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The Moral Roots of Prenatal Diagnosis

Ethical Aspects of the Early Introduction and Presentation of Prenatal Diagnosis in Sweden

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ABSTRACT

Motives put forward by specialists on prenatal diagnosis in support of this procedure when it was introduced in Swedish health care during the 1970's are described and analysed. The motives are set in relation later criticism of prenatal diagnosis as well as general bioethical issues.

Three motives are described: 1) Prenatal diagnosis is a tool for improving genetic counselling, thereby promoting the autonomy and reducing the anxieties of pregnant women who fear having children with some disorder or disease. 2) The point of prenatal diagnosis is to effect medical prevention by reducing the number of children born with diseases or disorders. 3) Prenatal diagnosis has an economic advantage in that it may save society from some of the costs involved in the care for disabled or retarded people. These motives are found to communicate an unclear and partly inconsistent body of ethical values. First, complex ethical issues in connection with abortion were not addressed. Secondly, it is highly unclear how considerations of autonomy was weighed against considerations of well-being and economic aims. This unclear picture of the support of the autonomy of patients is also relevant when the economic motive is set in relation to accusations that prenatal diagnosis springs from similar moral values as eugenic policies of the past. Three interpretations of this motive are distinguished of which only one may actually support eugenic policies. However, even if the economic motive is interpreted in a very defensive way, it still expresses a tolerance of policy-makers setting aside the autonomy of individual patients in order to achieve economic aims. It is argued that the expression of such tolerance can only be blocked by a clear willingness to actively fight any threat against the autonomy of patients, and that the expression of such an attitude is incompatible with the use of the economic motive.

Key words: bioethics, eugenics, genetic counselling, medical ethics, prenatal diagnosis, research ethics, selective abortion

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FOREWORD

When prenatal diagnosis was introduced in Sweden in the 1970's and, in connection therewith, presented to the public by specialists, motives were given for the use of the procedure. This study describes and analyses these motives from an ethical point of view. The analysis is related to more general bioethical and basic ethical issues, as well as to how critics have in fact interpreted the specialists' motives in public debate.

The study is the first in a series of three planned within the research-project *Genetic Counselling and Prenatal Diagnosis: Survey and Analysis of Ethical Aspects*, led by Stellan Welin, director of the Centre for Research Ethics in Göteborg, in collaboration with Jan Wahlström, head of the Department of Clinical Genetics at the Eastern Hospital in Göteborg. To both of these I would like to extend my gratitude for valuable help during the work, especially for reading and commenting on drafts of this study.

The project is financed by the Swedish Council for Research in the Humanities and Social Sciences (HSFR), which is hereby acknowledged.

One source of information used in the study has been interviews with a number of key-persons in the early Swedish debate about prenatal diagnosis. To all of these, a most sincere thank you. I would also like to thank Torbjörn Tännsjö, professor of practical philosophy at Göteborg University for helpful criticism of an earlier draft of this study.

Chapter One
INTRODUCTION

The subject of this study is the introduction of techniques for prenatal diagnosis in Swedish medical practice which took place from the very late 1960's and proceeded throughout the 1970's. The emphasis is on how these new techniques and their (possible) uses were presented in print by specialists on prenatal diagnosis. In particular, ethical positions and/or values implied or hinted at by these presentations are analysed and related to more basic ethical standpoints and controversies.

The history of public presentation of prenatal diagnosis in Sweden during this period is quite easily divided into two parts. The second part covers 1978 and 1979 and was characterised by intense, sometimes even furious, public debate in more or less all kinds of public venues. This debate, especially the substantial portion of criticism against prenatal diagnosis, has been thoroughly surveyed by Sture Gustafson.[1] Following the debate, an expert-group for surveying facts and problems regarding prenatal diagnosis was formed within the Swedish National Board of Health and Welfare (NBHW), which published a report in 1982[2] (published again in a revised form in 1988).[3] Eventually, a government committee regarding "the unborn child" was formed, which produced a white paper at the close of the 1980's.[4] A government bill was

1 Gustafson 1980, 1984 and 1991.

2 *Fosterdiagnostik. Rapport från en av Socialstyrelsen tillsatt expertgrupp.*

3 *Fosterdiagnostik. Fakta och problembeskrivningar.*

4 *Den gravida kvinnan och fostret - två individer.*

finally presented to and accepted by Parliament in 1995.[1]

Notwithstanding the importance of these events, however, the present study instead focuses on the time preceding the above-mentioned debate (i.e. the period of 1969-1977). This period has not been previously presented or given much attention - other than a few short remarks on its relative silence. However, although not as dramatic and bold in its rhetoric as the period of 1978-1979, it was during 1969-1977 that the actual introduction and presentation of prenatal diagnosis in Sweden took place. Therefore, it is in these years that we can hope to find the original ethical basis of Swedish prenatal diagnosis - an essential part of any explanation of why it gave rise to such an intense debate so suddenly in 1978, the content and structure of this debate and, in effect, the timing and nature of later debates and related events.[2]

Sources of Information

Two kinds of sources have been used, the primary of which has been printed publications. The other kind of source has been interviews with four leading specialists on prenatal diagnosis from the period in question, and four critics of their activities from the later debate.

All quotes from publications written in Swedish have been translated into English by me - the original Swedish formulations are available on request.

Unless otherwise indicated, the interviews have been used purely as a background for interpretations. They have provided information about unknown events and publications as well as inspired ideas regarding how to interpret the material. However, the actual illustrations of views, perspectives and opinions present during the

[1] *Fosterdiagnostik och abort*.

[2] Gunilla Lindmark (1991) has given an account of some administrative, organisational and scientific factors which certainly played a role in this.

period are exclusively taken from printed publications. The same holds regarding evidence given for and against different interpretations. Nevertheless, it might be of interest to briefly present the persons interviewed, some of whom will be mentioned quite a few times below.

Specialists
1) Professor Karl-Henrik Gustavson
2) Professor Berndt Kjessler
3) Professor Jan Lindsten
4) Associate professor Jan Wahlström

As will become obvious below, all these four were central in introducing prenatal diagnosis in Sweden.

Critics
1) Sture Gustafson, journalist
2) Roland Nordlund, almoner
3) Anita Wester, psychologist
4) Bertil Wik, physician

Gustafson is a pioneer in criticising prenatal diagnosis. He has already been mentioned as surveyor of the debate in 1978-1979, but he has also been quite active within the Swedish Society for the Mentally Retarded, FUB. The other three at the time all specialised in special care for the mentally retarded in the region of Västerbotten in the north of Sweden. Together, they wrote an article which initiated the debate in 1978.[1]

[1] Nordlund, Wester & Wik 1978.

Plan of the Study

The study proceeds as follows. In the rest of this chapter, the scientific, technological and historical context in which Swedish prenatal diagnosis emerged is described. The main acting parties among the specialists on prenatal diagnosis in the Swedish introduction and presentation of this procedure are presented. I will also give a brief general overview of the flow of printed information about prenatal diagnosis during the period.

The presentation and analysis of the specialists' presentations from this period focuses on the motives for prenatal diagnosis put forward by the specialists. These are three, to each of which one chapter is devoted. In Chapter Two, the view of prenatal diagnosis as a tool for better genetic counselling is scrutinised. Chapter Three focuses on the medically preventive role that some specialists assigned to prenatal diagnosis. Prenatal diagnosis was also motivated in economic terms, and this line of reasoning is the subject of Chapter Four. Each of the chapters Two-Four conclude with a summing up of the most important results. In Chapter Five, attention is given to the few attempts by the specialists to address ethical issues in connection with prenatal diagnosis. The results of the study are summed up in chapter six.

The general finding is that the specialists' motives for prenatal diagnosis expressed an unclear and partly inconsistent body of ethical values. In particular, it was not clear how considerations of the personal autonomy of individual patients were weighed in relation to medically preventive aims and pure economic objectives. It is recognised that this made some room for interpretations of the specialists' motives for advocating prenatal diagnosis that bear some resemblance to motives that had underpinned eugenic policies of the past. Moreover, some of the motives actualise basic ethical issues, the complexity of which was not fully appreciated at the time, even among professional moral philosophers.

Background

When prenatal diagnosis is spoken of in this study, it is to be taken to refer exclusively to determinations of the medical status of the foetus during pregnancy, arrived at with the help of modern techniques for analysing human cells or their chemical products. The most common type of prenatal diagnosis in this sense, especially during the period considered here, is chromosomal or biochemical analysis of foetal cells in amniotic fluid which has been sampled from the womb through the abdominal wall - a technique commonly known as amniocentesis.

Prenatal diagnosis has three main scientific roots - apart from the general medical knowledge of different states of the human body and mind.[1] First, different findings and techniques from the field of medical genetics and biochemistry. Secondly, a technique for sample-taking of amniotic fluid during pregnancy. Thirdly, applications of the findings of medical geneticists and biochemists made and developed in many medical fields, particularly in obstetrics and gynaecology, paediatrics and psychiatry.

The idea of prenatal diagnosis through studies of foetal cells in amniotic fluid was present already in the 1950's, inspired by prenatal sex-determination by such means performed by the Danish researcher Fritz Fuchs. However, most of the research underlying prenatal diagnosis was not directly aimed at any particular application. Rather, this research was typically of a "pure" or "basic" scientific nature, aimed at obtaining medically relevant knowledge in general, with the hope that this would eventually lead to actual cures for various diseases. As will be seen below, in the cases where the research had a more specific aim, this was normally not to facilitate prenatal diagnosis.

When medical geneticists in the 1950's and 1960's strived to make scientific study of the genetic mechanisms of humans possible in order to accomplish further advances in medical knowledge,

[1] The main source of this historical overview is Jan Wahlström's historical survey in Wahlström 1973, pp. 1-2.

Sweden was in the forefront. Only a handful of laboratories throughout the world were engaged in this ground-breaking work in human genetics, and of these, two were Swedish. In 1956, at the department of medical genetics at Lund University, the team of Tjio and Levan determined the number of human chromosomes to be 46, and about the same time the same discovery was made in England by Ford and Hungerford. Such findings could not have been accomplished without new techniques for the cultivation of human cells and observation of their genetic content. It also marked the starting point for attempts at mapping correlations between genetic makeup and medically interesting states. One of the earliest of these was the correlation between Down's syndrome and the presence of three chromosomes in pair no. 21, found in 1959 by the French geneticist Lejeune and his co-workers.

The techniques were then frequently improved upon and applied in different medical fields, resulting in a fast and steady growth of skill, precision and knowledge. One particular later Swedish finding of relevance for prenatal diagnosis was the so-called fluorescence banding-techniques for marking parts of chromosomes, developed by Lore Zech (under the leadership of Torbjörn Caspersson) in 1970. This method, and others similar to it, made possible accurate identification of the different chromosomes as well as detection of structural changes of the chromosomes.

For physicians of different specialities, it was natural to investigate to what extent the methods developed in medical genetics could be applied to and put to use in their own field. These applications concerned a wide range of pathological states and caused a steady growth of corroborated correlations between symptoms of different kinds and specific states of the chromosome constitution. The natural curiosity of the physicians was further enforced by the fact that applications of the methods of medical genetics offered numerous options for research-projects and career-routes. In Sweden, such research were funded in various ways, but mostly within general projects or research-grants from the Universities and/or the Medical Research Council.

An interesting curiosity in this context is that the research under-

lying prenatal diagnosis was enthusiastically supported by the Expressen fund for prenatal research. This fund was set up and run by Sweden's second largest daily newspaper, *Expressen* ,from 1958 and onward. The money in the fund was to some extent obtained by donations, but mostly through light-hearted competitions for the readers of *Expressen* which were presented by a well-known Swedish singer. Money-wise, however, the fund does not appear to have played a significant role in the rise of prenatal diagnosis in Sweden.[1]

During roughly the same period, medical researchers also used new biochemical findings and techniques for studying the chemistry of the human cell, in particular its metabolism. Also here, known symptoms and diseases were linked to states detectable by the new techniques, in this case biochemical conditions of the cell's metabolism. Since many of these diseases were known to be strongly hereditary, such findings were of course closely linked to medical genetics. Also here, *Expressen*'s fund for prenatal research gave financial support.

Parallel to these developments, techniques for sample-taking of amniotic fluid were developed within the field of obstetrics and gynaecology in connection with research on the problem of immunisation in pregnancy. Of these techniques, the most successful proved to be the one carried out through the abdominal wall, now commonly known as *amniocentesis*. One particular discovery made in this context was that the amniotic fluid contains an amount of viable foetal cells large enough for the techniques of medical genetics and biochemical analysis to be applicable.

That far ahead, it was only a question of someone getting the idea of putting these different results together and performing chromosome or biochemical analysis on foetal cells in amniotic fluid extracted by amniocentesis, in order for prenatal diagnosis to see the light of day. The first international reports of such perfor-

[1] The history of this fund as well as the kind of research it supported is set out in Engel 1981.

mances were published in 1966,[1] and were taken up in Sweden a few years later. After that, the practice could be gradually expanded as new diagnostic possibilities occurred, for example the above mentioned banding-technique for chromosome analysis and discoveries of the biochemical nature of various metabolic diseases. Also this practice of expanding the area of application for prenatal diagnosis was enthusiastically supported by *Expressen*'s fund for prenatal research.[2]

The level of activity was quite low to begin with. In 1972 (the first year for which reliable statistics exist), 90 cases of prenatal chromosome-analysis were registered. These grew to 627 in 1975. During that period, most of the practice was financed by research-grants. Up to 1975 Sweden had only one department for clinical genetics (formed in 1970), at Karolinska Hospital in Stockholm, although a smaller unit had been set up within the department of psychiatry at Saint Jörgen's Hospital in Göteborg as early as 1967. In 1975 a second department started in Lund. In 1976, an expert-report on clinical genetics to the NBHW[3] initiated an expansion of prenatal diagnosis by recommending that each of the six health care regions in the country should have their own department for clinical genetics - an aim which was achieved during the 1980's. In 1980 the number of performed prenatal chromosome-analyses had risen steeply to 3499 and in 1988 (the latest year from which reliable statistics are available) to 5245.[4]

[1] Steele, M. W. & Breg Jr., W. R. 1966, and Thiede, Creasman & Metcalfe 1966.

