municipal federations, municipalities, organizations, service producers and buyer organizations, and companies require data and information. Data and information is also required by elected representatives, the media, citizens, researchers, teachers, and students. Statistics Finland is the central authority responsible for data coordination. STAKES is the statistics authority for health and social welfare. Other data and information producers are the National Public Health Institute, the Finnish Institute of Occupational Health, the Social Insurance Institution, and other social insurance organizations.

Data and information can be produced in many different ways. Some data is created as part of the normal activities of the institutions in the sector. Social welfare and health service providers and organizations paying cash benefits produce highly detailed data in their own operations. Data and information covering regions and the whole country can be assembled from this massive data. Besides the data based on statistics and registers, research and its findings are needed in the sector. Research can investigate matters in greater breadth and depth, as well as try to establish the associations between various factors and their effects. Interviews, observations, health examinations, and register studies can be used as research methods.

In the institutions and agencies under the Ministry of Social Affairs and Health, data and information is created mainly in the following ways:

- 1. Authorities/organizations collect data for administrative decision-making and for paying benefits. Administrative data comprises data contained in applications and notifications made by citizens and associations to officials/organizations and data acquired to support the payment by officials/organizations of benefits and for their decision-making. Administrative data is also used for supervision.
- 2. Data collected in supervisory activities requiring permits or announcements.
- 3. Health centres, hospitals, social welfare offices and other offices maintain client and patient documents and registers for providing social welfare and health services. This data is used to monitor, assess, and plan the activities of municipalities' and others' facilities. The data can be used to assess the allocation of services to different population groups. Various authorities and organizations have by statute the right to obtain this data.
- 4. The institutes in the sector carry out research and separate studies, for which new data is collected by sample surveys and existing administrative and register data is also used.

Subject to the provisions of the data protection legislation, data and data sources can be combined to produce more comprehensive and/or detailed data.

In data and information production, it is possible to differentiate the needs of the subject of the data and information of those needing it. Data can be produced at a highly detailed level, starting from individual citizens and clients and ending with national-level compiled data. Similarly, the data and information needs of different users vary widely. The person needing data and information can be an individual citizen, a client, a social welfare or health care professional, a service-providing unit, a municipality, a municipal federation, a region, central administration, or the media.

A citizen mainly needs data and information on the availability and quality of the services produced by various professionals, providers units and other organizations, and their own municipality, as well as on the size and payment of various benefits. To be able to compare the functioning of their own municipality with that of others, citizens need data on the actions and activities of other municipalities. On the other hand, citizens appear more interested in comparative data and information at a national and international level that at a regional level. Citizens' data and information needs vary greatly depending on the individual.

Table 2.	Data and information users and the level and object of their data and information
	needs in social welfare and health care

Data/information users Object and level of data information	Citizen	Client	Professional	Pro- vider unit	Mu- nici- pal- ity	Mu- nicipal federa- tion	Region (provinces)	Na- tion*	International organizations	Media
Citizen	$(\mathbf{x})^1$	-	-	(x)	Х	Х	(x)	(x)	-	(x)
Client	$(\mathbf{x})^1$	x ¹⁾	X	X	X	X	(x)	(x)	-	X
Population	X	X	(x)	X	X	X	X	X	-	X
Professional	(x)	(x)	X	X	X	(x)	(x)	(x)	-	X
Provider unit	X	X	X	X	X	X	(x)	(x)	(x)	X
Municipality	X	X	X	X	X	X	X	X	(x)	X
Municipal federation	(x)	(x)	(x)	(x)	X	X	X	X	-	X
Region (provinces)	(x)	(x)	(x)	(x)	Х	(x)	X	X	X	X
Nation*	X	X	(x)	(x)	X	X	X	X	X	X
International data	X	X	(x)	(x)	(x)	(x)	(x)	X	Х	X

^{*} central administration, research and register functions

Though a client's data and information needs are close to those of a citizen, it can be assumed that, as a client they will also be interested in data and information on social welfare and health care professionals and the activities of various units.

Social welfare and health care experts and professionals need data and information on the factors affecting their own sectors and for the assessment of their own expertise and actions. For this, they need data not only on their clients, but also on the functioning of other professionals and units.

Service providers require data mainly on their clients and the population of their area as well as on the activities of their employees. Any unit also needs data at a municipal and regional level. To improve producer-specific actions, comparative data on the functioning of other units is needed. Data concerning functioning of various units improves the quality of their work and promotes cost-consciousness.

Municipalities are responsible for social welfare and health care. Thus municipalities need data on the well-being and health of the population in their areas and on the use of social welfare and health services and on their clients. To plan and develop municipal services, and for municipal decision-making, municipalities need quite detailed data on both their own activi-

¹⁾ only data/information concerning self

⁻ does not need data/information

⁽x) possibly needs data/information

x needs data/information

ties and comparative data on other municipalities, as well as on the services produced by municipal federations. Municipalities also need national-level data for planning and international data for comparisons.

Regional-level service providers are mainly health care districts, special-care districts, regions, and provincial administrations. In decision-making and supervision, they need data on the population of the area, on sector professionals, and on the activities of municipalities/social welfare and health care service providers in their area.

In central administration, data is needed at the national level, to be able to monitor the use, availability, quality, and efficacy of various cash benefits and social welfare and health care services, and to plan necessary reforms. Individual-level data is needed in central administration mainly in certain supervisory tasks and in registers. Individual-level data is needed mainly when combining data from different sources, but never used in compiled statistics and research reports. Municipal and regional-level data is needed in central administration for investigating differences between regions and municipalities. Central administration is also interested in developments and situations in other countries and therefore requires international data in a comparable form.

At the international level, there is interest in data on Finland at a national level. In recent years, there has also be international interest in regional-level data.

The media is interested in the social welfare and health sector and needs many kind of data and information of current interest.

3.4. New data and information requirements

The form of social welfare and health actions have changed. The emphasis has moved to non-institutional service and entirely new functions and services have been developed. In addition, the need for data and information has changed, the viewpoint having moved from individual activities to the care and service as a whole received by the patient/client. Existing data systems are not able to describe these information needs and functions comprehensively. At the same time, interest in regional statistics has increased. In addition, there is a need to monitor costs more accurately than before. The private sector and voluntary activities have also become more important in the social welfare and health sector. All in all, data and information needs are more diverse than before. They demand the combination of different data sources and separate studies, as well as new ways to collect data.

Most of the data and information on the well-being and health of the population is based on national sample surveys, which rarely allow regional or local-level analysis. In recent years, the need for regional and municipal-level data has, however, increased. Statistics and registers

should be increasingly prepared at the municipal-level, so that data suitable for various regional purposes can be formed from them. In regards of research, the need for regional data has also increased, but often the survey samples are so small that sufficiently reliable regional-level data cannot be formed from their material. In the future, procedures should be developed, to allow sample surveys to obtain data also for regional and local-level data purposes.

Increasingly it is also wished to compare data and the situation in one's own country with that of others. The EU in particular has created an increased need for more comparable data harmonized between EU state.

Political decision-makers, the population, and clients demand increased transparency and wish to influence the social protection system and decisions and choices affecting its implementation. For this they need data and information on the level and allocation of cash benefits and the functioning of the system. Users need to be not only given data, but also supported by being told how the data should be used and interpreted.

An increase and change in data and information needs, accompanied by decisions to reduce data collection, have led in recent years to an increase in the number of separate studies. Special studies are usually more expensive and a greater burden on data producers than regular data collection, because the data required in special studies is generally not available directly from the basic systems of the data and information producers.

Needs to increase data collection can be seen in the near future. New data collection is at least partly implemented without co-ordination between statistics authorities, as these are bound by decisions of the Council of State. A report by the Ministry of Finance in 2000 already stated that studies have shown that reduction/rationalization has taken place widely and there appeared to be few further possibilities for reduction. Statistics authorities - i.e., in social welfare and health sector matters Statistics Finland and STAKES – report pressure to increase data collection.

4. Data and information producers, their tasks, and the co-ordination

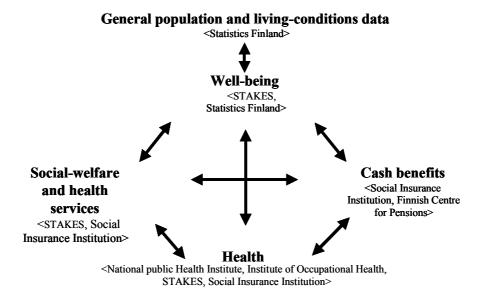
The Ministry of Social Affairs and Health has a broad administrative sector. Each of the sector's institutes and authorities needs and produces data and information from its own area of responsibility.

4.1. Present division of responsibilities

Implementation of the social protection and responsibility for data collection is distributed to several organizations. The Ministry of Social Affairs and Health does not primarily collect data itself. In social policy and health policymaking, the ministry utilizes the data produced by the institutes under it and the Social Insurance Institution, the Finnish Centre for Pensions, Statistics Finland, and municipalities.

