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Piia Jallinoja

# GENETICS, NEGOTIATED ETHICS AND THE AMBIGUITIES OF MORAL CHOICES

ACADEMIC DISSERTATION

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Kansanterveyslaitos (KTL)
Mannerheimintie 166
00300 Helsinki
Puh. Vaihde (09) 4744 1, telefax (09) 47448408

Folkhäsoinstitutet
Mannerheimvägen 166
00300 Helsingfors
Tel växel (09) 4744 1, telefax (09) 47448408

National Public Health Institute
Mannerheimintie 166
00300 Helsinki
Telephone (09) 4744 1, telefax (09) 47448408

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**Supervised by**

Professor Pekka Sulkunen, PhD.
Department of Sociology
University of Helsinki
Finland

**Reviewed by**

Docent Marja-Liisa Honkasalo, MD.,PhD.
Department of Cultural Anthropology
University of Helsinki
Finland

and

Professor Elianne Riska, PhD.
Department of Sociology
Åbo Akademi
Finland

**Opponent**

Professor Raymond DeVries, PhD.
Center for Bioethics
University of Minnesota
USA

## *ALKUSANAT*

Ensimmäinen ajatus nyt käsillä olevasta väitöskirjastani syntyi 1990-luvun alkuvuosina Kansanterveyslaitoksella, jossa tautiperimän tutkimus juuri silloin oli kiihkeää ja innostunutta. Oma kiinnostukseni syntyi havainnosta, etteivät kaikki genetiikan kysymyksiä pohtivat olleet suinkaan yhtä optimistisia kuin entusiastisimmat geenitutkijat.

Ensimmäinen kiitokseni kuuluukin Kansanterveyslaitokselle (KTL), jonka Mielenterveyden osastolla mahdollistui tutkijanurani alku kesästä 1989 eteenpäin ensin tutkimusapulaisena myöhemmin tutkijana. Erityisesti kiitän Arja Aroa, joka minut alunperin palkkasi KTL:ään virkamiesharjoittelijaksi, tutustutti artikkelinkirjoittamisen ja kommenttien vastaanottamisen taiteeseen ja on aina sen jälkeen tavalla tai toisella pitänyt ryhmässään. Ensin Jouko Lönnqvist Mielenterveyden osastolla ja nyt Antti Uutela Terveyden edistämisen tutkimusyksikössä ovat mahdollistaneet työni KTL:ssä. Molemmissa osastoissa on ollut ilo työskennellä monestakin syystä, ei vähiten mukavien kollegoiden ja ystävien sekä huolehtivien sihteereiden ja toimivan infrastruktuurin.

Toinen institutionaalinen kiitokseni kohdistuu Helsingin yliopiston Sosiologian laitokseen, jonne tulin tekemään väitöskirjaa keväällä 1995. Sosiologian laitosta voin parillakin syyllä kutsua termillä *alma mater* – ensimmäiset muistoni sijoittuvat aikaan paljon ennen kuin tulin Franzeniaan opiskelijaksi. Laitos mahdollisti vapaan tutkimustyön ja oman tien etsimisen. Kiitän laitoksen esimiehiä Elina Haavio-Mannilaa, Tapani Valkosta ja Kari Pitkästä työhuoneista ja koneista. Heitä ja koko laitoksen henkilökuntaa kiitän myös Sosiologian laitoksen sallivuudesta ja individualistisesta yhteisöllisyydestä.

Sosiologian ja sosiaalipolitiikan laitosten tutkijakoulut olivat keskeisessä osassa tieteellisen argumentoinnin rakentamisessa. Kiitos tästä seminaarien vetäjille Risto Alapurolle, Risto Eräsaarelle, Elina Haavio-Mannilalle, Arto Norolle ja JP Roosille sekä tietenkin koko seminaarijengille. Seminaariin oli aina jännittävä osallistua.

Toinen, yhtä tärkeä seminaari ja yhteisö oli ohjaajani Pekka Sulkusen interventio-seminaari. Ensinnäkin Pekka Sulkunen on innostava ohjaaja. Toiseksi Pekan kotona kokoontuvassa seminaarissa oli ainutlaatuinen tilaisuus olla kommentoitavana ja kommentoijana. Täälläkin tärkeää ei ollut vain tutkimuksen yksityiskohtein tarkasteleminen vaan tutkimustyön motiivien ja reunaehtojen pohtiminen. Kiitos tästä kaikille interventio-seminaarilaisille ja Pekan vieraanvaraisuudella.

Kaksi väitöskirjatyöni artikkelia on kirjoitettu EU-BIOMED2-rahoituksella. Jälleen kerran saan kiittää Arja Aroa, joka pyysi minut mukaan projektin Kansanterveyslaitoksen osuuteen sekä Elina Hemminkiä, joka pyysi minut mukaan projektin kätilötutkimuksen Stakesissa. Elinan huolellisuus töiden kommentoinnissa ja lakkaamaton uteliaisuus suomalaista terveydenhoitoa kohtaan olivat arvokkaita väitöskirjatyön kokonaisuuden hahmottamisessa.

Kaikissa edellä mainituissa yhteyksissä olen onnekseni tavannut suuren joukon mukavia ja älykkäitä ihmisiä, jotka ovat kommentoineet töitäni ja joiden töitä olen saanut itse kommentoida – osaa voin ilokseni kutsua myös ystäviksi. Tässä joukko ihmisiä jotka jo mainittujen lisäksi on syytä mainita: Pilvikki Absetz, Priscilla Alderson, Anna-Maija Castrén, Anu Hakonen, Ilpo Helén, Taina Huurre, Outi Konttinen, Tiina Kosunen, Michaela Laurén, Maaria Linko, Pekka Louhiala, Päivi Santalahti ja Hanna Toiviainen.

Esitarkastajiani Elianne Riskaa ja Maisa Honkasaloa kiitän haasteellisista kommenteista, mutta ennen kaikkea vilpittömästä kiinnostuksesta työtäni kohtaan sekä ymmärryksestä, että aihe ei tyhjentynyt tähän.

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Olen myös erittäin kiitollinen kaikille väitöskirjatyötäni varten haastattelemilleni terveydenhuollon ammattilaisille ja asiantuntijoille Helsingissä, Turussa ja Kuopiossa. Jokainen haastattelu valaisi tärkeältä osaltaan geeniseulontojen ja perinnöllisyysneuvonnan maailmaa.

Vanhempiani Tettiä (Riittaa) ja Reijoa kiitän geeniperinnöstä, mutta ennen kaikkea sosiaalisesta perinnöstä ja huolenpidosta, joiden uskon olevan geeniperimää tärkeämpiä. Minä ja siskoni Tuua olimme valtavan onnekkaita kun vanhempia jaettiin. Reijo ja Tetti ovat myös loistavia isovanhempia Venlalle ja Vilmalle. Tuuan puolisoa Basse Cedercreutzia ja Reijoa kiitän lisäksi työni kannen suunnittelusta, jossa pikkupoika kuvan keskellä on Reijo.

Puolisoni Jari Keränen varoitti joskus minua itseironiseen tyyliinsä, etten saa häntä kiittää, koska työni ei valmistunut hänen ansiostaan vaan hänestä huolimatta. Ollakseni rehellinen, on ollut pari ohikiitävää hetkeä, jolloin tältä on todella tuntunut. Näistä hetkistä huolimatta, tai ehkä kuitenkin juuri niidenkin ansiosta elämä Jarin kanssa on haastanut minut ihmettelemään maailmaa ja sitä kuinka hyvää elämä on.

Helsingissä 27.2.2002

Piia Jallinoja

## Contents

## Tiivistelmä

*Genetiikka, neuvoteltu etiikka ja moraalisen valinnan vaikeus*

Tutkimuksen aiheena on geeniseulontojen, geenitestien ja näihin liittyvän perinnöllisyysneuvonnan käyttöönotto suomalaisessa terveydenhuollossa 1990-luvulla, ts. kliininen genetiikka. Tutkimuksessa analysoidaan tarkemmin myös genetiikkaan liittyvää lääketieteen etiikkaa vuodesta 1970 vuoteen 2000 sekä sikiötutkimusten ja sikiön vammaisuuden vuoksi tehtyjen abortin, ns. selektiivisten aborttien erityiskysymyksiä. Tutkimus muodostuu viidestä alkuperäisjulkaisusta sekä yhteenvetoartikkelista.

Väitöskirjassa analysoidaan mm. geenitesteihin, sikiöseulontoihin ja yksilön autonomiaan liittyviä ristiriitaisuuksia sekä keinoja, joilla näitä ristiriitoja ja jännitteita on pyritty erityisesti lääketieteen piirissä ratkomaan.

Tutkimusaineistot on kerätty kyselylomakkeilla (väestökysely ja kysely kätilöiden ja terveydenhoitajien keskuudessa), haastattelemalla suomalaisten geeniseulonta- ja perinnöllisyysneuvontahankkeiden työntekijöitä (lääkärit, terveydenhoitajat, kätilöt, psykologit) sekä keräämällä näihin hankkeisiin liittyvä tekstiaineisto.

Valtaosa suomalaisista, niin tavallisista kansalaisista kuin asiantuntijoistakin, hyväksyy geenitestien käytön, mutta on myös huolissaan testeistä ja seulonnoista sekä näihin liittyvistä tulevaisuudennäkymistä. Erityisesti selektiivinen abortti nähdään vaikeana ja jopa ratkeamattomana kysymyksenä. Tämä heijastalee sikiön asemaan liittyviä ristiriitaisuuksia.

Lääketieteen piirissä genetiikkaan liittyviä ongelmia on pyritty ratkaisemaan lisääntyvässä määrin mm. kehittämällä eettisiä suosituksia, perustamalla eettisiä toimikunta ja herättämällä keskustelua etiikasta. Tällaisissa ohjeistoissa testien vapaaehtoisuus ja yksilöiden autonomia ovat tulleet yhä keskeisimmiksi. Tilanne on kuitenkin paradoksaalinen: toisaalta eettisiä sääntöjä toivotaan kehitettävän yhä enemmän, toisaalta ne jäävät pakosta pinnallisiksi, sillä niiden on oltava joustavia suhteessa uusin tieteellisiin keksintöihin ja yksilöiden elämäntilanteisiin. Lopullinen moraalinen vastuu valinnoista ja niiden seurauksista jääkin yksilölle. Valinnanvapautta voikin pitää jopa imperatiivina.

Yksilön tekemää valintaa yritetään terveydenhuollossa helpottaa jakamalla hänelle mahdollisimman neutraalia informaatiota sairauksista, testeistä ja vaihtoehdoista. Asetelma ei kuitenkaan tyhjene faktuaaliseen tietoon, vaan yksilölle avautuu loputon sarja kysymyksiä hyvästä elämästä, vammaisuudesta, vanhemmuudesta, vastuusta ja vapaudesta. Vapaan valinnan periaate tiukimmillaan edellyttäisi, että yksilö – esimerkiksi raskaana oleva nainen – yksin punnitsisi moraalista valintaansa suhteessa sikiöönsä. Näin ei kuitenkaan tapahdu: autonomiseen valintaan sekoittuu toiveita, sääntöjä, testituloksia ja niiden tulkintoja, kustannus-hyöty laskelmia ja monenlaista informaatiota niin terveydenhuollossa kuin tiedotusvälineissä.

## Abstract

The present study focuses on the introduction both of genetic screening and testing and of the related counselling in Finnish health care during the 1990s, i.e. clinical genetics. In addition, the formation of medical ethics as it pertains to clinical genetics is analysed from 1970 onwards. The study consists of five original publications and a summary.

The material consists of data collected by means of questionnaires (conducted among lay people, public health nurses and midwives), semistructured interviews (of physicians, public health nurses, midwives and psychologists) and text material collected in connection with four genetic screening and counselling projects carried out in Finland.

In general, Finns approve of gene tests, but this general approval is combined with disapproval of certain aspects and prospects of such tests. Furthermore, clinical genetics creates agonizing situations where all options have undesirable consequences. Abortion because of a disorder of the fetus is an especially perplexing issue reflecting the ambivalent status of the fetus.

Within the field of medicine, problems related to the increasing number of applications of clinical genetics have been addressed to an increasing extent by developing ethical guidelines and recommendations, by establishing ethics committees and by encouraging public discussion on ethics. In the guidelines, voluntariness and autonomy are repeated principles, and they are also widely accepted principles among lay people and professional groups. Choice may even be regarded as an imperative. What is feared is its opposite, concretized in the fear of eugenics.

The situation is paradoxical, however, and characteristic of modern societies: On the on hand there are constant demands for more ethical rules; on the other hand these rules cannot but remain superficial, since they have to be open and flexible in the face of new scientific discoveries and individuals' life situations. A contradiction exists between modern ethics setting the rules for advancing genetic technologies and the real-life situations of clients seeking genetic screening and counselling. Individuals are at the same time struggling to form their own choice and influenced by a plethora of expectations, interests, medical determinants and technological conditions.

## Original publications

I Jallinoja, Piia, Hakonen, Anu, Aro, Arja R, Niemelä, Pirkko, Hietala, Marja, Lönnqvist, Jouko, Peltonen, Leena & Aula, Pertti (1998) Attitudes towards genetic testing: analysis of contradictions. *Social Sciences and Medicine* 46, 1367-74.

II Jallinoja, Piia & Aro, Arja R (2000) Does knowledge make a difference? The association between knowledge about genes and attitudes toward gene tests. *Journal of Health Communication* 5, 29-39.

III Jallinoja, Piia, Santalahti, Päivi, Toiviainen, Hanna & Hemminki, Elina (1999) Acceptance of screening and abortion for Down's syndrome among Finnish midwives and public health nurses. *Prenatal Diagnosis* 19, 1015-1022.

IV Jallinoja, Piia (2001) Genetic screening in maternity care: preventive aims and voluntary choices. *Sociology of Health & Illness* 23, 286-307.

V Jallinoja, Piia (2002) Ethics of clinical genetics: the spirit of the profession and trials of suitability from 1970 to 2000. *Critical Public Health,* 12, in press.

In the following summary article these publications will be referred to in *italics*.

# 1. Introduction

The subject of the present study is the introduction of genetic screening and testing and related counselling in Finnish health care during the 1990s. During the decade the worldwide human genome sequencing programme progressed rapidly, increasing the possibility of diagnosing hereditary diseases. Also in Finland, genetic research was active, leading to mapping of several mutations. Alongside with these developments there have been demands that public attitudes towards genetics and ethical considerations, for example, should be taken into account. Hence, the rapid development of clinical genetics has also given rise to critical questions and pursuit to control the applications of the new technology. The present study focuses on this situation and it is analysed from the perspectives of five original publications and the present summary.