[2] Engel 1980, pp. 56ff.

[3] *Klinisk genetik.*

[4] Lindmark 1991, p. 71. In addition to the figure for 1988, the number of prenatal chromosome analyses on cells obtained by the new method of chorionic villus sampling (introduced in 1985) may be mentioned: 434.

The Acting Parties

The nature of the scientific side to the rise of prenatal diagnosis (sketched in the foregoing section) has some consequences for the identification of the acting parties in the introduction and presentation of this technique. Prenatal diagnosis does not seem to have been a product of deliberate research and development programs, but rather an incidental spin-off of basic medical research which was put into clinical practice and eventually evaluated and expanded. This means that, at least for those with knowledge of the subject, it was apparently possible to foresee the prospect of combining different results into a procedure for prenatal diagnosis by studying presentations of the basic research underlying prenatal diagnosis. Such presentations of basic research may therefore also be seen as *implicit* presentations of prenatal diagnosis. In other words, there is a grey area of publications which could be seen as implicit presentations of prenatal diagnosis (if read by a person with appropriate knowledge). Keeping this in mind, however, I have chosen to focus on presentations explicitly devoted to prenatal diagnosis.

The original development, introduction and practice of prenatal diagnosis in Sweden were mainly conducted in three places (taken from the north): Uppsala, Stockholm and Göteborg.

In Uppsala, prenatal diagnosis was taken up at the Academic Hospital by the paediatrician Karl-Henrik Gustavson and the obstetrician Berndt Kjessler. These had both been educated at the Department of Medical Genetics at the University of Uppsala and pursued research at that department. While Gustavson's research correlated chromosomal factors with various birth-defects, Kjessler concentrated on the role of chromosomal factors in infertility and spontaneous abortions. Later on, Kjessler went on to contribute to the expansion of prenatal diagnosis to include neural tube defects such as spina bifida through analysis of the amount of the protein AFP. He eventually developed methods for measuring indications of this by means of a blood test on the mother and used that for a screening-project. Today Gutavson has retired, while

Kjessler is head of the Women's Clinic at the University Hospital in Linköping.

In Stockholm, prenatal diagnosis was taken up at Sweden's first independent department of clinical genetics at the Karolinska Hospital. The leader of the work was Jan Lindsten, originally educated and active as researcher at the Department of Medical Genetics in Uppsala in the 1950's. Since then he had done a lot of work in the field of chromosome analysis at Karolinska, being among other things part of the team behind the above-mentioned fluorescence-method. Today he is Professor of Clinical Genetics at Karolinska Hospital.

In Göteborg, the interest came from psychiatrists bent on the role of genetic factors in psychiatric syndromes. Both Hans Forssman, professor at the Psychiatric Research Centre at Saint Jörgen's Hospital, and Professor Hans Olof Åkesson in Psychiatric Department III at Lillhagen's Hospital, had been very active in the work of studying the relation between mental retardation and chromosomal factors. Among other things, it was Forssman and Åkesson who in 1967 initiated the clinical genetic unit at Saint Jörgen's Hospital mentioned above. It is also of interest to note that Åkesson received his basic training in genetics at the Department of Medical Genetics in Uppsala. His interest in prenatal diagnosis was transmitted to the research-student Jan Wahlström, who wrote a doctoral thesis on prenatal diagnosis under the supervision of Åkesson.[1] Today (1996), Forssman is deceased while Åkesson is professor of psychiatry at Sahlgrenska Hospital in Göteborg. Wahlström is presently head of the Department of Clinical Genetics at the Eastern Hospital in Göteborg.

All of the people mentioned so far specialised in the prenatal diagnosis of *chromosome aberrations*. Since such analyses at the time made up the vast majority of those requested in prenatal diagnosis, it seems natural to consider these people as constituting the hard core of those who contributed to the introduction of prenatal diagnosis in Sweden. In addition, there were also the biochemical anal-

[1] Wahlström 1973.

yses of hereditary metabolic diseases. These were few during the period in question, partly because few could be diagnosed, partly because of the extreme rareness of these diseases. However, something should also be said about the leading people in the introduction of prenatal diagnosis of hereditary metabolic diseases.

Three crucial participants were Bengt Hagberg, a specialist in the neurology of children working first in Uppsala and later in Göteborg; Patrick Sourander, a neuropathologist from Göteborg; and Lars Svennerholm, a biochemist from Göteborg. Together, they conducted research on the biochemical nature and diagnosis of certain metabolic diseases. The project ran from the late 1950's and eventually came to include prenatal diagnosis of the diseases studied. At the Department of Clinical Chemistry at Lund University, a team led by Per-Arne Öckerman worked on a project from the beginning to the middle of the 1970's, specifically aimed at developing the prenatal biochemical analysis of metabolic diseases. Lars and Kerstin Hagenfeldt at the Karolinska Institutet in Stockholm ran a similar project during roughly the same time.[1]

Some of these people were also active in the *presentation* of prenatal diagnosis. Others who contributed to this were specialists in prenatal diagnosis from other Scandinavian countries, other health-care professionals, organisations for disabled people - especially FUB - a society for the mentally retarded, a few politicians, journalists, ethicists and various free writers.

Overview of the Presentations

Before discussing the content of the presentations of the specialists it is useful to consider a brief general overview of all presentations of prenatal diagnosis made during the period that I have come across. Such an overview has here been accomplished by relating presentations to four variables: time, number of written items, type

[1] Engel 1980.

of author and type of publication in which the presentation occurred.

The purpose of the overview is not to make a statistical analysis, but mainly to get a rough picture of the information-flow. Therefore, not much work has been invested in making the taxonomies used for the last two variables as clear as would otherwise have been needed. The types of authors and publications described below are all more or less vague and therefore allow for some variations regarding the correct classification of data.

Authors

The authors were divided into five categories: specialists, journalists, free writers, politicians and ethicists. These were seen as ”social roles” of the authors which are often stable in relation to the person in question but which may also change from one occasion to another. This means that one author may appear in several categories. This, however, only happened once and will be commented on.

Specialists denote people with special knowledge of prenatal diagnosis. Journalists denote people writing as employees of magazines or newspapers. The free writer category is a broad one, including ordinary people as well as moulders of public opinion. Ethicists include all types of alleged specialists in ethics and ethical analysis, theologians, philosophers and others. However, the ethicists actually present in the material all had more or less clear religious connections.

The politician category also includes officials. It is here that we find one person appearing in several categories. The person in question is Kerstin Anér. Now deceased, she was at the time an active and organised Christian, a politician of the Swedish Liberal Party, editor of a Christian popular journal for the humanities called *Vår Lösen* and a popular writer on science-related issues. Anér has written four items in the material. In two of the cases - a popular book on ethical issues in biotechnology and an editorial in

Vår Lösen - she has been classified as a free writer, but in the two others she has been classified as a politician. The latter two items are in fact the same text, appearing first as a motion (Anér was a member of parliament) and then as an article in *Vår Lösen.* It seems to me that Anér is close to an exemplary case of a person able to appear in different social roles in the public arena, and that the present instance is an example of this in the way indicated by my classification.

Publications

The publications were divided into six categories: scientific, professional, patient-organisation, popular, daily and official.

The scientific category includes publications primarily directed at and probably only read by fellow specialists. Doctoral dissertations, anthologies predominantly made up of medical papers on prenatal diagnosis, and international scientific journals are the most typical instances of this category. The scientific category is the only one which contains texts in a non-Scandinavian language (English).

The professional category includes publications aimed at and reaching most members of a particular profession or a special class of professions. One such profession is of course that of the physician, and typical cases of this category are the Swedish weekly magazine for physicians, *Läkartidningen*, the Scandinavian medical journal, *Nordisk medicin*, and a Swedish journal on mental retardation, *Psykisk utvecklingshämning.*

The patient-organisation category contains publications published by societies for certain groups of patients and publications primarily aimed at such groups. The actual material gives a sample of only one such publication, *FUB-kontakt*, published by the above-mentioned society for the mentally retarded, FUB.

Contrary to the scientific, professional and patient-organisation categories, the publications of the popular category are not primarily aimed at readers belonging to a particular social group, but for a quite broad readership. However, as opposed to daily newspa-

pers, the typical popular publication still demands a certain degree of education and special interest on the part of their readers in order for the information presented to be communicated properly. It is also a fact that, perhaps with the exception for one item, none of the items placed in the popular category occurred in publications with any real potential for reaching out to the public at large. Typical examples of this category are magazines and books on popularised humanities, science and technology.

The category of daily newspapers should be self-explanatory.

The official category includes official records and publications on local, regional and state levels. Expert-reports and white papers from governmental or parliamentary committees are typical examples of this category.

The Data

A total of 64 items mentioning prenatal diagnosis and published during the period have been found. The number of items per year is illustrated by diagram 1 below. This can be compared to the number of items from the one year of 1978 only: 47. In diagram 2, the number of items from 1978 is included as an illustration of this difference.

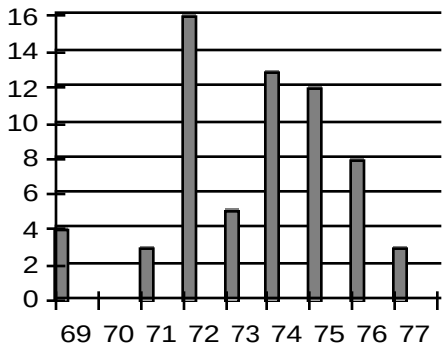

Diagram 1: Number of items 1969-1977 related to year of publication

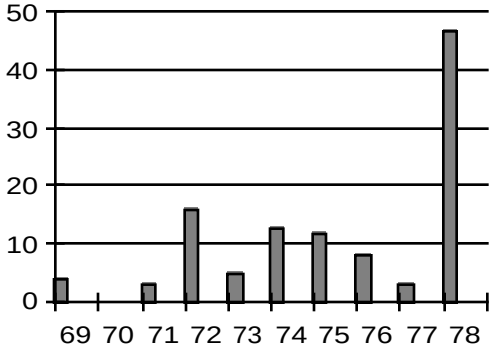

Diagram 2: Number of items 1969-1978 related to year of publication

The ”peak” year of the period was 1972 (16 items), followed by 1974 (13 items) and 1975 (12 items). At the other extreme lies 1970, when no items appeared. Not too much should be made of

these and other differences or tendencies regarding the number of items during the period, however, since the total amount is so small to begin with.

The collection of material underlying these numbers has not included a systematic manual search either of official records below state level or of major daily newspapers. The numbers for the daily, the official and, to some extent, the journalist and the politician categories are thus more uncertain than the other numbers. Since the lack of material from daily newspapers from the period under consideration has been confirmed by other sources,[1] and since the lack of involvement from politicians and officials has been confirmed in all interviews, the joint uncertainty resulting from this should not be exaggerated. Still, it adds to the main reason for abstaining from more subtle statistical analyses: insufficient data.

However, keeping this in mind, some particularly striking facts deserve comment.

All items written by ethicists (8 in all) were published in popular publications with no or very small potentiality for reaching either specialists, politicians or a larger audience.

Four items were written by politicians and, as mentioned above, of these two are the same text by the same writer published in two different settings. The other two are one question raised in parliament and one decision-proposal to form a department of clinical genetics which was voiced in a regional parliament in the south of Sweden.[2] The politicians thus were the smallest group contributing to the information-flow.

By far the largest such group was that of the specialists, who authored over half of the presentations from the period.

Approximately 4/5 of all items written by the specialists were

[1] Gustafson 1980.

[2] The question raised in parliament came from Nils Hörberg in 1973 and answered by the then Minister for Health and Welfare, Sven Aspling. The debate is reported in "Prenatal diagnostik av ärftliga sjukdomar angelägen fråga för socialstyrelsen". The decision-proposal was entitled *Anslag till klinisk genetisk verksamhet inom södra sjukvårds- och omsorgsregionen* .

published in scientific, professional or official publications. Nothing at all was published in the daily press. However, brief *interviews* with specialists occurred in daily newspapers on two occasions.[1]

Only two out of the 33 items written by specialists were published in publications directly aimed at the patient-groups concerned. However, some items appeared in professional or popular publications which could be expected to be read by at least some members of this group.

Undocumented Presentations

All of the interviewed specialists have given accounts of verbal and undocumented presentations that were made during the period. These were typically presentations of the new techniques to various patient-groups or to colleagues. Mostly, the groups that were present to receive these presentations have been reported to have been rather small.

I have chosen not to base any part of the study on accounts of such undocumented presentations. I have had three reasons for this. First, nothing has emerged in the accounts of these presentations that alter the picture one gets from the printed presentations alone. Secondly, the timing of the presentations accounted for has been hard to determine reliably. In particular, it is very unclear to what extent many of the verbal presentations accounted for occurred *after* the debate had started in 1978 or not. Thirdly, there are general uncertainties involved in recollections of past events as far back as 20 years or more, especially when opportunities to correlate these with checkable sources are lacking. Therefore, I have judged that basing the study on any such recollections would rather weaken than strengthen the quality of the study.