Many different factors affect the functioning of the social welfare and health care sector and the results of those activities. Therefore, institutes in the sector require very many different kinds of data and information from different sub-areas. Organizations in the sector need data and information produced by other organizations. The combination and analysis of data produced by different organizations is also needed. The sector needs a permanent network between data-producing organizations. Joint publications, statistics, and research are also needed.

Figure 2. Main data and information producers in the social welfare and health care sector



Data is also produced by ngo's, research institutes and universities

4.1.1. Ministry of Social Affairs and Health

The Ministry of Social Affairs and Health must develop all of the data and information production in social welfare and health care and particularly ensure operation of the reporting and monitoring system needed for national decision-making and strategic planning. The Ministry must also ensure sufficient resources for the sector's data and information production and their sensible use, promote co-operation, and support development of data-resource expertise.

4.1.2. Statistics Finland

Statistics Finland is the general state authority for statistics. Statistics Finland produces three-quarters of public-sector statistics. Statistics Finland's statistics important in social policy and health policy are living-conditions surveys, population statistics, cause of death statistics, income-distribution statistics, labour statistics, labour-cost statistics, consumption statistics, employment statistics, and income and wealth statistics. The data needed in statistics come from administrative registers and interviews, some of it from Statistics Finland's own registers. Statistics Finland also processes register and other data into statistical reports, most of which are very important to The Ministry of Social Affairs and Health and the institutions and agencies under it. Interview data plays a large part in many of Statistics Finland's statistics.

Statistics Finland is responsible for the international and national co-ordination of statistics production. It is also responsible for generally monitoring the population's living conditions (income distribution, domestic-household's consumption, income and wealth, employment, unemployment, working conditions, use of time, and leisure), population statistics, causes of death, economic data, and data on activities of municipalities. Statistics Finland is chiefly responsible for international statistics co-operation and supplying statistics to the EU's statistics authority Eurostat.

4.1.3. Finnish Centre for Pensions

The Finnish Centre for Pensions is the statutory central body of the Finnish earnings-related pension schemes, which looks after the general running of the system and ensures its uniform implementation. The Finnish Centre for Pensions takes care of, for instance, registration, statistics, and research relating to earnings-related pension schemes.

The pension register of the Finnish Centre for Pensions' contains data on pension decisions given by pension providers in the private and public sector (excepting old pensions from municipalities and the churches). The Finnish Centre for Pensions publishes statistics on private-sector earnings-related pensions and employment contracts. It also collects and produces annual overall statistics on rehabilitation within the earnings-related pension schemes. The Finnish Centre for Pensions, the Local Government Pension Institution and the State Treasury produce a joint annual publication of recipients of statutory earnings-related pension in

Finland, and from 2002 of those entitled to an earnings-related pension in Finland. Together with the Social Insurance Institution, the Finnish Centre for Pensions produces overall statistics on Finnish pensioners. Some pensions statistics also show pensions paid abroad by country of domicile. The Finnish Centre for Pensions produces data serving the pensions system and its decision-making, such as studies and calculations needed for reforms of the earnings-related pension schemes.

The Finnish Centre for Pensions also makes studies of working capacity, of factors affecting employment, and reason for retirement, of trends in social and labour-market change, and how they affect pensions insurance, and comparative studies of international pensions schemes.

4.1.4. Social Insurance Institution (SII)

The task of the Social Insurance Institution is to ensure, through its benefits systems, the basic income of the population in various life situations. It is also responsible for information services, statistics, assessment, predictions, and research in its own sector. The statistics of the Social Insurance Institution are based on administrative data comprising the decisions and payment of benefits administered by the institution. An individual-level statistical file is made in each of the benefit areas, from which statistics are produced. Besides its data bank, the Social Insurance Institution also produces regular statistical publications of different benefits areas. Joint publications are Statistics of Finnish pensioners with Finnish Centre for Pensions and Finland's medicine statistics with National Agency for Medicines.

The Social Insurance Institution makes many studies of questions relating to the quantitative and financial development of benefits, their allocation, the finances of social security, and the income of benefits recipients, as well as of rehabilitation, work capacity and functioning.

In its data production, the Social Insurance Institution is responsible for statistics, publications, databases, and data services relating to old-age pensions, health insurance, basic unemployment security, rehabilitation, study allowances, rent-support benefits, and some cash benefits that it administers.

4.1.5. National Public Health Institute

The National Public Health Institute promotes people's opportunities for a healthy life. It is responsible for ensuring that policy-makers, professionals, and citizens have the best possible information available to support choices affecting health.

The National Public Health Institute's task is to promote public health and prevent disease: it should monitor, supervise, and study public health and the occurrence of disease and participate in studies and interventions needed to promote public health. According to the Infectious Diseases

Act and regulations, the National Public Health Institute must maintain a national register of infectious diseases and acquire and distribute vaccines for the public vaccination programme.

The research and development work of the National Public Health Institute aims to improve the information and understanding required to promote the health of the population. The National Public Health Institute's research work is applied research aimed at the health of the population. In its research, the institute utilizes the data of the monitoring systems it maintains. To ensure a high level of applied research, basic research is also carried out in the institute, which helps to identify future problems and find solutions to them.

The National Public Health Institute's central supervision and monitoring tasks are the maintenance of an infectious-diseases register and monitoring systems, the collection and analysis of regularly repeated studies on the state of public health, disease-specific register-based monitoring surveys, and reference-laboratory functions.

In data and information production, the National Public Health Institute is responsible for monitoring both the health and functioning of the population (children and young people, adults, pensioners) and determinants of health. The National Public Health Institute is also responsible, together with STAKES, for supplying data for the EU's Public Health Programme.

4.1.6. National Research and Development Centre for Welfare and Health (STAKES)

STAKES's task is to promote well-being and health and to ensure high-quality social welfare and health services for the entire population on an equal basis. To this end, it produces and transmits social welfare and health care data and information and expertise to decision-makers and operators in the sector. STAKES is an expert centre acting under the Ministry of Social Affairs and Health, its core operations being research, development, and data resources. STAKES acts as the statistics authority for social welfare and health care.

The steering by information implemented by STAKES is based on databases, research, and development. STAKES's other statutory tasks (monitoring and assessment, data transmission, training promotion and implementation, and initiatives and proposals) rely on the data and expertise resulting from the core activities. STAKES's main task is to develop social welfare and health care.

In data production, STAKES is responsible for statistics, registration and research, and personnel statistics on social welfare and health service, the well-being of the population (and factors affecting them), and the substance-use by the population. STAKES is also responsible for preparing Finland's social protection expenditure and health care cost and funding statistics. STAKES is responsible for sending the above data to international organizations (such as

WHO, OECD, NOMESCO⁶, NOSOSCO⁷). STAKES is jointly responsible with the National Public Health Institute for supplying data for the EU's Public Health Programme.

4.1.7. Federation of Accident Insurance Institutions

The Federation of Accident Insurance Institutions is a statutory central organ for accident insurance, which is mainly concerned with the co-ordination of the implementation of statutory accident insurance. The Federation of Accident Insurance Institutions maintains accident and occupational disease registers. In the case of cash benefits, The Federation of Accident Insurance Institutions compiles statistics mainly on loss of income compensation, i.e. daily allowances and its continuation as accident pensions and family pensions on the other hand. The statistics are compiled from event-specific data provided by every private insurance company and the State Treasury. The statistics are part of the work accident statistics collected by Statistics Finland from various sources and sent to the EU Commission.

4.1.8. National Authority for Medicolegal Affairs

The task of the National Authority for Medicolegal Affairs is to supervise health care professionals to ensure the quality and patient-safety of the health services provided for citizens. In addition, National Authority for Medicolegal Affairs is responsible for tasks concerning forensic psychiatry, the termination of pregnancy and sterilization, the medical use of human organs and tissues, medical research, and the investigation of cause of death, and other assigned to it in legislation. For its tasks, National Authority for Medicolegal Affairs maintains registers of health care professionals.

4.1.9. Finnish Institute of Occupational Health

The Finnish Institute of Occupational Health promotes the health at work, work safety, and healthy working conditions of Finland's population of working age, with the aim of achieving good work capacity and quality of working life, and the prevention of unemployment. Finnish Institute of Occupational Health produces, collects, and transmits data based on scientific research on the interactions between work and health and promotes the practical application of the data.

Finnish Institute of Occupational Health's tasks include practising and promoting studies of the interactions between work and health, carrying out studies, measurements, and services relating to the prevention and removal of health hazards and risks at the workplace, or otherwise in the work environment, carrying out independent health care, treatment, and laboratory procedures to determine, care for, and prevent occupational hazards and work-related diseases, and practise training, publication, and information services relating to its sector. Fin-

⁶ Nordic Medico-Statistical Committee

⁷ Nordic Social Statistical Committee

nish Institute of Occupational Health studies the causes and case-mechanisms of occupational and work-related diseases and their effects on functioning in working life.