## *1.1. Composition of the summary*

In the introduction I will present the composition of the summary, the sociological perspective on technologies, the original articles, materials and methods and the medical context of the study.

The following chapters investigate in detail the ways in which the applications of clinical genetics are enmeshed within the lives and moralities of humans, thus creating various puzzles and tensions. These puzzles are analysed from the angles of three groups of actors; first, as a question of lay people, clients and patients undergoing genetic counselling and screening and second, as a question of the fetus and consequently of abortion. Abortion is presented here as a special question related to

clinical genetics, since it is here that several complexities of modern genetics are intensified. The third angle is the experts' position; e.g. physicians, midwives and public health nurses involved in clinical genetics. These three groups of actors may not be conclusively distinguished in the analysis from each other, since they never act alone. For example, the fetus is the target of experts' examinations and mother's decisions, and clients never act alone and independently, but are set in situations defined by experts, for example, and characterized by estimations and choices over future lives.

However, although the above separation is partly crystallized here for purposes of the present analysis, it also reflects certain argumentative and practical arrangements in relation to clinical genetics. As will be shown, there are major negotiations on the status of lay people and the fetus, the limits of experts' conduct and advice and about who should be heard when decisions about genetic screening undertakings are made. Finally, although in principle various aspects of screening are brought together in health technology assessment, the discrepancy between codes of experts, ethical discussions and agonizing choices of clients remains. As has been pointed out, at the heart of the debate over prenatal genetic testing are contested choices and rights: a woman's right to choose, the civil rights of disabled people, the postulated rights of the unborn child and the rights of the individual versus the rights of the collective (Shakespeare 1998, 665).

In the chapters to follow, I will investigate the disputes over and contradictions of clinical genetics and prenatal screening and abortion as special issues in these disputes. The paper will scrutinize circumstances in which individuals make troublesome moral choices over genetic tests and abortions as well as the ways in which professionals have tried to govern the situation.

### *1.2. Sociology, technology and genetics*

Sociologists have been increasingly interested in analysing technologies in the lives of modern individuals and in modern societies (for example, Beck 1996, Beck-Gernsheim 1996). This concerns also medical technologies and genetic technologies. Peter Conrad and Jonathan Gabe (1999) list dilemmas of counsellor-client interaction, public images and discourse around the new genetics, lay and professional perspectives on genetics and social implication of genetic screening as areas examined by sociologists. These are central view points on the new genetics and will be discussed also here. However, in comparison with many previous sociological studies on genetics, the present study brings more light to the complex setting in which certain discoursive and rhetorical acts are made by taking fuller account of the whole puzzle of argumentative and practical arrangements including their material and human context – gene tests, researchers, nurses, research publications, health care planners, health care centres, mothers and people with disabilities.

The role and consequences of technologies in modern societies has been a debated issue. The Chapter 2 begins by presenting human and clinical genetics as a progressive, scientific endeavour. This is the perspective presented by both protagonists of the new genetics and by those writers who view with great concern the accelerating technologization of modern societies (for example Stivers 1996, 1999). These viewpoints are then challenged and enriched in Chapters 3 and 4 by further notes on the deterministic progress of technology. Hence, although it appears that the technologies are increasingly enmeshed in the lives of humans, the paths of individual techniques or technological projects are contingent (Casper & Clarke 1998, Bijker & Law 1992). In other words, there are detours and puzzles in the tracts of progress as Bruno Latour (1999) noted.

Consequently, the sociological view point on genetics and technologies applied here views the introduction of genetic screening as a sociotechnical process where the technology and surrounding networks of people, cultures, ideas and regulations, for example, mutually shape each other - not that it would be possible to define the primacy of either one in the process (see Latour 1993a). Technologies do contain qualities and expectations of arrangements in the health care system that in turn possibly create tensions between actors. However, the dilemmas related to new technologies do not occur deterministically or naturally, but in a heterogenous network of actors with varying competences, motives and aims. This complex process is the objective of the present study and will be scrutinized and discussed in Chapters 5 and 6.

### *1.3. The studies: materials and methods*

The articles of the thesis are based on various data sources and methodologies since the articles were done as parts of several research projects. This situation has provided data on various actor groups: lay people, midwives and public health nurses, geneticists and other physicians, psychologists and ethicists. Furthermore, it has been possible to collect data on the one hand by questionnaire studies, thus providing estimations about generality of the phenomena under analysis, and on the other hand by qualitative interviews and text analysis with which the more detailed logic of the circumstances has been analysed.

In the following, material, methods and study settings are described. A more detailed description may be obtained from the original publications.

*Population*

The first article is based on a project of the National Public Health Institute (Kansanterveyslaitos) and University of Turku (*Jallinoja et al 1998;* see also Hietala et al 1995, Aro et al 1997).

A stratified sample of the Finnish population (aged 15-69 years) was selected (*n*=1967). The data were gathered in September and October 1993 and the response rate was 59% (*n*=1169). The non-respondents did not significantly differ from the respondents in terms of gender, age, level of education, social class, or area of residence. The questionnaire was based on a self-reporting questionnaire consisting of 50 questions about genetic testing in general and willingness to undergo gene tests in specific situations. Thirteen of these questions were used in *Jallinoja et al 1998* in which attitudes towards genetic testing among lay people were examined by focusing special attention on the ambivalence of attitudes, i.e. how positive and negative attitudes towards genetic testing coexist. This survey will be referred to in the following as the 1993 survey.

The second project was an EU-BIOMED2-funded research project 'Prenatal screening in Europe: the past, the present and the future' in which I participated in two subprojects. In the first, conducted at the National Public Health Institute, basic knowledge of genetics and attitudes towards gene tests were examined among lay people.

The study subjects were obtained from a population registry as a random sample (n=2000, age 16-65 years) of the Finnish-speaking population in Finland. The initial questionnaire and two reminders were sent between October 1996 and January 1997. The total of 1,216 respondents were included in the study; response rate was 61%.

Fifty-five percent of the respondents were women. Compared with the population, the respondents were representative of the Finnish population with the exceptions of women and married people, who were slightly overrepresented, and young people, who were slightly underrepresented. The questionnaire consisted of 86 structured and three open-ended questions. In *Jallinoja and Aro* (*2000a*) the results were given for 16 structured items measuring knowledge (see Jallinoja & Aro 1999a) and for 14 attitude statements.

In *Jallinoja & Aro 2000a* the association between knowledge and attitudes was analysed (see also Jallinoja & Aro 1999a, 1999b, 2000b). In the following this survey will be referred to as the 1996 survey.

*Midwives and public health nurses*

In the second subproject of the overall EU-BIOMED2 project, conducted at the National Research and Development Centre for Welfare and Health (Stakes), the attitudes of public health nurses and midwives towards prenatal screening were examined. A random sample of 400 midwives and 400 public health nurses (<60 years) was taken from the Central Register of Health Personnel. The questionnaire was mailed in February 1998, and a reminder in April 1998. The final response rate was 79% (*n*=571). 99% of the respondents were women.

The questionnaire consisted of multiple-choice and open-ended questions on prenatal screening and genetic screening. In the article based on these data, respondents' attitudes towards prenatal screening for Down's syndrome and abortions because of Down's syndrome were analysed *(Jallinoja et al 1999,* see also Kooij et al 2001).

*Genetic screening and counselling projects*

The fourth and fifth papers were based on semistructured interviews and text material collected in relation to four genetic screening and counselling projects in Finland.

The fourth article (*Jallinoja 2001*) is based on nine interviews conducted with physicians and public health nurses involved in the prenatal genetic screening in Kuopio in 1995 and 1996 and text material related to the programme. Individuals holding key positions in the project, or those whose viewpoints were essential to its launch or closure, were interviewed. The interviews were retrospective (conducted from autumn 1997 to winter 1998 and January 1999) and were based on an interview scheme with approximately 50 pre-planned questions. The main question areas of the interviews were: the aim of the screening, practical arrangements of the project, benefits and disadvantages of the screening, discussions and possible disagreements related to the project, circumstances of the closure, interviewees' own opinion of the project and its closure, ethical issues in the project, the role of the media and opposition and activism against the project (cf. Latour 1987, 1996). The interviews lasted from 30 minutes to 2 hours and were tape recorded and transcribed.

The text material consists of all available documents related to the screening and it includes scientific articles, newspaper and magazine articles, leaflets delivered at maternity care centres for pregnant mothers, minutes of a meeting of the Board of Social Affairs and Health and documents of the ethics committee of the Kuopio University Hospital. In the article the launching and circumstances of closure of a prenatal genetic screening project in Kuopio were analysed. Special attention was focused on the coexistence of and tensions between the two major objectives of the project: preventing disability and increasing mothers' possibilities to choose (*Jallinoja 2001*).

The fifth article (*Jallinoja 2002*) is based on the analysis of interviews of physicians and psychologists and text material conducted and collected in the same manner as in *Jallinoja 2001*. The material was collected in relation to Type 1 Diabetes Prediction and Prevention project in Turku, cancer counselling of the Finnish Cancer Associations and genetic counselling at the Family Federation of Finland (Väestöliitto). In addition the interviews of physicians and the text material analysed in *Jallinoja 2001* were further analysed here. Altogether nine interviews of physicians and two interviews of psychologists, conducted from August 1997 to February 1998, were analysed.

In addition, guidebooks of medical ethics published by the Finnish Medical Association and articles of prominent physicians in the field of medical genetics in Finnish publications were collected from 1970 to 2000. The total number of articles collected was 105.

The fifth article examines how medical ethics gradually became part of the argumentation and practices of genetic counselling and screening during three decades (1970 – 2000). The article analyses the medically and morally complicated situation in which new formulations of ethics as well as revival of old foundational medical ethics gained ground.

### *1.4. Medical context of the study*

In medical terms, the empirical object of this thesis is genetic counselling, screening and testing for hereditary diseases and disorders and prenatal screening for congenital diseases and disorders. Thus, under analysis is *clinical genetics*, i.e. genetics applied to the diagnosis, prognosis, management and prevention of genetic diseases (Stedman's Medical Dictionary 1995, 713), although other related specialities are also referred to.

Hence, whereas the clinical geneticist is engaged in the care of patients, other specialities of genetics are more focused on laboratory research. For example, *human genetics* refers to the study of the genetic aspects of humans and *medical genetics* to the study of the etiology, pathogenesis and natural history of human diseases which are at least partly genetic in origin (Stedman's Medical Dictionary 1995, 713). *The new genetics* is often used to refer to contemporary genetics based on advances in molecular and cell biology that have lead to new methods for isolating and determining the structure of genes and their functioning - it is the study of inheritance at the molecular level (Weatherall 1991, 2-3).

With respect to actual diseases, the analysis, in principle can include any hereditary disease or disorder, since they are all potential subjects for genetic counselling, testing and screening at the point when a gene test has been developed. More specifically data have been collected from most of the few genetic screening and counselling undertakings that were conducted during the 1990s in Finland. This includes counselling for hereditary cancer by the Finnish Cancer Associations, genetic screening of newborns for a gene related to susceptibility for childhood diabetes at Turku University Central Hospital and prenatal genetic screening for three gene defects at maternity care centres in Kuopio (for more detailed description of the diseases and projects in *Jallinoja 2001, 2002;* see also Holli et al 1997 and Ryynänen et al 1999). Attitudes towards screening for one congenital disorder, Down's syndrome, were also specifically investigated among midwives and public health nurses.

In the course of this paper I will use terms such as screening, testing and counselling that refer to different, although related practices. As has often been defined, *screening* is the systematic search for a specific condition among a large, asymptomatic subpopulation selected by demographic characteristics such as age, sex or ethnic

background (Alderson et al 2001a). Moreover, screening typically identifies at-risk groups in need for further diagnostic testing.

*Testing* refers to diagnosing individuals who have actively sought for diagnosis of their symptoms, for genetic counselling because their families showed histories of genetic disorders or who for these reasons had been referred to genetic counselling by another physician. The difference between screening and testing has been a pivotal issue in debates on the proper ways of applying new medical genetics: by screening asymptomatic population groups or testing only those who already have symptoms themselves or hereditary disease in the family. Genetic *counselling*, as Susan Michie and Theresa Marteau define it, is "a communication process aimed at helping people with problems associated with genetic disorders or the risk of these in their family" (1996, 104). A pivotal component of counselling is provision of information, and it is almost without exception expected that both genetic screening and testing should be accompanied with genetic counselling - issues that will be discussed later in this article.

*Prenatal* refers to the period of pregnancy up to birth (Alderson et al 2001a); thus in the present paper, prenatal screening and testing refer to techniques used in detecting diseases and disorders of the fetus. Genetic conditions may be diagnosed prenatally, in newborns or at any point later in life, and may be analysed from tissue samples, such as blood. To detect the genes of the fetus, usually a sample of *amniotic fluid* (*amniocentesis*) is taken from the mother's womb. C*horionic villus sampling* (CVS) is also used to obtain fetal cells. Both tests are associated with a risk of spontaneous abortion (about 1 in 150 for amniocentesis and about 1 in 50 for CVS; Green & Statham 1996, 142). The term *selective abortion* refers to abortions conducted because of undesired characteristics of the fetus, e.g. disability.

## 2. The fast train of technology

The progress of genetics has been rapid since discovery of the double helix structure of DNA in 1953. Furthermore, recombinant DNA technology developed in the early 1970s and advancements in information technology made it possible to collect, retrieve, store and assemble increasing amounts of gene data (OECD 1995). Gradually these technologies and discoveries had a huge impact on health care practice.

After World War II in Finland, genetic counselling was first started by the Väestöliitto (Family Federation in Finland) in cooperation with the Department of Genetics, University of Helsinki in 1951. For two decades, few people were referred to counselling or themselves sought for advice. Furthermore, the feasibilities for actual prenatal diagnosis were very limited. In 1971 the Department of Medical Genetics was founded at the Family Federation. (Kääriäinen 1991.) Since then, the number of clients has increased: whereas in 1971 there were 34 requests for counselling, the figure was 662 in 1981, 665 in 1991 and 936 in 1999 (Väestöliitto 2000).

Elsewhere there were also signs of institutionalization of the discipline of medical genetics. In 1972 the first professorship in medical genetics in Finland was founded at the University of Helsinki and in 1976 the Association for Medical Genetics in Finland was founded. In the 1970s and 1980s several departments of genetics were founded at university hospitals. (Kääriäinen 1991, 254.) The first specialist licences in medical genetics were granted in 1982 (R. Luhtala, Finnish Medical Association, unpublished observations, 1996). In 1992 there were 16 specialists in medical genetics (Suomen Lääkäriliitto 1992) and in January 2001 25 (Suomen Lääkäriliitto 2001).

