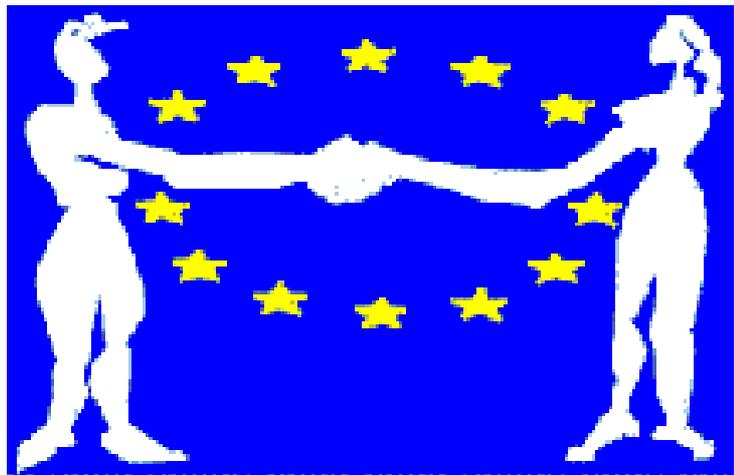


**EWHNET**

European Women's Health Network



**Networking  
Topics  
Lobbying**

An extended documentation of a transnational  
conference in Lund/Sweden

**June 2000**

**EWHNET** is a project in the fourth Medium-Term Community Action Programme on Equal Opportunities for Women and Men (1996 -2001) and is financially supported by the Federal Ministry for Family Affairs, Seniors, Women and Youth (BMFSFJ).

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## 1. Preface

This brochure represents a collection of articles which mostly were held as speeches at the conference of the European Women's Health Network (EWHNET), which took place in Lund, Sweden, in June 2000.

This conference was the last one of the third project year of the network. Three aims had been to be met:

- To look back on the first three years of networking;
- To document the grown network's identity;
- To develop perspectives for future activities.

Because the conference took place in Sweden, the participants of the host country were invited to present important topics and actual debates in the field of women's health in Sweden.

In detail this document contains the following articles:

In the first section *Lea den Broeder* describes the phase of building up a network as a participant of the first hour. Although two of the three organisations, which had been involved at the starting point of the project in 1997, meanwhile had to close down, her review and prognosis for the future development are positive and hopeful.

The next article is the position paper of EWHNET, which was developed as a result of a review of three years networking, describing the network's self-definition. It represents a step to a corporate identity, which is very important on the way to institutionalise the network. This paper was adopted by the members of EWHNET at the conference in Lund. It is available in a flyer-format.

Looking in the future the EWHNET-members discussed the necessity of lobbying in the field of women and health on European level. In this third project year EWHNET built up contacts to lobby-organisations and developed perspectives of cooperation with two of them: the European Women's Lobby (EWL) and the European Institute of Women's Health (EIWH). The director of the EIWH, *Peggy Maguiré*, in her article presents the basis of effective lobbying on the background of her experiences in the EIWH.

One result of lobbying is the strategic action plan for the health of women in Europe. *Assia Brandrup-Lukanow* from the World Health Organisation (WHO) Regional Office for Europe explained the approach to operationalise the health aims, written down in the WHO document „Health 21 – Health for All in the 21<sup>st</sup> Century“, in behalf of women's needs. The strategic action plan takes as its rationale the need to make the health of women more visible and a priority for action. The paper in this brochure is a draft version which is not yet officially adopted by the Regional Committee.

Last but not least, the Swedish colleagues in their texts give an overview over recent debates in Sweden in the field of women and health. *Margareta Söderström* reports about approaching the gender perspective in the medical research ethic committees in Sweden. She analyses the motives of not including women in medical research studies. It is a very new and exciting piece of work.

*Johanna Esseveld* discusses the topic „Women's bodies at mid life“ and shows that dichotomising nature and culture is a false approach. She gives a review of different discourses about menopause, as the medical one, the sociological/psychological discourse and the one in literature.

We hope that you will enjoy reading and join the network activities in one or another way.

## 2. Looking back at three years networking: a personal impression

Lea den Broeder

The EWHNET has existed for three years now, and in this meeting we are looking forward to the future. We will discuss how to go on networking both in terms of contents and in terms of strategy.

But how did we get here in the first place, how did the network develop, which successes and problems did we meet on the way? This is the central theme of my presentation.

I would like to tell you about my experience being involved in this network. It would be nice to hear your reactions. Maybe you will recognise some aspects, and there will probably be other opinions or experiences as well, thus giving us a starting point for some discussions during this meeting.

When I was asked to tell something about the past three years, I realised straightaway that I can only do so starting from my personal point of view.

There are two reasons for this:

- The first one has to do with developments within the field of women's health on an organisational level. In the past few years changes have occurred that we would not have expected when the network was first set up. Two of the three organisations that were initially involved were closed down. One was the organisation that co-ordinated the project, the Institut Frau und Gesellschaft (Institute Women in Society), the other one was the organisation I represented, Aletta, the Netherlands Centre of Women's Health. After Aletta's closing down I became somehow a contact person in the Netherlands for EWHNET, but with no organisation behind me. And since January of this year I represent the Unit Gender and Health of the NSPH within the network. So my involvement is more a personal involvement than necessarily connected to an organisation.
- Secondly, thinking about my experiences in EWHNET, I started feeling that they reflected the development of the network to some extent. I will try to show this in my presentation.

Let me go back to the first acquaintance with the network.

It was rather coincidental really; Aletta had agreed to write a country report for the new network and my colleague, who was initially planning to do so had to change plans due to internal circumstances. So I was asked to do the job.

My first job within the network thus was to try and create an overview of women's health in the Netherlands. Who are these organisations and what do they do was the main topic.

These questions were also central within the network. The first need was to get to know the field, getting into contact with relevant organisations and persons, and defining goals for the network other than 'promoting contact and discussion between partners from different countries'. At the same time a lot of discussion was spent on basic topics like: could there be a common attitude towards women's health? If so, what kind of attitude and how to communicate this? Hours were spent on defining criteria for women friendly, or gender sensitive health care. Of course these turned out to be very broad and abstract, since the network was in an early stage of development.

Now the network's position, its aims and views are much more concrete. Several workshops were held sharpening thoughts and opinions.

An important meeting was the one in Glasgow where women's health was defined as a social issue (June 98). This approach has two sides:

- health is more than 'what doctors are working on' and
- every social issue can be looked upon as a health matter.

This last point of view can be very fruitful. We can see this for instance in a very actual topic: the European Commission is at this very moment preparing legislation that makes employers responsible for sexual harassment in the workplace. Instead of a juridical

approach you could also define the problem as a health issue. This would mean that prevention comes into sight: safety (from sexual harassment or violence) can be considered as an aspect of working circumstances to be assessed just as toxic substances, noise or work pressure.

It has also become more clear what makes this network so special in terms of how it is built up. Interdisciplinarity in professions, organisations (grass roots, national, NGO or governmental, academic or outside the university (with links) etc. is one of the strengths of the network.