In data production, Finnish Institute of Occupational Health is responsible for monitoring well-being on work, occupational health, working conditions, and the factors affecting them. Finnish Institute of Occupational Health maintains several different registers and is responsible for sending data on occupational disease to the EU's statistics office.

4.1.10. Insurance Supervision Authority

The Insurance Supervision Authority supervises and ensures that the insurance and pensions institutions and other entities supervised by the authority follow the law and good insurance practice, and apply correct procedures in their operations. The authority particularly supervises the financial development and standing of insurance and pensions institutions. Insurance Supervision Authority publishes annual Insurance-company statistics, which include statistics from the financial statements of insurance companies. Insurance Supervision Authority's benefit-recipient register contains data on the benefits paid by unemployment funds and their recipients, from 1999. Data from the register is used to supervise the unemployment funds, collect statistics on the benefits paid by the funds, investigate misuse, and prepare and monitor legislation.

In data production, Insurance Supervision Authority is responsible for statistics on the benefits of unemployment funds and the operation of insurance companies.

Jointly with Social Insurance Institution, Insurance Supervision Authority publishes monthly statistics containing data on payments and benefits, differentiated by type. Insurance Supervision Authority produces annual Unemployment Funds statistics.

4.1.11. State Treasury

To compile statistics, the State Treasury maintains statistical registers of state pensions paid at an individual level, a pensions-applications statistical register, and a statistical register of employment contracts under the scope of the State Pensions Act. Annual statistical registers are also made of accident compensation and traffic accident compensation by the state. The data in these statistical registers starts in 1992. Statistics made from the statistical registers are published on the State Treasury's website.

4.1.12. Other data and information producers

In addition to the above, data and information from the social welfare and health care sector is produced by *inter alia* the Association of Finnish Local and Regional Authorities, provincial administrations, NGO's, research institutions, university hospitals, and universities.

4.2. Co-operation and its development

4.2.1. Joint publications, reports, and statistics

The institutions and agencies under The Ministry of Social Affairs and Health have several registers, statistics, studies, reports, and databases produced jointly by different organizations. Co-operation has taken place in individual sub-areas for several years already and the following data entities have been developed:

- STAKES's *Social Protection and Health Care Expenditure* statistical publication collects data from all the institutions in the sector,
- Joint pensioners statistics compiled by the Finnish Centre for Pensions and the Social Insurance Institution and the register they are based on,
- Medicine statistics produced jointly by the National Agency for Medicines and the Social Insurance Institution,
- Statistical bulletin on the all of unemployment cash benefits, produced jointly by the Insurance Supervision Authority and the Social Insurance Institution,
- Research (1999, 2000) on basic unemployment benefits, housing assistance, and social assistance, produced jointly by the Social Insurance Institution and STAKES,
- Statistics Finland produces income-distribution statistics, employment statistics, and rent statistics by assembling data it has collected itself, and register data created in the operations of various entities.

The Finnish Centre for Pensions co-operates with the Social Insurance Institution to produce overall statistics on Finnish pensioners, which contain not only all statutory employment and old-age pensions, but also the military, traffic-accident, and accident pensions received by those who are also entitled to an employment or old-age pension.

In addition, STAKES has already from 1995 maintained a *Statistical social welfare and health care database* (SOTKA), which includes not only social welfare and health care data, but also the data required for monitoring, planning, and development. The statistical data and indicators depict not only the use of social welfare and health services, but also municipal economics, the population, families, housing, incidence of disease and mortality, and social welfare and health care labour and costs. The data are entered in the database mainly during the year following the statistical year. The data of the database comprise original data from STAKES, Statistics Finland, and the Social Insurance Institution.

Statistics Finland has produced reports on housing, the position of children, families, and the distribution of income, jointly with other entities.

4.2.2. The co-ordination and development of operations

Statistics Finland has overall co-ordination responsibility for all statistics activities. A social welfare and health care statistics working group was established in 1996, to develop these statistics and to increase co-operation. The group was established by STAKES and includes representatives of the Ministry of Social Affairs and Health, the Association of Finnish Local and Regional Authorities, Statistics Finland, and STAKES. In the spring of 2003, the group was expanded with representatives of the National Public Health Institute and the Finnish Institute of Occupational Health. The managements of the institutes represented in the group meet regularly and agree large joint development projects and inform each other of matters of current interest.

International health statistics are co-ordinated in a group founded by Statistics Finland, which also has members from STAKES, the National Public Health Institute, and the Ministry of Social Affairs and Health.

Nordic social protection statistics are co-ordinated by the so-called Finnish NOSOSCO⁸ Group appointed by the Ministry of Social Affairs and Health. The group has representatives of STAKES, the Social Insurance Institution, the Finnish Centre for Pensions, and Statistics Finland.

In the case of social services, it has not been felt necessary to set up a separate national coordination group, because there is still little international work. When necessary, matters in this field are dealt with in the social welfare and health care statistics co-operation group.

In the spring of 2003, the National Public Health Institute, STAKES, the Radiation and Nuclear Safety Authority, and the Finnish Institute of Occupational Health investigated the state of research and development in the sector. According to their report, each institute in the sector has its own role in research and development, which is relevant to the sector as a whole. They support implementation of the strategic goals set by the ministry and produce and transmit data and information and activity models relevant to their own areas to national, regional, and local operators. The division of responsibilities between the institutes is natural and complements each other. Co-operation between the institutes generally works.

According to the study that there was too little co-ordination between institutes in research and monitoring of children's welfare and health. There is also a need to agree on co-operation and the division of labour between institutes in the sector in the definition of rehabilitation and the functioning of the elderly and of factors affecting them. The directors-general of the institutes have agreed to develop co-operation through regular meetings of the institutions' upper management. The institutes will also increase co-operation, particularly in regards reg-

⁸ Nordic Social Statistical Committee

isters, research material, surveys, data resources, data collection, and their utilization, as well as in information services. The directors-general propose that the Ministry of Social Affairs and Health and the research and development institutes jointly develop procedures, by which their expertise can be effectively exploited in political decision-making and in drafting legislation and implementing national programmes.

All in all, co-operation between the institutes in the sector should be further intensified, to make the flow of information and the utilization of data more effective. Much data produced by Statistics Finland is also needed in the sector. Co-operation with Statistics Finland has mainly worked well, though problems have also arisen concerning payment policy for the supply of data and data-protection regulations. These limit the possibilities to respond to all the data needs of data users.

4.3. The development of register-based research

The health-research committee of the Academy of- Finland granted two year's funding for the start-up stage of the Finnish Data Centre for Register Research. Operations began in STAKES on 1 August 2003. After the initial funding, the sector research institutes under the Ministry of Social Affairs and Health (the National Public Health Institute, STAKES, and the Finnish Institute of Occupational Health) have decided to participate in the further funding of the centre. Other possible co-operating organizations are the Finnish Centre for Pensions, the Social Insurance Institution, the National Agency for Medicines, the Radiation and Nuclear Safety Authority, and Statistics Finland, as well as universities.

The Finnish Data Centre for Register Research aims to promote the use of national registers in research, especially in medical and social science, by supporting the planning and implementation of register-data-based research, improving the abilities of researchers to use register data, increasing co-operation between registers, and improving procedures in using register data.

The Finnish Data Centre for Register Research operates nationally and its basic services are free of charge to all users. Operation began with a restricted network model, but the centre aims to expand operations.

5. International statistics co-operation and data demands on Finland

Finland participates in the activities of several international organizations. Much of the work of many organizations concerns the monitoring of the activities of different countries and the production of comparative data and statistics between countries. As a member state of the EU, Finland is committed to supplying certain data and statistics to the EU's statistics authority. In recent years, the EU actions have gained increasing importance and the development of statistics and data production according to the community's regulations has become a considerable challenge alongside national data requirements.

The EU's harmonization development has not brought large structural changes to Finnish social statistics. Existing national statistics form a basis, the international comparability of which is continually improved. There is only one new annual social survey in sight, the EU-SILC⁹, income and living-conditions survey, which commenced in Finland in 2004. It is being implemented by integrating the new study with existing income distribution statistics. The EU supports the increase of the uniformity of regular surveys in various ways. The European statistics system is being developed, on the basis of both regulations and gentlemen's agreements.

Eurostat continuously develops the population and social statistics contained in the European Statistical System (ESS), in the form of both basic statistics collection and the collection and maintenance of databases. Other data in the form of statistics arises from the construction of indicators and from research related to them. In addition, the Commission frequently orders *ad hoc* studies relating to social-policy programmes. The income-distribution and living-conditions statistics skeleton law is already in force and the executive decree is at the decision stage. In the Commission's programmes, the data field concerning welfare comes under many headings, the most important being the programmes on poverty and social exclusion prevention, employment, equality, and lifelong learning.