The late 1980s and the 1990s may be regarded as the decade of take-off of human and medical genetics. An important part of the take-off was organization of the Human Genome Project in the USA during the late 1980s, aiming at sequencing the human genome (Lee 1991, 12). Furthermore, there were several other genome projects organized by European countries, Japan, Russia and private foundations (Kere 1993, 724). It has been claimed that a new era in human biology has now begun - a silent revolution that will shape our perceptions of diagnostics and treatment as well as our whole understanding of diseases (Kere & Palotie 1996). In fact, genetics was gradually integrated in practically all medical disciplines from obstetrics to oncology and from paediatrics to psychiatry. Genetic explanations were sought for practically any disease, disorder and abnormality and for behavioural characteristics like shyness, homosexuality, 'novelty seeking' and bed wetting (Conrad 1999, 2000, Conrad & Gabe 1999). Peter Conrad (1999) further noted that in the media and public discourse we see a privileging of genetic explanations and even genetic determinism that assumes that there are specific genes for specific traits under all circumstances.

By the mid-1990s clinical research and treatment of hereditary diseases and genetic counselling in Finland were "on a firm and established level", as leading geneticists have expressed the situation and research in molecular genetics was well above the average European level (Kääriäinen, Palotie & Kontula 1994, 639). Human genetics in Finland was characterized as a centre of excellence largely through the efforts of Albert de la Chapelle and, more recently, Leena Palotie (Molecular Biology and Biotechnology Research in Finland 1996: 14). The relatively isolated population of Finland was often seen to offer exceptionally favourable conditions for gene research (Palotie 1996).

In the mid-1990s the first genetic screening projects were conducted (Simonen 1997, Hietala et al 1998, Ryynänen et al 1999). These were research undertakings and pilot

programmes, mainly at university hospitals. The expansion may also be seen in the increasing number of DNA analyses performed. For example, at the Helsinki University Central Hospital the number of gene tests performed was 125 in 1992, whereas it was 2177 in 1995 and 4421 in 1998 (A. Orpana 1999, unpublished observations).

From the position of gene researchers and clinicians, genes may be regarded as simply amino acids containing information about the human body. Thus, gene test may be seen as technologies revealing information that as such is merely neutral with no any value judgement or intentions. Genetics itself may be regarded as simply making previously unseen genes, chromosomes and mutations visible (cf. Shapin & Schaffer 1985, 36-37). In this respect, one of the main concern of researchers and clinicians has been the reliability and specificity of the tests (e.g. Hietala et al 1993), i.e. how effective they are in making the genes visible.

Recently, however, viewpoints and research results challenging this medical view of genetics have been increasingly presented. Sociologists, behavioural scientists, philosophers and ethicists have analysed recent developments and their impact on social relationships, morality and perceptions of health and individuality. Although in general trust in medicine and scientific progress prevails, cracks are being increasingly seen and various groups have expressed doubts over the overall direction of geneticization and medicalization (for example, Nelkin & Tancredi 1989, Miringoff 1991, Petersen 1998, Conrad 1999, 2000).

## 3. Technological determinism?

Based on the above short history of clinical genetics in Finland, it would be simple just to describe the progress of the new human genetics in Finland: new technologies were developed, new clinics were founded, new professional titles were established and the number of articles and dissertations published in the area increased rapidly. Technology could be - and indeed often is - described as proceeding rationally in a deterministic way and the train of technology as practically unstoppable.

In the literature the unstoppable train of medicine has often been regarded either as a salvation of the human collective or as its destruction. Among physicians and geneticists, for instance, the healing impact of progressive genetics is commonly expressed and taken for granted *(Jallinoja, 2001, 2002*). Genetics is seen as an advanced solution for the problems of diagnosing hereditary diseases and in the future also for providing cure and treatment. Furthermore, it is sometimes regarded to be futile to attempt to stop developments in gene research because it is in human nature to proceed with everything that is practically and technically possible, hence the human genome should be mapped simply because it is possible (Huhtaniemi 1996, 296).

In the humanities and social sciences, on the other hand, criticism towards accelerating technologization has been an enduring tradition. Here, the situation of 'technological civilization' (Ellul 1976) or 'technopoly' (Postman 1993) has often been pictured as rather gloomy because its impact on morality is devastating. Jacques Ellul regarded that modern technology impairs genuine morality and moral sentiments (Ellul 1976). Thus, autonomous moral choices are practically impossible in the face of techniques, since

efficiency determines the outcomes of all choices. In ‘technological culture’, as the situation has been called, the obsession to engineer what is engineerable leaves no space for moral restrictions (Hamelink 2000, 6-8).

Zygmunt Bauman (1993, 198) is also pessimistic about current technologization: he regards that the transfer of morality to machines and overall fragmentation make up a world where the moral self does not survive. Thus, since interests and obligations are partial, no overwhelming responsibility for other people or the world is likely to be patched up. Recently, Richard Stivers (1996, 12) has also lined up with the path of Ellul and Bauman and claims that technical and bureaucratic rules are in effect the morality of technology, that in turn do not leave any room for individual ethical decision (1994, ix). Stivers (1994, 169) believes that this new technological morality creates enormous unhappiness and stress in the lives of individuals and in their relations with each other. Technology brings only momentary pleasure, and moreover creates still new problems.

Another core argument in the tradition has been that there is an automatic growth of everything that concerns technique. Ellul (1976, 87) interpreted this as a self-generating process. Hence, once a technical procedure has been discovered, it is applicable in many fields other than the one for which it was primarily invented. Networks tend to be increasingly larger, and improvements that result from the application of technique to the matter at hand can be added uninterruptedly (Ellul 1976, 90). In other words, technology can only continue to grow as long as people remain its followers (Stivers 1994, x). Bruno Latour (1993a, 109; 1999, 197-201) also notes that enlargement of sociotechnical networks appears to characterize contemporary societies as being irrevocable, although Latour does not consider this situation to be as much of a worry as Ellul did. Latour (1999, 197-201) claims the phenomenon is not new since for millions of years humans have extended their social relations to other actors with which and with whom they form collectives. What has occurred is that now we have

“imbroglios of humans and non-humans on an ever increasing scale” (ibid. 201), i.e. more than in the past. Thus, in the future we will live in a complexity of science, technology and society even more tightly than before. The analysis to follow will present the ways in which new medical genetics and its applications increase situations in which technologies, diseases, humans and moralities are increasingly entwined.

## 4. Detours in the tracts of progress

The present article is not simply lined up with either of the above deterministic viewpoints. Instead, certain further notes to the above description of the main trends in progress and interpretations of their consequences are presented. These notes point out that technology does not simply proceed in its own inner logic, unaffected by the forces and actors outside its realm. Instead, as has often been repeated in science and technology studies, things may have been otherwise and the paths of individual technoscientific enterprises are contingent (e.g. Bijker & Law 1992, 3). This situation is the starting point for the present article.

The introduction of a new medical technology does not occur by just transferring laboratory findings into the health care setting. Hence, technology does not just ‘enter the context’, nor is it simply forced into the world. Instead, the new technology must be adjusted to its surroundings - and vice versa. For instance, if a geneticist wants to use a new gene test in the health care setting, she/he must enlarge the group of people who think, pay and are interested in innovations in human genetics (cf. Latour 1993b, 380). In other words, various interest and expert groups must be made interested and recruited. Moreover, the health care system must be moulded, additional technologies have to be taken into use and even new specialities formed.

Hence, as new technologies are defined, hypotheses are also made of the entities that make up the world into which the technology is to be inserted. This implies that designers should define actors with specific competences, motives and aspirations, and assume that morality, technology, science and the economy will all evolve in particular ways. (Akrich 1992, 207-209.) Recruiting allies thus involves further development of the argument and artefact (Latour 1993b, 381). In other words, instead of straightforward application of the initial artefact created in the laboratory, there are interruptions and detours, while goals must be articulated anew and new strategies developed (Latour 1999, 184-187).

Even if some screening technology would have been or will in the future be taken into routine use in healthcare, it is actually in constant threat of being moulded or even ended - although often what is once taken into routine use, tends to remain so for years or even decades (Singleton & Michael 1993). The ambivalences and even instabilities of seemingly established screening practices have been brought up in recent debates on prenatal screening for Down's syndrome[1] and mammography screening for breast cancer (de Koning 2000). Hence, the technological or clinical effectiveness remains contested, relative, situated and contingent (Casper & Clarke 1998, 257, see also Clarke & Fujimura 1992, 18) and self-evidences are in effect always unstable (Foucault 1991, 82). For example, there are negotiations over what elements should be assessed in health technology assessment and what kinds of measurements should be used, i.e. how different aspects of screening should be translated into numerical scores. Quality of life and psychological disturbance caused by screening and consequent treatments have been some of the debated elements of these calculations[2]. Moreover, in time new elements and aspects may be included in calculations and estimations, perhaps changing the outcome of previous calculations.

A glance at the progress of clinical genetics in Finland indeed shows that there have been forces outside genetic laboratories, e.g. disability activists and some critical physicians, that have at least tried to set hindrances, detours or conditions to the widening use of genetics. Thus, despite the increasing enthusiasm from the 1980s onwards, the new developments have not always been welcomed. In addition to the rather cautious notes on the ethical issues involved in genetic screening in medical journals (*Jallinoja 2002*), there have been several peaks of public debate on selective abortion during the last 20 years. One of the earliest occurred in the mid-1980s and was related to the extension of the gestational week limit for abortions of severely disabled fetuses[3]. In winter 1993/1994 discussion arose because the City of Helsinki began to offer maternal serum screening for Down's syndrome for all pregnant mothers at municipal maternity care centres[4]. The cloning of Dolly the sheep and later of other mammals and plans to clone humans have also given rise to peaks in discussion on genetics in general. The latest peak related to prenatal screening was initiated by the decision of the City of Kuopio to terminate screening for Down's syndrome by measuring increased nuchal (neck) translucency with ultrasound and continue screening with maternal serum analysis[5]. A related debate continued in the course of spring 2001[6].

In general it appears that new developments, e.g. cloning of mammals, and widening use of existing technologies, such as turning from the testing of high-risk groups like cancer families, to systematic screening of low-risk population groups have given rise to public discussion and controversies. Basically, the positions and arguments of participants in the debate have remained the same: on the one hand there are clinicians and researchers arguing for the screenings to provide voluntary informed choices, and on the other hand there are those concerned who criticize the lack of discussion on ethics, rights of the disabled and problems related to voluntary participation.

In Finland activism against prenatal screening and new human genetics has remained somewhat moderate and limited compared with the activism in the Netherlands, for instance (Petrogiannis et al 2001). One association of people with disabilities (Kynnys) has been rather clearly against prenatal screening, but other associations have been more cautious or permissive and suggest that the decision is up to the parents. [7]

Among physicians still in the 1980s, criticism was sporadic (Pimenoff 1988, see also Haapala 1994). However, in the course of the 1990s attitudes towards population-based screenings even among geneticists themselves became more cautious: in the early 1990s population-based screenings had been seen as "possible within the next few years" (Syvänen & Peltonen-Palotie 1993, 198, see also Palotie & Ranki-Pesonen 1994, 650), whereas in 2000 genetic screening was regarded to contain many disadvantages and issues to be further discussed (Kääriäinen 2000) and not as "particularly promising" (Kere 2000). It appeared that negotiation over the conditions and contents of clinical genetics was on its way: enthusiastic projections were accompanied by statements that accounted for other than medical points of view. Furthermore, given the enthusiasm and projections of the early 1990s, there have been relatively few genetic screening undertakings - actually, at the time of writing this article, there is currently only one ongoing genetic screening project in Finland (the Type 1 Diabetes Prediction and Prevention Project). Since the mid-1990s new screenings to detect gene defects have not been started. However, prenatal screening based on other methods than DNA analysis continued throughout the country.

In the following, the introduction and widening use of a new medical technology, and the tensions, negotiations and disputes related to the process as well as attempts to solve these disputes are analysed. Here not only discourse over tests, but diseases, scientific articles, maternity care centres, research plans, geneticists, nurses, media debates, health care planners' decisions and intentions, are seen to be involved in the

negotiation over proper clinical genetics and gene research. Hence, in the introduction of genetic screening it has not been a question only of technical details or a technical network of laboratories and test tubes, but neither has it been a question only of social interactions between human actors (see Callon 1991, 153; Latour 1991, 110; Latour 1993b, 380; Latour 1999, 15; Bijker & Law 1992, 4, Leskinen 2000). Hence, the locus of enquiry is neither the technical object itself nor solely the social interests (Latour 1993b, 391).

Under analysis is a technosocial situation. Technology is not seen as simply entering some context; instead the technology and context are seen to be produced simultaneously (Latour 1991, 106). For this reason, Adele Clarke and Joan Fujimura (1992, 17) propose the word 'situation' instead of the word 'context' because all things, attributes and elements involved in the process under analysis are in the situation itself - not in some external context. Hence, even though not always physically present, elements such as stockholders in a biotechnology company are very present elements in the biotechnology laboratory and should not be regarded as merely contextual or external elements.

## 5. The puzzles of clinical genetics

### *5.1. Citizens and the survey population*

In Finland, ordinary citizens seldom express their views on genetics in public. In some cases they do; e.g. in journal interviews they are usually in some way concerned with the question. They have, for instance, a hereditary disorder themselves or they are parents of disabled children, i.e. their expertise is based on their own experiences of disability. Accordingly, the general population or common people is a group of actors that is mainly spoken for (Latour 1987). These silent actors are, however, central to

formation of the ethics of genetic screening and counselling, because arguments about them, their qualities, wishes, concerns and fears are central to the negotiations of acceptable screening and its conditions.

In this section I will first analyse lay people in the light of results of two surveys. Second, I will analyse the sample survey as a conceptual apparatus and discuss why lay people's opinions are regarded as worthy of analysis. Third, the population will be regarded as the target of education and enlightenment. The fourth angle for citizens is the analysis of voluntary choices as clients' rights in the healthcare. Since voluntary choice is of great importance in clinical genetics, it is analysed in a separate chapter.

### 5.1.1. Attitudes towards gene tests and screening among lay people

The results of the 1993 and 1996 surveys showed that most people regard genetic screening in rather a liberal way (Table 1). The liberal attitude is accompanied by ideas on enlightening the citizens and that the state should be involved in the financing of genetic screening - although actual state control gained less support.