However, it should be noted that the possibility of a number of

[1] ”Fostersjukdom spåras i moderns blod” and ”Prov i fostervattnet avslöjar sjukdomar och missbildningar. Ökad risk för äldre föderska - men informationen är dålig!”.

undocumented verbal presentations could be added to the printed presentation directed at the patient-groups concerned.

Chapter Two

THE OFFICIAL VIEW: A TOOL FOR GENETIC COUNSELLING

The typical perspective taken by the specialists in their presentations of prenatal diagnosis was that of a tool to be used in *genetic counselling.* This expression here denotes the activity of determining the probability of a pair of prospective parents to have a child with a certain medical condition, informing them about the result and also about possible lines of action on the basis of this result. This perspective shone through more clearly in some presentations than in others, but even in cases where prenatal diagnosis was viewed more or less in isolation from other activities the perspective of the genetic counsellor was evident.

Background

Due to the results of medical genetics mentioned earlier, the area of genetic counselling had undergone a remarkable development during the 1960's. Physicians were put in an entirely new position in relation to patients who had had a child with some kind of incurable medical condition, believed themselves to be bearers of some kind of hereditary predisposition, or were worried about having a sick child for some other reason. Prejudices and unnecessary fears regarding genetic diseases, such as exaggerated beliefs concerning

probabilities of the appearance of hereditary conditions in the offspring, could be fought more effectively. Moreover, the methods for chromosomal analysis could be used to demonstrate the actual probability of a particular couple who had had a child with a chromosomal disorder of having another child with the same condition. This is to be compared to the past, when only average statistical information could be given, and the actual probability in the particular case can vary between the ”normal” probability of approximately one percent and the 100% probability in the very rare cases where one parent is the bearer of a certain kind of balanced translocation of genetic material. The new knowledge and techniques gave the physicians means for meeting the request for more precise information coming from couples who wanted to have children, but who worried over the prospect of having a (or another) child with some genetic disorder.

Prenatal diagnosis of course fitted nicely in this setting. Here was a technique which could be used for determining the probability of the occurrence of a certain medical condition, not only in an *average* expected child of a particular couple, but in a *particular* expected child of this couple. And not only that, the probability in question in many cases could be made radically more precise, often either 0 or 100%. Prenatal diagnosis thus could help these couples to form families notwithstanding their fears of having a child with some disorder or disease.

One aspect of this which was sometimes taken up as a motive in its own right for the value of prenatal diagnosis was that a couple’s or a woman’s anxiety about having a child with some genetic disorder or disease was sometimes so large, that she was prepared to have an abortion performed if the probability of the child lacking this condition could not be reliably shown to be rather low. Since prenatal diagnosis for the most part shows the foetus to lack the medical condition looked for, the use of prenatal diagnosis thus serves to avoid ”unnecessary” abortions.

This perspective on prenatal diagnosis as a tool for better genetic counselling was evident in the first (very cautious) public reference to prenatal diagnosis. This was made by Karl-Henrik Gustavson

and appeared in a chapter on genetic counselling in a popular anthology on the mentally retarded:

> If a woman is a bearer of a predisposition for a severe recessive X-chromosomal disease or retardation, a determination of the sex of the foetus through examination of cells from the amniotic fluid might be of value in taking a stand on the issue of a possible termination of pregnancy.[1]

> Female bearers of translocations are generally normally developed but [...] run a considerable risk of having children with chromosomal conditioned retardation. A determination of the set of chromosomes through cultivation of cells from amniotic fluid may in these cases be of value in taking a stand on the issue of a possible termination of pregnancy. [2]

The same tendency was shown two years later, in a Swedish-Danish presentation occurring in a publication aimed at physicians in general and specifically devoted to prenatal diagnosis:

> While one in the clinical genetic counselling work earlier had to limit oneself to informing the families about the risk percentages of having sick children, it is [...] today in some cases possible to determine prenatally if an expected child will suffer from a given genetic disease... [3]

In the first presentation appearing in a publication specifically aimed at professionals in mental retardation the angle was similar. The author - the Danish clinical geneticist Margareta Mikkelsen - started out with the situation where a couple had had a sick child or was known to have an increased probability of having offspring with some hereditary disorder or disease:

> In all these cases, one has only been able to predict whether there was a risk in general and how high it was on average, but nothing about whether the expected child was sick or healthy. In cases of higher risks, abortus provocatus was performed if the parents so wished, at least in the Scandinavian countries.[4]

1 Gustavson 1969, p. 61.

2 Gustavson 1969, p. 67.

3 Therkelsen, Lindsten & Bruun Petersen 1971, p. 1141.

4 Mikkelsen 1972, p. 27.

She then went on to mention the possibility of prenatal sex-determination in cases of X-chromosome-linked recessive hereditary disorders (such as haemophilia):

> Thus, one can content oneself with performing an abortion on male foetuses in cases of sex-linked diseases.[1]

She finally moved on to prenatal chromosome analysis:

> If the examination of the amniotic fluid shows a chromosomal abnormality in the child, an abortus provocatus can be performed, while a pregnancy with a healthy child can continue.[2]

When prenatal diagnosis was presented for the first time as an homogeneous and organised clinical activity to the medical community in Sweden, the only motive given for it by the authors was formulated like this:

> Every genetic risk assessment involves anxiety about a repetition of the genetic disease. With the help of prenatal diagnosis of the foetus one has been able for the last couple of years to determine whether or not the foetus has a particular hereditary disease at a relatively early point in pregnancy.[3]

The Aim of Genetic Counselling

Genetic counselling was generally presented by the specialists as an activity solely aimed at the satisfaction of the needs and desires of the couple or woman in question. The text from 1969 quoted above reads:

> The aim of genetic counselling is to give objective information about the hereditary or non-hereditary nature of the disease or retardation and to inform about the magnitude of the risk for subsequent children. Genetic counselling does not have any eugenic aim, but is intended for the individual

[1] Mikkelsen 1972, p. 27.

[2] Mikkelsen 1972, p. 27-28.

[3] Kjessler, Lindsten, Zetterström & Öckerman 1972, p. 2362.

person or family.

[...] The risk-numbers which are given are intended as objective information and one should certainly not influence the parents in their decision regarding the issue of having further children or not.[1]

In a quite ambitious discussion of ethical and psychological aspects of genetic counselling a few years later, the aim of genetic counselling was said to be ”not to *advise* against procreation but to *inform* about the risk”.[2] The unacceptability of every attempt at distorting, changing or withholding information from the patient as well as trying to change her personal aims or values was also stressed very forcibly.[3] Although strict neutrality was seen as an impossible ideal, this was considered as being compatible with helping the patient to make a good decision from her own point of view.[4] More or less the same balanced idea of genetic counselling was, in essence, expressed by Hans Olof Åkesson as early as 1968, in the first Swedish text-book in medical genetics.[5]

This view was further sharpened in a report from a European conference on prenatal diagnosis which was held in Stockholm in 1975, where it was stressed that...

...[w]hatever the parental decision may be, they should be supported by the medical personnel involved. If the decision is to attempt another pregnancy this support should continue throughout the pregnancy whether or not prenatal diagnosis is carried out.[6]

The first printed public presentation of prenatal diagnosis to a primary patient-group (the mentally retarded and their parents) also took the patient’s request and need for information (and the chance to avoid abortions) as the sole motive for genetic coun-

1 Gustavson 1969, p 69.

2 Lindsten, Eneroth & Lambert 1975, pp. 74-75.

3 Lindsten, Eneroth & Lambert 1975, p. 74.

4 Lindsten, Eneroth & Lambert 1975, p. 76.

5 Åkesson 1968, p. 169.

6 Lindsten, Zetterström & Ferguson-Smith 1976, p. 12.

selling and prenatal diagnosis,[1] as did a popular presentation of genetic research published in 1977.[2]

This paints a picture of prenatal diagnosis as a procedure motivated by a concern for helping couples and women to make ”the best” decision according to *their own* aims and values. There seems to be no room in this picture for coercion, pressure or manipulation. On the contrary, the primary aim seems to be to respect and promote the autonomy of the individual patient. Additional reasons for using prenatal diagnosis were that suffering caused by not daring to form a family in the way one wants because of fear of having children with some kind of disease and that unnecessary abortions caused by the same fear could be avoided. In the rest of this study I will call this view of prenatal diagnosis and/or genetic counselling *The Official View*.

Not all physicians at the time embraced The Official View. Some claimed that genetic counsellors should give concrete recommendations to patients/couples in order to correct allegedly mistaken evaluations of risks and thereby make them to take ”the right” reproductive decision.[3] In some cases such recommendations were also given publicly in a very strong manner, for example the statement in a popular book on gynaecology that pregnant women who had got rubella at an early stage of pregnancy (which increases the risk of foetal disorders) ”have to” have the pregnancy terminated.[4]

As far as I have been able to determine, attitudes like these were not typically expressed by specialists on prenatal diagnosis. There is one exception to this, however, which will be set out below. Also, some scattered statements and ways of expression might be interpreted as pointing in a similar direction. Moreover, there were initial controversies regarding the proper indications for pre-

[1] Lindsten 1973.

[2] Müntzing 1977, pp. 488-490.

[3] See Jerndal 1971a, Lindsten’s criticism of his views in Lindsten 1971 and Jerndal’s response in 1971b.

[4] Furuhjelm 1977, p. 40.

natal diagnosis which indicate that the view of genetic counselling taken by the specialists was not as homogeneous as seems on the surface. Finally, it seems that The Official View was inconsistently applied on one particularly central point in the presentations. I will comment on these matters in turn.

One Exception and some Slips of the Pen

Only one explicit statement which goes against The Official View has been found. This was made by Lars Svennerholm in 1972 at a symposium on mental retardation. Following a comment regarding the ethics of aborting foetuses with recessive hereditary metabolic diseases (which are typically very rare and extremely severe), Svennerholm addressed the X-linked metabolic diseases:

> Nor is it any ethical problem to *advise* an abortion when a woman carries a male foetus with muscular dystrophy or haemophilia, but what about a female foetus who is a carrier of this defect? Up to this day, approximately 250 amniocentesis in connection with metabolic diseases have been performed. Already, a *praxis* has been formed: in the cases where there has been doubt whether the foetus is a carrier of or homozygous for the disease and there has been no time for a new test, a termination has been performed. Consequently, *rather one abortion too many than the birth of a sick child.*[1]

The joint effect of the formulations used in this statement seems very hard to reconcile with a view of the genetic councillor as someone engaged in serving the patient with information in order to help her make as good a decision as possible from her own aims and values. Not only is categorical advice to the patient trivialised, but a praxis for when abortion is performed is also described without even mentioning the wishes of the pregnant woman. The last paragraph strengthens this tendency to let the will of the patient play a secondary role even more by setting out a principle which supports such a move.

[1] Svennerholm 1972, pp. 37-38. My emphasis.

Note that the quotation concerns very serious and incurable diseases which often inflict extreme agony followed by early death. The point here is not to argue that Svennerholm was wrong in claiming abortion to be comparably easily justified when the foetus has such a disease.[1]Nor is the point to suggest that Svennerholm at the time was coercing pregnant women into having abortions performed. Rather, the point is that his *view* of the genetic councillor as a person for whom it is proper to make explicit recommendations to the patient in order to reach the aim of avoiding the birth of a sick child is incompatible with The Official View.

This does not mean that Svennerholm was alone in rationing references to the wishes of the couple or pregnant woman in question, however. Jan Wahlström frequently wrote that women ”should” be subjected to prenatal diagnosis, without connecting this to their wants.[2] He also wrote about prenatal diagnosis as something which might be followed by abortion if that would prove ”desirable” or ”necessary”[3] (not *desired* by the woman) and about ”recommending” abortion.[4] Even Jan Lindsten, otherwise the foremost spokesman of The Official View, had moments when he wrote about abortion being performed because of a particular result of prenatal diagnosis without mentioning the pregnant woman.[5]

Because of Lindsten’s strong explicit support for The Official View, it seems quite easy to classify these scattered formulations of his as momentary slips of the pen. Wahlström’s case is slightly more difficult to judge. However, since he never expressed a clearly *motivated* and *explicit* opposition against The Official View similar to Svennerholm’s, and since he explicitly stressed the need

[1] On the contrary, I have myself defended such a claim (see Munthe 1992). The connection between the morality of prenatal diagnosis and the morality of abortion is pursued further in Chapter Three.

[2] Wahlström 1973, p. 15; Wahlström 1974, pp. 73 & 74.

[3] Wahlström 1973, pp. 2 & 7;Bartsch, Lundberg & Wahlström 1974, p. 3388.

[4] Wahlström 1974, p. 74.

[5] Caspersson, Lindsten & Zech 1971, pp. 12-13; Lindsten 1973, p. 7; Lindsten, Eneroth & Lambert 1975, p. 73.

for excessive advance information in order for the pregnant woman to be able to make her own decision whether to have prenatal diagnosis or not,[1] in my view he came closer to Lindsten than to Svennerholm when it comes to expressed acceptance of The Official View.