Since the start of the network, it has grown steadily and it is still growing. Of course the number of countries involved increased, and the network is still looking for new partners, especially from southern European countries and the pre-accession countries. The network has also grown in content, as I have just shown. A clear line can be discovered in the approaches and views that are shared within the network. And, very importantly, the network has developed more self-confidence. The partners involved are all high ranking experts in different fields of women's health, and as such the network has become an potentially powerful source of expertise, knowledge and views.

What are results of the past years of networking? They are to be seen within particular organisations, on a national and an international level. For the organisations involved the network provides interesting new views or analyses. Being part of a network gives women working on gender issues in a regular organisation (such as the NSPH) a better position: it shows that they are part of a broader movement. And in this way the network is a supporting factor to their work.

On a national level it can also be said that being in an international network can be supportive, for instance if the organisations involved are dependent on government financing and have to argue why they should get continuing funding. National networks are strengthened by the network. For instance, experts are invited to workshops or meetings, or we ask each other for contacts in the respective countries.

On an international level the network has some tasks which are just starting to develop: views, approaches, standards, and criteria are developed and communicated on a European level. More and more transnational co-operation plans are developed. Last but certainly not least: the network is aiming at communicating women's health views to the European policy level.

It wants to function as a critical voice, monitoring developments and showing alternative, more gender-sensitive ways of looking at health in Europe.

Back to my personal impressions. I have experienced that taking part in this particular network takes a lot of time, preparing for meetings, reading, writing, discussing. And yes, building up a network does take time and effort: we needed these past years to get to where we are right now, and I guess a lot of energy and time has to be spent still to start working on especially the last tasks I just mentioned: developing standards, co-operating transnationally, and communicating with European policy makers.

Nevertheless, and I would not be here if I did not think so, it is worthwhile. Networking pays off. And looking at the future, which is what we are supposed to do here today, I would say: the best is yet to come!

Lund, June 2000

### **3. EWHNET - The Organisation**

EWHNET is a transnational network of organisations in the field of women's and girls' health. The network is multiprofessional and interdisciplinary; the project partners are organisations such as women's health centres, research institutions, non-governmental organisations (NGO's) and providers of public health services.

The network addresses agencies, key individuals and organisations that influence policy and practice in the fields of health services, health care, health education, health promotion, research and prevention.

Organisations from ten European countries are currently represented in the network: Austria, Denmark, Finland, Germany, Great Britain, Greece, Ireland, Italy, the Netherlands and Sweden. The network is coordinated by the Association for Health Promotion in Lower Saxony, Germany. The network welcomes further participants.

EWHNET member organisations seek to

- empower women to make personal decisions on health issues based on informed consent;
- raise the awareness and improve the response of health services to gender and social inequality;
- support women's professional and self-help organisations in the field of health;
- increase gender awareness in all areas of social policy especially in regard to health.

EWHNET is interdisciplinary. Its membership includes social scientists, psychologists, midwives and nurses, medical doctors as well as women's health activists.

#### **Guiding principles**

The foundation of all EWHNET-activities is a social model of health that includes socio-economic circumstances, lifestyles, and living conditions. The Ottawa Charter of health promotion (WHO, 1986) defines health promotion action broadly and based on the dimensions of building healthy public policy, creating supportive environments, strengthening community actions, developing personal skills, and reorienting health services. EWHNET also bases its work on the Vienna Statement on Investing in Women's Health in the Countries of Central and Eastern Europe (1994) and the Agenda 21 declaration of Rio de Janeiro (1992).

EWHNET focuses on health not disease. To achieve this, an intersectoral approach is required. Empowering strategies are a central component in the network. It also emphasises the necessity of linking gender mainstreaming to specific equality strategies, women's participation and advocacy.

#### **Aims**

EWHNET is committed to:

- supporting a resource-oriented approach empowering women and countering unnecessary medicalisation;
- focusing on the question of how to produce and maintain health instead on how illness can be avoided
- raising awareness of the specific needs of women in the health system and health care;
- identifying models of good practice that contribute to women's and girls' health and seeking to communicating and profiling good practice;
- promoting the implementation of a social model of health at local and regional level;
- developing networking on key topics and communication on good strategies on national and transnational European level;
- developing political strategies to achieve equity for women.

## **Fields of Work**

To achieve these aims EWHNET works to

- provide information on approaches to women's health promotion and to improve access to good practices and to potential cooperation partners
- disseminate information through country reports
- build partnerships between projects and key individuals in the field of women's health;
- develop communication and mutual understanding among diverse participating organisations with different cultural, professional and practical backgrounds;
- develop common strategies for better integration and acceptance of women-centered practical methods in the field of health;
- identify the characteristics of innovative strategies and stimulate their transfer;
- develop, document and disseminate standards of good practice;
- establish working groups on important topics such as women, work and health, health promotion for girls at school, women-centered psychotherapy;
- uncover and explore issues of concern for women's health in the European context.

## **Working Methods**

The network is based on collaboration, mutual respect, participation and active membership. It works through

- building partnerships, personal exchange and discussion of perspectives;
- workshops and working groups focussing on specific topics.

The network operates through transnational meetings. As an umbrella organisation EWHNET offers its support for networking and for disseminating information.

## **Membership**

Each new member country provides a country report on the main topics and the structures in the field of women and health with a list of relevant addresses in the field of women's health (self-help groups, NGOs, initiatives, women's health providers). Participating organisations take responsibility for conferences and transnational meetings of EWHNET. Members are responsible for maintaining a flow of information within each country and cooperate in regional or national networks. Members identify new topics, research studies and models of practice for the network. They are encouraged to promote the visibility and profile of EWHNET in their home countries.

Working language of EWHNET is English.

## **Future Activities**

EWHNET will initiate or intensify cooperation with relevant organisations, that lobby in the field of women's health. The expertise of EWHNET members will be made available at the political level. EWHNET is developing a trainee exchange programme as a new strategy to share experiences. EWHNET is in the process of developing a basis for communication between partner-organisations in Southern and Northern European countries as well as between Eastern and Western countries.

## **Funding**

Funded in 1997 as a project in the Medium-Term Community Action Programme on Equal Opportunities for Women and Men and financially supported by the Ministry for Family Affairs, Seniors, Women and Youth (BMFSFJ, Germany), EWHNET is seeking funding in order to establish sustainable network structures.

## **4. Effective lobbying for non governmental organisations**

Peggy Maguiré

In recent years, one of the most important changes in policy development and the implementation of health, social and economic programmes at EU and national level has been the increasing involvement of, voluntary and non governmental organisations in the policy process. The European Union is extending its competencies into areas which are at the heart of the voluntary sector which has seen the growth of health activists in such areas as food, the environment, equality and campaigns like “Europe Against Cancer”. The European Commission is paying increasing attention to the social, voluntary dimension of the community.

In such a political climate, interest groups are becoming aware of the opportunities to achieve their goals at the European level and as a result lobbying in Brussels has changed considerably in recent years with interest groups becoming more organised and sophisticated in their methods of advocacy, presentation and debating.

### **What is lobbying?**

Lobbying is the ability to access key decision-makers in the corridors of power. Lobbying describes the actions that may influence the attitudes of key decision-makers in the policymaking process.