The regulations on which the EU's social statistics are based continue to spread. The surveys regulated by decrees are defined in great detail, down to the data collection methods, the data content, and data processing. The regulation bases for labour statistics, wage structure and labour cost surveys, and work accident statistics already existed in autumn 2003. The income and living-conditions statistics skeleton law (EU-SILC¹⁰) and executive decrees were completed in autumn 2003. The regulation basis for education and immigration statistics is being drafted.

The EU harmonization of consumer research, time-use studies, cultural statistics, and many other population and social statistics is based on recommendations and individual agreements. Harmonization takes place by creating uniform concepts, definitions, and classifications, or

⁹ Statistics on Income and Living Conditions

¹⁰ Statistics on Income and Living Conditions

by planning common modules for surveys, in which data collection and processing are made uniform. The harmonization of the statistical framework of social protection systems (ESSPROS¹¹) is one of the more significant EU-level achievements.

In the case of substance abuse, a development challenge in the near future is to create a permanent monitoring system for the EU's substance-abuse operations programme (2000 - 2004).

Finland has been generally able to supply most of the internationally collected data for which it has been requested. Data is collected by different organizations (EU, OECD, WHO) using different definitions and classifications and these data have not been sufficiently exploited either in Finland or internationally. The UN's and OECD's recommendations also greatly affect statistics operations. The organizations do not, however, oblige the data supplier to modify the content or methods of their data system to ensure international comparability.

In regards of data and information on the health of the population, Finland is one of the world's most progressive countries. It is also very active in this field both in the EU's Public Health Programme, in Eurostat and in WHO. Finland aims to use its influence to ensure that the international health information systems develop sensibly and that Finland's existing data systems need not be replaced by entirely new systems harmonized by the EU.

The greatest problems of health statistics in Finland are a lack of data on out-patient primary health care, on active social welfare and health care personnel, and more detailed data on the costs and funding of health care, as well as on open care services for the elderly and disabled people.

As yet, few statistics on social services are compiled internationally. At present, this takes place mainly between the Nordic countries. The EU is, however, gradually expanding its activities in this sector, particularly in the case of homelessness, children's day-care, labour policy measures and gender equality. Other possible sub-areas include the social conditions of immigrants, statistics on disabled people and substance-abuse statistics.

The move of the EU's statistics regulations to the decree level and the simultaneous expansion of the EU's statistics actions to ever more subject areas will be a considerable future challenge to Finland's statistics and data production. A present danger is that work required by the EU will take the lion's share of the limited resources available to Finland in this field. Data production harmonized by the EU will not necessarily produce the data essential to Finland's national needs.

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¹¹ The European System of integrated Social Protection Statistics

In regards of data and information reform in social welfare and health care, it is important to take into account international data requirements, particularly the EU's data requirements, in the present situation in which the European social model is being actively developed with open co-ordination means. A major challenge is to ensure the continuity of statistics production and the depiction of possible special national characteristics, when systems that have worked well nationally are overhauled to improve international comparability.

6. Indicators

Among current challenges is the construction of core indicators, which has been started by several organizations in the broad area of social welfare and health policy, both nationally and internationally. The aim has been for a few important indicators to be used to monitor the achievement of goals set for social welfare and health policy. However, this has proven difficult. Indicator lists have become long, as it is difficult to produce needed essential data only a few indicators

6.1. National indicator projects

As part of the result steering of institutes and agencies under the Ministry of Social Affairs and Health, the ministry has initiated the construction of indicators, using a Balanced Scorecard (BSC) frame of reference. In recent years, various programmes and quality recommendations have been made, with attempts made to use central indicators to monitor their implementation. It has been difficult to make indicators to monitor the achievement of goals. Programmes and their goals are often stated in such a way that they are difficult to convert to a measurable form.

Major efforts have been made to create indicators to monitor the implementation of the Health 2015 public health programme. The National Public Health Institute, STAKES, and the Finnish Institute of Occupational Health co-operated in the preparations. The programme's goals were broken into parts and possible monitoring indicators were sought.

Indicators concerning health (e.g. mortality, entitlements to specially reimbursed medicines, disease incidence and prevalence, subjective health, and chronic disease) have been long used. Development is still needed especially in the measurement of specific diseases and functioning and in the creation of composite indicators. This work is mainly done by the National Public Health Institute.

STAKES has a current well-being and health indicator project. In this, indicators depicting the well-being of the population are defined by age group and generally and are either municipality-specific or regional, depending on the material. An indicator database has already been constructed in the project. Next a comprehensive interface serving various user groups will be developed, and an electronic-document handbook on interpreting and using the well-being indicators will be created. The project has been allocated health-promotion funds, up to 31 December 2004

Because indicators are constructed in various sectors, indicators concerning the development of well-being can also be found outside of the sector of the Ministry of Social Affairs and

Health. The Finnish Environment Institute has compiled its own indicator list to describe sustainable development. It is divided into 1) ecological, 2) economic, and 3) social-cultural areas, of which especially the latter includes indicators on well-being.

6.2. International indicator projects

At the international level, several indicator projects are under way. The OECD has published both social and health indicators. The Council of Europe is planning indicators based on its declaration of human rights.

The implementation of the growth strategy agreed at the European summit in Lisbon in 2000 requires measures in economics, employment, and social development. Applying open coordination, the EU member states drawn up national plans to achieve the agreed common aims. To monitor and report on the achievement of the goals of these plans, jointly agreed and comparable indicators have been developed at the EU level. The EU has created pensions, employment, poverty and inclusion indicators. The Council of Europe approved the poverty and inclusion indicators at Laeken in 2001, which are still under development.

The implementation of the Lisbon strategy is monitored annually, using so-called structural indicators, which cover all important sub-areas of policy: employment, innovations and research, economic reforms, social cohesion, the environment, and the general economic situation. Development in each sub-area is monitored using seven indicators, which are selected by applying the work on indicators referred to above. Social cohesion indicators mainly depict economic well-being (poverty and income distribution), but also employment and unemployment, and deficient education. Reporting in 2004 will use a so-called short list of apparently only fourteen indicators, instead of the previous forty-two indicators.

The EU's previous Health Monitoring Programme and the present Public Health Programme developed both individual health problem indicators and a list of European Community Health Indicators (ECHI).

NOMESCO¹² and NOSOSCO¹³ (cf. Section 7.1.), which are responsible for joint Nordic social protection and health statistics, have assembled an Internet-based database of central social and health indicators. NOSOSCO and NOMESCO have also developed sustainable development indicators for social and health policy.

¹² Nordic Medico Statistical Committee

¹³ Nordic Social Statistical Committee

6.3. Further work on indicators

Due to the Working Group's tight schedule and the extremely diverse indicator projects presently running in various organizations, the Working Group decided that it was not worth proposing its own indicators for the sector. Existing national projects should combine their resources to develop common indicators. The Ministry of Social Affairs and Health will continue the development of indicators in the sector, for instance, in connection with the development of the publication *Trends in Social Protection in Finland* while STAKES will continue to construct a well-being and health indicator database, in co-operation with the institutions in the sector and Statistics Finland. Many of the data reforms being developed and planned will permit new indicators to be developed in the future.

7. Uniform concepts, definitions, and classifications

The production of data comparable at national and international levels is made possible by using uniform concepts and classifications. Their definition is central to co-operation and the utilization of data and a precondition for the construction of a homogenous data system. They also create a foundation for rapid data production. Due to the number of data producing organizations in the sector, and the variety of methods, no completely uniform concepts or methods have been available so far, but work on development in this direction must be continued.

The electronic client-data and patient-data systems in social welfare and health care provide a good basis for the development of data collection for national statistics, registers, and research. The definition of the core data of unified national client and patient documentation will play a central role in the National Development Programme on Social Welfare and National Health Project. This is a prerequisite for municipalities creating the uniform classification of data, which is necessary, for example, in the implementation of seamless service chains. Data protection for clients also demands this.

Data producers must ensure documentation of data, the understandability of data and concepts, and must use similar processing and dissemination means. This will help data users to utilize these definitions, which will facilitate use of data.

STAKES's classification centre maintains, develops, and co-ordinates social welfare and health care classifications, jointly with, *inter alia* the Association of Finnish Local and Regional Authorities, The Finnish Medical Society Duodecim, and the Finnish Institute of Occupational Health. As part of the National Health Project, STAKES has initiated the development of a national codes server, together with other actors. The codes server will contain social welfare and health care statistics and register actions concepts, classifications, and nomenclatures. It was intended to have the following classifications on the server by 31 December 2003: ICD-10, Nordic classifications for surgical procedures, procedure classification for oral health care, procedure classification for radiology, nomenclature for laboratory, physiotherapy and occupational therapy, guidelines for reporting to the Care Register and the National Statistical Classifications for Social and Health Care.

Statistics Finland is responsible for co-ordinating the definition of basic statistical classifications and concepts. To develop social welfare and health care concepts and definitions, and to co-ordinate the work, this should be the responsibility of STAKES. The clarification of concepts of cash benefits and services, in order to construct comprehensive information data sets requires that the Social Insurance Institution, the Finnish Centre for Pensions, STAKES, and other data producers make their concepts uniform.