Controversies: Anxiety and Abortion

The general indications for prenatal diagnosis, accepted by all specialists, were 1) increased probability of having a child with a chromosomal, genetic or some other kind of disorder or disease which it was possible to diagnose, and 2) an earlier child born with some such disorder. Beyond that, however, there seems to have been some initial controversy regarding two proposed additional indications.

The Anxiety Indication

One controversy considered whether or not strong anxiety about having an abnormal child of some kind should function as an indication by *itself* - i.e. regardless of whether the anxiety was well-founded or not. This proposal was first expressed by Hans Olof Åkesson[2] and was further defended by Jan Wahlström and his co-workers.[3] The other specialists did not really express opinions on the matter, rather they simply omitted to include strong anxiety among the indications in their presentations. However, one popular book on foetal disorders and diseases - enthusiastically reviewed by Karl-Henrik Gustavson[4] - argued against ”the anxiety-indication”

[1] Wahlström 1974, pp. 72 & 79.

[2] Åkesson 1972a, p. 30.

[3] Bartsch, Lundberg & Wahlström 1974, pp. 3388-90. Wahlström 1974, pp. 74-75.

[4] Gustavson 1974.

on the ground that the risks to woman and foetus involved in amniocentesis (at the time assessed to be approximately 1-2 per cent) had to be balanced by a similar probability of there actually being something to diagnose.[1] The ”Göteborg-group” for their part saw the risks as being balanced by the prospect of relieving anxiety and by avoiding unnecessary abortions.

Obviously, the position of the Göteborg-group fits well with The Official View. A denial of ”the anxiety-indication” seems to presuppose that the best judge of whether or not the risks involved in amniocentesis are worth taking is not the person taking them - i.e. the patient - but the physician.

It might be retorted that such an attitude merely reflects the common view that physicians may refuse to undertake actions that are not in accordance with established praxis or what has been scientifically demonstrated. Such reasoning is doubtful in cases of *new* procedures, however, since the use of these amounts to *creating* that very praxis which will eventually become established and against which future actions may be evaluated. Moreover, regardless of whether or not it is in accordance with commonly adopted views, the refusal to perform a medical action requested by a patient on the ground that it is ”too risky” still clearly reflects an openly paternalistic attitude towards the patient. The physician is seen as a better judge of what is good for the patient than the patient herself. *Full* respect for the personal autonomy of patients therefore rules out a denial of the anxiety-condition on such grounds.

The controversy was formally settled in 1976, when the anxiety-indication was included among the officially recommended indications for prenatal diagnosis put forward in the above-mentioned expert-report on clinical genetics made to the NBHW.[2] However, no public discussion whatsoever preceded this consensus.

[1] Källén 1974, p 100.

[2] *Klinisk genetik*, p. 16.

The Abortion Condition

The other controversy partly reverses the picture. The Göteborg-group held that willingness to follow up a positive diagnosis with abortion should be regarded as a necessary condition for receiving prenatal diagnosis. At the least, they claimed, the physician should advise against prenatal diagnosis when this condition was not met. Partly, this was seen as self-evident,[1] partly it was motivated by the claim that it is psychologically very burdensome for a pregnant woman to know that the child she will carry for four more months is ”seriously handicapped”.[2] In this case, the Göteborg group was not alone, however. Besides being set out in an early presentation which focused on prenatal sex-determination by people active at an American clinic,[3] ”the abortion condition” also appeared in a consensus-statement of a Scandinavian symposium on prenatal diagnosis held in 1974.[4] In both cases, the condition was motivated by the risks involved in amniocentesis.

However, the same year as the consensus-statement mentioned in the foregoing paragraph was published, one of the organisers of the symposium - Jan Lindsten - objected to the abortion condition. His and his co-authors’ grounds were that prenatal diagnosis for the most part shows that the foetus *lacks* the feared disorder, that knowledge of the foetus having a certain disorder serves to prepare the parents to receive the child and that it is simply best for the parents to know rather than not to know.[5]

The position ofthe Göteborg group seems to be at odds with that part of The Official View which sees prenatal diagnosis as marked by respect for the patient as an autonomous individual. Besides the fact that the abortion condition as such appears incompatible with the idea that the patient should not be manipulated towards certain

1 Åkesson 1972a, p. 31. Wahlström 1973, p. 37.

2 Bartsch, Lundberg & Wahlström 1974, p. 3388. Wahlström 1974, p. 79.

3 Cederqvist & Fuchs 1971, pp. 1017-18.

4 ”Nordisk Symposium. Prænatal diagnosticering af genetisk betingede sygdomme”.

5 Lindsten, Eneroth & Lambert 1975, p. 75.

procreative decisions, their reason for the condition was openly paternalistic with regard to the pregnant woman.

This, of course, also holds for the support of the abortion condition expressed in the consensus-statement referred to above. The latter, however, goes even further than the Göteborg group in that it abandons the idea of prenatal diagnosis as a tool for obtaining information (and thereby also The Official View) altogether. At least, that appears to be the consequence of the demand for acceptance of certain *therapeutic undertakings* in order to balance the risks involved in amniocentesis. Such a demand presupposes that the aim of prenatal diagnosis is formulated in terms of *what may be accomplished by such therapeutic undertakings* and not in terms of information being obtained. Had the aim of the diagnostic procedure only been to obtain certain information (i.e., the position of The Official View), all that would have been needed to balance the risks was a high enough probability of obtaining that information.

Also this second controversy was formally settled in 1976, when the abortion condition was excluded from the expert-report mentioned above, in which the anxiety-indication was included.[1] However, in this case there seems to have been some outside influence through the European conference on prenatal diagnosis held in Stockholm in 1975. In the report issued by that conference the abortion condition was explicitly rejected.[2] Not on any of the grounds mentioned above, though, but apparently because it made the practising of prenatal diagnosis impossible in countries where abortion is legally prohibited.[3]

Two Ways of Caring for the Patient

The controversies regarding the anxiety indication and the abortion condition point to a latent value-conflict in The Official View. The

[1] *Klinisk genetik.*

[2] Lindsten, Zetterström & Ferguson-Smith 1976, p. 11.

[3] Lindsten, Zetterström & Ferguson-Smith 1976, p. 14.

room for this conflict is set up in standard-formulations of The Official View such as the 1969 quotation from Karl-Henrik Gustavson above. He writes that ”genetic counselling does not have any eugenic aim, but is intended *for the individual person or family*” (my emphasis). The controversies point to two separate and ultimately incompatible ideas of what it means for a medical activity to be intended *for the patient* to operate within The Official View.

The expression used by Gustavson goes back to the 1960’s and early 1970’s, when medical geneticists publicly criticised old eugenic ideas and certain old (but, at the time, still effective) laws which had originally been motivated by such ideas.[1] Eugenic motives for, say, performing sterilisations typically express care for abstract entities such as the race, the society or the population, while the individual person is hardly mentioned. In the place of such care the critics of eugenics wanted to stress care for the individual person. This implies that medical undertakings can only be motivated by care for the patient under consideration. However, nothing specific was ever said regarding *how* it can be so motivated or what *kind* of care was intended.

As demonstrated above, some of the arguments for the abortion condition and the only articulated objection to the anxiety indication rested on reasons which exclusively connect to the pregnant woman and her family. This is also true of the reasons given against the abortion condition and those given for the anxiety condition. Both sides of the controversies thus seem to have met the condition to motivate medical undertakings only from the point of view of care for the patient and to see prenatal diagnosis and genetic counselling as being intended ”for the individual person or family”. But nevertheless they supported incompatible conclusions.

To some extent, this of course may have to do with differences in opinion regarding the existence and size of different benefits or inconveniences and also how these should be weighed against each other. The latter kind of disagreement is of a clearly normative na-

[1] The relation of the reasons behind prenatal diagnosis to these eugenic ideas is discussed in Chapter Four below.

ture and a quite subtle one at that. However, it seems impossible to assess its more precise nature from the available material.

However, the benefits to the patient pleaded by the opposing parties of the controversies also partly seem to have been of substantially different *kinds*. Wahlström's argument in favour of the abortion condition, for example, clearly related to the pregnant woman's *experienced well-being*. Lindsten's argument against this condition also mentioned such considerations. However, Lindsten *moreover* claimed that "it is best for the parents to know rather than not to know" *without motivating this in terms of well-being*. This hints at the possibility that The Official View - besides giving room for disagreements as to the balancing of gains and losses of well-being - also incorporated a *further* ultimate value *besides* well-being and, moreover, one which gives rise to considerations which may *conflict* with considerations of well-being. This possibility of conflict means that, given the same account of the facts of a situation, the two kinds of ethical considerations may lend support to incompatible recommendations. An example of this is the proposal to employ the abortion condition with regard to prenatal diagnosis and the rejection of this proposal.

One of the two kinds of considerations was welfare or well-being. The other was literally formulated by Lindsten as *knowledge*. However, it is both natural and in tune with the general spirit of The Official View to interpret this to mean that "it is better to know" *because of the role this plays in the patient's autonomy*. There is an intimate connection between one's ability to govern one's own life - which is what autonomy is all about - and one's access to knowledge. If the patient is prevented from obtaining the knowledge offered by prenatal diagnosis, she is deprived of the chance to make her own choices on the basis of this knowledge. Such a prevention therefore constitutes a restriction of her autonomy in the same way as would any distortion or withholding of information obtained through prenatal diagnosis. The only exception to this is if the patient does not want the information in question. If such is the case, to force the information upon the patient would constitute a restriction of her autonomy.

The possibility of conflict between considerations of well-being and considerations of autonomy is a well-known theme within moral philosophy and one around which many discussions in medical ethics circle. Since The Official View gave room for both of these considerations without any principle of priority in cases of conflict, a possibility was left open for considerations of well-being relating to the patient to override the respect for the patient's autonomy. There is, of course, also another possibility, namely that considerations of autonomy are seen as an absolute requirement, excluding restrictions of the patient's autonomy for the sake of her well-being. However, the sweeping standard-formulations of The Official View did not address that issue and therefore allowed for the possibility that paternalistic reasons in favour of obstructing the will of the patient might be put at work.

The Desire for Healthy Children

In the debate which started in 1978, quite some criticism was directed at the way in which The Official View was applied (or very inconsistently applied, as the critics would have it) in the actual *practice* of genetic counselling and prenatal diagnosis, especially in connection with programs for screening pregnant women for increased levels of AFP in the blood (a predictor for neural tube defects). This criticism of the practice will not be touched upon in this study, but before moving on to the other reasons given for prenatal diagnosis, I will comment on one particular feature of how The Official View was applied *in the presentations*. This theme was later taken up as central by critics of the practice.

As mentioned above, The Official View does not exclude that the genetic councillor influences the patient's wants. On the contrary, a main point of genetic counselling is to supply information in order to effect changes of the patient's wants when these (because of lack of information) conflict with more *basic* wants of hers. For example, if a pregnant woman wants to have children but fears to have

children with some particular disease or disorder and therefore wants to have an abortion, prenatal diagnosis may be used to obtain information that makes her change her mind about the abortion. Also, the information of the mere existence of such a possibility might motivate women with similar aims to attempt pregnancy in the first place. (This feature of The Official View holds even if we disregard the ambiguity regarding its basic values touched upon in the foregoing section, and only consider the strong support for respecting and promoting the autonomy of the patient.)

It is obvious that this leaves plenty of room for criticising or influencing the wishes of patients in genetic counselling (including prenatal diagnosis). As soon as a patient's desire is based on lack of correct information regarding how to reach a more basic aim of hers, respect for her autonomy seems to call for communication of that information, since to withhold it would prevent the patient from achieving the more basic aim. Such a process of influencing and criticising the wishes of patients in a way which *promotes* their autonomy may continue until their most basic wants and aims (which are not based upon factual beliefs) are fulfilled. The only exception to this is if the patient does not want to be informed.

This consequence of The Official View holds for all kinds of information which may be relevant in the light of the patient's beliefs and desires. However, since the presentations were written by physicians and therefore concentrated on *medical* information, desires of the patient which to a large extent depend upon beliefs regarding *non*-medical matters were not presented as being open to criticism. I am here particularly thinking of the patient's desire not to have children with certain diseases or disorders.

Descriptions of The Official View and/or presentations of prenatal diagnosis sometimes - though not always - mentioned the need for descriptions of the symptoms of the disease or disorder in question, available treatments etc. This is surely something which is of importance for how the patient views the prospect of having a child with some genetic disorder. Also, the need for considering psychological aspects such as parental guilt feelings was mentioned.

What was generally *not* mentioned, however, were the *social*

and *societal* aspects of having disabled and/or retarded children, such as available (non-medical) care, societal support, social training-programs, education etc. Also, the large *social psychological* area of *what it is like* to have a family which includes a disabled or retarded member was entirely disregarded. Since all this concern as to what extent it is possible to live an acceptable life although one's child is disabled or retarded and the prospects for such a child to achieve a decent quality of life, knowledge of such aspects are surely very important for the degree of willingness to have such a child.

The only societal aspect touched upon in the presentations occurred quite often and concerned the fact that care for disabled and retarded people costs society money and that such costs may be avoided if affected foetuses are detected with prenatal diagnosis and aborted. I will return to this economic motivation for prenatal diagnosis in chapter four below. At present, the point is only to demonstrate how the patient's desire not to have children with some disorder or disease was given a rather privileged position in the descriptions of The Official View in comparison to wishes which are based on that desire. My point is that this was an effect of not mentioning social, societal and social psychological aspects.