Table 1. Attitudes towards gene tests among lay people in 1993 and 1996, percentages of those who fully or partially agree with the statement (*Jallinoja et al 1998*, Jallinoja & Aro 1999b, *Jallinoja & Aro 2000a*, Jallinoja & Aro 2000b, see also Hietala et al 1995).

| | *1993* | *1996* |
|---|---|---|
| Genetic tests should be available to anybody who wishes to have information about her/his disease genes. | 94% | 86% |
| Gene tests should not be done at all. | 17% | 5% |
| Every woman has the right to have the genes of her fetus tested. | - | 75% |
| It is important that Finns are informed of the feasibilities of gene tests. | - | 91% |
| Public health care system should finance genetic screenings of serious diseases. | - | 84% |
| Gene tests should be controlled by the state. | - | 52% |

Furthermore, gene tests were seen to have both positive and negative impacts on the lives of the tested individuals (Table 2).

Table 2. Attitudes towards consequences of gene tests among lay people in 1996, percentages of those who fully or partially agree with the statement (*Jallinoja & Aro 2000a*, Jallinoja & Aro, unpublished observations).

| | *1996* |
|---|---|
| Gene tests may increase people's control over life. | 64% |
| Prenatal gene tests increase possibilities of family planning. | 66% |
| Prenatal gene tests increase anxiety-provoking choices | 63% |
| Prenatal gene tests should be considered from the ethical viewpoint. | 61% |

The survey results also show that a considerable proportion of Finns regard genetic testing as problematic on a more general level as well. More than half were much or somewhat worried that results of gene tests could be used for other scientific purposes without informing the person in question and the majority were worried that results of gene tests could get into outsiders' hands (*Jallinoja et al 1998*, see also Hietala 1995). A total of 54% were concerned that gene tests may lead to eugenics, but only 21% were concerned about that in time gene tests would become obligatory (*Jallinoja & Aro 2000a*).

A more detailed analysis showed that as many as half of the respondents of the '93 survey solely expressed their approval of genetic testing and did not agree with any of the conflicting statements analysed in the article. On the other hand, although a considerable proportion agreed that there were disadvantages in genetic testing, only a small minority appeared to be unambiguously against genetic testing. Among those who opposed genetic testing the most acceptable purpose for testing was the right to know about one's genes so that one could influence her/his health, whereas the reason

that gene tests would save the government money by reducing the costs of healthcare gained less support. (*Jallinoja et al 1998.*) Likewise among public health nurses and midwives societal savings were less often seen as an advantage of screening for Down's syndrome compared with the advantage that parents could prepare for the birth of a disabled child during pregnancy (*Jallinoja et al 1999*). In summation, economic arguments for screening and testing were not as widely supported as arguments related to individuals' or families' lives.

With regard to confidence in the process of genetic testing and its implications, the proportion of those who seemed to be unambiguously confident in independent decision-making and control over the use of gene test results was as low as 5%. The most worrisome aspect was that genetic testing would lead to eugenics; in all 40% were greatly and 39% somewhat concerned about this prospect. A third of even those who were fully confident in their autonomy regarding genetic testing were greatly concerned about eugenics. (*Jallinoja et al 1998.)* In the '96 survey, 54% agreed fully or somewhat that they were concerned that gene tests may lead to eugenics (*Jallinoja & Aro 2000a*).[8]

Eugenics, in fact, seems to be an epitome of fears and concerns attached to genetic screening and selective abortions. As we have seen, many lay people were concerned about eugenics, especially those with the highest levels of knowledge of basic genetics (60%, whereas the corresponding figures among those with medium or low levels of knowledge were 57% and 37%, respectively; *Jallinoja & Aro 2000a*). In public and scientific publications, it is not in fact rare to parallel modern fetal diagnostics and selective abortions with the eugenic policies of the first part of the 20$^{th}$ century (e.g. Eräsaari 1997, Shakespeare 1998, Hietala 1999). Thus the worry over eugenics in the surveys is in line with these analogies and comparisons. Eugenics is a concrete historical example of medicine that does not respect patient autonomy in the way it is currently understood. For many, it is the epitome of inhumane physicians. All in all it

is an era that the representatives of the new genetics are actually strongly distancing themselves from (e.g. Kere 1999).

Although actual contradictions in attitudes were not evaluated in the 1996 survey, there were certain issues over which there was relatively high agreement among the respondents. Agreement was most clear regarding privacy and voluntariness of gene tests and of the matter that Finns should be informed about the possibilities of gene tests. This result is in accordance with the current mainstream bioethics, in which autonomy, privacy, equality and justice are regarded as the prime values that should guide healthcare (Beauchamp 1994). Also according to physicians involved in genetic screening and counselling projects, autonomy, delivery of proper information, respect for privacy, honesty, beneficence and non-maleficence were regarded as characteristics of ethically approvable clinical genetics (*Jallinoja 2002*).

In conclusion, for many the morality of genetic testing seems to be situational, i.e. not absolute. It does not imply an outright rejection of genetic testing in all situations nor its acceptance in all its forms and for any purposes. Likewise attitudes, depending on the situation of the family in question, also appear to prevail among many people with disabilities (Laurén 2001). Acceptance also seems to be accompanied by a concern over future developments. “Where to draw the line” with respect to gene research and technology seems to be a central theme in discussions about the new genetics among lay people (Kerr, Cunningham-Burley & Amos 1998a, 116). Since the morality is not absolute, the situation is favourable to negotiations and attempts to stretch the area of acceptable uses of genetics. Negotiations on acceptable applications appear to be especially legitimate when individuals’ and families’ health, diseases and sufferings are used as rationalizations (compared with rationalizations related to societal savings). Individuals in difficult situations, struggling with severe disease, cannot be denied relief.

### 5.1.2. The survey population as a conceptual apparatus - listening to the silent actors

Opinions of ordinary people have been increasingly regarded as important by geneticists and other biotechnologists. Since in practice not everybody's opinions may be listened to and considered, various means have been developed to pack the opinions of the more or less silent citizens into a compact format. In Europe, for instance, several consensus conferences have been organized since the 1980s. Their aim has been to "take discussions about contentious, or potentially contentious, areas of science and technology beyond the traditional debate amongst experts and special interest groups" (Joss & Durant 1995, 9) and to bridge the gap between the general public, experts and politicians (Grundahl 1995, 31). This has been considered as important because science and technology influence the general public, and because "science and technology cannot be expected to flourish for the benefit of humankind without a basis of public understanding and public support" (Joss & Durant 1995, 9).

In the Danish model, for example, the consensus conference has been defined as a meeting between an expert panel and the lay panel and the final statement document of the meeting is written by ordinary people (Grundahl 1995, 31). According to Reijo Miettinen and Esa Väliverronen (1999, 17) the inclusion of lay people in the consensus conferences in Finland has been weak[9] reflecting the Finnish tradition of reliance on specialists in technology assessment, and more generally lack of tradition of critical debate and dialogue. Moreover, the public understanding of science has never become a major science policy issue in Finland as, for example, in the UK (ibid. 15).

An important instrument to make citizens' opinions heard has been the questionnaire study and survey, results of which were presented in the previous section. The idea of

investigating the population's morality or attitudes is not new. Since the 18th century, European rulers gradually had to account for the views of the masses (Ginsberg 1986; Stivers 1994, 113). The first sample surveys were dated to the 1930s (see Herbst 1991, 230) and in Finland, attitude surveys have been conducted regularly since the end of World War II (Suhonen 1991, 12).

The overall trend appears to be that opinions about health issues and new medical technologies and psychosocial adjustment to these new technologies and their outcomes have been increasingly measured. For example, the European Commission has conducted surveys related to biotechnology since 1982 (Eurobarometer 1997, 1). Davison, Barns and Schibeci (1997, 320) also reported a similar phenomenon in North America, Australia and Japan. As the physicians of Tampere University Central Hospital have put it, in planning and launching screening programmes, attitudes and wishes of the target population as well as ethical issues are of primary importance (Nyberg, Tuimala & Simola 1997).

Since the early 1970s the interconnection between public opinion, mass media publicity and political decision-making has become more intense; thus, decision-makers present themselves as spokespersons of the people by appealing to opinion polls (Suhonen 1991, 15). Suvi Ronkainen also noted that the social impact of surveys has increased especially recently (Ronkainen 1999, 97) and claims that the survey culture has even become part of our everyday life (ibid. 135; also Ross 1998, 152). She argues that measurements and barometers are part of the public debate that shapes our understanding of the surrounding world, our perception of public opinion and the general directions of development.

Hence, 'the public' or 'the public opinion' is not a naturally occurring entity, community or phenomenon but a construction as Davison and his colleagues claim

(1997, 330). For them public opinion surveys privilege the aggregated view of uninvolved mainstream individuals and marginalize active minority viewpoints. Indeed, what is central to sample surveys is that they appear to be democratic and representative of the entire population: all demographic groups are given the opportunity to express their opinions, everyone's opinion is equally important and all views are considered interesting. In the words of Stivers, polls are an abstract and impersonal force making everyone's view equal (Stivers 1999, 100). In consequence – as in elections - the average opinion colours the overall result of the survey. Some have even spoken of 'Gallup-democracy' (see Suhonen 1991, 11).[10] In effect, public opinion polls are closely related to argumentation over free society, since they are claimed to determine the will of the free people (Rose 1999, 65). Thus as opinion polls are presented in public, they reinforce the idea of individuals freely forming their opinions about various subjects.

What is central in questionnaire studies is that they are based on scientific measurement, expertise and experimentation; thus they are identified with value-neutrality, objectivity and nonintentionality. They are regarded as simply revelations of the true state of things, hence, they are in itself neither good nor bad. In comparison to ethical contemplation or individuals' accidental outbursts that are vague or loaded with unreliable emotions, questionnaire studies provide clear, numerical results (*Jallinoja 2002*). Polls, claims Andrew Ross, have become the neutral arbiters of competing claims of rights (Ross 1998, 135). Thus, numbers are like nature in biosciences - the final ally that settles the controversies (see Latour 1987, 97).[11]

Consequently, when questionnaire studies are referred to, estimations of the acceptability of genetic screening, for example, are not presented to be the geneticists' personal opinions. Instead, they are revelations of a disinterested and just instrument that objectively interprets the opinions of the whole population. As one paediatrician

has expressed it, it is not enough to discuss the ethics of gene technology and screening; instead it had to be tested, studied and sorted out. Accordingly, in his screening project the participation rates and families' behaviour were constantly followed up and analysed in a subproject in which psychologists were also involved. *(Jallinoja 2002.*)

Hence, here we have the diverse opinions and perceptions of the population, an instrument (a questionnaire) and a verbal commentary of the scientist (a scientific article based on the survey data) (c.f. Latour 1987, 71). Neither the population, nor the questionnaire, nor the data in themselves imply anything about the acceptability of genetic screening. The scientist thus acts as a spokesperson for the population and transforms their diverse opinions into calculable variables and further into statements on 'the public opinion'.

Actually, even to simply act as a spokesperson of the population is an important endeavour. This means that not only the very results but also the evaluations as such have been used as arguments in the introduction of genetic screening in Finland. They are arguments about taking public opinion into account and about caring what the lay people feel and think. Instead of being hindrances to screenings, they are proof that the common people were listened to and taken into account - they are proof about lining up with democracy and developing future screenings according to the wishes of the citizens. Measurement of acceptance is the technology that provides the medical staff with the means to verify the actualization of voluntary choice, and consequently argue in public over the acceptability of genetic screening (*Jallinoja 2002*). From now on, it was not only the geneticists' personal view or professional interest that the critics were faced with but the opinions of the entire population.

An indication of the importance of surveys has been debates about which groups should be surveyed and thus given a voice: nonsymptomatic population groups to be screened

or individuals with experiences of disability. Some disability activists have claimed that people with disabilities are the only true experts in the area (e.g. Sjövall 1985, Könkkölä 1994, also Alderson, Scott & Thapar 2001b, 168). Since people with these experiences are a minority, their opinions are not loud in sample surveys. Accordingly, questionnaires and other studies on families with a disabled child (Itälinna, Leinonen & Saloviita 1994, 42-43) and with members with hereditary cancer (Aktan-Collan 2001, 20) have been increasingly conducted. In effect, fetuses have also been proposed as the actors to be listened to, although not with the help of questionnaire studies, but with the visual manifestations of 'the silent scream' of the fetus. These are the prolifeists, who thus far have gained only limited support in Finland.

Hence, here we may observe a contest over whose viewpoint should decide the acceptability of genetic screening: experts', lay people's, people with disabilities, parents with disabled children or the fetus itself. To repeat, at the heart of the debate around prenatal genetic testing are contested choices and rights: a woman's right to choose, the civil rights of disabled people, the postulated rights of the unborn child and the rights of the individual versus the rights of the collective (Shakespeare 1998, 665).

### 5.1.3. Informing the citizens and the cornerstones of successful screening

A prominent gene reasearcher in Finland, Albert de la Chapelle (1990) claimed that fears related to the new genetics are due to lack of correct information. Another gene researcher also has suggested that insufficient knowledge and misconceptions are likely to lead to unfounded fears or expectations (Hietala 1998, 10) and that "the only way to avoid misunderstanding and unrealistic fears and hopes related to genetic testing, is adequate information on the basic principles of genetics, sufficient information on the particular screening program, open discussion, and voluntariness" (Hietala 1998, 65).

Sufficient information and counselling have also been connected with the success of genetic screening programmes (Aula & Leisti 1994, 756); and "the optimal utilization of the potential of genetic testing" has been seen to depend greatly on the knowledge and attitudes of the population (Hietala et al 1995). Thus, there appears to be a triangle of information/knowledge, acceptance and successful screening. Proper information is seen to lead to acceptance and both information and acceptance are seen to lead to successful screening programmes. Midwives and public health nurses also trusted in the relieving impact of information: three in four of them agreed that if one fully informs the pregnant woman, serum screening for Down's syndrome will not give any difficulties (*Jallinoja et al 1999*).

The experts' argumentation thus involves the idea that tensions and concerns would be erased with knowledge and that facts 'themselves' would lead to acceptance and support. Likewise argumentation was also used in relation to prenatal genetic screening in Kuopio. One proponent of screening in Kuopio was of the opinion that as the new phase of medicine brings along numerous new issues to think of, many people cannot keep up with the speed. What follows is that more than facts and objectivity, ideas emerge mingled with fear. (*Jallinoja 2001*.)

Ann Kerr and her colleagues (1998b) also noted this phenomenon in the UK. They claim that professionals relate the public's mistrust in genetics with ignorance of scientific facts. Among geneticists, objective and factual scientific knowledge was seen as an antidote to the illogical, exaggerated and fearful views of lay people (Kerr, Cunningham-Burley & Amos 1997, 292). Thus, the geneticists' point appears to be that if the public only knew what the researchers already know, the public would be put at ease - otherwise they are just irrational (Beck 1996, 58). In this line of thinking, the truth will be grasped when people are properly equipped to observe the facts (Addelson 1994, 165). To truly understand what the new genetics is about would erase irrational

fears related to genetics, such as eugenics. This, indeed, is the message of the classical Enlightenment.