The National Public Health Institute and the Finnish Institute of Occupational Health, in cooperation with Statistics Finland, are responsible for creating definitions relating to the health and functioning of the population. Inasmuch as concepts and classifications are based on, or relate to classifications maintained by STAKES, the National Public Health Institute, the Finnish Institute of Occupational Health, and Statistics Finland should co-operate with STAKES.

The creation of national concepts, definitions, and classifications should be based on uniformity, or at least compatibility with international concepts, definitions, and classifications.

8. Assessment of the existing data and information system and its challenges

According to the reports by the Working Group's sub-groups, there are many information systems and much data in the social welfare and health care sector. The data and information systems have been developed in different organizations on the basis of proposals made by previous working groups. There are practically no overlapping data sources. Many data-producer organizations have used the Internet as an data and information dissemination channel and exploited the new opportunities provided by new technology.

A great deal of data and information is produced in and concerning the social welfare and health care sector. There are many individual data, but they are widely scattered and difficult to find. Use of the data requires familiarity with the sector and its benefits system. The data in the sector largely serves the needs of its producers, which often relate to the payment and administration of specific benefits, or the provision of an individual service. The data requirements of the sector vary from individual and family-level data to studies of national overall effects. Data is needed about the whole comprising services, cash benefits, preventive measures, and the promotion of health. It is necessary to be able to combine various data sources and methods to investigate the associations between phenomena and to gain a comprehensive view of the whole system and sector.

8.1. General evaluation and challenges

Co-operation

The existing organization of data and information production in the sector is workable and justified. The tasks of the institutes in data production sometimes overlap, but this is natural, as many similar factors operate in the areas of responsibility of the institutions. There is presently much co-operation between data-producing organizations. Co-operation should be still closer, so that existing data sources and information will be better utilized. One way is to increase joint data and information production projects between the institutes in the sector, so that the collected data will become rapidly known and available to the various parties.

Data utilization

It should be easy to find essential data and information. The core data on well-being, health, social welfare and health services, and cash benefits should be collected from the sector's extensive register, statistics, and research material and user-interfaces to them arranged through a common portal of the sector.

In addition, indicators of various levels, for the needs of different users and user groups, should be extracted from the mass of data. The social welfare and health indicator database being presently developed in STAKES provides an opportunity to construct such a data system. Monitoring of the implementation of the sector's central goals, programmes, strategies, and result steering can be combined with it.

Users outside the sector feel that the slowness of permit and other procedures is the greatest obstacle. Another factor limiting the use of data is unfamiliarity with the registers. The usability of certain regularly collected national statistical data by users other than statistics authorities themselves should be enhanced. The utilization of register data in research should also be enhanced and training in the field should be improved in universities and other institutes providing basic and postgraduate educational. The Finnish Data Centre for Register Research will help to overcome this problem.

Further processing of data

There is a need to produce various sub-area statistics, publications, and reports, which will serve data and information users. The preparation of such compiled statistics requires uniformity of methods used in organizations and of concepts and definitions.

The most important of the sector's statistics collections, reports, studies, and statistics should be published electronically on the Internet and also, if possible, as printed publications. In addition, core statistics should be available in such an electronic form that further processing of the data is possible for different users' own purposes.

Speed

Social and health policymaking requires the latest data. According to Finnish Official Statistics' quality principles, statistics and register data should not be more than one year old. Data production can be accelerated by connecting it directly to existing electronic benefits and payments registers and to the patient and client systems of social welfare and health care facilities. In regard cash benefits, the situation is already mainly like this and data can be collected over the entire country several times a year. However, in regard of data produced on the social welfare and health services of municipalities the situation is different. Data must be collected separately from municipalities at the end of the year, once their financial statements have been completed, because municipalities' own accounting classifications are designed to support their own activities and cannot be linked directly to the classifications used in the national municipalities' financial statistics. This hinders the preparation of national data and has made it very difficult to obtain similar combined data from various municipalities across the whole country.

In an increasing number of social welfare and health care facilities, client and patient data is based on electronic systems. As they become common and the use of uniform concepts and definitions becomes established, entirely new and faster forms of data collection will be pos-

sible. Social welfare and health care concepts and definitions will be harmonized in the National Health Project and the National Development Programme on Social welfare.

Some research data is based on sampling surveys carried out at 2 - 10-year intervals. In large-scale, infrequent surveys, it is rarely possible nor necessary to follow the aforesaid one-year criterion. On the other hand, the results of annul or bi-annual questionnaire surveys are generally published the same year and also comprehensive surveys aim at publishing their main findings as soon as possible after the field work.

Forecasts

Existing data sources in social welfare and health care mainly describe the past and to some extent the present. Social policy and health policy making nowadays needs the latest data, but also forecasts of the future. For a long time already, Statistics Finland has produced population forecasts while the Social Insurance Institution and the Finnish Centre for Pensions have predicted the future of the benefits they administer. For its part, the Ministry of Social Affairs and Health predicts the development of various benefits and social expenditure, by applying data produced by the institutions in the sector. Work to forecast health and the need for care has been done to some extent in Finland in the National Public Health Institute and the Finnish Cancer Register. In the future, forecasts should be a central part of the data system in the sector's data and information system.

Regional level

The sector's own data and information production should start basing on national-level data on the data produced and needed at the regional and municipal levels. On the other hand, detailed data that is not necessary at the national level is needed regionally and locally.

The need for regional and municipal-level data has increased. Overall data covering the entire country permits municipal and region-level comparisons. In a small country, the monitoring of rare cases demands the use of the whole data. The data material of national sample surveys is generally so small (a few thousands to ten thousands persons), that only coarse regional data can be produced from it. New measures, such as regional sample surveys, are therefore needed to obtain corresponding regional data.

Electronic documents

National electronic patient and client documents are presently being developed in social welfare and health care. When implemented, these documents will provide completely new opportunities for producing comprehensive, up-to-date data, without placing an undue burden on municipalities. Electronic patient documents also permit the monitoring of services and new types of efficiency analyses.

Continuity

In the collection and processing of data, the most important factor is to ensure the continuity of central, regular studies representing the entire, or nearly the entire country. Many such data sources function on uncertain separate funding. Uncertainty of the future drives competent experts to other fields. It is also difficult to find funds for developing these data sources. Data and information production, its development, and expertise are thus continually threatened. The very tight funding often means that though data is collected, its analysis and processing remains deficient. In operation plans and budgets, each organization should take into account beforehand the statistics, research, and studies to be carried out in the next few (about five) years and the funds for them by prioritizing resources and development work.

Data gaps

There are obvious data gaps in some sub-areas in social welfare and health care data production. Deficient data is available at present particularly on the welfare and health of children and young people, on the use of social welfare and health services, and especially on outpatient primary health care. More comprehensive data are also needed on the well-being, health, and functioning of the elderly. The Working Group makes several proposals to fill these data gaps.

Equality

Increasing emphasis is being placed, in decision-making and monitoring in social welfare and health care, on the realization of equality. Equality can be viewed from various angles (sex/gender, regional, population group, etc.). One of the most central is gender equality. New draft legislation proposed by the Ministry of Social Affairs and Health must include an assessment of its possible effect on gender equality. According to the government's programme, assessment of effects on gender equality will be extended during the present government to cover all drafting of legislation. This is a challenge. Existing data production provides quite good opportunities for it. To be able to assess effects on gender equality, statistics differentiated by gender are required. Whenever possible, the sector should always produce statistics and data differentiated by gender.

International challenges

So fare, it has been possible to produce from the social welfare and health care sector the data required for international co-operation. To ensure this also in the future, the Finnish data system should be both maintained and also developed to meet the challenges. International classifications should always be taken into account when developing national data. At the same time, care needs to be taken to ensure that the existing Finnish data system, which functions well nationally, is not replaced by inferior systems possibly resulting from harmonization by the EU. This will demand full participation to influence the work of the EU.

8.2. Detailed evaluation

8.2.1. Social welfare and health services

Nationally, there is a need to develop an electronic client/patient record data system, for both social welfare and health services. The core data should be based on agreed common concepts, definitions, and classifications. At present evaluation is difficult, as existing data is in several databases and the definitions are different.

Health care must strive to ensure that various local data sources can be exploited by using common indicators in the core data and developing common classifications (diagnoses, operations, laboratory tests, x-rays and assistive equipment). This requires that organizations use electronic documents, and are able to utilize the existing infrastructure.

Data on the length of queuing time for access to care has become a central data demand. However, there are still problems in defining the queue concept. Queue data is important, as it is linked to the availability of health care services.

The expansion of dental care also signals the need for a reform in data collection. In specialist (secondary and tertiary) health care, more detailed data and indicators are needed on, for instance, service pricing, quality, and effectiveness. These data can be produced from existing registers, by developing data quality, indicators, and new measurement methods, as well as by measuring and comparing the cost-effectiveness of the care chain for different health problems. It is also difficult to use data production to gain an overall picture of the radical reduction of institutional mental-health services, the fragmentation of community care, and the increased role of private service providers. The monitoring of mental-health services requires data on the whole service chain and on the use of social welfare and health services.