Only one statement that goes against this trend has been found. In a comment on the above mentioned paper by Lindsten and co-authors on ethical and psychological aspects of genetic counselling, the Norwegian paediatrician Margarethe Wehn, also mother of a child with Down's syndrome, claimed that the desire for not having children with some disorder or disease is to a large extent dependent on non-medical factors. Therefore, Wehn claimed, genetic counselling should be conducted by a team which, besides the geneticist, includes a psychologist, an almoner and a parent of a disabled or retarded child or a group of such parents.[1] However, no public reaction to this proposal from Swedish specialists has been found.

[1] Wehn 1975, p. 183.

Summing Up

The Official View saw prenatal diagnosis as an instrument for obtaining information requested by couples and women in order to help them to make well-founded procreative decisions according to *their own* aims and needs. Although this view was generally accepted by the specialists, there were some inconsequences in their application of it. Controversies regarding the proper indications for prenatal diagnosis indicate that The Official View incorporated potentially conflicting ethical considerations, which gave room for possibilities of justifying paternalistic restrictions of the patient's autonomy. Moreover, as a result of ignoring the psychological, social and political aspects of having disabled or retarded children, the desire not to have children with some disorder or disease was given a very privileged position in the presentations of prenatal diagnosis as a tool for genetic counselling.

Chapter Three

THE PREVENTIVE AIM

As may be guessed from the not entirely homogeneous and consequent attitudes towards The Official View demonstrated in the foregoing chapter, there were also other perspectives around. One such perspective was to see prenatal diagnosis in the context of preventive medicine. Looked upon from that angle, the motive for practising prenatal diagnosis was expressed in terms of an aim to prevent children with genetic disorders from being born.

This preventive aim was expressed in 1971, by the early Scandinavian presentation of prenatal diagnosis and the paper focused on prenatal sex-determination referred to above. The former wrote about using prenatal diagnosis for...

> ...preventing the birth of a seriously defective child through induced abortion.[1]

And the latter that...

> ...a positive prenatal diagnosis may be of value [...] for the prevention of the birth of incurably sick children through termination of pregnancy...[2]

In the earlier quoted paper by Margareta Mikkelsen, she wrote, directly after the statement in the last quotation above:

1 Therkelsen, Lindsten & Bruun Petersen 1971, p. 1141.

2 Cederqvist & Fuchs 1971, p. 1021.

> Some births of abnormal children may thereby be avoided, for example, the incidence of Down's syndrome could be reduced by half if all women over 38 were to establish whether the child had normal chromosomes.[1]

And when she summed up her presentation, she mentioned as one *separate* advantage of prenatal diagnosis (besides The Official View) that it "can reduce the number of defective children".[2]

In the same year, Hans Olof Åkesson wrote that...

> ...prenatal chromosome-determination makes it possible to prevent severely defective conditions and therefore [must] be said to constitute an important medical advance.[3]

In the next two years his words were echoed by his student Jan Wahlström.[4]

Bengt Källén was quoted above as the only one putting forward an argument against the anxiety indication. In the same book, after having described the possibilities for determining the probability of a couple having a child with Down's syndrome, he wrote:

> ...it would be possible to eliminate only a small part of the mongoloids who are born each year in Sweden in this way.
>
> During the last years another possibility has surfaced, namely that of determining if mongolism is present or not through a test taken on a foetus during ongoing early pregnancy.[5]

In 1976, the expert-report on clinical genetics to the NBHW which led to the establishment of this discipline within Swedish public health care emphasised the "possibilities to prevent disease [...] through prenatal diagnosis".[6]

In 1977, Karl-Henrik Gustavson wrote in a revised version of the text from which the 1969 quotation in Chapter Two was taken:

1 Mikkelsen 1972, pp. 27-28.

2 Mikkelsen 1972, p. 29.

3 Åkesson 1972a, p. 31.

4 Wahlström 1973, pp. 69 & 71; Wahlström 1974, p. 73.

5 Källén 1974, pp. 94-95.

6 *Klinisk genetik*, p. 20.

> Prenatal diagnosis of genetic diseases and retardation in an early stage of pregnancy will provide totally new possibilities for making genetic counselling more precise and contribute to fewer children with genetic retardation and diseases being born.[1]

An article from the same year which dealt specifically with preventive pre- and perinatal medical measures mentioned prenatal diagnosis, and then added:

> However, it is improbable that the number of disabled or sick children can be reduced drastically even with intensive prenatal diagnosis. [...]
>
> Not until it is the case that an investigation of all pregnant women with reference to some specific defect of the foetus can be undertaken, may we hope for a crucial reduction in the number of sick children.[2]

In this context it is also of interest to note that the paper which provoked the initial critical reactions of the debate that started in 1978 was entitled (in English translation) ”Prevention of Mental Retardation”.[3]

Two Interpretations

The preventive aim expressed by the quotations above ties prenatal diagnosis to the taking of a particular action (abortion) in the case of positive diagnosis. Therefore it may seem obvious that it is incompatible with The Official View’s stress on respect for the patient as an autonomous individual. Suppose that people turned out to be unwilling to undergo a test which would have a preventive effect and/or to follow it up with some action which would have such an effect. In that case the preventive aim alone would seem to recommend that people are made to change their minds about this or even that they are being subjected to the test or action in question

1 Gustavson 1977, p. 63.

2 Kjellmer 1977, p. 4402.

3 Gustavson & Hagberg 1978.

in spite of the fact that they do not want to. This aspect is especially clear in the last quotation, where it is said that the preventive aim will not be achieved unless successful general screenings of pregnant women are executed.

A Special Case of The Official View?

However, there is at least one way to interpret the preventive aim of prenatal diagnosis which makes it into an attempt at applying the strong autonomy aspect of The Official View.

According to this interpretation, the authors just quoted take for granted that people do not want to have children with genetic disorders and that this wish is not based on any false beliefs or distorted views. In Chapter Two we saw that this is what seems to have been generally assumed by the specialists. There I also argued that the practice of making this assumption seems hard to reconcile with The Official View. However, *given* that the assumption is *correct,* The Official View does seem to support the claim that it is desirable to prevent the birth of children with genetic disorders. The reason is that such a prevention in that case would meet people's (well-informed) wishes.

However, there is reason for rejecting this interpretation (and others which make the preventive aim into a special case of The Official View's stress on respect for the patient's autonomy) as *generally* valid. In at least one of the quotations above, the preventive aim is explicitly put *beside* the advantages of prenatal diagnosis in genetic counselling. This hints that, for at least *some* of the specialists, preventing the birth of children with genetic diseases was seen as important in a way which made this preventive aim at least *potentially* capable of overriding considerations of autonomy.

Who is the Patient in Prenatal Diagnosis?

This leads to a second interpretation, which again opens up the unresolved conflict between reasons of well-being and reasons of au-

tonomy shown above to be inherent in The Official View.

Preventive aims in medicine, such as reducing the incidence of this or that disease, are general welfare-aims and as such they may of course conflict with the wishes of some individual. Normally, such conflicts concern the well-being and autonomy of one and the same individual, as, for example, when someone is pressured by increased taxation and anti-smoking legislation to quit smoking. Also, the *effect* of such preventive action (such as not getting lung-cancer) is normally in accordance with other wishes of those being subjected to it. In the case of prevention by prenatal diagnosis, however, the potential conflict occurs between the *autonomy* of *one* party - a woman or couple - and the *well-being* of *another* party, namely a possible future child *whose very existence is at stake.*

The adoption of a preventive perspective hence involves a shift regarding who are considered to be included as *patients* in connection with prenatal diagnosis. The preventive aim directly involves the foetus or, rather, the future child the foetus may become if the pregnancy continues, in a way which is not the case in The Official View.[1] This move has two kinds of basic ethical importance, which will be commented on in the next two sections.

Away from Paternalism

The potential conflict between considerations of autonomy and considerations of welfare opened up by a preventive aim for prenatal diagnosis concerns different parties. The autonomy of, say, a pregnant woman could, if she opposed a prenatal diagnosis or following up a positive result of such diagnosis with abortion, conflict with

[1] This should not hide the fact mentioned at the beginning, that the *research* which led to the development of prenatal diagnosis and still keeps on contributing to its possibilities was and is very much focused on the welfare of the expected child, since the ultimate goal of this research is to cure the diseases that can be diagnosed pre- as well as postnatally. However, this does not really concern the clinical *practice* of prenatal diagnosis at the time.

the alleged welfare-gain of preventing the birth of disabled or retarded children.

There is an important difference between this potential conflict between autonomy and welfare and the one which was shown in chapter two to be latent within The Official View. The latter is a conflict which shows the possibility of justifying *paternalistic* restrictions of a patient's autonomy - i.e. restrictions which are motivated by care for the welfare of the very *same* person whose autonomy is being restricted. The present conflict, however, shows the possibility of justifying restrictions of a person's autonomy in terms of care for the welfare of *others.*

Traditionally, there are three principal standpoints with respect to these two types of autonomy-restrictions. One of these is found among those who have chosen to follow John Locke in seeing all restrictions of autonomy which are not necessary for preventing other restrictions of autonomy as equally bad on a basic level.[1] This point of departure is found in the writings of contemporary philosophers such as Robert Nozick and Judith Jarvis Thomson.[2]

A second standpoint is found among supporters of the moral philosophy of Immanuel Kant, who also saw respect for the autonomy of the individual as a strong requirement. At the same time, however, Kant is also famous for stressing that a person is to be treated "always as an end and never as a means only" - a phrase which has become an important cornerstone in large parts of contemporary Christian ethics.[3] This latter thought seems to lend some support to the view that paternalistic restrictions of autonomy are somewhat *easier* to accept than non-paternalistic ones. In the case of paternalism, a supporter of Kant could argue, the person who gets his autonomy restricted is always treated as an end in that the motive for the autonomy-restriction concerns *his* well-being and

[1] Locke 1690.

[2] Nozick 1974 and Thomson 1971.

[3] Kant 1785. The quotation is taken from an extract of the relevant section entitled "The Categorical Imperative", p. 279. Two largely influential Christian ethicists who base much of their ethical thinking on this idea (as well as others) of Kant are Alan Donagan (1977) and Paul Ramsey (1970).

not someone else's.

In contrast to this, the liberal tradition following John Stuart Mill[1] sees no problems in principle with the restriction of a person's autonomy when this is necessary to protect the well-being of *other* people. However, paternalistic restrictions of autonomy are seen as unacceptable. Contemporary expressions of this standpoint are found in the applied and medical ethics of Jonathan Glover, John Harris and Torbjörn Tännsjö.[2]

The relevance of this is, of course, that these main strands regarding the ethical importance of autonomy will have different things to say about the move away from the possibility of paternalistic autonomy-restrictions and closer to non-paternalistic ones. The Lockean school will not see any significance of this move, since all autonomy-restrictions are considered to be equally bad. Modern Christian ethicists building on Kant, however, would seem to have some reasons to view the move towards non-paternalistic restrictions of autonomy in a sceptical light. In contrast, Mill-type liberals would presumably welcome such a move.

Preventing Possible People from Existing

The second ethically important feature of the inclusion of the expected child as patient has to do with the alleged preventive welfare-gain of prenatal diagnosis. Although there are some variations in the quotations above, this gain seems to have been seen to consist in that at least one child with a genetic disorder or disease is never born.

[1] Mill 1859.

[2] Glover 1977, chapter 5; Harris 1985, chapter 10; and Tännsjö 1995.

Two Kinds of Prevention

Normally, prevention of some disease means that, after the prevention has taken place, there is at least one person who has been *saved* from getting sick. The success of a preventive medical action thus consists in that there *exists* at least one person who does not get sick in the way he would have, had the action not been taken.

However, in the case of the preventive aim of prenatal diagnosis things are different. There, the prevention rather consists in that a person who would have been sick if he had existed is prevented from *ever existing.* Thus, prevention by prenatal diagnosis and selective abortion does not leave anyone who has been helped.

This means that an assessment of the preventive aim must involve the question of to what extent it is desirable to prevent a person with certain unavoidable medical conditions from ever existing.

The Morality of Abortion

One answer to this question is of course that this kind of prevention is *never* desirable as long as it is brought about by abortion, since abortion involves the killing of an innocent human being, a (potential) person etc. This would be the natural view to take for the traditional opposition to free abortion which bases its argumentation in that context on such an ethical position.

In Sweden, however, the rather weak anti-abortion movement in the first half of the 1970's tended to view selective abortions as more defensible than abortions in general.[1] Selective abortions did not really come to be looked upon as particularly ethically prob-

[1] This is seen very clearly in the official Christian responses to a white paper from the parliamentary commission whose suggestions eventually led to the formal adoption of "free" abortion up to the 18th week of gestation in 1974. The archbishop, with whom the vast majority of religious commentators (catholic as well as protestant) chose to agree, criticised the committee, but this criticism was *explicitly* declared not to be applicable to abortion in cases where the foetus has some form of disorder or disease or where there is a heightened probability for this being the case. See *Abortfrågan. Remissyttranden över 1965 års abortkommités betänkande Rätten till abort (SOU 1971: 58),* pp. 102 & 107.

lematic until *after* prenatal diagnosis had been widely criticised in 1978-79.

Also, the fact that Sweden formally had free abortion from 1975 and in practice had had it since the late 1960's has to be taken into account. Possibly this reflects the fact that abortion was not in general taken to be equivalent to murder in the way suggested by the traditional anti-abortion argument.

Leaving ethical arguments against abortion in general aside, there are several ways to try to justify the desirability of preventing the existence of an incurably sick child.[1]

Care for the Parents

One way is of course to refer to the potential parents, in particular the pregnant woman, and see the prevention as favourable for their welfare or autonomy or both. The desirability of prevention is then not at all connected to the welfare of the expected child.