The term lobbying was first used in the United Kingdom over 150 years ago, and the words come from the “Lobby” – outside the Chamber of the House of Commons where people or groups wanted to influence members of parliament gathered in order to meet politicians and present their case. There are differences in lobbying styles throughout the member states. Generally speaking in the southern member states lobbying is based on whom you know and long standing relationships with government officials and politicians. In northern member states, advocacy and debating are the basis for lobbying.

To be a successful lobbyist, you must know your subject, be able to communicate your ideas in a clear, concise manner to the appropriate decision makers and have an understanding of the legislative process.

### **The political arena**

Lobbying is normally perceived to occur in the political arena. This, in the main consists of:

1. The permanent government, the public service.
2. The elected government – The political representatives in power.
3. Other elected representatives - the opposition.

### **Why lobby?**

There are a range of reasons why lobbying may be considered to be an appropriate activity for an organisation.

These may consist of the following:

1. To change an existing policy.
2. To oppose a potential change in policy.
3. To redress perceived grievances.

*In the above cases, the organisation will normally have a clear idea of the desired outcome that they wish to achieve.*

*The desired result will normally be a very specific outcome that may, however, be unobtainable through political action.*

Overturning a legal decision would be an example of this.

1. To update the major political players of an organisations and interests, without necessarily invoking specific issues.

2. The desired result may be simply ongoing communication and updating decision-makers about current activities of the organisation.

### **Effective communication**

Once the process of lobbying is initiated through the political process, you have entered the political arena and it is therefore important to complete these activities efficiently and effectively.

Effective lobbying requires mastery of both style and content, if you don't know what you are talking about, no one will listen to you. If you know what you are talking about but don't know how to present your views without offending bureaucrats and parliamentarians, no one will listen to you either.

The most important step in effective lobbying is to communicate your viewpoints to the appropriate people dealing with your organisation's issue. Depending on the range of the issues, this can be anyone from a *local representative*, a *national leader* or an *international forum*.

The first step is to find out whom, in government, deals with your organisation's issue of concern. In some cases, it may be best to deal with the public servants that administer the department or agency. However, when there are broad questions of policy involved, the legislators should be approached.

The specific areas of responsibility will vary, depending on your local political system and its organisation. Usually there will be one or more senior members of government in charge of the area of interest, who may be contacted. These leaders will also have their equivalents in other opposition parties, who may also be approached. Then there are local representatives and finally *local* representatives of other *geographic* areas.

It is vital to present government officials with clear, well thought out arguments. It is important to remember that these officials are very busy people and do not have the time to read a hundred page report, to get to the core of an argument, or to understand an interest groups activities and interests. To get the immediate attention and respect of officials, provide specifically tailored information, that is easily understood and of direct interest to the person to whom it is sent. One objective of any interest group should be to *develop a long term, and open relationship with government officials*.

Many interest groups produce "*position papers*" which present, in less than 20 pages, their views on a particular issue. If a position paper is well researched it can be of great value to officials who are planning reports or drafting legislation. At a European level for example, Commission Officials and Members of the European Parliament welcome comparative research that includes European surveys and other data that will help them in assessing the impact of proposed legislation in the 15 member states. An interest groups efforts will be received much more positively if they support the aims of Europe and the European Union treaties, much more can be achieved by *working with the aims of policy* as opposed to going against it, as this can be counterproductive.

### **The lobbying process**

#### *Direct lobbying*

The following are the most common methods of communicating your message to politicians:

*Personal meeting* – Face to face contact is usually the most effective way of communicating your viewpoint. It may also be the hardest to arrange. Politicians may represent thousands of people and your request might be one of many. It will be necessary to be patient.

If you arrange a meeting, ensure you have the experts present at the meeting, who know the issues thoroughly and that are able to answer any questions or objections that may arise.

Presentations should be simple and straightforward. If politicians require additional information they will tell you. Leave a written summary for reference, and do not expect an

instant response. Most politicians, through experience, have learned to avoid making impulsive decisions.

#### *Telephone conversations*

This has the quality of immediacy and personal directness, approaching that of a personal meeting, but takes less time and effort, to arrange. When telephoning politicians, you will normally contact a staff member with a range of varying responsibilities. However, you may be lucky in that the staff that you encounter may be in charge of your issue and in any case, they may have some influence on policy.

#### *Written mail*

This includes letters, faxes and email communications.

Written mail is currently the most common way of presenting your views to politicians. It falls into the medium range of effectiveness, however, busy politicians are more likely to read and answer your letters, than meet you in person. Mail provides the politician with the opportunity to provide you with a considered answer, which may not be achieved from a personal meeting.

Letters should not be more than two pages in length and it is preferable if they begin with a brief statement of the issue and the organisations position on that issue. A concise summary of the issue should be next, followed by the reasons why the representative should adopt the policies that you recommend. Lengthy and detailed documentation should be avoided if possible at this time. Although references to evidence and sources of further information should always be provided.

#### *Mass mailings*

If you have gone to the effort of writing a good letter, you may use technology to address a number of public representatives. These letters may be slightly less effective than individually written letters, particularly if the representatives realise that everyone has received the same letter.

#### *Indirect lobbying*

These are the processes used to assist you in influencing the political environment. These can consist of, media campaigns, targeted political campaigns and media hits.

#### *Media campaigns*

Such campaigns are designed to influence the political process by enlisting the aid of the mass media through the persuasion of journalists and their editors to write articles in support of your interests. These methods are usually the province of professional interest groups. On rare occasions, they might also be useful to individuals.

#### *Targeted political campaign*

Interest groups concerted efforts may influence the outcomes of elections in key areas. Usually a few strategic electorates are targeted, where a relatively small number of votes have the potential to change the outcome. These concerted efforts if used effectively, can be influential and may even change governments. These methods tend to be used by larger organisations.

#### *Media hits*

These consist of press releases, special media events and other methods used to generate reports on specific issues of interest. Politicians normally monitor the media in areas of relevance to their interests. The effect of media hits, may be enhanced by targeting media in the representatives electoral area.

### *Professional help*

As you can see, a number of skills are required to present an effective case to politicians. The non-governmental organisation may be able to access these skills through their staff or support groups. Professional campaigners can vary in quality and price. They may not have commitment to and the knowledge of the issue. If you are considering professional assistance, then, consider the type of help required and the associated costs of providing these.

### **When should you lobby?**

The effectiveness of the lobbying process depends on timing as well as a number of other factors. Usually sooner is better, although late efforts can sometimes be successful. If you fail on the first attempt, it may be time to consider a longer term campaign, targeted months or even years ahead.

The knowledge of *an impending election* concentrates the political mind excellently. The months immediately preceding an election are usually the best time to approach your representatives, as they will then be most receptive to anything that will increase their ability to gain votes. Do not neglect rival candidates as they want to be elected too, and might just succeed. If you want to lobby all candidates, it is best not to favour one over the others.

If you know your issue is about to receive media exposure, then ensure that politicians are briefed before this happens. This is appreciated as they do not want unexpected questions to asked!

### *Before the issue gets to Parliament!*

If an issue is likely to require legislation, it is desirable to lobby the government and the opposition parties, before a policy decision is made. It is easier to influence a policy that is not yet formed than change one that is in place.