In response to new data demands, STAKES has started an out-patient, sample-based, pilot study, in which data is collected at the personal identification number (PIN) level, in disease or operation groups. The electronic out-patient primary health care patient/client data system will be further developed on the basis of the data obtained from the study.

Social welfare data needs have changed and the emphasis has moved from institutional care to the development of open care services. This can also be seen in growing demands to develop the monitoring system of various social welfare services, especially in the care of the elderly, care for substance-abuse, and care of the disabled. In addition, different and new ways are needed to collect data from some social welfare areas, such as substance abuse and services and assistive devises for the disabled. Social welfare activities also include new kind of service, about which data is not collected, or only covers part of a phenomenon. Examples in-

clude victim-offender mediation and rehabilitating work experience. Areas to be developed jointly with health care include measurement of functioning and services and rehabilitation for the elderly.

Good client service and efficient activities require a functioning data system in social welfare too. Data systems must support the social sector's own information needs, goals, and procedures. To improve usability and co-operation in data production in the social sector, the data structures, concepts, terms, and classifications of client data systems must be made uniform. Local and regional data is increasingly required. Regional data collection requires guidelines, as there are no regional organizations like the hospital districts in health care. Possibilities for social welfare clients to handle matters and obtain data electronically must be increased, according to the public administration electronic operations programme.

8.2.2. Cash benefits

Existing data systems already provide a good basis for data production on cash benefits. The statistics and register data on cash benefits are comprehensive and of high quality. The most important data of each benefit is comprehensively available from the benefit system, while the statistics are of high quality and comprehensive also in international comparisons. In Finland, a relatively accurate picture of the number of benefit recipients can be produced from the existing detailed data, also allowing for overlap in the systems. The reform of benefits and studies of benefits as a whole require further development of register-based combined data from different administrative sectors. The development of the statistics architecture and reporting of statistical systems built at different times with various means and the unification of concepts, as well as the integration of the data production process are also necessary.

Detailed data from different systems can be combined for research purposes. However, more integration of data than at present is needed, such as monitoring of temporal cross-sections, various changes and life situations. More extensive comprehensive data sets are also needed for individual research projects.

It is difficult to use sample surveys to examine benefits paid to a small group only. Complete register-based data is required alongside sample-based data. The rapid development of data processing capacity allows extensive data to be processed at reasonable cost. Total data sets also allow monitoring over time and can be used to assess the effect of the goals of changes in legislation. There is also a need for studies over less than a year, when examining, for example, the simultaneous receipt of different benefits. Besides benefits paid, the data content of the registers should be developed so that it also includes the other central factors affecting entitlement to benefits.

Statistics and separate studies of cash benefits and income during sickness, maternity, and parent-leave should be co-ordinated and collected together on the basis of existing data production. A central development object is to improve statistics describing the number and duration of sickness absences by special studies, to increase comparability, as well as to create better statistics on wages and salaries during sickness.

Pension statistics do not include data on voluntary (3rd pilar) pensions insurance. The significance of such pensions is still small in Finland, but it is increasing. To obtain a comprehensive view, it would be important to develop pension statistics to give an overall picture of all pensions.

Although benefit-register statistical data are comprehensive, society's policy-makers need a picture of all cash benefits of individuals/families to check its adequacy and to assess the need to supplement cause-based cash benefits. The whole can be investigated by combining the data material of the Social Security Institution, the Finnish Centre for Pensions, the Insurance Supervision Authority, STAKES, Statistics Finland, and the Ministry of Labour, subject to the provisions of data-protection regulations and associated legislation.

8.2.3. Well-being of the population

Nationally, regionally and locally there is too little information on the well-being of the population. Though much data is produced on the various sub-areas of welfare, it is not always possible to monitor time trends and local circumstances. Data collected from the social welfare and health services system may be comprehensive, but it does not always provide a basis for an overall picture of the well-being of the population and the direction of its development. However, the population's well-being seldom changes very quickly and changes are scarcely noticeable in annual monitoring.

At a national level, the annual database is enough, especially in the case of statistics and registers describing living conditions, but delays in production reduce its usefulness. Delays are mainly a local problem, national studies do not meet local data needs fast enough.

In many sub-areas of well-being, a lack of continuity in data production is obviously a problem. While on the one hand, the national data infrastructure is reduced, on the other one-off surveys, isolated temporally and locally are created. A surprisingly large part of both national and local monitoring of well-being comes from data collection maintained by separate funding. It is then difficult to combine data from different sources. Thus processed and interpreted data on the population's well-being is available to only a limited extent. The lack of longitudinal monitoring data is also a serious gap in statistics production. This lack has been filled by Statistics Finland's longitudinal survey domestic households' questionnaire (ECHP¹⁴ 1996-2001), by the income and living-conditions survey (EU-SILC¹⁵) starting in 2004, and to a small extent by longitudinal data from the population and work statistics. Due to the comparability of the time series producing longitudinal data and the complexity of interpretations, the user of the material demands not only routine monitoring data, but also an investigative approach. New sources of longitudinal data have been developed, especially by the more efficient use of administrative material and by exploiting the location data system and person-level combinations.

There is not enough information on the accumulation of deprivation. Individual-level data is available on factors associated with deprivation, such as poor health, insufficient financial resources, education, and housing, but not on the accumulation these factors. This is due to a lack of links between statistics, which appears as a varied and apparently random selection of background data, incompatible statistical units, and variable reporting. The common use of data is then difficult, as it demands expertise and the reprocessing of basic data.

Information is needed regularly on NGO activities and participation in them. Information production on the functions of organizations and organizations' own data production is dispersed and partly random, though the organizations employ the unemployed, produce services and provide peer support, as well as use voluntary work to produce services. Statistics Finland's use of time survey provides little data on participation in organization work and voluntary activities; the leisure survey fills out the picture slightly. A more exact definition of the forms of voluntary activity would shed more light on those concerned and the volume of operations.

Instead of extensive structural changes to the statistical data system, the possibilities of the existing statistics systems to produce well-being indicators should be utilized and their production made regular. This goal could be approached by unifying the classifications and subject-groups' definitions. On the basis of the existing division of labour, a national well-being research system can be developed, which would be based on clarification of the division of responsibilities between institutions and an increase in their co-ordination and co-operation, in reporting, material collection, and analysis of data contents. An data system on the population's living conditions, well-being, and health, based on questionnaires would have the following form:

¹⁴ European Community Household Panel

¹⁵ Statistics on Income and Living Condition

Table 3. Proposal for the structure, organizations responsible, and timetable of a question-naire data collection system on the well-being of the population

Living conditions	Well-being		Health		
BASIC MONITORING					
Statistics Finland	<u>STAKES</u>		National Public Health <u>Institute</u>		
Income and living conditions survey (EU-SILC)	Welfare and service survey (even-number years)		Health behaviour and health among Finnish adult population (odd-number years)		
Labour Force Survey (LFS) (annual)	School health survey (each year on alternating sides of Finland, local)				
IN-DEPTH ANALYSIS					
Statistics Finland	Finnish Institute of Occupational Health	Social Insurance Institution (with STAKES and National Public Health Institute)	National Public Health Institute		
Consumption and wealth (every 3 - 6 years) Use of time and leisure (every 10 years)	Work and health survey (every 3 years) Work capacity barometer (every 3 years)	State of health and use of services in domestic households (every 5 – 7 years)	FINRISK (about every 5 years) Health 2000 health examination survey (about every 10 – 15 years)		
Working conditions survey (every 6 - 7 years)					

The welfare and service survey and the adult-population health behaviour surveys produce up-to-date monitoring data and deeper data at regular intervals on health and the well-being of the population. In the case of living conditions, similar annual monitoring data is produced by Statistics Finland's income and living-conditions survey EU-SILC¹⁶ and by the labour force survey. In the case of young people, regular monitoring data comes form the school health survey.

 $^{\rm 16}$ Community Statistics on Income and Living Conditions

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Data production grouped by phase of life or target group, cannot be based on a general data system, as both special questions and survey-technical challenges relate to different phases of life. Examination by target group also demands coverage of a wider data content than that possible within the framework of a general well-being questionnaire (e.g., drinking habits). In addition, the sensitive nature of a subject (substance use), or the nature of a special group (immigrants) may require a specific research set-up. The basic data and information system of the institutions and agencies under the Ministry of Social Affairs and Health produces data and information on the various phases of life, according to the following table:

Table 4. Basic data and information collection of well-being and health, arranged by phase of life

Phase of life, main themes	Title of study	Responsible organization
Children and adolescents - health (incl. health examination) - well-being	Children's risk-factor survey	National Public Health Institute + STAKES (in the case of well-being)
Young people - well-being, local - health - health services	School health survey	STAKES
Working age - well-being - use of services - health (behaviour)	Welfare and service survey	STAKES + National Public Health Institute (in the case of health)
Working age - health - health behaviour - well-being	Health behaviour and health among adult population -survey	National Public Health Institute + STAKES (in the case of well-being)
Elderly - health - functioning - well-being	Health behaviour and health among elderly population –survey (as part of the survey mentioned above)	National Public Health Institute + STAKES (in the case of well-being)

New development projects that are needed are especially data collection systems for children and young people, and the elderly. Their implementation will require co-operation between the sector's institutes, operational co-ordination, and mutually co-ordinated questionnaire scheduling, to create an effective basic data production system in the sector.