With respect to information, both educating and informing the general population or population subgroups in schools or the media for example and counselling people in an actual genetic counselling setting are regarded as important. In the latter context, the often-used term is 'informed consent' that refers to the requirement that in healthcare, patients must provide their informed consent, i.e. their permission to proceed, often in written form, before any procedure can be carried out. Hence, information is a concept covering a wide range of practices and contents.

At the core of information are the facts about diseases, risks and tests. For example, a leaflet delivered for pregnant women in Kuopio, contained many bits of information that may be regarded as 'facts'. Examples are sentences describing the patterns of inheritance of fragile X and AGU (Saarikoski & Ryynänen 1995; see also *Jallinoja 2001*). However, bits of information very rarely remain in the realm of scientifically proved facts, but also contain interpretations. In the leaflet, for example, since 2% of Finns are carriers of the AGU mutation, the disorder is interpreted to be 'very common'. Furthermore, the leaflet contains statements about voluntariness of all tests and procedures. Hence, as another research group has reported, the implicit certainty and precision in many leaflets on disability illustrate how, many kinds of tentative, ambiguous concepts are repackaged into authoritative medical certainties (Alderson, Farsides & Williams 2001c, see also Lippman & Wilfond 1992).[12]

Accordingly, although in principle it might seem that the limits of facts and proper information are easy to be defined, in effect, they are ambiguous and hazy. When it concerns information on psychological consequences or experiences of disability the factuality is contested especially.

Many studies on public understanding of science have equated public appreciation of and support for science with the public's correct knowledge of it (Wynne 1995, Davison, Barns & Schibeci 1997). Indeed, in the late 1990s in Europe there was wide agreement among scientists that the public should be educated, but also heard, and that there should be discussion with the public about technoscientific developments (see e.g Geeniseulontatyöryhmä 1998). The consensus conferences discussed earlier are part of this pursuit.

The result of the 1996 survey, however, showed that better knowledge about basic genetics was not associated only with optimistic and accepting attitudes but also with more sceptical or negative attitudes towards genetic testing (*Jallinoja & Aro 2000a)*. Thus, better knowledge did not lead to unambiguous acceptance. Others have also reported that, for example in morally contentious areas, the well-informed are more strongly opposed to research funding than the less informed (Evans & Durant 1995). It was also discovered that those with low levels of knowledge more often than others chose 'don't know' response to various attitude statements. Accordingly, there were people who have both low levels of knowledge and for whom taking a stance towards these technologies is not an easy matter (*Jallinoja & Aro 2000a)*.

Moreover, if eugenics was feared among lay people (*Jallinoja et al 1998, Jallinoja & Aro 2000a*), who may be considered to be rather uneducated in genetics, there are also highly educated specialists who are actually of the opinion that current fetal screening is based on eugenic thinking. Elina Hemminki and her colleagues determined that 2% of the leading gynaecologists and paediatricians were of this opinion, while 16-17% believed that current fetal screening is partly based on eugenic thinking (Hemminki, Toiviainen & Santalahti 2000). In addition, 23% of physicians and 37% of midwives and public health nurses were concerned over the new developments in prenatal

diagnosis (Toiviainen, Jallinoja, Aro & Hemminki, unpublished observations). Many respondents in both groups also agreed that prenatal screening for Down's syndrome includes some disadvantages (*Jallinoja et al 1999*, Hemminki, Toiviainen & Santalahti 2000).

Accordingly, the triangle of knowledge – acceptance - successful screening is not as straightforward, and the association between the angles of the triangle are not simply positive and mutually supportive. Not even education in medicine or even in the specialities of paediatrics or gynaecology erase all concerns. Furthermore, although it is often regarded that information should be factual, nonbiassed and nondirective, the factuality of facts remains contested, and actual information always contains interpretations, suggestions and estimations in addition.

Another component of the triangle remaining weakly defined or fluctuating is what makes a screening successful or, conversely, unsuccessful. An often-cited example of unsuccessful screening is screening for sickle-cell[13] in several states of the USA in the early 1970s. The programme has been described as having been "loaded with misunderstandings and misuse of the test results" leading to discrimination of sickle-cell gene carriers in insurance companies and employment (Hietala 1998, 23). Thus, in sickle-cell screening lack of proper knowledge - not only among those tested but among employers and insurance companies - has been seen to lead to unsuccessful screening.

In contrast, screening for thalassaemia[14] in Greece was initiated in the late 1970s and has been regarded as a success (Petrogiannis et al 2001; also Hietala 1998, 23). Here, the success is closely seen to correlate with the fact that the number of children born with thalassaemia has dramatically decreased. In addition, it has been noted that especially in rural communities those people who knew they were carriers of the

thalassaemia gene rarely married; thus screening is seen to have diminished discrimination and stigmatization. It also appears that in Greece there has been no - at least in public - overt criticism expressed against the screening since the major round-table discussion and public discussions of the late 1970s. (Petrogiannis et al 2001.)

Furthermore, in Finland results of the sociopsychological and attitude evaluations in relation to genetic screening programmes have provided researchers support for the view that the genetic screening in question may be continued (Simonen 1997, Ryynänen et al 1999, see also *Jallinoja 2001; Jallinoja 2002*). However, more pessimistic conclusions have also been drawn from the result that 65% of those tested in childhood and who had been told their test result, had correctly understood the carrier test (Järvinen et al 2000). Despite the above result and the finding that genetic carrier testing in childhood did not cause serious harm in adulthood, Outi Järvinen is clearly sceptical about childhood genetic testing, because "many had misunderstood, or had not received their test results" (Järvinen 2001, 59).

It appears that a high participation rate as well as public approval and lack of negative psychological side effects are regarded as marks of successful screening. The interpretation of uptake rates and questionnaire studies is however ambiguous, as Järvinen's interpretation has shown (see above). Furthermore, in Tampere the rather low uptake rate (68%) in maternal serum screening was hoped to be a sign of women's freedom to decide for themselves whether to participate in screening (Nyberg, Tuimala & Simola 1997), instead of interpretation that many women are sceptical about prenatal screening. Hence, the range of results that justify an interpretation as supporting or opposing screening is rather wide. The factuality melts again into interpretation.

It should be pointed out that high uptake rate is also a problematic measure of success. Since the tests are strongly regarded as a private and voluntary matter, public

argumentation for high participation rate - not to mention high abortion rate - would contradict voluntariness. Whereas in relation to many other medical screenings figures related to participation, prevention of diseases and money are often used as rationalization for the screening, the situation is more problematic with respect to genetic screening and especially in relation to prenatal genetic screening.

Cost-effectiveness calculations especially have been increasingly seen as insufficient or even unethical arguments for genetic and prenatal screening. In effect, also more generally, money is regarded as a nonissue in questions of life and death. (*Jallinoja 2001*, 299.) This phenomenon was also present in the surveys; e.g. only 22% of midwives and public health nurses considered that the decrease in societal costs for caring for disabled people is an important advantage of screening for Down's syndrome (*Jallinoja et al 1999*). Here another type of argumentation, related closely to voluntary informed choice is used.

### *5.3. The imperative of choice*

One of the most central qualities of proper or even successful screening is regarded to be voluntariness of all procedures. Today, choice of gene tests and abortions is both a necessity and a source of dilemmas. Individuals' right to choose, even though the choice is highly difficult, may be regarded as self-evidence in discussions on genetic screening and testing. Genetic screening must be adjusted to the surroundings of contemporary society that place high value on individual choice and autonomy.

### 5.3.1. The right to choose

The reign of discourse of voluntariness is very strong with respect to gene tests and is central to several recommendations in the area (*Jallinoja 2001, 2002*; see also World Medical Association 1987, 1992; Council of Europe 1990a, 1990b, 1992; Lääkärin etiikka 1996, 2000), and was also revealed by the survey in which 87% considered that gene tests should be voluntary and 93% agreed that uptake of gene tests is primarily a private issue (*Jallinoja & Aro 2000a*). [15]

As Elizabeth Beck-Gernsheim (1996, 141) points out, in relation to genetic technologies individuals' task of making their own health-related choices is especially manifest. In a liberal society, claims Nikolas Rose, freedom is seen as autonomy, the capacity to realize one's desires in one's secular life, to fulfil one's potential through one's own endeavours and - what is perhaps most pivotal with respect to the subject of the present article - to determine the course of one's own existence through acts of choice (Rose 1999, 84). People are even obliged to be free (ibid. 87). Rose further suggests that freedom is in effect, an artefact of government (ibid. 63). Thus the ethics of freedom has come to underpin our conception of how we should be ruled, how our practices of everyday life should be organized, how we should understand ourselves and our predicament (Rose 1999, 61). Hence, we are living so deeply in a world defined by the imperatives of autonomy and choice that the situation appears to be neutral, self-evident and universal, and such that it is practically impossible to argue or act against it.[16] In effect, to argue against choice in Western societies would be to argue against individual rights, as Ruth Chadwick points out (1999, 296). Autonomy of citizens may be regarded as an inseparable quality of liberal democracies.

Likewise conclusions have also been presented by other sociologists. For Anthony Giddens, reproductive technologies and genetic engineering are part of the more general processes of the transmutation of nature into a field of human action and of the human body becoming a phenomenon of choices and options (Giddens 1991, 8, 219). George Ritzer interprets genetics through his McDonaldization thesis and claims that with the McDonaldization of birth and death the principles of rational consumer society have extended into the prebirth process (Ritzer 1996, 166). Lealle Ruhl notes that the contemporary control over reproduction emphasizes individual responsibility and negotiation of risk (Ruhl 1999, 97; also Petersen 1998). Emphasis on autonomy has been seen to be associated with the view that individuals are in effect consumers in the face of medicine and health care (Petersen & Lupton 1996, 67, also Nettleton & Bunton 1995, 49).

Indeed, the analysis of a single prenatal genetic screening project revealed the importance of voluntariness and information in argumentation over screening *(Jallinoja 2001,* 296-299; also *Jallinoja 2002*). In the screening, voluntariness and information were not only set as the conditions for screening but were set as its very aims that sometimes even go beyond the aim of promoting health. Consequently, doubts that were also expressed about screening were mostly related to the question of whether the voluntary informed choice about the gene test had been actualized among mothers. A major source of tension for public health nurses was the situation in which there were the coexisting goals for screening: detection of gene defects, i.e. decrease in disease and increase in families' choices (*Jallinoja 2001*). Hence the 'pure choice' was seen to be in conflict with the aim of promoting health - both of which were appealing. This tension should be seen in the light of the tradition of Finnish health care system where the focus has been on the universal access to medical care for all residents of Finland, guaranteed by the government (Hermanson, Aro and Bennett 1994)[17] - instead of the

model of consumer-citizen choosing of various options provided by public and private sectors.

Argumentation about free choice may also be interpreted as the manifestation of a new etiquette, as the term is used by Frank Furedi (1997) - a new form of morality. This, as Furedi argues (1997, 150-151), does not stigmatize any activity *per se*, hence it claims to be non-judgemental. Likewise Christina Hoff Sommers (1984, 386) has noted that increasingly in the USA, the only virtue that teachers dare to praise is the virtue of tolerance. Hence, she interprets the situation as fear of indoctrination. However, as Furedi continues, the new etiquette contains its own moralizing, its own classification of what is appropriate and what is not. The self-evidence of free, informed choice does not, thus, mean that all choices would be appropriately free or that anybody could define the limits of free, informed choice. On the contrary, negotiations about what kind of choice is truly free and what kind of information should be related to it are at the heart of negotiations on genetic screening, counselling and selective abortions (*Jallinoja 2001*).

For example, choices are seen to be truly voluntary only if the client or patient has adequate and proper knowledge about the gene test and risks in question (*Jallinoja 2001*). Hence, choice is closely connected with the project of counselling and informing people, discussed in the earlier section. Thus, choice as seen in the debate on genetic testing resembles rational decision-making, weighing different aspects of testing (Petersen 1998, 65; also Helén 2001), instead of being based on emotions or other people's judgements. Hence, genetic information and nondirective counselling are offered to make subjects more knowledgeable consumers (Petersen 1998) - not directed from the outside, but who direct themselves. However, as has been shown, there is no final definition of what "adequate and proper knowledge" consists of, i.e. how much and what kind of information is needed in order that the informed choice actualizes.

Further, it has often been stressed that choices should not be based on routine. Maternity care centres, for instance, with their inherent motive of promoting health, have been seen as a context in which gene tests are difficult to be seen as free choices, but instead are easily seen as part of the maternity care routine and in that respect as self-evident acts. Other tests and measurements, for example, measurement of urine glucose or blood-group antibodies, offered at maternity care centres are not offered as free choices but are often recommended in order to guarantee the health of the fetus and mother. In this situation, public health nurses offering gene tests have been concerned that women are too well-behaved and accept everything that is offered at maternity care centres, while many do not really understand what they are participating in. (*Jallinoja 2001*.)

In the previous section it was shown that information has often been associated with *acceptance* of new technologies. Here, I have shown that information is also seen to be associated with actualization of proper *free choice*. Thus informing people would lead both to acceptance of the gene test and free choices over tests. This seems to be paradoxical, since in principle choice may be free whether the individual accepts gene tests or not. Whereas the first association between information and acceptance is rather normative (the consequence of information should be acceptance, fears are due to biased information), the latter association between information and free choice seems to leave the position of the citizen subject open (any freely reached decision or attitude is tolerable). In the end there remains a copresence of normative will to educate, to enlighten and the liberal wish to guarantee freedom to choose for everybody, no matter what the decision is.

### 5.3.2. Nightmares and illusions of choosing

With regard especially to prenatal genetic testing, criticism has been targeted at the illusion of choice, because in case the fetus is diagnosed as having a gene defect the only choices are giving birth to a disabled baby or termination of the pregnancy. Choices have been described as nightmarish, even "like hell" (see Santalahti et al 1996, 105-106) and inhumane (Puskala 1995, 43; also Eräsaari 1997, 208-209). Moreover, prenatal screening is seen to spoil mother's pregnancy experience (Rothman 2001). The situation in which the mother receives a positive test result in amniocentesis or CVS has also been stated to be a choice with no good options by obstetricians (Hiilesmaa & Salonen 2000, 885). The consequences of choice, like abortions, are only such that the individual has not intended or desired (Helén 2001, 108).