### *During the legislative process*

If you have missed the policy formulation stages, there are opportunities for inputs before the parliament has finished dealing with the matter. Your chances of success may be smaller, but at least you will gain information about the political environment, that you will need to manage in later negotiations.

### **The lobbying experience – the European Institute of Women’s Health**

The European Institute of Women’s Health (EIWH) is a non governmental organisation whose objective is to place women’s health on the political agenda, at *European, Regional and National levels*, seeking balance and equity in health care access, delivery and treatment.

The idea for the EIWH was mentioned initially in late 1994 at a forum “Women’s Health - Into the new Millennium”. During discussions, the need for women’s specific health policies was raised, together with the need to have a European ‘umbrella’ organisation, which would ensure the development of women’s health policies at European level. The reasons were very specific, women live longer than men and occupy a unique role in society. To date clinical research has focussed primarily on men. Women are physiologically different from men and engage in different social roles, therefore risk factors for disease may differ as may response to therapy.

One particular issue of great concern to the delegates was the lack of emphasis on mid life and older women’s health in medical research and education. A small group of people from the conference remained in contact and developed the terms of reference for a potential organisation.

The Institute started working at European level in 1995.

It was decided that the task of the Institute would be to identify gaps in the provision of health for all women over their life span. The strategy adopted was, where necessary, create the focus on specific health concerns through research, education and advocacy.

The first work of the EIWH was to produce a report on Mid life and older women's health, highlighting particular issues of concern for older women e.g. osteoporosis, cancers etc. It was decided that this report should function as a tool to create awareness amongst EU politicians and women's organisations of the need to address the health needs of women, not only in their reproductive years, but also in older age.

In the compilation of the report, an international multi-disciplinary committee of experts was established. The role of this group was to comment on the report and give credibility to the report's recommendations.

Included in this expert group were Members of the European Parliament, who could in the future give support to the EIWH in approaching the EU institutions.

The EIWH was formally launched in 1996 at a conference in Dublin. This conference marked the launch of the Institute's first publication "Women in Europe towards Healthy Ageing", a review of the health status of mid life and older women's health in Europe. The report concentrated on four health areas of interest to midlife and older women, namely *cancer, osteoporosis, coronary heart disease and depression*. The consensus of the delegates at the end of the meeting was that women's health, particularly older women's health, must be made a priority for policy makers at a European level.

The delegates formulated a future strategy and decided on specific actions to bring the recommendations from the conference forward at a political level.

Delegates at the conference approved the establishment of a working group to ensure further action on the papers findings. One of the key objectives in any future action was to forge a consensus amongst the various stakeholders dealing with women's health including medical and health professionals, politicians, non government organisations, patient groups and industry. Delegates also urged that the paper be presented at the top level of European policymaking bodies. MEP's present agreed to bring the findings of the report before the European Parliament Inter Group on health.

The Members of European Parliament's also agreed to submit questions on the paper's findings to the European Commission and Council.

This activity provided the cornerstone for the development of our lobbying strategy.

### **Lobbying results**

In 1997, a presentation was given to the Inter Group on Health at the European Parliament, asking the MEP's present to support the recommendations of the report. Meetings were also arranged with Commission officials concerned with public health. These included the Commissioner for Public Health in Europe, The Director General of Public Health and other leading officials in the Commission.

When the new public health strategy was being developed, the European Institute of Women's Health approached the rapporteur for the Public Health and Environment Committee, with inclusions for the new programme.

Amendments to proposed legislation were tabled on our behalf by various MEP's at the Parliament. Supporting information was presented by various MEP's at the Environment and Public Health Committee meetings.

Over the last few years, the Europe Institute of Women's Health has been actively networking at a European Level creating an awareness of women's health issues. The EIWH policy papers have been disseminated widely across Europe and are included in our web site at, [www.eurohealth.ie](http://www.eurohealth.ie). Through many presentations at conferences and seminars across Europe, the EIWH has developed an extensive membership base for exchange of information, research partnerships and joint lobbying campaigns.

At a European and International level, the EIWH has been invited to take part in many expert advisory groups on women's health, including the United Nations and the WHO expert

meeting in Tunisia to formulate a framework document for mainstreaming the gender perspective into the health sector. At national levels, the EIWH has worked with affiliates and member organisations, to initiate positive and ongoing dialogues with Ministries of Health.

### **Conclusions**

Lobbying is now an established part of the European decision – making process. Up until recently, the industrial and corporate sectors were the pro-active and powerful groups in the lobbying arena. However, the growing organisation and co-ordination of social, health and environmental interest groups has begun to redress this imbalance.

Health is now a priority issue for all citizens living in the European Union. The rapid changes Europe is undergoing will have a huge impact on peoples lives and on their health. There is now a need to develop a community health strategy that is comprehensive enough to respond to present conditions and to emerging trends. This new strategy must reflect the new public health powers in the Treaty of Amsterdam, and, must be able to meet key challenges to the health of women and men. The European Institute of Women's Health, based on discussions at a European Conference in Dublin from 9<sup>th</sup> – 12<sup>th</sup> September 2000, prepared a position paper on Mainstreaming the Gender Perspective into the Health Sector. Over the coming months we will lobby the European Parliament, The Commission and National Governments on the importance of including gender, into the new public health framework programme.

For further information on this and related issues discussed in this presentation, please contact The European Institute of Women's Health, [info@eurohealth.ie](mailto:info@eurohealth.ie)

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## **Strategic Action Plan for the Health of Women in Europe**

### *Draft Resolution*

The Regional Committee

RECALLING the WHO commitment to the implementation of the ICPD +5<sup>`</sup>, 1999 and Beijing +5, 2000 recommendations and the relevant WHA Resolutions;

CONSIDERING that the health of women is one of the priority issues of the European region; and,

CONCERNED by continued inequities between men and women in the European region which particularly affects the health of women and concerned by the effects of social and economic inequities between the countries which further limits women's health:

RECOGNISES that the document Health 21 identifies the gender implications of some health issues but RECOMENDS a stronger focus on women's health to ensure gender equity in all aspects of health;

URGES Member States to make HEALTH21 targets relevant to the improvement of women's health in Europe and to develop country specific action based on the REGIONAL Action Plan and to allocate the necessary resources to implement it;

URGES European IGOs, NGOs to join forces to maximise their contribution to take up women's health as an important Public Health and health promotion issue;

REQUESTS the Regional Director to ensure that a gender equity perspective is incorporated adequately in the implementation of all WHO regional programmes by:

Taking into account the proposals and comments made by the Regional Committee in concluding the Action Plan for the health of women

- Allocating resources and intensify efforts to raise voluntary contributions to disseminate the Action Plan for the health of women as widely as possible to interested parties (women's organizations, universities, medical schools etc)
- Establishing a European committee to monitor, follow up and give guidance/leadership to the process in collaboration with UNECE, Council of Europe, UNFPA, EU, UNICEF, UNDP
- Giving visibility and support to the Action Plan at all levels
- Organizing a high level regional meeting on women's health
- Reporting regularly to the Regional Committee on the progress made in the implementation of the Action Plan, according to the indicators decided upon
- Supporting the collection of quantitative and qualitative evidence on the gender determinants
- affecting women's health

## **1. Aims of the document**

This document has been prepared within the context of Health 21, which provides the framework for countries of the European region to construct systematic policies and strategies for improving the health of their populations. The Action Plan:

- highlights the need for an explicit focus on the health of women
- provides an overview of past and current policy developments with implications for the health of women
- identifies the key social and economic prerequisites which form the foundation for good health in women
- summarizes the important themes which need to be taken into account in promoting the health of women
- identifies appropriate action to be taken and where responsibility for this action lies

In addition,

Appendix 1 has been produced as a supporting document to Health 21 as a policy guide to enable the targets to be considered from the perspective of women.