Obviously, such a move takes us back to the interpretation which makes the preventive aim into an instance of The Official View.

Care for the Expected Child

In some cases, however, the desirability of preventing the existence of a sick child might also be supported from the point of view of this child. This concerns the case when the expected child can be predicted to suffer some incurable condition which leads to unavoidable and extremely severe suffering and early death, such as Tay-Sachs disease or Edwards' syndrome (trisomy 18). In these cases, because of the extreme level of unavoidable suffering and lack of compensatory benefits, it seems possible to argue convincingly that the child will benefit, from the point of view of well-being, by being prevented from existing - it is saved from a destiny

[1] Munthe 1992 presents a comprehensible critical discussion of different positions and arguments regarding the morality of abortion.

worse than non-existence.[1]

This line of argument cannot reasonably be expanded to cover more ordinary genetic disorders such as Down's syndrome or spina bifida unless other criteria than well-being are used. However, as is evident from the quotations above, no specialist limited the preventive aim to the most severe diseases only. On the contrary, either Down's syndrome or spina bifida were mentioned as typical examples in connection with the preventive aim, or else all genetic diseases, chromosome aberrations etc. were treated more or less alike. However, when someone criticised the activity, the specialists tended to concentrate on the more severe diseases.[2]

This, of course, actualises the basic ethical question what it is that makes a person's life worth living (or, if this possibility is granted, worth *not* living). Is well-being all that matters for this? Are reduced mental or physical capacities any reason for judging a person's life as being less worth living? Can a life be dominated by heavy suffering but still worth living? These are just a few questions whose answers determine to what extent the preventive aim may be justified by care for the expected child.

Since these questions here arise in relation to a specific medical procedure, they also give rise to quite complicated policy issues. First and foremost of these is the question regarding *how* and by *whom* judgements regarding which lives are to be considered worth living should be made in the clinical practice.

Interchangeability of Possible Future Persons

However, even if only well-being is taken to be what makes life worth living and even if most genetic diseases are granted not to make life worse than non-existence, the general preventive aim ex-

[1] See, for example, Glover 1977, p. 146; Munthe 1992, chapter VI, section 2; and Tännsjö 1991, pp. 50-60.

[2] Since there was not very much debate during the period I am investigating, this mostly concerns the debate in 1978-79. However, in the one case from "my" period of a specialist answering criticism the strategy is evident. See Dreborg 1974.

pressed in the quotations above may still be justified. This has to do with the fact that, in most cases of prevention by prenatal diagnosis and selective abortion, the aborted child is later ”replaced” by another child which does not have the disease or disorder in question. Even if the disease or disorder does not make life worse than non-existence, it may still make life at least slightly less worth living as compared to if it had not been present at all. If so, it would seem that the prevention often involves, not only the non-existence of a possible future child which would have had a life worth living, but also the *exchange* of this possible child for *another* possible child whose life will probably be *more* worth living and which would not have existed if the first child had been born.[1]

The strength of this reasoning is that its logic is similar to that in the apparently sound reasoning of couples or individuals who, because of care for their possible future child, postpone procreation. Instead of having a child *now* which would probably lead a life worth living, one chooses to have a child *later* because that child's life will probably be even more worth living (because the parents are then more ready to welcome and take good care of a child). But these children will not be the *same* ones, depending on the vast difference in the timing of their respective conceptions. Thus, what we have is an exchange of *one* possible child now for *another* possible child later, motivated by the higher level of well-being expected to be enjoyed by the latter child.

At the same time, however, the idea of persons being interchangeable seems to be intuitively repulsive to many people. In more recent Swedish debates about prenatal diagnosis, the disabled and retarded have expressed outrage at such a way of thinking. Partly, this may be due to not having considered the fact that all family-planning in the light of what one sees as best for one's possible children involves a choice between different possible future children. But, besides that, there is also opposition to expanding the motives behind family-planning into the area of abortion.

[1] C.f., Glover 1977, p. 146, Hare 1975, pp. 212-213, and Tännsjö 1991, pp. 60-65.

The standard objection against the application of the interchangeability involved in family-planning to selective abortion is that, in the latter case, it is not a question of interchanging two possible future children. Rather, the objection goes, the interchange concerns one *actual* child (existing as foetus) that is being killed and replaced by a possible future child. The objection is then completed by the claim that the killing of children existing as foetuses is morally unacceptable, even if they are replaced by a new child that would otherwise never have existed.

This objection obviously presupposes a certain answer to the question of the moral status of the foetus - a question which has generated quite a few incompatible answers in the abortion-debate.[1] Moreover, the objection is not specifically aimed at *selective* abortion, but is identical to the traditional argument against abortion in general. We are thus brought back to the first objection to the preventive aim mentioned above.

The Moral Status of Possible People

Justifications of the preventive aim of prenatal diagnosis which refer to possible future children (or interchange of such children) raise the question of the general moral status of people who *might* come to exist in the future depending on choices made today - so called *possible people*. However, to answer that question in a satisfactory way has turned out to be quite hard. It requires reflection on certain hypothetical examples which seem to be pulling most people's intuitive opinions in opposite directions.

If possible people are granted the kind of moral status needed by the justifications in question, we seem to be forced to admit that we have a strong obligation to procreate (as long as the additional people thus created would have lives at least somewhat worth living).[2] The simple reason for this is that to act otherwise amounts to

[1] C.f., Munthe 1992, chapters 2-5.

[2] In practice, this obligation may of course be counterbalanced by other factors. This, however, raises further ethical issues. C.f. Munthe 1995.

forcing possible people away from the pleasures of existence.

This consequence has been extended by Derek Parfit to what he calls *the repugnant conclusion.* In a hypothetical example, Parfit invites us to compare two imagined worlds: one with a moderate population with a quite good quality of life and another with an enormous population where each person has a life worth living but only just. Which of these imagined worlds would be best as the real one? If refusal of existence to possible people is always objectionable on the grounds mentioned we are forced to conclude that the overcrowded world where each one lives a barely worthwhile life would be the best one. Furthermore, no matter how we imagine the not so crowded world, it is possible to imagine a much more crowded one where all people lives barely worthwhile lives, but which is still superior in an analogous way.[1]

If, on the other hand, possible people are denied the moral status that gives rise to the repugnant conclusion we face a problem typified in the following hypothetical example, introduced by Parfit.[2] When planning their future parenthood, a couple learn that one of them suffers a temporary medical condition such that if they procreate in the following year, their child will be born severely handicapped in a way which makes life barely worth living. If they wait a year for the condition to vanish, their child will most probably be healthy, but that child, because of the largely different timing of its conception and thereby of its genetic origin, will not be the *same* child as that which would have been born handicapped had they decided not to wait. Therefore, if possible future people are denied the moral status needed for the interchange-argument to work, there can be nothing wrong in a decision of the couple not to wait, although this means deliberately seeing to it that they have a child whose life is barely worth living.

Denial of the moral status of possible future people needed by the interchange-argument also has a further consequence worth noting. Such a denial also undermines the most common argument

1 Parfit 1984, chapter 17.

2 Parfit 1984, chapter 16.

against abortion. This is a consequence since the latter is typically based on an ascription of great moral significance to the potential of the foetus as a future child.[1]

The question of the moral status of possible future people was just beginning to be systematically discussed by moral philosophers in the 1970's, mostly as a consequence of the revived philosophical debate regarding the morality of abortion. The problems mentioned in the last four paragraphs (as well as numerous other issues) were uncovered by Derek Parfit in the first half of the 1980's.[2] Parfit's writings and the debate following these has demonstrated that this is an area where even the most plausibly sounding ethical idea may force one to accept strange and counterintuitive conclusions.

Summing Up

According to the preventive aim, prenatal diagnosis is to be seen as an instrument for preventing children with diagnosable diseases and/or disorders from being born. Since this aim ties prenatal diagnosis to the taking of a particular action (abortion) in the case of positive diagnosis and thus involves the possible future child in a way that The Official View does not, the preventive aim involves a shift regarding who is considered to be the patient in prenatal diagnosis. One aspect of this is that the preventive aim increases the possibility of conflicts between considerations regarding a woman's or a couple's autonomy and considerations of well-being - in this case the well-being of the possible future child. Another aspect is that the preventive aim ties prenatal diagnosis to the large and complex issue regarding the morality of abortion. In particular, the preventive aim opens up extremely complicated questions regarding the moral status of people that may come to exist in the future.

[1] Munthe 1992, chapter 2.

[2] Parfit 1984, chapters 16-19.

Chapter Four
THE ECONOMIC MOTIVE

Economic factors constituted the third motive for conducting prenatal diagnosis put forward by the specialists. The idea was that such an activity would reduce society's costs for the care of children with genetic disorders. It was the expression of this motive in an article by Karl-Henrik Gustavson and Bengt Hagberg in 1978 which provoked the critics to react and thereby unintentionally started the public debate. Gustavson and Hagberg, who preferred to talk about the combination of prenatal diagnosis and selective abortion as "the preventive approach", ended their article by stating:

> The preventive approach is not only strongly motivated from a humanitarian point of view but also from the point of view of economics. The cost to society of only one severely mentally retarded child kept in an institution amounts to approximately 1.2 million Swedish kronor per ten year period at 1976 values.[1]

However, the motive was expressed as early as 1969 in an anonymous editorial in Sweden's largest daily newspaper, *Dagens nyheter*.[2] Actually, this provoked one critical reaction, although in a much too obscure publication for being able to start a public debate.[3]

The first time a specialist expressed this motive in print was in

1 Gustavson & Hagberg 1978, p. 416.

2 "Mot förståndshandikapp".

3 Gustafson, Sonia & Gustafson, Sture 1969.

1972, in the above-mentioned article by Lars Svennerholm. In connection with describing a screening-program for Tay-Sachs disease in the USA, Svennerholm wrote:

> ...it is estimated that the total cost for diagnosis of carriers, diagnosis of amniotic fluid and abortions over a period of 30 years would, at a constant financial rate, amount to 6 million dollars. The cost for the care of the expected number of born cases of Tay-Sachs disease, 990 during this period, would in comparison amount to 35 million dollars.[1]

The preamble to the first presentation of prenatal diagnosis to Swedish physicians in general included the following formulation:

> Prenatal diagnosis of the foetus is hence of great importance both from the point of view of the individual family and that of economics.[2]

More explicit formulations appeared in an expert-report from 1973 to the Board of Health Care in the County of Malmöhus regarding the conditions for starting a department for clinical genetics:

> Increased precision of the repetition-risks through prenatal diagnosis of genetic diseases is of great importance for the individual family and person and has a medically preventive as well as an economic importance.[3]

> There are probably few areas where the humane and economic value of a prophylactic activity is so salient as in the case of prenatal analyses. Preventing the occurrence of only a few cases of grave genetic aberrations means - apart from the purely humanitarian side - large economic profits in the form of disappearance of future costs for health care.[4]

Almost identical formulations were used by Gustavson a year later:

> There are probably few areas where the humane and economic value of a prophylactic activity is so salient as in the case of prenatal diagnosis in these

1 Svennerholm 1972, p. 36.

2 Kjessler, Lindsten, Zetterström & Öckerman 1972, p. 2362.

3 *Klinisk genetik inom södra sjukvårds- och omsorgsregionen*, p. 2.

4 *Klinisk genetik inom södra sjukvårds- och omsorgsregionen*, p. 26.

risk-groups.[1]

The expert-report to the NBHW which led to the establishment of prenatal diagnosis as a routine clinical practice included an appendix which surveyed different attempts at balancing the costs for conducting prenatal diagnosis against the costs of care for children with genetic disorders. It was stressed that large difficulties are included in all attempts at assessing a ”possible economic profit”. Nevertheless, it was emphasised that ”the profit is very large” for prenatal diagnosis of Down’s syndrome on women 40 years and older.[2] The experts concluded:

> Prenatal diagnosis prevents the birth of a number of children with genetically conditioned disorders. Against this background it is natural that one has attempted to relate the costs for diagnosis of genetic diseases, prenatal diagnosis included, to the advantages. One has not been able to assess the psychological importance for the individual and family of such diagnosis, but has had to let oneself be satisfied with calculating the costs for the tests in relation to the cost for care which a sick child would have requested. All assessments of this kind may be criticised and therefore no monetary amounts will be given, but all authors have shown that the practice with the magnitude it has today is carrying its costs from an economic point of view.[3]

Economics and Eugenics

These different statements convey an ambiguity regarding what the economic motive is supposed to amount to. Understood in one peculiar way, there are connections between economic motivations for prenatal diagnosis and typical motivations for Swedish eugenic policies of the past. However, there are at least three interpretations of the economic motive available. These can be sorted into two main lines of interpretation: one offensive and one defensive.

[1] Gustavson 1974, p. 17.

[2] *Klinisk genetik*, pp. 42-43.

[3] *Klinisk genetik*, pp. 23-24.

Two Offensive Interpretations

The offensive line of interpretation is that the specialists were actively promoting prenatal diagnosis as an instrument for saving money for society (or the tax-payers) and perhaps *making* some as well. This line of interpretation is supported by the clear enthusiasm in many of the statements regarding the ”large economic value” of prenatal diagnosis. The offensive line of interpretation is enforced when this value is described in terms of ”profits” and similar words.

