

USER NEEDS AND CONFIDENTIALITY IN SWEDEN

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The issue of data confidentiality has become an important problem for discussion and legislation in many nations. Legislation dealing with data confidentially can have an impact on social science research as well as on methods for archiving and retrieving data. Erika von Brunken, in a paper delivered originally in Ottawa, discusses Sweden's response to the issue.--Editor.

INTRODUCTION

Since May 1973 Sweden has a Data Protection Act (Datalagen, 1973)[1]. As questions related to registration of personal data have attracted considerable attention since the passing of this law, it became obvious that amendments would be needed in a near future. Several parliamentary bills on this subject have been proposed during the past years. In May 1976 a Swedish Government Commission on Data Legislation (DALK) was set up for a general review of the Data Protection Law and of the activities and experience of the Data Inspection Board. DALK examined the legal regulation of the protection of privacy in conjunction with registration of personal data, chiefly problems associated with the use of ADP. As a result of this investigation the report "Personregister - Datorer - Integritet" (Person registers - computers - integrity)[2] was submitted (June 1978). Emanating from this report, a Government Proposal[3] on certain amendments in the Data Act was submitted on March 22, 1979, which will come into force on July 1, 1979. DALK is now investigating the way in which computerization affects the principle of public access to official records, as well as the use of computers in public administration and by the business community as an international phenomenon.

In the following I shall not dwell on the concepts of privacy, integrity, confidentiality, ranging from "the right to be left alone" to "being able to decide and act on one's own", but restrict myself to the legal aspects of privacy protection and their impact on research in the social sciences.

THE IDENTITY NUMBER AND THE PRINCIPLE OF PUBLIC ACCESS TO OFFICIAL RECORDS.

Discussions on privacy and data protection in Sweden revolve around two basic problems: the identity number, assigned to every person living in Sweden, and the principle of public access to official records, confirmed by law in 1766.

The identity number, in Sweden called "person-nummer", has existed since January 1, 1947, and comprises the birth date (year, month, day) and four digits, e.g. 650213-1193. The last four digits are coded information on country of birth, sex, and a control figure. As all information on an individual is stored by this identity number, it was easy to sort immigrants by their national origin. This discrimination has been cancelled

lately, so that now even immigrants get their identity number from the Swedish series. The identity number, the name, address and family relations are entered in a personal file drawn up by the registration office of the parish in which the individual is registered. In the personal file instances of marriage, children, divorce, change of address and death are recorded. If the person moves to another parish, this file is transferred to its registration office. While in most countries the population statistics are still based on censuses, Sweden now has a fully developed system for the continuous recording of population changes in local, regional and national registers. A vast amount of personal data has so been stored in Sweden in machine-readable files, and the identity number makes it technically easy to merge information from different files, originally stored for other purposes.

The principle of public access to official records was established by the Press Law (tryckfrihetslagen) in 1766. According to this law any Swedish citizen has the right to take part of, to read or to copy official records and to publish their content.[2] Even the records of the municipal administration are official records due to this law. Certain records, however, are not official, as documents concerning state security, central financial policies, interests to prevent crime or legal action against it, the economic interests of the society, etc. These documents are classified as secret material by the Secrecy Law and are not accessible. Information stored on machine-readable media can be obtained in the form of printouts for a fee. Personal data are not accessible. The Press Law has been amended several times. The latest amendment has been made

in 1976 with special application to automatic data processing and other technical recording. The new rules came into force in January 1978.

#### The Data Inspection Board and its role in the protection of privacy.

The Data Inspection Board is a central administrative agency for examination of matters relating to licenses and supervision in accordance with the Data Act, the Credit Information Act and the Collection of Debts Act.[2] Because of the large amount of personal data stored on machine-readable media since the beginning of the 1960s, the use of ADP was considered to involve such risks of intrusion upon the privacy of a registered person, that special attention had to be paid. Special legislation was therefore demanded for regulation of both public and private personal registers kept by ADP. Since July 1, 1973, every person, firm or authority, who wants to register personal data by ADP, has to apply for a license at the Data Inspection Board. Now even for collection of personal data for automatic data processing at a later date a licence is needed.

The Swedish Government Commission on Data Legislation (DALK) recommends that the following considerations should be taken into account when licence applications are examined:

- " - it should still be permissible to start a personal register if it can be assumed that - having regard to the various regulations which may be issued - the register involves no risk of undue

encroachment upon the privacy of the registered persons

- the significance of the term undue encroachment upon the personal privacy of those registered cannot be decided in general, but must as now, continue to be judged from case to case
- in making this judgment special consideration should be given to whether the purpose of the register complies with the activity conducted or to be conducted by the responsible keeper of the register
- special attention should be paid also to the nature and quantity of the personal data, as also to which persons shall be included in the register, and to whether the nature and quantity of data and the category of persons concerned comply with the purpose of the register
- special attention, too, should be paid to whether the data to be included in the register were originally collected for another purpose than the register is to serve
- special attention, finally, should be paid to the attitude to the register held by or assumed to be held by those who may be included in it."