Jacques Ellul was especially pessimistic about choices in a technological society. He claimed that humans in effect do not make choices but only decide in favour of the technique that gives the maximum efficiency (Ellul 1976, 80). He went on to suggest that nothing can compete with technical means, and thus the choice is made *a priori* - in effect the individual has no choice (Ellul 1976, 84).

Indeed, participation rates in Finnish genetic and prenatal screening undertakings have been rather high. In screening for a gene for susceptibility to childhood diabetes among newborns, only 1.4% of families refused analysis of the blood sample (Simonen 1997, 6). Attendance of prenatal screening for Down's syndrome (Ryynänen et al 1990, Salonen et al. 1997a, Santalahti et al 1999), genetic screening for AGU (Hietala et al 1998) and fragile X (Ryynänen et al 1999) has varied from 84% to 96%, although lower attendance rates of 68% have also been reported in Tampere (Nyberg, Tuimala

& Simola 1997). It has also been reported that since the early 1990s attendance rates in screening for Down's syndrome have decreased at least in some areas[18]. In cases where the pregnant women in screening is defined as having elevated risk of having a child with Down's syndrome, the uptake of amniocentesis or CVS is even higher, 98.4% in Helsinki for example (Salonen et al 1997a).

Furthermore, high uptake rates have been interpreted quite positively by geneticists themselves. For instance, in relation to serum screening for Down's syndrome high participation rate has been interpreted as a sign of mothers' interest in prenatal diagnosis (Salonen et al 1997b). In another study, participation in the initial session of genetic counselling and giving a blood sample were interpreted as a completely positive attitude towards screening for fragile X (Ryynänen et al 1995, 1237). Thus, by these physicians participation is equated with actively formed opinions, not with passive consent to a technology offered by the health care system, as would be the interpretation following Ellul's suggestions.

With regard to mothers' reactions and emotions, it seems that the closer the choice is to abortion, the more difficult the situation experienced. Riitta Salonen and her colleagues determined that 94% of mothers found the initial decision to participate in maternal serum screening, i.e. blood test for low-risk mothers, as *easy*, (Salonen et al. 1997b). In contrast, Päivi Santalahti and her colleagues (1996, 104) showed that as much as 82% of the pregnant women they interviewed had found the time of waiting for the results of diagnostic amniocentesis or CVS as *difficult*. The difficulty in taking a stance on selective abortions was also revealed among public health nurses and midwives. Whereas 79% accepted *screening* for Down syndrome, 15% did not accept *abortions* because of Down syndrome, 4% did not accept abortions at all and 37% were unsure of the acceptability and/or the proper gestational week limits for abortions for Down's syndrome (*Jallinoja et al 1999*). Elsewhere, waiting for diagnostic test results

of amniocentesis for Down's syndrome has been described by one mother as "so traumatic an experience that I would never again participate in the blood test if more children would be planned in our family"[19].

These results suggest that the initial screening offered to all pregnant mothers may be regarded as merely information about the fetus. Information appears again as neutral and not pointing to any necessary action. All options are open; however, when further examinations have shown that the baby will have a disability and the mother is asked to decide on abortion, it is clearly a question about a future life - thus the moral question is different and more difficult to solve. Among midwives and public health nurses it was especially the negative emotional reactions caused in mothers that were seen as a disadvantage of serum screening for Down's syndrome. In all, 76% considered the matter that false-positive findings cause worry for women to be an important disadvantage of screening and 72% the matter that screenings cause pressure to have late abortions that are emotionally difficult for women to be an important disadvantage (*Jallinoja et al 1999*).

In effect, what mothers are faced with at maternity care centres is not simply a situation with no choices but one in which the pursuit of free choice is combined with various expectations and forces (*Jallinoja 2001*). Thus, it is not a pure choice situation but a situation in which the individual must decide on *consent* to the procedure that health care planners have already estimated to be appropriate (Helén 2001, 106). Thus, it is not as some geneticists cited above claim that participation is equated with positive attitude. Still, argumentation over free choice - even if it does not lead to completely free choices - affects the clients: there still are two options and a choice or consent to be made, and many desperately struggle to determine what they truly and freely want.

Hence, there is the obligation to be free (Rose 1999) and the technology that is

promised to increase the possibilities to choose (*Jallinoja 2001*). This imperative of choice does not actualize in full force, but still leaves its marks on those touched by it. The imperative of choice - although very central - is not the only imperative at work here: although not always so loudly proclaimed, the imperatives of efficiency and health and the search for comfort, control and happiness have an impact on the situations in which choices are made. Thus, the greater the agony. In the following the case of abortion is analysed in more detail.

### *5.4. The fetus and the difficult case of abortion*

In the late 1960s the liberation of abortion was the goal of feminists in several Western countries. At the core was the idea of women's right to control over their bodies and their lives. Feminist criticism was also targeted, however, towards medicalization, as gynaecology and reproductive technologies were seen to diminish women's control over their own bodies and lives. In this respect abortion as a medical procedure was an ambivalent issue, because abortion that increased women's control over their bodies was actualized in health care institutions that for their part controlled women (Helén 1997, 11, see also Wrede 2001a, 3).

Hence, increasingly from the 1980s onwards some feminists, especially in the UK and USA, have been critical of developments in reproductive technologies and the new genetics, especially as they are targeted on women (e.g. Birke et al 1980; Arditti, Klein & Minden 1984; Corea 1988). Criticism has been focussed especially on the medicalization and technicalization of 'natural' events like pregnancy, labour and motherhood (see Nätkin 1997). Concern has been raised by feminists that bodily integrity and contraception would be in danger of being lost as new prenatal screening technologies are developed (e.g. Eräsaari 1997, 215).

The new Act on Induced Abortions came into force in Finland in 1970. According to the Act, a pregnancy can be terminated on a woman's request for several so-called social reasons and on the grounds of the child's mental deficiency, other severe illness or physical disability. Moreover, in 1985 the upper limit for performing an induced abortion due to verified fetal injury was changed from 20 to 24 weeks of gestation (Rasimus 1999).

Although the rather liberal abortion law came into force 30 years ago, the choice of whether or not to undergo abortion for any reason is still agonizing for many women (Sihvo & Kosunen 1998) and a highly problematized matter (Helén 2001). The liberal abortion law has not lead to easy choices nor to unambiguous acceptance among the general population or among professionals.

The puzzling morality of abortion reflects the ambivalent status of the fetus, the silent but nevertheless central actor in relation to prenatal screening and abortions. The fetus is a relatively new actor in medicine. Although the fetus had been there all along, at the time when its features could not be effectively observed, speculations about its disorders were relatively weak and were not strongly connected with abortions. By the development of foetal diagnostics, the fetus became conceivable separately from the bodily processes and medical condition of the pregnant mother (Helén 2002). As Lorna Weir (1996) noted the new prenatal diagnostic tests are distinctively different from prior forms of practice in that they are predictive at the individual level rather than being general statements about the subpopulations. The fetus has thus become a patient although a special type of patient, first of all since the conditions that may be revealed with current prenatal diagnostic methods may not be cured prenatally or after birth[20]. Accordingly, the only 'treatment' is abortion of the fetus (thus the sometimes used morbid term 'therapeutic abortion'). This matter has been seen to contradict the point presented in several suggestions for medical screening that there should be available

treatment for the condition screened for (Aro & Jallinoja 2001; see also e.g. Wilson & Junger 1968, Nuffield Council of Bioethics).

Furthermore, with new diagnostic methods questions regarding limits of life and individuality have become more intense, complicated and ambivalent (*Jallinoja 2002*). The fetus is now at the same time diagnosable and human, but unable to express his or her will. The fetus is often both wanted and planned, but its life is tentative and conditional (see for tentative pregnancy, Rothman 1994). In addition, with the development of treatment of premature babies, the fetus could be during the same gestational week both kept alive if born prematurely or aborted due to severe disorder (from the 19th to 24th gestational weeks, National Research and Development Centre for Welfare and Health 2000). Thus, as Thomas Lemke (unpublished observations) has expressed the circumstances, depending on the test results, the fetus would be either legally enhanced and protected, or would forfeit its legal status and mutate into fetal tissue.[21]

In obstetric care abortion has an ambivalent character: it is both a routine operation and an exception (I. Helén, unpublished observations). As a technical operation, abortion is a routine procedure, conducted thousands of time each year as any other operation. On the other hand, as a choice in a woman's life, as a solution to a life situation abortion is an exception, to be considered carefully and seriously - never to be taken lightly. Even the grand old man of genetic counselling in Finland, Reijo Norio, has recently defined abortion as "an act of violence" and "an emergency solution" (Norio 2000, 114). All in all, abortion in prenatal screening programmes is clearly a troublesome issue - the situation may be illustrated by the observation that in medical articles on prenatal screening for fragile X, abortion is very seldom explicitly referred to (*Jallinoja 2001*).

The morality of abortion is perplexing, reflecting the ambivalent status of the fetus. With the abortion choice, mothers are in an agonizing state in which, following Bauman, the moral self is her only interpreter and remains forever unsure of the correctness of the interpretation (Bauman 1993, 80). The ambivalence and privacy related to abortion is especially poignant in the following comment by a mother in a newspaper: First, the mother stresses that for her abortion would mean murder. Later, however, she states that every mother should make her own decisions because the relationship between mother and child is so intimate that no-one can judge others' decisions.[22] Hence, the morality of abortion is different from that of the murder of a born human being, in which the decision to murder is not usually regarded as up to each and everyone. To conclude, morality of abortion is on the one hand an extremely serious question of life and death but on the other deeply relative, subjective and personal. Indeed, claims the director of the Birth Control Trust in London, Ann Furedi (1997, 1165), many people who personally disapprove of abortion are prepared to allow others to act in accordance with their own judgement. She continues that abortion is sometimes seen by the woman as wrong, but the right thing to do in her particular circumstances.

### 5.4.1. Two categories of abortions

As has been already discussed in the above sections there are more than one kind of legal abortion. Hence, the ambivalent status of abortion becomes even more problematic and its situationality is highlighted. First, there are abortions because the mother or parents do not want any children and second, there are abortions because they do not want a certain kind of child. There are also abortions performed because of the mother's medical condition or limited ability to care for the child, but these will be not discussed here.

Statistically, since the new abortion law was enacted, the majority of abortions have been those conducted for so-called social reasons. For example, in 1997 there were 10,238 legal abortions in Finland. Of these 86.9% were done because of social indication and 1.7% were done due to potential or identified fetal injury. (Rasimus 1999.) In a population survey of women 18-44 years of age in the mid-1990s, 15% of the women reported they had undergone an induced abortion at some point in their lives and of these 2% reported that the reason for the abortion was fear of disability of the child (Sihvo & Kosunen 1998, 50-51). Given these figures, selective abortion appears to be a relatively minor issue, as has been expressed by geneticists (Aula 1978, 22; Aula 1988, 1301).

In opinion polls, selective abortion is accepted more often than abortion for social reasons. Abortion because of the disability of the child was approved in the 1996 survey by 73% (Jallinoja & Aro 1999b) and by 88% in another study conducted in 1989 among Finnish women (Notkola 1993). These figures suggest that the acceptability of abortions because of disability of the fetus would have slightly decreased although it is still acceptable by a majority.

On the other hand abortion due to the financial situation of the family was approved by 49% of Finnish women, due to the fact that the mother was not married by 44%, that the mother should quit her job or interrupt her studies by 44% and that the mother should either change her job or career plans by 42% (Notkola 1993, 16). Corresponding figures have been reported in a British study (Wise 1997). In all, 40% of the respondents in Notkola's study always approved abortions when a woman wanted it and only 4% stated that they do not accept abortions at all (Notkola 1993). In the 1996 survey 8% agreed that abortion is not acceptable in any case (Jallinoja & Aro 1999b). The corresponding figure among midwives and public health nurses was 4% (*Jallinoja et al 1999)* and among physicians less than 2% (Hemminki, Toiviainen & Santalahti

2000). Here again, for a considerable proportion the morality appears to be situational, i.e. most approve abortions in various life situations, and only a minority is absolutely against all abortions. Interesting also is the result obtained by the Research Institute of Evangelical Lutheran Church of Finland that a quarter of respondents considered abortion to be a sin and a third that abortion is never a sin (Kirkon tutkimuskeskus 2001).

Despite the position of selective abortions in abortion statistics and surveys, actually, it is the question of selective abortion that seemingly forms the present-day abortion problem (Helén 2001, 102). Increasingly in public, mothers' agonizing experiences of prenatal screening and families' positive experiences of life with a child with Down's syndrome and also families' more burdensome experiences with disabled children have been presented [23]. For many critics of prenatal screening, it is precisely the selection that has been seen as problematic, because through selective abortion motherly or parental love is seen to become conditional and dependent on the qualities of the child. Critics have seen the difference between selective and other abortions, not as quantitative, but as qualitative, as an indication of what kind of people are wanted in our society (e.g. Gustafson 1983, 25; Könkkölä, Könkkölä & Ranne 1983; Degener 1995, 37; Könkkölä 1998). Hence, the parental position would ban some choices. In other words, the total autonomy of an individual is seen to contradict the requirement for a parent to love and accept without conditions.

In a similar vein, Barbara Katz Rothman claims that by prenatal diagnosis and selective abortion the elements of choice enter into the maternal role, indicating a fundamental challenge to the social institution of motherhood (Rothman 1994, 242-43). For Ulrich Beck human genetics, among many other things, is also breaking apart the traditional unity of the family, i.e. setting mother against child (Beck 1996, 117). In other words,

gene technology is being claimed to revolutionize the biological and cultural foundations of the family (Beck 1996, 200).

In comparison, Frank Furedi (1997, 164) claims that it is actually the wider anxieties about parenting and family life that are reflected in the so-called dilemmas over new reproductive technologies. Thus, he claims, dilemmas are actually not the outcome of the technologies. The point is that reproductive technologies were not initially a target of these widespread controversies but have become such because of overall anxieties about family life.

To go one step further, I suggest that the process should not be seen as one-way in either direction. Instead, it should be considered as a sociotechnical process where reproductive technology and ideas about family mutually shape each other - not that it would be possible to define the primacy of either one in the process. Hence, it is not only the technology that breaks the unity of the family as Ulrich Beck states, but neither that there is nothing in technology itself that may have an impact on our conditions and perceptions about parenting and individuality. Technologies do contain qualities and expectations of arrangements in the health care system that in turn possibly create tensions between actors. Furthermore, certain cultural, legislative and political arrangements enable the development and widening use of new technologies. However, the dilemmas related to new technologies do not occur deterministically or naturally, but in a complex network of actors with varying competences, motives and aims. Hence, the dilemma of selective abortion does not naturally occur as the prenatal screening technologies are used. For example, when prenatal screening was first started in Kuopio, eastern Finland, in 1979, it was not regarded as an ethical issue as widely as prenatal screening has been considered two decades later.