Appendix 2 provides a summary of relevant policy agreements over the past ten years.

## **2. The need to focus on the health of women**

Women's health has been recognized by WHO as a key health issue for many years although the dominant view has been to consider women's health as synonymous with reproductive health. However, with the growing appreciation of the links between social economic factors and health, there has also been a greater understanding of the relationship between gender and health.

For women, the impact of gender on health is determined by the continued subordinated status in society and any health policy, which seriously aims to improve the health of the population needs to take this into account. Of concern, is the best way to bring this about. In Europe, gender mainstreaming within all policy has recently become recognized as a means of realizing the importance of gender. It has been defined as "... the (re)organization, improvement, development and evaluation of policy processes, so that gender equality perspective is incorporated at all levels and at all stages by the actors normally involved in policy making."

In order to achieve gender mainstreaming it is necessary to ensure appropriate measures to address women's inequality. Similarly, to ensure gender mainstreaming in health it is necessary to make explicit how women's physical, psychological and social health should be addressed.

The strategic action plan for the health of women in Europe will therefore seek to:

- address the links between gender inequity and health
- ensure that women's health needs at every stage of their lives are fully considered
- facilitate the implementation of gender mainstreaming in health

By specifically addressing women's needs in health in this way the expected benefits are:

- a significant contribution to realizing gender equity and human rights
- a significant contribution to the social and economic development of the population
- a significant improvement in the health of families

## **3. Recent progress on women's health and gender equity in Europe: the last decade**

Since 1999, women's health is one of the five priority areas of the WHO and one of the six priority areas for the EUROHEALTH program. Repeatedly, the issue of women's health was highlighted at the WHO Regional Committee.

### *3.1 International and Regional conferences*

The Action Plan for the Health of Women in Europe builds upon the relevant recommendations of the World Health Assembly, the International Conference on Population and Development (ICPD) held in 1994 and the Declaration and Platform for Action from the Fourth World Conference on Women held in Beijing in September 1995. All affirm the WHO goals for the health of women and girls, as does the Platform for Action of the Social Summit held in Copenhagen in 1996. The global conference on the 10 year review of the Safe Motherhood Initiative held in Sri Lanka in 1997 concluded that despite concerted efforts, little progress had been made worldwide in reducing maternal mortality and recommended specific investment and action, giving rise, among others to the new WHO Making Pregnancy Safe project.

Before these UN conferences were held, the WHO Regional Office for Europe organized in Vienna in 1994 the first European conference on women's health *Investing in Women's Health*, which resulted in a set of recommendations to Member States concerning data collection on women's health and priority actions to promote women's participation, encourage health promotion and reduce women's morbidity and mortality in the Region. In 1995, the UN Economic Commission for Europe (UNECE) developed a Regional Platform for Action to improve the status of women in Europe, including a section on action to improve the health of girls, women of reproductive age and elderly women, and specifically addressing the ill-health effects of trafficking and violence.

In 1997, 165 countries signed the Convention on Elimination of All Forms of Discrimination against Women (CEDAW). CEDAW includes reference to ill health effects of gender discrimination.

The Human Rights perspective was brought into the Health discussion at the Council of Europe Human Rights and Health Conference held in April 1999 in Strasbourg, 1999 ICPD +5 and 2000 Beijing +5.

In November 1999, a European meeting, Health Issues of Ethnic Minority Women living in Europe was organized by WHO, the National Institute of Public Health and Göteborg City to discuss strategies and formulate recommendations to improving the health status of ethnic minority women, migrant and refugees.

### *3.2 Country response*

These initiatives have had considerable impact and many European countries have made in-depth analyses on women's health published as Women's Health Profiles in collaboration with WHO as well as regional or city women's health profiles. Some have developed national action plans, such as Norway and Kazakhstan, Kyrgyzstan and Turkey and others such as Glasgow, Vienna and Göteborg developed city action plans, and Styria (Graz), in Austria, is in the process of developing local action plans.

### *3.3 Health sector response*

There have been advances in some fields of research affecting the health of women, above all research related to the social determinants of health, reproductive health, perinatal health, screening for breast and cervical cancer, the role of social support in health, the role of women among health professionals and the effects of violence on women.

Non-communicable and communicable diseases can affect women and men differently; a fact, which has to be incorporated into the proposed strategies for tackling them at a national, and community level. Some conditions are more prevalent in women, for example, breast cancer, osteoporosis and rheumatoid arthritis, whilst others are sex-specific e.g. cervical cancer. For diseases affecting men and women differently there is little research on how they experience them differently. However, for those diseases/ill health states that affect both women and men such as cardiovascular disease, traditional research focuses on male subjects making sex differences in symptoms, diagnostic indicators, prognosis and relative effectiveness of different treatment largely unapparent. Also, gender differentials such as

determinants of health, risk behaviours, treatment seeking and burden of disease have not been systematically addressed. As a result the findings have suffered from a lack of inclusiveness, comprehensiveness and have limited application across the female population.

While national reproductive health plans are well developed and existing in many European states there is still a gap with respect to broader concept of women's health. An analysis on whether the health sector is responding with gender sensitivity to the varying health care needs has not been undertaken in depth. However, in the past decade, considerable effort has gone into improving the quality and accessibility of reproductive health services at all levels of health care.

#### **4. Prerequisites to improving women's health**

Member States committed to improving women's health must be committed to:

*4.1 Implementing human rights legislation and instruments already existing and signed by the WHO member states.*

*4.2 Ensuring equity in women's status across Europe and within the European countries through empowerment, education and women's participation in decision making processes. Even where equal access to education at all levels exists, this is not always reflected in the career options, labour market, wages, decision-making and economic power. Promoting the sharing of family responsibilities through appropriate legislation and changing social attitudes will make a significant contribution to reducing inequity. Among women in Europe, migrants and refugees, women belonging to ethnic minorities, elderly women and disabled women are groups with an especially low socio-economic status.*

*4.3 Elimination of discrimination against women.*

All women are likely to face discrimination in some aspects of their lives. Furthermore, women are not a homogenous group. Race and ethnicity, socio-economic status, disability or sexual orientation often compounds the inequalities facing them as a result of their sex. Implementing the Convention on the Elimination of All Forms of Discrimination against Women and monitoring its implementation are important prerequisites to protecting and promoting the health of women.