8.2.4. State of health of the population

At a national level, there is quite a lot of data and information of health. However, there is little regional and local health data. More data than at present are needed on health needs,

preventive health care, the efficacy of various measures, the accumulation of health problems and other difficulties, and functioning.

There is little data on many diseases that are central to public health, or the data and documents are deficient. Sufficient monitoring data on most diseases can be obtained by including them in the future phases of the *Health 2000* -health examination study, the health care survey, and the surveys of the Finnish Institute of Occupational Health. The continuity of these studies must be ensured.

The information on disease in the population only provide a partial picture of each disease or condition. STAKES's care register covers only persons using institutional care, the Social Insurance Institution's medicine prescription data only include persons buying medicines, and the data on specially reimbursed medicines only concern persons granted such an entitlement.

Disease-group-specific national statistical registers are STAKES's malformation, cancer, and visual impairments, and the National Public Health Institute's register of infectious diseases. When studying other diseases and injuries, register data from the data system must be combined to form a research or statistical register. According to the present interpretation of data-protection legislation, registers cannot be combined continuously, nor can a register thus formed be permanent, which hampers the creation and maintenance of disease-specific registers. Though the data exist, it is therefore very difficult to create time series on the incidence of, for example, coronary disease, hip fractures, strokes, or heart failure.

The health of the population is linked to lifestyles. Data and information on lifestyles is available from various sources.

Life expectancy has traditionally been used as an indicator of the health of the population. Attempts have been made to develop an indicator that would better take into account susceptibility to disease, functioning, and quality of life related to health. Fully functioning life expectancy (years lived with no major functional limitations or activity restrictions) would be a useful composite indicator of the state of health of the population. The production of this data requires comparable data on mortality and the health and functioning of people. The data should be comparable both temporally and between countries, but much work is still needed to reach this goal.

Health of children and young people

Data and information on the health of children and young people is very deficient. The most important gap in data production is the paucity of data on the health of the under-12s. Many data are collected in child health clinics and school health care, but these have not been utilized nationally. The acquisition of the data is also a problem, as they must be obtained either directly from children or their parents.

There are four questionnaire studies on young people. They provide data on liking school, school problems, diet and nutrition, exercise, sexual behaviour, overweight and obesity, smoking, alcohol and other substance abuse, subjective health, long-term illness, and the most important health problems in youth. However, data collection overlaps and two of the data collection systems rely on uncertain funding in universities.

To supplement data and information production on children and young people, further house-hold-specific interview surveys and new data based on regular health examinations are required.

A challenge in monitoring children's health is to obtain data and information on the development and differences between population groups prior to adolescence of features relating to physical, mental, and social development. The possibilities to use data collected in the clinics and in school health systems to create such indicators should be investigated, as should the possibilities to use other ways to collect data.

Health of working-age adults

Data on the state of health, incidence of disease, subjective health, long-term illness, the most important public health diseases, health problems, working conditions, and functioning of working-age adults are available from several different sources. The National Public Health Institute is planning the establishment of a national vaccination register.

Major changes are not needed in the health monitoring of working-age adults. In the future, the National Public Health Institute will reduce the interval between its *Health behaviour and health among adult population* -surveys to two years and group surveys including health examination elements in such a way that every third Finrisk survey will be replaced with a Health 2000-type survey including a health interview and an extensive health examination.

Health of the elderly

The health and functioning of, and the use of social welfare and health services by the elderly has been studied by domestic household, including those in institutional care, in the years 1995 - 1996 and 2000 - 2001. One data collection covering 65 - 84-year-olds and repeated at two-year intervals is the National Public Health Institute's *Health behaviour and health among elderly population* -survey, based on a postal questionnaire and implemented as part of the study of the adult population.

In the future, research on the elderly must produce data on the health, functioning, and quality of life of those living at home and of the institutional population. Data is needed, not only on physical, but also on mental and social functioning.

Measures required in monitoring health

The content of existing data and information systems should be developed or supplemented, at least in the cases of the health of children and young people, the health, work capacity and functioning of the aging and elderly, of mental health and its disturbances, home and leisure accidents, diseases of musculo-skeletal system, respiratory diseases, allergies, dementia, sensory disabilities, and oral health. Sufficient data on many of the above diseases can be obtained by including them in the *Health 2000*—health examination survey and the future stages of the health care survey. New data and information systems are needed, however, to monitor children's and young people's health, home and leisure accidents, and health promotion.

8.2.5. Children, young people, and families with children

Children's well-being is affected by the composition and completeness of families, income, employment, and housing conditions. Though a reasonable amount of data on these is available, the statistics are generally not made from children's points of view. It is also difficult to use statistics to depict all the present-day types of families.

Data on children and young people mainly relate to the receipt of benefits. Data on children's health are, in turn, mainly based on mortality data. At present, up-to-date and comprehensive data is not available on children's health, incidence of disease, lifestyles, and well-being. Some of the necessary data is available from the care register and the Social Insurance Institution's registers. The construction of the planned out-patient primary health care and especially the child-health clinic activity's data system will fill existing data gaps. In addition, sample-based health interview and health examination surveys are needed.

Somewhat more data is available on the health of young people than on that of children, as four questionnaire surveys are available. A major problem is the uncertain continuity of their funding. The present questionnaires should be supplemented with data from health examination surveys.

More data is also needed on services for children and families. In the case of children obvious areas for increasing statistical and register operations are child-health clinic operations, children's day-care, upbringing and family counselling, child protection, school health care, and pupil well-being. Children, young people, and families with children regularly visit child-health clinics, and use school/pupil health care, but so far little data on these functions, by municipality, region, and the whole country is collected for use.

8.2.6. Working-age adults

A reasonably comprehensive picture of the state of life of working-age adults, their income, employment and housing conditions is gained from the statistics of Statistics Finland. Rela-

tively good data and information is also available on their well-being, health, lifestyles, factors threatening health, working conditions, and work-related diseases and accidents, from various population surveys. The development and continuity of functioning monitoring the health of working-age adults should be ensured.

Occupational health care should be seamlessly linked to the health care service networks. The assessment and control of working-condition risks is central to work safety and work-health activities at workplaces. Occupational health care produces not only preventive services, but also a significant part of all health care of the working population. The provisions of the Work Safety Act and the Occupational Health Act and the goals set in the occupational health development strategy demand a good data and information base. Besides data depicting the health and work capacity of individuals, company-level data and information is also needed on a person's work, working conditions, exposure to risks, and the load imposed by work. Occupational health care itself, companies, and public officials also need monitoring data on the operation of occupational health care and its effectiveness. The needs of occupational health care should be taken into account when developing the regional information system and electronic social-security card.

Data collected in occupational health care on work loading and exposure to risks, as well as on health and work capacity should be uniformly available not only at a national level, but also in the planning, implementation, and monitoring of public health and special health care at the municipal and regional levels.

The data in patient records should take occupational health aspects into account. Every visit to the primary health care should have an entry as to whether the cause was related to work, what measures maintaining work capacity, relating to the person and workplace, were initiated and whether the person was referred to medical or professional rehabilitation. Technically, this is already possible and data could be carried with the person in the memory of a smart card, without endangering the individual's data protection.

The flow of data and information should be made more efficient and developed, both between occupational health care and companies, and between the occupational health care compensation system, rehabilitation system, work-safety officials, and labour administration and education and social welfare operators.

Very little data and information of working life flexibility and certainty of employment are produced. Data is available from regular working condition surveys. Existing data production gives a deficient picture of the balance between work and the rest of life. The multiplicity of labour markets, which includes not only immigrants' working conditions, but also membership in the labour force by age-group, stage of life, and gender, are depicted deficiently.

8.2.7. The elderly

As the population ages, there is a greater need of data and information on the elderly, their well-being and health and their use of social welfare and health services. In the case of the elderly, there is presently relatively extensive data collection. A reasonable amount of data on the health of the elderly is available from the population surveys of the Social Insurance Institution and the National Public Health Institute. The continuity of these surveys must be ensured.

Existing systems do not, however, produce a comprehensive overall picture of the services used by the elderly and their costs. Existing systems also cannot produce a picture of the whole service chain and its comprehensiveness, nor of the part played in it by various service producers. There is also insufficient data on services supporting living at home and on the functioning of those in institutional care. The investigation of the health, functioning, and need of help of the elderly also demands the development of the measurement of functioning.