The offensive line of interpretation connects the economic motive to the above-discussed preventive aim of prenatal diagnosis in that it provides a fourth way of explaining its desirability. The prevention of the birth of children with genetic disorders is desirable because of the ”large economic profits” made available by it - the underlying ultimate aim being to maximise economic profit. In doing this, the offensive line of interpretation exhibits clear ties to the thinking behind the old Swedish eugenic policies briefly mentioned in chapter two. These policies were often motivated in similar economic terms.[1]

The ties between the offensive line of interpretation and past eugenic policies become even clearer in the light of the fact that the preventive aim can only be realised to a *large* extent by general screening-programs where the vast majority participates and the vast majority of the positive diagnosis is followed by abortions. Thus, to see to it that this is what occurs would seem to be what is recommended from the point of view of economics - worries about the autonomy of pregnant women would apparently be subservient. If a longer time-perspective is adopted, a systematic eugenic program for sorting out ”costly” and ”unprofitable” kinds of people by means of a Nazi-type euthanasia policy or genetic technology might even be anticipated.

Possibly, it is these features of the offensive line of interpretation that have led some critics to see prenatal diagnosis as springing

[1] Broberg & Tydén 1991.

from or at least being associated with the same kind of values as older Swedish eugenic policies.[1]

Another possible explanation for this is that eugenic ideas were just barely a matter of the past at the time. In fact, such ideas left traces in Swedish legislation up to the middle of the 1970's when free abortion without any kinds of eugenic indications was adopted and the old legislation prohibiting marriage for the mentally retarded and prescribing obligatory sterilisation on eugenic grounds of the same group was abandoned.[2] The eugenic ideas underlying these policies of course had their roots in the practice of genetics during the first half of the 20th century. The department of medical genetics in Uppsala, from which clinical genetics in Sweden may safely be said to have originated, was originally named the Institute for Racial Biology and did not get its present name until 1959.[3] Furthermore, Jan-Arvid Böök, who was head of that department during the time when chromosome-analysis was introduced in Sweden was a supporter of the sterilisation-legislation during the 1950's. The same applies to Hans Forssman, who, as mentioned in chapter one, was an important figure for the rise of chromosome analysis and prenatal diagnosis in Göteborg.

With time, both Böök and Forssman came to change their opinions and contributed to the abandonment of the eugenic policies. Fatal critique from these two and other medical geneticists such as Carl-Henry Alström, Gunnar Lambert, Jan Lindsten and Hans Olof Åkesson[4] regarding the scientific underpinnings of eugenic ideas served to undermine the old eugenic legislation.

However, although Swedish geneticists by these means paved

1 Broberg & Tydén 1991, p. 188; Gustafson 1991, pp. 35-39; Nordborg 1987, pp. 85-87; Nordlund 1979. In more recent public debate, to accuse those who defend prenatal diagnosis against different proposals to forbid or restrict it for being motivated by eugenic ideals has been very common.

2 The lives and times of this law as well as Swedish eugenic policies in general are set out in Broberg & Tydén 1991.

3 The institute was founded as early as 1922. See *Klinisk genetik*, p. 7.

4 See, for example, Alström & Böök 1960, Broberg & Tydén 1991, *Fri sterilisering*, Grunewald 1970, and Åkesson 1972b.

the way for the abolishing of eugenic policies, the *objective* of eugenics was never officially and explicitely rejected by the geneticists. The criticism established that prohibition of marriage and sterilisation do not constitute effective means for reducing the frequency of the mentally retarded in the population. However, the very aim to reduce this frequency was never explicitly rejected, nor was the view that it could be acceptable to use coercive measures in the realisation of this aim.

Add to this the above-mentioned fact that some of the geneticists who criticised the eugenic laws had originally been quite enthusiastic supporters of them, and it is perhaps not strange that the road could appear to lie open for prenatal diagnosis to be adopted as a more effective instrument for reaching the old eugenic objective.

A natural reaction to this is that it would be very odd for a physician or a medical scientist to reject the aim to reduce the incidence of disorders and diseases. The fact that, in the case of prenatal diagnosis, such prevention was effected by abortion was probably seen as having very little bearing on the issue of prenatal diagnosis. The abortions would, it was thought, often occur anyway, let alone on the basis of considerably less certain information. The only difference that prenatal diagnosis could make regarding this was that some of these abortions were *prevented* by showing that the foetus did not have the feared disorder. Another factor is the wide acceptance of selective abortion even among anti-abortionists.

Most important, however, is not to forget the adoption of The Official View and its stress on respect for the patient's autonomy. Taken seriously, The Official View rules out the taking of coercive or manipulative measures against patients for the sake of society - a characteristic part of traditional eugenics.

This means that it is possible to distinguish between two *different* offensive interpretations. Of these, the *extreme* offensive interpretation honours the preventive aim (on economic grounds) but does not observe the requirement to respect the autonomy of the individual. The *moderate* offensive interpretation also retains the preventive aim, but, contrary to its extreme competitor, excludes the taking of preventive measures which would restrict the autonomy

of the individual. If the economic motive is to be seen as an attempt to motivate the use of prenatal diagnosis in some kind of eugenic program, it needs to be understood according to the extreme offensive interpretation.

Another factor which has given rise to accusations of alleged eugenic ideas behind prenatal diagnosis is the belief that the preventive aim needs to adopt the absurd view that most disabled people would be better off if they were prevented from being born. This, it has been claimed, is a typical smoke-screen for eugenic aims.[1] However, as was noted in chapter three, an aim to prevent the occurrence of genetic disorders in general does not have to be seen as based on the simplified view that all such disorders make life not worth living. Rather, such prevention can be justified as an interchange of possible future persons.

Of course, it is possible to widen the concept of eugenics and claim that also this kind of justification is essentially eugenic. This is not a move to be recommended, however. Since the interchangeability of possible future persons is a prerequisite for all family-planning which takes into account the expected well-being of a possible child, such a move would make most, if not all, people into supporters of eugenic aims.

The Defensive Interpretation

According to the defensive interpretation, the economic motive is conceived of as a tactically used counter-argument, aimed at neutralising possible questioning of the practice of prenatal diagnosis on the basis of its costs. According to this interpretation, the economic argumentation in favour of prenatal diagnosis functions as an *ad-hominem* argument - i.e., an argument based on premises thought to be accepted by one's opponents but not necessarily accepted by oneself. Thus, it conveys no acceptance of an underlying aim to use clinical genetics as an instrument for maximising profit.

[1] Such a line of reasoning is particularly pursued in Nordborg 1987.

The defensive interpretation is supported by the fact that economic analyses of the kind in question are not really capable of demonstrating any economic *result*, like a profit or a loss. Rather, what they may show is that the estimated costs for practising prenatal diagnosis (and selective abortion) are balanced by an expected reduction of certain costs in the future. That is compatible with the claim that the practice runs at a loss, all things considered.

The defensive interpretation is also supported by the more cautious and vague talk of ”economic importance” in the quotations above, and by the fact that this importance is in some cases explicitly said to consist in nothing more than a balancing of certain expected costs against each other. Another reason for the defensive interpretation is that, when the expressions of the economic motive went beyond loose talk, so that calculations were actually set out or analysed, rather mixed feelings were expressed by the specialists. On the one hand, one seems to have felt somewhat uneasy about the economic aspect, but on the other hand the economic aspects were still analysed and used as a motive. After the debate had started in 1978, this feeling was openly admitted in at least one case.[1]

In one case, the defensive interpretation was explicitly formulated. Just before a calculus aimed at supporting the economic motive was set out, the expert-report to the county of Malmöhus from 1973 stated:

> It is of course the humanitarian aspects which foremost should be decisive for introducing the activity. The additional fact that the economic consequences concur in this may be seen as a further argument.[2]

The defensive interpretation is also supported by a statement from 1979 by Gabriel Romanus, then Minister of Health and Welfare since 1976:

> Naturally, [...] one cannot attach an economic value to the fact that it is possible to perform an early abortion and in that way save the health care-costs of a person which otherwise would have become very sick. That is certainly no way

[1] Boström & Ljungstedt 1980, p. 44.

[2] *Klinisk genetik inom södra sjukvårds- och omsorgsregionen*, p. 26.

> to use any cost-analysis - to say that termination of pregnancy should be recommended for economic reasons. [...] But if one is working on a budget where it is possible to put forward humanitarian arguments in favour of practically every item of expenditure and knows that one cannot force them all through confrontation with the Minister of Finance and others who handle the money, then it may be good to say regarding some items that "this at least you can approve, for here you earn money in the long run by venturing".[1]

In all, this seems to support a picture of the specialists striving for establishing clinical genetics in general and prenatal diagnosis in particular by moving it from the uncertain word of research-grants into organised public health care. This effort is of course partly explained by the specialists' personal career ambitions, but also by genuine care for patients - as expressed in the Official View and the preventive aim. In this process, the economic motive was a powerful instrument for meeting any objections based on the costs of the activity. Also, it seems clear that the use of this motive was welcomed and perhaps also encouraged by politicians and administrators. Apart from the statement by Romanus above, this is supported by the fact that, in spite of the importance of the economic arguments being played down in the expert-report to the county of Malmöhus quoted above, it was the economic arguments which were stressed in the decision-proposal which eventually was put to the county parliament.[2]

The fact that I believe the defensive interpretation to be the correct expression of the minds of the specialists does not reduce the importance of their use of phrases and words which rather suggests an offensive line of interpretation. On the contrary, this points to a genuine inability of the specialists (probably caused by overwhelming enthusiasm for the prospect of establishing clinical genetics on a broad and permanent basis within public heath care) to properly restrict their use of economic argumentation and to phrase it in a way which communicated nothing more than the defensive interpretation. As things were handled, not only the defensive, but also

1 Boström & Ljungstedt 1980, p. 53.

2 *Anslag till klinisk genetisk verksamhet inom södra sjukvårds- och omsorgsregionen.*

an offensive line of interpretation was actually communicated. The inconsistencies in applying The Official View, for example regarding people's desire not to have disabled or retarded children, even made it possible for the *extreme* offensive interpretation to be communicated in some cases. I would maintain merely that the latter communication was probably no expression of an aim for prenatal diagnosis actually *held* by the specialists.

Controversial Aspects of the Defensive Interpretation

Although much more cautious and less openly evaluative compared to the offensive lines of interpretation, the defensive interpretation is not uncontroversial. Many disabled and retarded people, as well as people working in the field of special care for such people, have remarked that the defensive interpretation expresses tolerance regarding the aim to save money for society by cutting the costs of special care for disabled and retarded people. In the debate that started in 1978 this was taken up by the critics from two points of view.

First, it was claimed that the defensive interpretation could be criticised as being unjust. Since it spoke in favour of transferring resources from clearly badly-off groups (the disabled and, especially, the mentally retarded) to groups that are much better off (the possible parents of disabled and retarded children), it was seen as an example of benefiting well-off people at the expense of worse-off people. In particular, the exceptionally low social status of the mentally retarded in a society based on individual productivity was pointed out by the critics to illustrate this point.[1]

Secondly, the aim to reduce costs for the special care of the disabled and retarded was also related to the claims of The Official View. Lower costs for the care of the disabled and retarded was seen as leading to worse care. This, in turn, would make the choice to undergo prenatal diagnosis, and the choice to have an abortion

[1] Nordlund, Wester & Wik 1978.

after a positive result of such diagnosis, into choices made under the pressure of having a child for which adequate care, considering its special needs, would not be available.

Closer scrutiny seems to suggest that both of these objections are based on questionable assumptions. Since the alleged reduction of costs for the care of disabled and retarded people would be effected by an alleged reduction in the number of such people in later generations, no transfer of resources from any disabled or retarded person would ever be involved. In fact, it has been claimed that the effect would be the opposite: fewer disabled and retarded people would mean more resources for each one of them.[1] However, none of this cancels out the fact that these worries *were* present as a result of the economic motive being put forward, also when this motive was interpreted in a defensive way.

There is, however, a third controversial aspect of the defensive interpretation which seem to be at least partially warranted. This aspect again relates the economic motive to the fear of prenatal diagnosis being used as an eugenic instrument. For even if the defensive interpretation does not express *acceptance* of any economic aim, it certainly expresses a *tolerance* towards the *decision-makers'* acceptance of such aims. Unqualified, this tolerance may extend to cover also the case when the decision-makers have adopted an economic aim similar to the extreme offensive interpretation. In other words, the specialists appear vulnerable to becoming instruments for politicians who are prepared to side-step the requirement of respecting the autonomy of patients for economic reasons.

It seems to me that this vulnerability can only be avoided if the specialists both accept and *enforce* the requirement to respect and promote the autonomy of patients. The enforcement involved amounts to demanding that the decision-makers observe such an autonomy-requirement as a restriction on their economic objectives. Suggestions that would make the practice of prenatal diagnosis more questionable from the point of view of autonomy must, in other words, be explicitly rejected and opposed. This also holds, of

1 "Mot förståndshandikapp".

course, if such a suggestion involves an expansion of the practice. Moreover, emphasising the economic benefits of such suggestions may create the impression that they are considered acceptable in spite of their being ethically dubious. Therefore, it is doubtful whether enforcement of the autonomy-requirement would be compatible with efforts to motivate such suggestions economically.

As noted in connection with the extreme offensive interpretation, The Official View actually seems to imply such a strong autonomy-requirement. However, we have also seen that the specialists' presentations involved some significant unclarities and incoherences regarding the significance of autonomy. The unrestricted use of the economic motive adds to this, even if this motive is interpreted in a defensive way.