*Gender-based violence constitutes a significant public health problem. It encompasses a number of different forms of abuse, including domestic violence, rape, sexual assault, childhood sexual abuse, trafficking, prostitution, sexual harassment and harmful traditional practices such as female genital mutilation.*

*4.4 Action to alleviate poverty*

Poverty is mobilized as affecting health profoundly and is experienced by many Europeans, also in richer countries of the Region. Women are however over-represented amongst the poor in all European countries – estimated at 120 million women living in poverty. This marginalizes them even more than men from influencing the economic and health agendas. As poverty is a major determinant of ill health, the elimination of poverty will have a health benefit on the population as a whole. Introducing and enforcing policies specifically to alleviate poverty among women will have a positive effect on the health of women and of their families.

Ensuring that laws on equal opportunities and equal pay are implemented and that women's employment is promoted, and facilitated by the availability of childcare and support with elderly and disabled family members are important prerequisites for equity in health. Formulation of laws governing entitlements to free health care must ensure that those most in need are covered and have equal access.

Introducing bodies/working groups at ministries of health and other public health structures to specifically monitor and address how well the systems are responding to the health needs of poor populations, and the effects of socio economic developments on health are important instruments in taking this commitment forward.

Ensuring that policies for economic regeneration do not undermined social and health services that promote equity and support low-income groups.

## **5. Key issues**

This section is aiming to highlight the main issues to be taken by any action plan on the health of women, which is to be developed at the country level. It is not meant as a comprehensive list of issues but as an indication of what the main concerns are on the health of women in Europe.

For a more comprehensive recollection of the main issues related to women's health, an effort has been made producing a supporting document to Health 21, which enables the targets to be considered from the perspective of women.

### *5.1 Life course approach*

Throughout the course of their lives women's health needs vary. Applying the life course approach means that not only the period of motherhood is important but aims also to protect the health of young girls and adolescents as well as elderly women.

Identifying the most important potentials and threats to health at each stage is essential to creating the right prevention and effective interventions.

This includes protecting unborn girls from pre-natal sex selection, ensuring that infant girls receive the same vaccination coverage as their brothers, and ensuring that good food is distributed equally in households. It also includes protecting girls from sexual violence, unwanted pregnancies and abortions, sexually transmitted infections and harmful traditional practices. It includes promoting girls' self esteem and their capacity to fully develop their physical potential through *equal access to education*, participation in sports and recreation is also an important prerequisite for women's health.

Later on in life, women of reproductive age obviously require the conditions for good antenatal care, safe childbirth, post-partum care and family planning. They also require economic and social protection for the role that they play in child and family care.

The context of women's health in the post-reproductive years still carries the residua of the burdens of earlier reproductive ill-health to which is added the physiologic changes associated with menopause, which leads to skeletal, cardiovascular and other problems. Among the elderly, women form the majority and this greater female longevity requires strategies for both prolonging active life and providing long term care for the burden of functional disability and chronic disease such as osteoporosis, cardiovascular disease, mental disabilities and certain malignancies. The preponderance of women in the community of older people should mean that their needs must be made explicit in the planning of health and social care. Social supports systems are needed, as the carers are often young elderly women.

### *5.2 Causes of death and patterns of morbidity*

Even in the richest countries in the Region, there are differences and differentials in health for women and men, which are not taken into account. Although women live longer than men do, they suffer a greater burden of morbidity. Women are over-represented amongst the poor and female income is on average only 70% of male income. Women utilize the public health care system more than men do. Women are more likely to experience depression and stress linked to their experience of inequality and discrimination, to experience chronic conditions such as arthritis and osteoporosis and to suffer ill health and death as the result of abuse against them.

Women's health priorities across Europe may be different from some countries to the others. Special attention should be given to the special health problems of more than four million women belonging to migrant groups, refugees and ethnic minorities.

Women have the advantage of disease resistance biology but also the disadvantage of a lower social status and less access to wealth. Thus men and women have – to a certain degree- different disease patterns. This is due to their different biology, to women's reproductive function and to the fact that their life styles and risk factors differ because their gender roles are different. Thus the diseases of concern are:

- Diseases that frequently contributes to women's mortality such as cardiovascular diseases and cancers. These diseases are also common in men
- Diseases that affects women almost exclusively such as diseases related to pregnancy, birth and fertility and malignant and not malignant diseases in the reproductive organs (cancer of the breast, cervical cancer, etc)
- Diseases that are more frequent in women than in men such as reumatoid arthritis and anaemia
- Mental diseases. Depression, anxiety and eating disorders. Addressing mental health needs in Member States requires appreciation of the differences in social circumstances, aetiology, manifestation and duration of problems experienced by women.

In many instances there is a need for both gender specific prevention of disease as well as gender specific treatment schemes.

Socio-economic transition in certain parts of the Region have resulted in previous improvements in the health of women being lost and has generated greater disparities between countries in this respect. Morbidity and mortality differentials within the Region are significant. In the countries of Central and Eastern Europe and the newly independent states (NIS) poverty has seen a reduction in women's fertility accompanied by an increase in maternal mortality and abortion. Female life expectancy is also declining in those countries. The health of women in war and refugee situations is further compromised by the extreme and traumatising conditions.

In some parts of the Region, there remains a high risk of maternal mortality and morbidity which needs to be tackled with a degree of urgency through improving women's socio-economic status, improving their education, ensuring effective family planning, ante-natal care and adequate nutrition for the mother in the ante-natal period, workplace protection of pregnant women and the provision of mother and baby-friendly hospitals. The Safe Motherhood/Making Pregnancy Safe Initiative is a vital component in any strategy to improve the health of women.

### *5.3 Health care practice and service*

All health care services, even women's care services, should be sensitive to women's health needs.

*Measuring outcomes in terms of quality of care should include the degree to which women have been provided with appropriate information to allow them to make meaningful decisions about their health care. Guaranteeing that health services meet international quality standards and ensuring that the right to privacy and confidentiality are also key components in the delivery of services, which treat women with respect, should be accomplished within the whole Region.*

The role of women in all spheres of health should be re-examined. Women are one of the strongest means for improving health and closing the gaps at the different levels: individual, family and health services. Women form the huge majority of those working in health care are large numbers of them are in under-paid jobs with serious occupational hazards. Empowering women and avoiding medicalisation are health-promoting strategies that should be integrated into health care organizations. Self help and patient rights should be institutionalized as central party interests.

The partial

with economies in transition has led to an exclusion of certain women's health services from the public health sector. Within the on going health care reforms, countries should consider essential packages of women's health care that should be finance through the public sector, e.g., preventive care, maternity care. Within the existing health insurance schemes, care must be taken to ensure that unemployed women, married or not, have sufficient access to services.

Evidence is needed on qualitative research regarding access to, and utilization of, health services and health care seeking behaviour.

#### *5.4 Measures to address violence*

In addition to physical injuries, women who have experienced gender-based violence are, at greater risk of problems such as chronic pain, disability, unwanted pregnancies, sexually transmitted infections, miscarriage, abdominal symptoms leading to surgical interventions and somatic disorders. The psychological and emotional sequelae of abuse are often manifested in the higher levels of depression, anxiety, panic attacks, substance abuse, eating disorders and psychiatric disorders amongst abused women. Suicide attempts and self inflicted injury are also more common. The use of rape as an instrument of war increases women's vulnerability during times of upheaval and dislocation.