8.2.8. Services and assistive devises for the disabled

Attempts to promote the connection of the disabled to normal life and to permit them to participate in the activities of society have been made through benefits, services, and assistive devises. Data on cash benefits paid for the disabled is available through benefits registers and a reasonable amount of data on individual recipients of services for the disabled is available. The usability of data on disability services, produced by municipal financial statistics is hampered by the lack of clear concepts and the subsequent variety of accounting procedures in municipalities. There is a particular lack of clarity in data on service and supported housing. More detailed data is required on the whole of services for the disabled and on service chains. Comprehensive data could be obtained by constructing a complete data on cash benefits and services for the disabled.

Little data is available on assistive devises. So far, they have been seen mainly as a cost item, but data and information is also needed on its effects and benefits. In the future there is a strong belief that technology and equipment can ensure an independent life for the elderly and the physically handicapped. Electronic patient and client documents will permit better monitoring and assessment of the use and benefits of assistive devises than at present.

8.2.9. Accidents

Comprehensive data on traffic and work accidents are available through the insurance compensation systems for them. Monitoring of home and leisure accidents is, however, presently unsatisfactory, though these accidents are highly significant to all of society. Home and leisure accident prevention should be developed. A Ministry of Social Affairs and Health work-

ing group has investigated arranging a home and leisure accident monitoring and prevention system and proposed that it be located in the National Public Health Institute.

8.2.10. Rehabilitation

Rehabilitation concerns children, young people, those of working age, and the elderly. The importance of rehabilitation in maintaining and restoring working capacity and functioning has been emphasized in recent years and considerable investments have been made in it. The goal is to keep people of all ages functioning as well as possible. Rehabilitation of those of working life is intended to help them continue in working life for longer than at present and to return to work after illness and short periods of incapacity to work. However only deficient data is available about the whole field of rehabilitation and data collected is dispersed. The matter is also complicated by the vagueness of the concept of rehabilitation. Rehabilitation data collection should be further developed and a clearer definition of rehabilitation created.

8.2.11. Functioning and other classifications

Functioning and working capacity are increasing important in social policy. Good functioning and work capacity permit continuation in working life and an independent life. At present, very similar methods are used in different studies to measure them, but there are still no uniform recommendations for the measurement of working capacity and functioning. Information is, however, available on the loads imposed by work. It is important to develop the measurement of working capacity and functioning and this should take international development into account.

8.2.12. Immigrants

A great deal of data on the size of the foreign population living in the country is available from registers and the regular publications of Statistics Finland. The increase in the number of immigrants has added to the need for data and information on their well-being, employment, and health. Little such data is available in Finland. Country of birth may be registered, but not membership of an ethnic group or nationality, due to their sensitive nature. The immigrant population and other population groups liable to discrimination are small in number in Finland, so that data sources based on conventional population samples do not produce reliable data on the well-being of these groups. Statistics Finland has initiated a study of the living conditions of immigrants, the continuity of which is presently unclear. In the future, regular survey data on the living conditions and health of immigrants will be needed. The manner of producing the data, the time, and the organization responsible need to be settled by additional planning.

8.2.13. Substance abuse

Several authorities collect data on the consumption of various intoxicants and narcotics. STAKES is responsible for collecting monitoring data on the state of the use of substances, using population-based questionnaires. Other institutes too collect data on the use of substances using various questionnaires relating to the health behaviour of adults and young people, but the sensitive nature of the subject and the production of deeper subject-group data also demand separate theme questionnaires on the subject. Due to the sensitive nature of the subject and certain population groups being omitted from a sample, a reliable overall picture of substance use cannot be gained using population-sample based data collection.

Attempts are made to assess substance abuse either indirectly with the aid of substance-related detriments and the services used by problem users, or by various statistical methods. Data on substance detriments are produced by many registers, such as offence-report statistics, drunken-driving statistics, cause of death statistics, infectious diseases statistics, and the care register. Because the information provided by registers is narrow in scope, substance-specific data collection is needed along with it. Therefore, annual drug-treatment data collection, based on voluntary and anonymous data, funded by the EU, has been tried with the drug-abuse clients of substance-care treatment services. In addition, a national caseload count on substance-related use of services, carried out on one day every four years, is used to collect data on clients using various social welfare and health care services due to different substances, in order to estimate the load caused by substances on the social welfare and health services.

In the future, STAKES's substance questionnaires will be co-ordinated and rationalized so that the various questionnaires will alternate and complement each other more appropriately than at present. A questionnaire survey, directed to adults, emphasizing alcohol will be performed every fourth year and a drugs questionnaire also every fourth year. The questionnaires will alternate. The drinking-habits survey will be changed from an interview survey to a postal questionnaire and will replace the alcohol-weighted questionnaire every second time. The new survey system will be implemented until 2008, after which it will be reassessed. STAKES collects data on substance use by young people (15 – 16-years) using the so-called ESPAD¹⁷ questionnaire survey every fourth year.

8.2.14. Mental health

Changes in mental-health services have comprised a considerable reduction in hospital care, the fragmentation of out-patient services, and an increase in the share of private service providers. From the point of view of monitoring mental-health services it is a difficulty that most visits made due to mental problems are not recorded separately. Mental health issues are taken care of as a part of all care during doctor's or nurse's consulting hours, which is desir-

¹⁷ The European School Survey Project on Alcohol and Other Drugs

able but makes collection of separate statistics difficult. The collection of mental-health statistics in both social welfare and health services will be facilitated by the development of electronic patient and client documents. In their development mental-health aspects should be taken into account.

8.2.15. Health promotion and disease prevention

Several screening examinations allow certain common diseases to be found at the earliest possible stage, when their treatment is successful and economical. Data from the mass screening register provide data on the participation of the entire population in mass screening examinations (mainly cancer screening). The register will be expanded to colorectal and prostate cancer screening data, if screening for these cancers proves appropriate and is extended to the whole population. The National Public Health Institute is investigating the possibility to establish a national vaccination register, which would cover vaccinations given up to two years of age. The statistics reform in out-patient primary health care will allow more comprehensive data on preventive measures to be obtained.

However, the problem mentioned above under mental health remains since the majority of health promotion and prevention is integrated into to the everyday work of doctors and nurses. Currently data on health promotion and its effects are deficient. Consequently, separate statistics are not available. Health is also promoted by several actors outside health care, such as schools, voluntary organizations, etc. Furthermore, the activities can be directed to individuals, groups, communities or the whole population.

Special efforts are needed to create an information system for monitoring health promotion. However, the work is challenging and large. The work should be started by first defining the concepts health promotion and preventive work and constructing a framework concerning their integration into health care, social welfare and other activities. Only after the framework has been constructed and the concepts have been defined will it be possible to draw a plan for an information system providing a comprehensive view of health promotion and disease prevention.

8.2.16. Social welfare and health care personnel

The National Authority for Medicolegal Affairs is a register of authorised health care professions with protected titles. Statistics Finland collects data on social welfare and health care personnel through the Municipal personnel register. Data on those working in the private sector are available from the work statistics of Statistics Finland, but these lack detailed professional data. The present data are inadequate for regional personnel planning and for forecasting labour requirements.

8.2.17. Social welfare and health care economics

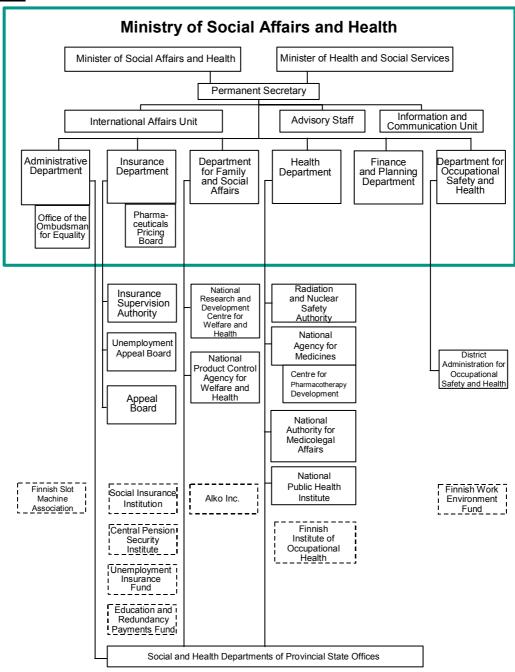
Data on social welfare and health care expenditure by municipalities are available from Statistics Finland's municipal activity and financial statistics. A problem has been the slowness of the preparation of the data, because the statistics are based on municipalities' financial statements. Some municipalities send their data to Statistics Finland only in the summer, so that the statistics are only completed in the autumn of the following year, by which time the next year's budgets have been under preparation for a long time. In some cases, there is also need to check the content of the statistics, particularly in the case of children's day-care and services for the elderly and the disabled. The municipal financial and activity statistics will be reformed in 2006.

Appendix 1



MINISTRY OF SOCIAL AFFAIRS AND HEALTH AND RELATED NATIONAL AUTHORITIES 1.3.2003





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