DALK proposed additions to Section 3 of the Data Act on these lines. The proposed additions have

been included in the amendment to the Data Act. DALK emphasizes the significance of public interest when a licence is examined, saying "that certain very delicate personal information may, under the Data Act, be registered if called for by a strong societal or other public interest".

When a license has been given to set up and to handle a personal file by ADP technique, the Data Inspection Board gives instructions in accordance with Section 6 of the Data Act on following points:

1. collection of information for the person register
2. how to perform the automatic data processing
3. the hardware
4. processing of personal data allowed by ADP
5. notification of the persons concerned
6. the kind of personal data which may be made available
7. the handing out and other use of personal data
8. preservation and sorting out of personal data
9. control and security.

Concerning the registration of soft data Section 6 was amended with the following: When considering if instructions are needed, special attention shall be paid in case the file contains personal data based on judgments or on appraised information on the registered person.

Person registers ordered by the Government or the Parliament do not need a license, but are supervised by the Data Inspection Board. The Data Inspection Board takes a fee for the license procedures corresponding to the time needed. At the moment the fee is skr.315:- per hour. Research workers sometimes pay reduced fees. Up to now the Data Inspection Board received about 20,000 applications and handled 18,000 of them, 65 per cent by a simplified procedure. The remaining 35 per cent often need a lot of work. Research files belong to this group.

Obligations of the holder of a person register.

Every person, firm or authority who received a license for setting up or holding a person register on ADP is must follow paragraphs 8 - 14 of the Data Act. I present these paragraphs in an abbreviated form:

8. If it can be suspected that some personal data in the file are wrong, the holder is responsible for immediate investigation and correction of the data in question.
9. If a file contains personal data which are incomplete with respect to the aim of the register, and which by its incompleteness might cause undue intrusion into the personal integrity of an individual or might have legal implications, the holder has to supplement the missing information.

10. If a registered person

requests it, the holder of the file has to inform the applicant about the content of the personal data stored on him/her. Even if no information has been stored, this has to be stated. Once information has been given, no new information has to be conferred to the same person before 12 months later. This kind of information is free of charge. Certain information is yet excepted from this rule.

11. Personal data may not be handed out if it can be suspected that the information will be handled by ADP in conflict with the law. In case information shall be handled by ADP in a foreign country, the consent of the Data Inspection Board is needed. Such a consent will only be given if no intrusion into personal integrity is involved.
12. The responsible holder of the file has the obligation to notify the Data Inspection Board if the register shall be closed. The Board will then give instructions what to do with the file.
13. The responsible holder or other persons working with a person register or collecting material for the file are not allowed to reveal information on an individual. The same is valid for persons who received information from a person register.

14. If authorities use ADP records for handling or hearing a case, the material shall be added to the records in readable form, if not special reasons give rise to another procedure.

Those who break the law can be punished by fines or prison. An individual has the right to claim damages if intrusion into personal integrity has occurred. The Data Inspection Board may recall a license in case personal integrity has been violated or cannot be secured.

MERGING INFORMATION FROM  
DIFFERENT FILES BY USE OF  
THE IDENTITY NUMBER.

The linking of files or merging of information from different files, originally set up for other purposes, has aroused public opinion and drawn attention to the need for protection of privacy. It is technically easy in Sweden to merge selected information from different file by using the identity number. All information on an individual is stored by this number. The tax office checks your declared income, the social welfare authorities make sure you have not received undue allowances, etc. The Cancer-Environment-Register, conducted by the National Board of Health and Welfare, is the result of merging information from the Cancer Register with census data on occupation, working place, living quarters, education, etc. A more restricted use of the identity number, even its elimination, have been discussed, but the advantages are surpassing the disadvantages. The joint running of files would not be as easy as now, but name confusions

would lead to infringement or privacy instead. It has been recommended that the identity number should not be printed in data outputs if not necessary.

DALK says: "As regards other aspects of linking, it has above all been pointed out in the debate that public agencies, with the aim admirable as such to fulfil their functions as justly and rationally as possible, have tended increasingly to make use of ADP and the possibilities of linking registers in order to check the correctness of particulars submitted by the individual in different contexts. But it is not unusual that the private sector as well, e.g. insurance companies and credit information agencies, uses data in various official registers to check information submitted by the individual relevant to a particular private sector. Apart from these instances, the linking and other joint use of data would appear to be commonly desired in scientific research, including community planning and the production of statistics. These aspects of the linkage problem involve, in DALK's opinion, a broader political issue, namely which methods should be accepted that public and private bodies use for checking the correctness of particulars submitted by the individual, often on oath or in similar forms, in a specific administrative matter or a specific customer relationship."