Traumatized women are extremely vulnerable, thus comprehensive policies to protect women and prevent violence should include working with the police and judicial system so that they become woman friendly.

Health services cannot act alone in seeking to eliminate such abuse but they have an important role to play in caring for battered women and collecting evidence on the level of damage. Training is required for health care professionals to ensure that abuse is identified and responded to appropriately. Strategies to address violence should be incorporated into health policy and integrated into models of health care.

Migrants and refugee women are particular vulnerable and require special attention because of their relative distance to their normal environmental social protection.

## **6. Responsibility of Member States**

### *6.1 National-based coordinating committees:*

If effective action is to be taken, it is necessary for every country to establish and maintain adequately funded national coordinating committees on women's health. Since such committees have already been set up in most countries in the follow-up to ICPD and Beijing, it is suggested that the intersectoral committees on women's health be based within the committees for the follow-up to the ICPD and Beijing Conference.

The national coordinating committees should have responsibility for developing, implementing and monitoring country-based action plans on women's health with specific targets and timetables for implementation.

*By the year 2003, adequately funded committees for coordinating action for the health of women should be operational for all Member States.*

### *6.2 Country based action plans:*

Country based action plans, should be comprehensive and include policy and programme elements of proven effectiveness. This action plans would ensure the integration of the health of women into Health 21. They would link with country institutions and programmes promoting gender equity

The action plans should have a clear timetable for implementation, and targets for the improvement of gender specific health

targets are not met, additional measures and interventions should be considered.

If effective action is to be taken, comprehensive women's health programmes need to be adequately funded through the public or health insurance sector.

*By the year 2005, adequately funded country-based plans of action for the health of women should be drawn up in all Member States.*

### **6.3 Progress report:**

Successful implementation of Women's Health activities requires effective monitoring and evaluation of women's health needs and of service responses. Monitoring and evaluation should cover action at the international, country and local levels, be intersectoral and address both governmental and nongovernmental action. Effective monitoring should include information on the enforcement of legislation regarding women's health and social protection. Ongoing research on effective policy development and implementation should be undertaken and documented.

*Starting in 2002, and every two years thereafter, each country in the European Region should prepare and publish a comprehensive report on the progress on plans of action on the health of women and the priority areas for intervention.*

## **7. Role of WHO Regional Office**

The regional Office:

- should act as a clearing house in this process, and give evidence feed back to the countries, monitor progress on target implementation, and disseminate examples of good practice through collaborating centres and networks.
- should undertake gender mainstreaming of all its technical programmes, and should make women's health relevant in all Mid Term Programmes of collaboration with Member States. Relevant technical materials produced by the WHO at global level should be regionally adapted.
- will identify specialized expertise within existing WHO collaborating centres and other relevant institutions.
- will establish an European Committee of experts to monitor, follow up and give guidance/leadership to the process. The European Committee would coordinate at the regional level with the main institutions promoting gender equity, European Union, Council of Europe.
- will establish an Interagency Group to coordinate strategies, share information and avoid duplications, with the different UN Agencies, multilateral organizations, NGOs, bilateral donors and agencies working in women's health in countries with economies in transition.

The objectives of this Interagency Group are:

- To integrate women's health in the development of the Country Common Assessment (CCA) and the development of United Nations Development Assistance Framework (UNDAF) in the relevant countries;
- To link with national mechanisms for ICPD and Beijing; and,
- To work with established national committees, agencies or bureaus that overlook gender equity issues, and or report on the implementation of CEDAW

In implementing this action plan, partners such as UNICEF, UNFPA, UNAIDS, UNHCR, ILO and the European Union, Council of Europe, will be mobilised to achieve the targets set.

## Appendix 1

### **Operationalising Health 21 for the Health of Women**

This document has been written as a companion piece to Health 21 –Health for All in the 21<sup>st</sup> Century and should be read alongside both the main document and the introductory document. It takes as its rationale the need to make the health of women more visible and a priority for action

It would be expected that the realisation of targets according to the recommended timetable will apply to both women and men

#### **Target 1 – Solidarity for Health in the European Region**

*By the year 2020 the present gap in health status between Member States of the European Region should be reduced by at least one third*

Poverty is recognised as affecting health profoundly and is experienced by many Europeans. Women are however over-represented amongst the poor in all countries - estimated at 120 million women. This marginalises them even more than men from influencing the economic and health agendas. Political changes in certain parts of the Region has resulted in previous improvements in standards for women being lost and has generated greater disparities between countries for women and their health than was previously the case. In the CCEE/NIS poverty has seen a reduction in women's fertility which is a significant indicator of their general poor health. Abortion, often unsafe, is used to reduce fertility. This has wide implications for the women's reproductive health and for the whole society. Female life expectancy is also declining in those countries.

For women in war situations or who are refugees (women constitutes 70% of those living in refugee camps) their health is further compromised. Minority women have a lower socio-economic status and a higher morbidity rate than men from the same ethnic group.

Overall, women's needs have to be made explicit in any strategies to address inequities across the Region. Each European Member State should have a system to ensure that an exchange of the existing expertise across the Region can take place.

#### **Target 2 – Equity in Health**

*By the year 2020 the health gap between socio-economic groups within countries should be reduced by at least one fourth in all Member States, by substantially improving the health of disadvantaged groups*

Even in the richest countries in the Region, there are differences and differentials in health for women and men, which are not taken into account. Although women live longer than men do, they suffer a greater burden of morbidity and they utilise the health care system more than men do. Women are over represented among the poor and female income is on average only 70% of male income. Women are more likely to experience depression and stress which is linked to their experience of inequality and discrimination, to experience chronic conditions such as arthritis and osteoporosis and to suffer ill health and death as the result of abuse against them.

Women cannot be regarded a homogenous group. Race, ethnicity, socio-economic status, disability and sexual orientation often compound the inequalities facing them as a result of their sex. Throughout the course of their lives women's health needs vary and these are linked to their role as child-bearers and as primary caregivers. Women obviously require the conditions for safe childbirth but also require not to be penalised economically for the role that they play in child and family care.

Tackling the social and economic conditions, which affect women's health, is not only important for the health of women but is fundamental in creating strong, vital and just individual Member States. Special measures such as positive discrimination (in, for example, employment and social welfare) may be in order to address past inequities and to prevent perpetuating current inequalities.

### **Target 3 – Healthy start in life**

*By the year 2020, all new-born babies, infants and pre-school children in the Region should have better health, ensuring a healthy start in life*

The health of infants and young children is largely dependent on the health of the mother. There still remains a widely held view that the needs of infants are of primary concern and that the mother is merely the 'incubator'. Mother and child programmes for example, often focus mainly on the proper development of the foetus and do not address women's health programmes. Not only is this perspective inequitable but can be dangerous because if women's health needs are not seen as distinct from the needs of the foetus, the newborn or the child, there is the possibility of delivering inadequate health care to women.

In some parts of the Region, there remains a high risk of maternal mortality and morbidity which needs to be tackled with a degree of urgency through improving women's socio-economic status, improving her education, ensuring effective ante-natal care and adequate nutrition for the mother in the ante-natal period, workplace protection of pregnant women and the provision of mother and baby-friendly hospitals. The Safe Motherhood Initiative is a vital component in any strategy to improve the health of women.