Summing Up

The economic motive for prenatal diagnosis - that it may save society money by preventing the birth of children who require expensive care - may be connected to typical motivations for eugenic policies of the past. However, the economic motive can be interpreted in at least three different ways, of which only one (the extreme offensive interpretation) could serve as a basis for eugenic policies. The economic motivations put forward by the specialists are most reasonably interpreted as a *defensive* argument, used to counter objections to prenatal diagnosis based on its costs. However, this does not exclude that some isolated statements may express a more offensive line of argument. A defensive economic motivation of prenatal diagnosis does not express any acceptance of an aim to save society money. However, it still expresses tolerance towards such motives held by decision makers. Unless thoroughly restricted by the requirement to respect and promote the autonomy of individuals, such tolerance may extend to the point where a possible decision maker adopts an economic motive of an extreme offensive kind. In order to avoid this the autonomy-requirement

needs to be not only clearly accepted but also *enforced* by the specialists. As we have seen in Chapters Two and Three, the specialists' presentations hardly communicated such a strong commitment to the autonomy-requirement. However, if consistently applied, The Official View itself indeed seems to support such a commitment.

Chapter Five

DISCUSSIONS OF ETHICAL ASPECTS

Ethical aspects were not a very frequent subject in the specialists' presentations. There were exceptions, however.

A translation of an article on prenatal diagnosis by the American geneticist Theodore Friedmann which appeared in a magazine for popularised science took up several worries and ideas of an ethical and political nature.[1] Friedmann's account of these as well as his discussion was rather confused, however - it is not easy to say what he believed to be a defensible position. He ended up with a plea for individual freedom, but only after having given enthusiastic accounts of various ideas about the society having a right to "shape" the population by genetic means. In any case, Friedmann's article appeared in a much too obscure publication to be capable of making any notable impact.

In one of his publications, Jan Wahlström pointed to the unwillingness of some women to consider abortion of chromosomal defective children as being an ethical problem in connection with general prenatal screening for chromosome aberrations.[2] Presumably, this was connected to his early support of the abortion condition which was demonstrated in Chapter Two.

The by far most active specialist in pursuing ethical questions in connection with prenatal diagnosis during the period was Jan

[1] Friedmann 1972.

[2] Wahlström 1974, p. 73.

Lindsten. His and his co-authors' article on ethical and psychological aspects from 1975[1] has already been quoted several times. There, the abortion condition, screening-programs for carriers of certain genes and ideas of withholding information from patients, or in other ways manipulating them into making certain choices, were discussed and rejected as incompatible with The Official View. Also, the process of communicating information regarding the probability of having children with genetic disorders to the patient was discussed from a psychological point of view and assessed on the basis of The Official View. Traces of these discussions are also found in Lindsten's other writings and in the above-mentioned expert-report on clinical genetics to the NBHW, which he edited.[2]

Besides these subjects, Lindsten also discussed the effects which genetic counselling and prenatal diagnosis may have on the future genetic makeup of the population, and whether or not such possible effects should be considered as reasons to stop, continue or even make obligatory the activity or certain parts of it. Primarily, these questions are actualised by the fact that one effect of genetic counselling and prenatal diagnosis is that some healthy carriers of predispositions for genetic disorders are helped to have children which lack these disorders, but who are also carriers. Statistically and in the long run, this may seem to involve an increase in the number of carriers in the future population. Nevertheless, Lindsten rejected all ideas of letting such possibilities motivate restrictions on the autonomy of individual patients. However, regarding prenatal sex-determination in cases where no probability for having children with a sex-linked disorder is at hand, he claimed such a practice to be unacceptable because of the uncertainties involved regarding the effects on the future population.[3]

As was demonstrated in Chapter Two, however, Lindsten (as well as his colleagues) failed to address the importance of the social, societal and social psychological aspects of genetic counselling

[1] Lindsten, Eneroth & Lambert 1975.

[2] *Klinisk genetik.*

[3] Lindsten, Eneroth & Lambert 1975, pp. 76-77. Ryman & Lindsten 1975.

and prenatal diagnosis, which were later taken up by the critics. Also, the ethical issues raised by the preventive aim were left unnoticed.

However, sometimes Lindsten actually addressed issues that come quite close to the ones later taken up by the critics. In one case, he raised the question whether genetic testing which identifies carriers of genetic disorders or diseases means that the discovered carriers are thereby ”marked out” in some negative sense. However, this suggestion was quickly dismissed on the ground that every human being is a carrier of a number of (rare) genetic disorders.[1] The ”marking out”-issue comes quite close to the view put forward later by the critics, that prenatal diagnosis and the reasoning behind it invokes a degradation of disabled and mentally retarded people, especially those with Down’s syndrome. However, this latter objection is not met by pointing out that everybody is a carrier of some genetic disorders.

In one case, Lindsten also took up the worry that society might come to apply pressure on pregnant women to undergo prenatal diagnosis and to have an abortion performed if the diagnosis shows that the foetus has some disorder or disease. His reason for touching upon this issue was that such apprehensions had been mentioned in the motion by Kerstin Anér mentioned earlier.[2] However, the importance of such possibilities was played down by Lindsten:

> The danger that society could be thought to execute pressure on the individual is of course real, but must not be exaggerated. Such pressure would […] in that case constitute a modest part of society’s restrictions of personal freedom.[3]

This quotation demonstrates, I think, that the specialists suffered a genuine inability to see the connection between the values applied in The Official View, in particular the idea of respect for personal

1 Lindsten, Eneroth & Lambert 1975, p. 75.

2 Anér 1972b.

3 Lindsten 1972a, p. 40.

autonomy, and the social and societal aspects of genetic counselling and prenatal diagnosis. What Lindsten seems to be claiming is that, if one is worried by the possibility of restrictions of individual freedom in connection with genetic counselling and prenatal diagnosis, one should direct one's attention away from these activities and instead focus one's critical eye on societal restrictions of freedom in general. However, while most people would presumably find such restrictions quite acceptable in *some* areas (such as traffic, violent crime or business), societal coercion or manipulation within the intimate sphere of our bodily affairs (in which health care belongs) are most certainly taken to be plainly outrageous.

For this reason, it is hard to get rid of the hunch that, when Lindsten wrote that the danger of societal pressure "must not be exaggerated", he was mostly interested in simply dismissing such worries from the agenda and therefore unwilling to consider seriously what later became a main-theme of the criticism against prenatal diagnosis. And then one must remember that Lindsten at least bothered to address the issue - most other specialists simply kept silent. One explanation of this is probably a - perhaps somewhat naïve - conviction that Swedish society had passed the point in its development where genetics could ever again be used by society against individuals.

Lindsten's and his co-authors' article on ethical and psychological aspects of genetic counselling marked the beginning of a debate in the Scandinavian magazine for physicians, *Nordisk medicin*. The next contributor to this debate was Margarethe Wehn, the Norwegian paediatrician who was quoted at the end of Chapter Two as the only specialist who problematised the desire for not having disabled or retarded children.[1] In this article Wehn, also a mother of a child with Down's syndrome, addressed many of the aspects later accentuated by the critics. Besides trying to put the desire for healthy children in a wider psychological and societal perspective, she pointed out the difference between prevention which leaves a patient that has been helped and prevention through elimination of

[1] Wehn 1975.

prospective patients. She also mentioned feelings of grown-up disabled and retarded people as being degraded and literally threatened to death by the enthusiastic talk about reducing the number of people with genetic disorders in connection with prenatal diagnosis, and the fear that prenatal diagnosis was just the first step into a new era of eugenics where prenatal diagnosis and abortion would eventually be replaced by active selective euthanasia.

Wehn's thoughts were commented on by her fellow countryman Kåre Berg - the then leading figure among Norwegian specialists on prenatal diagnosis.[1] Berg approved of Wehn's proposal to include psychologists, almoners and representatives of parents of disabled and/or retarded children in the team conducting genetic counselling. However, her more serious worries were quickly brushed aside with the comment that physicians are not in general very keen on performing euthanasia. Neither Lindsten nor any other Swedish specialist commented on Wehn's thoughts.

[1] Berg 1975.

Chapter Six
CONCLUDING DISCUSSION

It does not seem a very brave guess that the magnitude and structure of the flow of public information about prenatal diagnosis during the period played a role in the timing, rise and nature of the later debate. In particular, the strong tendency of presentations written by specialists to be published in publications not destined to reach very far outside the community of physicians and other health care professionals, and the apparent unwillingness of the specialists to openly address and debate controversial issues in connection with prenatal diagnosis should be paid some attention. Such lack of openness is a typical base for distrust and thereby makes it much harder to meet doubts regarding the respectability of the motives behind any activity.

Moreover, it seems clear that the lack of openness and dialogue with parties outside of the medical community prevented ethically relevant aspects to be uncovered and used by the specialists for revising the practice and the motivation behind it. As it actually turned out, these factors were eventually discovered and put to use anyway - but only through hard pressure of public criticism from outsiders.

When it comes to the ethical basis from which prenatal diagnosis was motivated, we have seen that it involved more ambiguity, confusion and unresolved conflict than might appear at first glance. This left room for interpretations which tend to put prenatal diagnosis and the motives behind it in a less than favourable light.

Two important confusions pervaded in the specialists' presenta-

tions. First, reasons for conducting prenatal diagnosis on the one hand and, on the other, reasons for performing selective abortion were not kept separate. While The Official View only provides the former, the preventive aim rather provides the latter. Secondly, reasons for using prenatal diagnosis (and, since the first confusion prevailed, for performing selective abortion) *in a particular case* were not clearly distinguished from reasons for *society* to tolerate, provide and/or enforce such practices in *general.* Both these confusions were eventually transferred to the later debate, where the specialists tended to accentuate reasons for prenatal diagnosis in the particular case without connections to reasons for abortion, while the critics typically objected to reasons for prenatal diagnosis on the societal level working through reasons for selective abortion (on both the individual and the societal level). However, what kind of reason was in fact discussed in relation to what topic and when was seldom very clear.

Although it is clear that the use of prenatal diagnosis was primarily motivated by care for individual patients, the specialists' presentations communicated an unclear picture of the importance attached to the well-being and autonomy of couples or women confronted with the possibility of undergoing prenatal diagnosis or abortion on the basis of such diagnosis.

Although expressing care for the patient as the sole aim for prenatal diagnosis, The Official View involved a latent conflict between considerations of the patient's autonomy and of his or her well-being. Also, The Official View was not consistently applied by the specialists in descriptions of how the practice should be organised and conducted. In particular, non-medical factors which may influence the wish not to have children with a certain genetic disorder or disease were not addressed as areas for information in genetic counselling. In some cases, formulations were used which may lead to doubts concerning the actual acceptance of The Official View. The conflict between considerations of well-being and autonomy was further expanded and deepened by the inclusion of the preventive aim as a motive for prenatal diagnosis, since this aim and The Official View may conflict.

Since the preventive aim ties the value of prenatal diagnosis to abortion in the case of positive diagnosis, this aim furthermore actualised the complex ethical issue of abortion. The kind of reasoning needed to justify abortion of foetuses with genetic disorders or diseases in the general way hinted at by the preventive aim, does not, as was often assumed in the later criticism, have to involve an assumption that disabled or retarded people live lives not worth living. However, it does seem to need an idea of interchangeability of possible future people, which in turn actualises complex basic ethical considerations which at the time were not fully appreciated even by professional moral philosophers.

Moreover, the combination of the preventive aim and economic argumentation for the value of prenatal diagnosis (based on alleged reductions of future costs for the care for children with genetic disorders and diseases) has some similarities with economic argumentation for Swedish eugenic policies of the past. I have argued that the economic argumentation in connection with prenatal diagnosis probably had a more defensive aim. In spite of this, however, since the economic aspects were often enthusiastically accentuated by the specialists, the presentation still tended to communicate a more offensive economic argumentation, at least to casual readers. Also, even if a defensive economic argumentation does not express acceptance of any economic aim, it certainly expresses *tolerance* towards those who have more offensive economic aims. Together with the unclear picture of the importance attached to the patient's autonomy, this made room for fears that prenatal diagnosis would mark the dawn of a new eugenic era in Swedish health care.

There were some attempts among the specialists to discuss ethical questions in connection with genetic counselling and prenatal diagnosis. However, since no real debate occurred and since the attempts were so few and restricted to the professional medical community, it is possible that they rather tended to impede realisation among the specialists of the unclarities and incoherences inherent in the standard-motivation for the practice. Again, it is clear how increased openness among the specialists could have contributed to a more fruitful intellectual climate.

Communication between different parties can of course never be the sole responsibility of only one of these parties. The isolation, passivity and silence of patients, ethicists, officials and politicians and, perhaps foremost, journalists certainly also played an important role in creating the situation just described. Yet, for all that, it is clear that the specialists were in a key position when it comes to initiating broader discussions, since they possessed the knowledge of what could be done. In fact, specialists *always* are in this position regarding new technology. At the same time, they normally - as in the case of prenatal diagnosis - also have a strong interest in getting the technology in question accepted and put to use. This is in many ways a good thing, but it may also inspire argumentation for use of the technology on grounds which are not very well considered or formulated, and dampen the enthusiasm for initiating serious and open critical debate regarding this use.

What can be learned from the history of prenatal diagnosis in Sweden is that these two phenomena are interrelated. The best cure for ambiguous and dubious argumentation is open and broad critical discussion. For this reason, it must be considered to be a main core of the work-ethics of any scientific or technological speciality that specialists have a strong responsibility to lay the ground for, initiate and participate in such discussions.

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