The question is to weigh the infringement on privacy against the demands of the public interest. DALK proposed that governmental instructions should define more clearly for which purposes data in official registers may be used. This might quiet the public uneasiness concerning uncontrolled use of individual data.

SOFT DATA AND OTHER SENSITIVE INFORMATION.

The need for and the use of soft data and other sensitive information and their handling has been discussed thoroughly by the research community and the authorities. The point of view differs, depending on who is discussing it. Largely the authorities agree that soft data should be handled with utmost care and should be judged from case to case. The Data Inspection Board emphasizes that it cannot be said generally which kind of information is sensitive, and which is not. Important is the feeling of the individual towards it. It is that perception which should decide from case to case. The Data Inspection Board attaches great importance to the viewpoints of the ethical committees at the respective faculties. These committees investigate research projects of sensitive nature, and examine if they can be performed in accordance with ethical rules. The restrictive view of the Data Inspection Board is shared by DALK, which proposed the amendment to Section 6 of the Data Act already mentioned earlier.

As expected, the strongest criticism against the proposed amendments have been expressed by research workers in the social sciences. Professor Carl-Gunnar Janson, sociologist and Dean of the Faculty for Social Sciences at Stockholm University, expressed the view of the Board of the Faculty in an answer to the Department of Justice, which submitted DALK's report for consideration.[4] He said that neither freedom nor right are absolute, neither the freedom to do research, nor the individual's right for privacy. The interests of the society had to be taken into consideration. If all risks should

be eliminated, research would be made impossible, which in turn would endanger society. The Board was afraid that DALK's way to balance the demand for integrity against the demand for research might become fatal for future research in the social sciences in Sweden. Janson stressed further that the Data Protection Law already has affected research in a negative way, and that the protection of privacy has changed for the worse. He foresees a strong bureaucratic impact on research, and as a consequence reduced empirical research. Janson proposed that a distinction should be made between administrative and pure research files, the latter ones should not need a licence. This idea had already earlier been presented by him during a symposium on "Forskning och integritet" (Research and Integrity), arranged by the Faculty of Jurisprudence at Stockholm University in March 1978[5], where research workers from different fields in the social sciences had met and discussed their experiences. Several participants of this symposium emphasized the need for soft data and the necessity to store them for later use in longitudinal and panel studies. The elimination of the identity number would make such studies impossible. Concerning archiving and sorting out data files it was pointed out that it should be born in mind what kind of data might be of value for research 20 years or more ahead, and that the demands of future research should be met.

The Research Council for the Social Sciences, well aware of the need to preserve research files, set up a working group on data archiving matters in March 1978. The final report of this group has just been presented, but no deci-

sion has yet been made. Ulf Christoffersson from the University of Gothenburg, a member of IASSIST, belongs to this group. Probably he will report on this work at a later date. The Board of the Research Councils, Forskningsradsnamnden, set up a committee on longterm research for investigation of the need for future access to data. The work of this committee has been presented in a report "Forkningens framtida datatillgang" (Future access to data for research) [6] by Christer Winberg and Sune Akerman.

advertisements filling their mail-boxes.

Still we are an open society. Research workers, representatives of the Data Inspection Board, the Research Councils and the Central Bureau of Statistics have been most helpful by providing me with information. Summarizing my impressions very crudely I could say: the farther away you are from research, the less you are worried about the impact of data legislation on future research.

#### References

#### FINAL REMARKS.

Sweden is known as an open society where information is allowed to flow freely. It might seem astonishing to people from other countries, that the Swedes are willing to accept the accumulation of a vast amount of personal data on them in official files, which later on might be used for supervision by governmental or local authorities. I think as the principle of public access to official records gives the citizen a possibility for insight into public administration, a feeling of reciprocity is created. There have been opinion polls after the Census of 1970 and 1975, as some questions asked in the census were seen as an intrusion into privacy, but I think people are not yet aware what possibilities for control are given by storage of those files by ADP technique. It just begins to dawn on them. What is embarrassing people most, are the personally addressed

1. Datalagen SFS 1973:389.
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4. Stockholms universitet, Samhällsvetenskapliga fakultetsnamndens remissyttrande över datalagstifningskommittens betänkande. 1978-11-01.
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6. Winberg C. and Akerman S. Forskningens framtida datatillgang. Samarbetkommitten för långsiktsmotiverad forskning. Juni 1976.