### 5.4.2. The disability question

Some disability activists and critical researchers in Finland and elsewhere have seen the question of prenatal screening and selective abortion as a social and political question related to the disability community, not simply a question of individualized or case-based ethics (Könkkölä 1994, Shakespeare 1998). As Päivi Santalahti (1998, 62) concludes, prenatal screening is ultimately a question of disability. More specifically, concern has been raised that advancing prenatal screening will diminish parents' abilities to receive a disabled child (Gustafson 1983, 21) and lead to negative attitudes towards people with disabilities (Sjövall, 1985).

The concern over negative attitudes towards disabled people was investigated among midwives and public health nurses (*Jallinoja et al 1999*). It was determined that 28% of the midwives and public health nurses were of the opinion that attitudes towards disabled people becoming more negative is an important disadvantage of serum screening for Down's syndrome. The corresponding figure among various physician groups varied from 10% (leading paediatricians) to 23% (ordinary paediatricians) (Hemminki, Toiviainen & Santalahti 2000). Thus, concern does not appear to be very common among these professional groups. Moreover, negative attitudes towards disabled people was not the disadvantage most often agreed upon in any of these groups. Instead, as has already been pointed out, disadvantages related to women's emotions gained more support.

Moreover, minority of lay people (Jallinoja & Aro 1999b) and midwives and public health nurses (*Jallinoja et al 1999*) considered the birth of a disabled child as a disaster for the family. In the same surveys attitudes towards the following situation were investigated: a couple has a 25% risk of having a child with severe mental impairment, but they decide not to take part in a gene test they are offered, in other words are

willing to take the 25% risk of having a severely disabled child. It was determined that 78% of lay people and 93% of midwives agreed that the couple has the full right to make such a decision, and that 16% of lay people and only 2% of midwives agreed that couples like this should not make children. Thus, attitudes were tolerant towards the couple's decision. However, less than a quarter in both groups would themselves do the same if they were in a similar situation. (Toiviainen, Jallinoja, Hemminki & Aro, unpublished observations.)

Furthermore, in circumstances where a woman whose fetus actually has been diagnosed as having Down's syndrome, it is very rare not to abort the fetus (J. Puolakka, Central Finland Central Hospital, unpublished observations; R. Salonen, Helsinki University Central Hospital, unpublished observations).

Again, these findings reflect the non-judgementality and even the phenomenon termed political correctness: people with disabilities must not be discriminated against, nobody's life may be judged as a disaster and all situational decisions are acceptable [24]. However, only a minority seems to be willing to take the 25% risk of having a severely disabled child. Putting these results together, disability turns out to be a delicate issue. As Santalahti and her colleagues (1998, 1073) report, some women regard disability to be an actively avoided subject in maternity care centres. One woman, working in a children's intensive care unit, for instance, reported that disability is like a ghost in maternity care centres; it is there but not discussed.

Thus, it appears that disability is a sensitive and troublesome issue: it is a negative matter to be avoided with help of medicine, but this negativity may not be overtly discussed.

### *5.5. Ethics and codes for the experts*

As the previous sections have shown, the morality of genetic testing and related abortions is situational, and the imperative of free, informed choice and autonomy is considered to be the core values of clinical genetics. Furthermore, what is at stake are the disputing rights and duties of various actor groups in various situations. As these points already suggest, the means to handle or at least touch on this situation may not be absolute prohibition of testing or abortions nor coercion to test or abort. Instead, clinical genetics has been increasingly seen as an ethical question, one to be dealt within bioethics and medical ethics.

Medical ethics, however, is not a new invention. Long before the takeoff of the new genetics, medical ethics has been pursued to promote good physicianship or nursing, aiming to help the suffering patient (*Jallinoja 2002*). This is the ethics that is often seen as the age-old ways of practising proper medicine, as the knowledge and conscience of a performer, and even close to professional etiquette, "dignified spirit and good comradeship", as the matter was expressed in the early 20$^{th}$ century (Suomen Lääkäriliitto 1910-1985). This package of good physicianship or nursing that previously comprised physician-patient interaction and collegiality among physicians as its loci was shaken by the fetus and fetal diagnostics, but also by the increasing demand for client autonomy and widening use of new technologies in large screening programmes.

Therefore, since the 1980s ethics has been increasingly mentioned - albeit usually only shortly - in medical articles as an important issue to be considered in relation to clinical genetic and prenatal screening. Arguments over ethics have begun to represent a general concern for the consequences of genetics without involving a fundamental scepticism towards the whole discipline and served as a viewpoint that almost everyone

could have or even should have. Controversies related to genetics were gradually articulated as questions of ethics. (*Jallinoja 2002*.) Likewise, this trend may be observed in American bioethics journals in which genetics became a subject of articles in the early 1970s and increased in frequency in the 1990s (Crigger 1998, 205).

Discussions of ethics were not limited only to suggestive or general considerations and concerns, however. New sites and new forms for medical ethics were developed. Ethics was formalized and institutionalized by physicians' associations and by public authorities governing medicine and healthcare. (*Jallinoja 2002*.)

Since the end of World War II several steps have been taken to govern experts' conduct, especially with respect to voluntariness and provision of information.[25] Hence, new medical technologies have been increasingly codified and regulated by codes of ethics and by the activities of ethics committees. Bioethics and medical ethics have increasingly taken the form of national and international ethical rules, codes and recommendations. In Finland, the Finnish Medical Association adopted its first Code of Medical Ethics in 1956 and the following in 1988. The first Manual of Medical Ethics was published in 1989, and from that edition onwards manuals have included separate chapters on genetic counselling and prenatal diagnosis (Lääkärin etiikka 1989, 1992, 1996, 2000).

The second forum of institutionalizing medical ethics has been the ethics committees that were first established in large hospitals and medical faculties since the 1970s (Eettiset toimikunnat 1983). Finally, in 1999 a law was enacted stating that all medical research plans must be evaluated and accepted in the ethics committee of the hospital district in question (Law on Medical Research 1999). Specifically related to genetics, the Working Group of Genetic Screening chaired by a prominent gene researcher, Leena Palotie, was appointed in 1997. The group provided suggestions for

recommendations for research on hereditary diseases and genetic screening, among others (Geeniseulontatyöryhmä 1998, 30-35).[26]

These kinds of attempts to regulate new genetic technologies are at the core of modern technologies. As several authors have pointed out, the side effects and problems caused by new technologies are solved with additional technologies (e.g. Ellul 1976, 92; Bauman 1993, 196-7; Stivers 1994, 92; Beck 1996, 161). Thus, claims Bauman (1993, 197), technology means fragmentation of life into a succession of problems, of self into a set of problem-generating facets that each calls for separate techniques and separate bodies of expertise. Therefore, whereas genetics is an answer to the problem of diagnosing hereditary diseases, codes of ethics are an answer to the problem of clients' anxiety in situations where they receive an unwanted diagnosis, for example. What is characteristic of these technologies is that they mainly govern experts' conduct and provide expertise-based solutions to new problems.

Beck has named the phenomenon as reflexive scientization (Beck 1996, 161). Here criticism of the developments of technoscience has become the driving force for the expansion of the technoscience itself. Latour (1991, 1999, 91-92) also suggested that technologies are created and developed in a process where an answer creates a problem or a question that is further answered by a new technology. Consequently, the process goes on endlessly.

In effect, it may be that hindrances of technology compel the technology to become, not something else, but even more itself (Ellul 1976, 94). What occurs is, enlargement of the sphere of technologies and expertise. In effect, the foundation of genetics is very rarely challenged; instead, criticism has been transformed into opportunities for expansion (c.f. Beck 1996). Thus, concerns over the anxiety that screening may cause do not discourage geneticists; instead, they open up possibilities to use additional

technologies to investigate and also govern the psychological sides of genetic screening.

Despite the increased discussion of and attempts to solve ethical issues and problems related to genetic screening and prenatal diagnostics many ethicists, physicians, concerned citizens and journalists were still in 2001 unsatisfied with the discussion on ethics in Finland. The situation in which there are no national recommendations for prenatal screening is regarded as 'wild'. [27] Often-repeated view points have been that technology has proceeded faster than ethics and that the ethical problems the new genetics has brought along are those we have not previously faced. Moreover, the claim goes, in Finland there is no discussion of the limits in which one can proceed in the name of medicine; instead technology proceeds by its own logic.[28] Concerns have also been expressed over the matter that the use of medical technologies runs ahead of proper evaluation, including evaluation of social and ethical aspects (Hemminki 2001), that the claim for discussion of ethical issues as presented by geneticists is only cosmetic and that there is no real will for proper public discussion.[29] Moreover, it seems that when the contemplations and ambiguities of ethicists meet the world of action of physicians, ethicists lose and are relegated to the sidelines (DeVries & Conrad 1998, 246).

One of the sources for continuous dissatisfaction with discussion on ethics is that although many expect that some consensus and solution should be reached, discussions on ethical questions provide only open solutions to every single new technology. Thus, every new question opens another debate over values and ethics as Frank Furedi has observed (Furedi 1997, 163). Developments in in vitro fertilization (IVF) and plans to clone humans, for instance, have been some of the recent new techniques that have raised anew the demand for ethical discussion. To borrow words from Bowker and Star, the tension between attempts at universal lists of ethically acceptable conduct and

local circumstances is permanent and recursive (Bowker & Star 1999, 139; also Bauman 1991, 230, Takala 2000). Hence, the demand for ethical discussion and codes of professional conduct will go on.

Another reason for dissatisfaction with codes of conduct and regulatory practices is that declarations of rights and entitlements do not offer a satisfactory account of how we should live our lives (Addelson 1994, 152). Clients are not provided with binding rules for choosing; instead they may collect hints, models and advice from their encounters with the health care systems as well as anywhere in the media. These models have, indeed, been increasingly present in interviews of people with disabilities or having family members with disabilities, for example, in the mass media and in the publications and Internet web pages of disability organizations.

As has been shown in the present paper, the majority of respondents in the surveys supported free choice in relation to tests and abortions. However, it seems to be that in personal lives the issue of good life, moral conduct and how to live one's life appear to create anxiety and agony. Furthermore, the situation of genetic counselling and screening is characterized by a discrepancy between regulation of experts' conduct and actual life situations of the clients.

In conclusion, our world is one of uncertainty and paradox: on the one hand, claims are expressed that a consensus, a common code of conduct should be reached. On the other hand, suggestions for consensus and codes are not sufficient for moral guidance in a classical sense, since they actually offer no guidance as to which choice is better than the other. Coexistence of modern ethics, as illustrated by the will to establish rules, to settle the dispute and to reach a consensus (see Bauman 1993) with the new etiquette of non-judgementality (F. Furedi 1997) is characteristic of the situation.

## 6. Discussion

It is clear that the sphere of medical genetics has widened during the last two decades. There are more tests performed, more researchers in the area, more interest in genetics in the public. However, this process should not be reduced to the logic of technological effectiveness. Instead, the above analysis of the circumstances surrounding clinical genetics has revealed other forces, arguments and schemes.

As has been shown, individual autonomy, voluntariness, choice and information delivered to clients are stated as the guiding principles of and argument for clinical genetics, as agreed by both lay people and by experts in the field. Gene tests are thus not simply performed but are offered in a certain way - as informed choices - thus they are moulded to meet the requirements of the ethos of autonomy, so prevalent in contemporary society. Furthermore, additional technologies - questionnaire studies - are used to investigate, measure and manifest the actualization of choice and to serve as such as hallmarks of a democratic society, composed of freely choosing individuals.

Informed choice and autonomy are the opposite to what is regarded as eugenics or racial hygiene of the first part of the 20$^{th}$ century. Eugenics at that time mainly aimed at preventing the expansion and advancement of hereditary degeneration and was also connected with the problem of population (Mattila 1999, 34-40). Hence, it was the antithesis to the practices of individualized care (Helén 1997, 129) that characterize the pursuits of present-day clinical genetics and screening. Consequently, people who are concerned that the new genetics will lead to eugenics are concerned about constraints, lack of autonomy and control over one's life that have been documented in relation to eugenic practices in Finland (Mattila 1999, 230, 250-252) and elsewhere in Europe and North America. For this reason, the economic reasons for prenatal screening and abortions gain little support, and money is regarded as an issue not to be used as a

rationalization for screening in the public. In the same vein, prevention of disability is a risky rationalization for screening.

In the situation characterized by the imperative of choice and fear of its opposite, clinical genetics and genetic counselling have been defined as questions of ethics. This implies that for the most part, the codes and guidelines of ethics have been focussed on guiding experts' conduct so that clients' autonomy and privacy would be guaranteed and clients would be provided adequate and proper information. By giving some direction, codes of professional conduct surely alleviate the work of physicians and protect clients from certain malpractices.

Here, ethics is the non-judgemental way of regulating new clinical genetics precisely because it does not judge any private choice and at least attempts to take all views into account. Ethics does not surrender the agent's autonomy (Bauman 1992, 202); instead, it is the articulation and estimation of rights and duties, benefits and drawbacks of all actors involved - of pregnant mothers, couples, fetuses, people with disabilities and health care professionals. The concrete form of ethics, guidelines and codes of ethics are kept flexible and constantly open to change and reformulation. This means that there must be flexibility and non-judgementality with respect to individuals' life situations and potential to change in the face of new technological innovations - hence the situational morality. In consequence, the guidelines remain rather general and therefore vague and transfer the final moral responsibility to individuals. Thus, clinical genetics is discussed as an individualized and de-politicized issue.

For instance, lists of acceptable genetic screening or acceptable selective abortions are not possible, but acceptability remains to be negotiated in health care offices (screening) and by individuals (uptake of test, abortion). In the atmosphere of choice and autonomy, lists would be almost impossible since they are an obstacle to the

autonomy of the individual and remind us of the eugenic policies of the first part of the 20th century, in which someone other than the person in question has made the decisions about the severity of the disorders. Likewise, conclusions have been drawn in another study on practitioners in the UK: agreement on the firm drawing of lines in terms of conditions or characteristics to be screened for or terminated proved difficult (Alderson, Farsides & Williams 2001c). Furthermore, it has not been possible to provide strict definitions of proper and adequate information. Instead, contents of information remain to be defined by changing situations.

A further indication of the current atmosphere is that disability and abortion appear to be troublesome and are delicate terms and issues. This may be seen as changes in the use of terminological choices (from mentally handicapped, mentally retarded, intellectually handikapped and mentally subnormal to people with learning difficulties in the UK, from disabled people to people with disabilities in the European Union contexts[30] and avoidance of the term abortion, using instead 'termination of pregnancy' or referring simply to 'choice') and also in public attitudes, where people are very tolerant towards disability, although themselves they are prepared to take action to avoid disability in their lives.

In this setting, there remains a discrepancy between the codes of professional conduct, governing the conduct of the experts and balancing the rights of various interest groups, and the actual ambivalent situations of making decisions. Further tensions arise as the normative will to educate is copresent with the liberal will to create more choices and freedom. More and more codes are generated, but there is no possibility other than to keep them open and non-judgemental in relation to individual life situations. As Bauman (1992, 201) suggests, the plurality of authority rules out the setting of binding norms each agency must obey. This is characteristic not only of the genetic technologies studied here but of practically any realm in current modern societies.

What is at stake, for an individual or couple deciding on abortion is their future life, their projection about the life course of the child, their perception of what kind of life is good, what happiness consists of and their ideas about selfishness, responsibility, sacrifice, suffering and guilt (Helén 2001, 2002). Here self-reflection and self-evaluation are central activities (Bauman 1992, 202) since no expert may know for sure the answers to these issues considered as so deeply private. Hence, an array of questions arises that is much more vast than the technical organization of voluntary, informed choice and consent, delivery of information, leaflets pinpointing the risks, symptoms and voluntariness and the vocabulary of professional ethics. These devices may ease the distress, but do not totally erase it, or they may even create new anxieties and concerns. Instead, choices and information give rise to an overabundance of impossible calculations, in the face of which, for many, the solution the consent to the technology. The consequences of actions to be taken are unknown: what kind of burden the abortion will be or a child with a disability will be and what kind of anxiety will the knowledge of a disease cause. In other words, negotiated, non-judgemental professional ethics does not coincide with the moral choice of an individual that is characterized by gravity, subjectivity and ambiguity.

The moral choice over tests and abortions would imply that the woman - or any person tested - acts as if she is the one in “the moral party of two”, the Other being the fetus (Bauman 1993, 110-111), as if the third - the society or any person other than the two - would not affect the moral choice. As has been shown in the present article, however, the “party of two” is interwoven from the very start with the tools to estimate the choice to take. The imperative of choice as presented in medical ethics is not only about the moral choice of the individual in the face of the Other, but of calculating rationally various actors and outcomes, lives and futures.

Genetic counselling aims at providing the woman with the tools to judge and estimate the situations, to weigh different options, their outcomes, the rights and futures of the woman and the fetus. Thus, the woman's lonely choice, is bombarded with the multitude of the "Thirds", and the selves of the mother and fetus become comparable, measurable and amenable to judgement by extrapersonal, statistically average and normative standards (Bauman 1993, 114). Morality is enmeshed with rules, gene test results, reports of public opinion, cost-effectiveness calculations, uptake rates, descriptions of symptoms and the other heterogenous messages provided in information leaflets, the media and elsewhere. The pure choice and the pure party of two humans/humans to be slips constantly out of reach. Since pure technology may not be detached from its situation, the moral choice of the individual may not be the purified form of technical details, codes of ethics, twists of DNA and the interests of fellow humans.

## Endnotes

1. Jouppila 1997, HS 14.1.2001, HS 25.1.2001

2. An example of a recent debate in Finland and elsewhere in Europe has been screening for prostate cancer, in which questions of societal costs, quality of life, postoperative mortality and psychological reactions have been debated (Auvinen et al 1996, Saksela 1997).

3. See the issue 4-5/1985 of Tiedotuskynnys 4-5/1985 and also Tiedotuskynnys 1983/1-2, Vaivaisen ääni 1983.

4. HS 21.12.1993, HS 12.1.1994, HS 17.1.1994, HS 6.3.1994, HS 15.3.1994, HS 22.3.1994, IS 3.1.1994; see also Laurén et al 2001 for quantitative analysis of newspaper discussion.

5. See for discussion HS 25.1.2001, HS 27.1.2001, HS 3.2.2001. Nuchal translucency is the thickness of the skin on the back of the neck of the fetus and it is measured by using ultrasound. In Finland, it has been suggested that it be performed during the 13$^{th}$ or 14$^{th}$ gestational weeks. The presence of an increased nuchal thickness indicates an increased risk of Down's syndrome and some other chromosomal defects. (Seulontatutkimukset ja yhteistyö äitiyshuollossa. Suositukset 1999, 43.)

6.HS 18.3.2001, HS 19.3.2001, HS 24.3.2001, HS 31.3.2001, HS 4.4.2001, KS 7.2.2001, KS 22.2.2001.

7. See for critical discussion, Könkkölä 1985, 1998; Degener 1994. The viewpoint stressing individual informed choice is present for example in a booklet on Down's syndrome published by Kehitysvammaisten tukiliitto ry (The Finnish Association of Societies for Persons with Mental Handicap) (Hölsömäki 2000).

8. Unfortunately, these figures of eugenics from two surveys may not be compared since the response options were formed differently. In the1993 survey the responses to the statements "I am worried that genetic testing may lead to eugenics" were "Much" (15%), "Somewhat" (54%), "Not at all" (27%) and "Don't know" (4%). In 1996 surveys the responses were "Completely agree" (31%), "Somewhat agree" (23%), "Somewhat disagree" (17%), "Completely disagree" (15%) and "Don't know" (14%) (Hietala et al 1995, *Jallinoja et al 1998*, *Jallinoja & Aro 2000a*, Jallinoja & Aro, unpublished observations).

9. The Research Council of Health of the Academy of Finland together with the Finnish Medical Society Duodecim have organized consensus conferences since 1985 and depending on the subject have included lay representatives of organizations and newspapers, for example, in the panel.

10. This view may be exemplified by Leena Palotie's comment that it is up to Finns whether they want genetic screenings and to what extent (Palotie 1996).

11. Actually, argues Latour (1987, 97) nature never settles anything for good. On the one hand, scientists herald nature as the only possible adjudicator of a dispute, on the other they recruit countless allies while waiting for nature to declare herself. Hence, as we read scientific papers, nature - or public opinion - does not simply reveal itself to any reader from the pages nor from the mere data. Instead, scientists have to use all kinds of tools, words, pictures, tables and references to previous aricles to speak for the more or less mute general population and as a consequence to convince the reader.

12. Alderson, Farsides and Williams (2001c) have discussed leaflets on Down's syndrome in the UK. They conclude that the leaflets tend to contain generalizing statements; e.g. the statement that "Down's syndrome is the most common form of mental handicap" is a highly contested and ambiguous one, since it is not unambiguous as to where to compare the incidence of Down's syndrome. In comparison, in the leaflet on prenatal screening delivered in Kuopio, Finland, fragile X is estimated to be the most common reason for mental retardation (Saarikoski & Ryynänen 1995).

13. Sickle-cell disease is a haemoglobin disorder that causes anaemia, tissue infarctions and infections (Jorde, Carey & White 1997, 33-34). It is especially common in some parts of Africa and among the African-American population. In North America about 15% of children with sickle-cell disease die before the age of 5.

14. Thalassaemia is a haemoglobin disorder, with a high incidence in the Mediterranean area (Jorde, Carey & White 1997, 34). The mutation causes severe anaemia, skeletal abnormalities, infections and is often fatal during the first decade of life if untreated.

15. In the 1996 survey and the study of midwives and public health nurses, the respondents' attitude towards a situation in which a couple has a 25% chance of having a severely mentally retarded child, the woman is in her third month of pregnancy but refuses to take part in the gene test their physician suggests was also investigated (Toiviainen, Jallinoja, Aro & Hemminki, unpublished observations). In all, 93% of midwives/public health nurses and 78% of lay people agreed that the couple had the full right to make such a decision, 75% and 42% that the solution may be best for them, 15% and 35% that the solution was wrong for the child, 7% and 33% that the parents were unthoughtful, and 2% and 16% that couples like this should not make children at all. A total of 24% and 21% agreed that if they were in a similiar situation, they would do the same. Hence, also here autonomy of the couple is respected.

16. In contrast, the government of Cyprus in 1973 established a policy of compulsory carrier screening and counselling that was actively supported by the Orthodox Church of Cyprus (Rabinow 2001, referring to the study of Stefan Beck). The Church will not marry a couple unless the status for thalassaemia is known. Marriages usually proceed even if both spouses are carriers, but in these cases prenatal diagnosis and abortion are used to avoid births of children with thalassaemia. In some Jewish communities in the USA there have also been carrier detection schemes for Tay-Sachs disease. (Richards 1996, 262-3.) Furthermore, in India for example, compulsory premarital genetic testing for thalassaemia has been recently proposed (The Times of India 7, indiatimes.com June 2000). Tom Shakespeare, commented on the practices of Cyprus and suggests that they may be seen as eugenic (1998, 669).

17. This idea is clearly present in services of maternity care (Wrede 2001b, 6). Practically all women attend municipal maternity care centres during their pregnancy.

18. In the interview, the Chief Physician Jukka Puolakka at Central Finland Central Hospital reports that in the early 1990s when serum screening was begun in the hospital, 80% of mothers attended the screening whereas in 2000 the percentage was 58% (KS 29.1.2001).

19. See KS 22.2.2001.

20. Fetal surgery has been done, but may not cure disorders such as Down's syndrome, fragile X, AGU and INCL that can be detected with current prenatal testing methods. On the other hand, treatment of children and adults with disorders screened in other parts of Europe, thalassaemia and cystic fibrosis, have improved during recent years and life expectancy has increased.

21. This situation was used as an argument in the Members's initiative in Parliament 1998 by Päivi Räsänen of the Christian League. She proposed that the upper limit for performing an induced abortion due to verified fetal injury should be changed back to the 20th week of gestation.

22. See for mothers' opinions in KS 22.1.2001.

23. See for devastating experiences of screening and positive experiences of life with a child with disability Pirkola 1999, KS 22.1.2001, Hölsömäki 2000 and for burdensome experiences HS 4.4.2001.

24. Characteristic of the phenomenon is that in the UK, some researchers and disability activists have suggested that people with 'mental handicap' or 'mental impairment' should be referred to as 'people with learning difficulties'. The latter term would erase the polarity between 'normal people' and 'disabled people', since we all have learning difficulties in some areas, as well as direct the focus from medical problems to educational issues. Hence, the suggestion continues that 'learning difficulties' is also an appropriately contextual term; people have difficulties in some contexts and not in others (Alderson, Farsides & Williams 2001c).

25. Actually, the Nuremberg trial of Nazi physicians who were engaged in experiments with humans during World War II is a central milestone in medical ethics. The Nuremberg Code was prescribed as part of the judgement in *The United States* vs. *Karl Brandt* in 1947 and is a 10-point statements on medical research and experimentation with humans (Faden & Beauchamp 1986, 153). In several European countries codes of ethics were published in the decade following the Code (Herranz 1998).

26. These suggestions have not been actualized as binding recommendations thus far. As brief example of a recommendation for the implementation of genetic screening, there were four points: 1) the target group must be provided enough information and counselling, so that they may make a personal decision based on information, 2) participation must be voluntary, 3) genetic screening may be targeted only to individuals capable of autonomous choices and 4) enough counselling related to the results must be organized for the participants and their families.

27. See for dissatisfaction related to ethical discussion Image 2000/9, HS 16.2.2001, HS 19.3.200 and for concern related to the 'wild' situation, interview of Matti Pietikäinen HS 14.1.2001.

28. For example, Gustafson 1983, 20; HS 16.2.2001

29. See HS 12.9.2000, also HS 6.9.2000.

30. For the terminology in the UK see http://www.peoplefirst.org.uk. In these terminological choices the trend is to see disability as just one component of life, instead of the main determinant of the whole of life. In Finland, Sydäntautiliitto (The Heart Disease Association) has changed its name to Sydänliitto (The Finnish Heart Association) and Keuhkovammaliitto (Association of the Pulmonary Disabled) into Hengitysliitto Heli (Pulmonary Association Heli). In Finland, the phenomenon has not yet been manifested at The Finnish Association of Societies for Persons with Mental Handicap, for example. For the terminology in Finnish and English, see Nouko-Juvonen 2000 and 2001.

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12.1.1994 Aalto, Maarit. Vammaisen ihmisarvo vaarassa.
17.1.1994 Seppälä, Markku. Naistenklinikka estää vammaisuutta.
6.3.1994 Heinonen, Taija. Kenen sallitaan syntyä?
15.3.1994 Palo, Jorma. Tutkimus ei ole syrjintää-
22.3.1994 Vuola, Timo. Sikiötutkimukset ovat arvelluttavia.

6.9.2000 Kere, Juha, Palotie, Leena, Lindqvist, Martti, Saarma, Mats, Sarvas, Matti, Söderlund, Hans & Ylä-Herttuala, Seppo. Geenitekniikka ei pysty ihmeisiin
12.9.2000 Myllykangas, Markku & Ryynänen, Olli-Pekka Mistä tunnistaa väärän geeniprofeetan?
14.1.2001 Pulkkinen, Pauliina. Kuopio lopettaa Downin syndrooman ultraääniseulonnan epäluotettavuuden takia
25.1.2001 Jouppila, Pentti, Ryynänen, Markku & Tekay, Aydin. Valtaosa äideistä osallistuu ultraääniseulontaan.
27.1.2001 Hiila, Helena. Myös vammaisille annetava tilaa elää.
3.2.2001 Wilska, Maija. Aina syntyy lapsia, joiden vammaisuus tulee yllätyksenä
16.2.2001Lindberg, Marjut. Ihmisalkion geenitutkimukset on aloitettu Suomessakin
18.3.2001 Hallamaa, Jaana. Etiikassa ei ole kyse vallankumouksesta.
19.3.2001 Vehmas, Simo. Voiko vanhemmuuteen sitoutumiselle asettaa rajoja?
24.3.2001 Jussila, Helena. Toivoisin neuvoloille esitteitä.
31.3.2001 Tirronen, Mika. Etiikka on myös ratkaisuja ja rajoja.
4.4.2001 Nuutinen, Raili. Vammaisuuden hyväksyminen vei voimia.

*Image*
Ainola, Olli (2000) Geenien everstinna jyrisee, no. 9.

*IS - Ilta-Sanomat*

3.1.1994 Kieltääkö Helsinki kehitysvammaisten synnyttämisen?

*KS - Keskisuomalainen*

29.1.2001 Kujala, Päivi. Sikiötutkimuksiin haluavien äitien määrä laskenut selvästi Keski-Suomessa
7.2.2001 Kujala, Päivi. “Downin syndrooma on yleistä käsitystä valoisampi asia”
22.2.2001 Kujala, Päivi. Sikiötestit herättävät tunteita.