Protecting unborn girls from prenatal sex selection, ensuring that infant girls receive the same vaccination coverage as their brothers, and ensuring that good food is distributed equally in households NEEDS.

Whilst policies are required which create a supportive family, the unequal burden of care which falls to women needs to be recognised and addressed both by their male partners and by Governments.

Acknowledging that pregnant women are working, there is a need for occupational health focus on pregnant workers.

### **Target 4 – Health of young people**

*By the year 2020, young people in the Region should be healthier and better able to fulfil their roles in society*

The health of young women is associated with the role and position of women in the society they inhabit. Recent research has shown that in some Member States a surprising number of young men consider it acceptable to physically and sexually abuse young women and young women consider that this is a fact of life, which they have to endure. Improving the general health and sexual health of young women has to be linked to improving their status and working with boys to educate them about their responsibilities in emotional and sexual relationships.

Preventing unwanted teenage pregnancy also has to be planned in the context of promoting greater equality for girls and young women in addition to the provision of comprehensive sex education, affordable and accessible health care and contraception for young women and access to safe abortion and counselling.

Creating a positive self image in young women is made difficult by the extent to which success and glamour in women in advertising and media is often portrayed as being associated with an excessively slim body, being sexually available and with smoking.

Addressing eating disorders, the increased prevalence of smoking amongst young women and unsafe sexual behaviour, by placing the emphasis on changing the behaviour of young women will only have limited effect in the absence of wider strategies to combat existing gender norms.

### **Target 5 – Healthy aging**

*By the year 2020, people over 65 should have the opportunity of enjoying their full health potential and playing an active social role*

Women comprise the majority of the elderly and this greater female longevity requires strategies for both prolonging active life and providing long term care for the burden of functional disabilities and chronic diseases such as osteoporosis, cardiovascular disease and certain malignancies carried by older women. Research has indicated that women care for their partner for five years on average at the end of his life and then live an average of eight years afterward without a similar level of intensive care and support. Older women are often responsible solely or partly for care of children and other relatives. They are also often to be found as the mainstay of community activities and community life.

The preponderance of women in the older community should mean that their needs should be made explicit in the planning of health and social care. Certain stereotypical images of women as either frail or confused still exist as does the view of older women having no desire to express their sexuality and these need to be overcome. Where these signs and symptoms do exist they are often as the result of underlying mental health problems such as depression, which can often be effectively treated when medical practitioners have had appropriate training in the diagnosis of health problems in older people.

### **Target 6 – Improving Mental health**

*By the year 2020, people's psychosocial well being should be improved and better, comprehensive services should be available to and accessible by people with mental health problems*

While patterns in morbidity in men and women and their significance are still a matter of debate, the excess of female psychosocial distress is undisputed. Women across the world have significantly higher presentations of mental health problems than men and the types of disorder generally differ. Women are more likely to be adversely affected by specific mental disorders, the most common being: depression and anxiety related disorders; the effects of domestic violence; the effects of sexual abuse; and escalating rates of substance abuse. There is also a greater prevalence of para-suicidal behaviour in women.

Addressing mental health needs in Member States requires appreciation of the differences in aetiology, manifestation and duration of problems experienced by women. The preponderance of depression, for example, has been linked to the greater stresses experienced by women in poverty, which heightens their isolation and social exclusion. The double burden of motherhood and work has been identified as a contributory factor in the poor mental health of disadvantaged women.

Much of the female excess in mental health problems is attributable to the pervasiveness of gender inequality, which includes direct and indirect discrimination and the cultural devaluation of the female. In relation to employment, for example, women experience discrimination in the workplace such as unequal pay, greater job insecurity, more part-time work and sexual harassment. Similarly the endemic nature of violence against women across all societies also has a major impact on their mental health. Studies consistently demonstrate higher levels of psychosocial distress including PTSD, eating disorders, self-mutilation and depression in women subjected to male violence.

The identification and implementation of measures to reduce gender inequality are thus prerequisites for sustainable improvements in women's mental health. In relation to health services, there has to be a shift in recognition of the above factors contributing to women's mental health problems, which will require training for mental health professionals to detect and respond appropriately to women's needs.

### **Target 7 – Reducing Communicable Disease**

*By the year 2020, the adverse health effects of communicable diseases should be substantially diminished through systematically applied programmes to eradicate, eliminate or control infectious diseases of public health importance.*

Certain infectious diseases affect women disproportionately or differentially and this needs to be considered when planning comprehensive prevention programmes. Women may also transmit infectious disease such as hepatitis and HIV to their unborn children or, as the result of their experience of disease, affect the health of their children. Women contracting rubella or toxoplasmosis are examples of this. Pregnancy can affect the immune system of women making them more susceptible to infectious diseases, such as malaria.

Recommendations regarding malaria prophylaxis should be specific for pregnant women. Childbirth itself can also be a time of risk for both mother and child and it is important to prevent sepsis in birth. Women comprise the majority of health care workers and are also at risk of infection as a result of their employment.

Health care seeking behaviour for communicable diseases can also be different for men and women and this has been well documented, for example, for the treatment of tuberculosis.

The way that women become infected with sexually transmitted infections (STIs) and the implications for their health and that of their families is important to consider specifically.

Male sexual behaviour may be a major contributory factor in women's ill health as with the transmission of the HPV virus and its subsequent association with cervical cancer or when women are forced into prostitution. Whilst safe sex practices would help to protect women and men alike, the means for women to protect themselves through barrier contraception may not be readily available or they may find themselves in vulnerable situations in terms of their relationships with men. In order for prevention campaigns and health promotion activities against STIs and HIV/AIDS to be successful, women will need considerable support to ensure that their rights to protection from disease are taken seriously by their male partners.

### **Target 8 – Non-communicable diseases**

*By the year 2020, morbidity, disability and premature levels of mortality due to major chronic diseases should be reduced to the lowest feasible levels throughout the Region.*

The prevalence of non-communicable diseases across the Region constitutes a major problem. Such conditions, however, can affect women and men differently. Some conditions are more prevalent in women, for example, breast cancer, osteoporosis and rheumatoid arthritis, whilst others are sex-specific e.g. cervical cancer. Cancer screening programmes are required at primary care level to ensure the early detection of such conditions.

There are important sex and gender differences in major conditions such as coronary heart disease. The traditional research focus on male subjects has meant that possible sex differences in symptoms, diagnostic indicators, prognosis and relative effectiveness of different treatment have been largely ignored. As a result the findings have suffered from a lack of inclusivity, comprehensiveness and have limited generalizability.

To be effective, preventative strategies have to address these issues. Both the general population and health professionals still largely perceive heart disease as a male condition alike despite the fact that it is the major killer of women as well as men. Raising awareness has to be a priority. The risk factors identified in contributing to such conditions, such as smoking and alcohol require different interventions for women and men. The growing incidence of smoking amongst younger women (particularly women in poverty), for example, has led to an increase in lung cancer and associated conditions. This needs to be tackled through specific targeted measures. Similarly with other risk factors such as stress, the circumstances giving rise to this for women have to be acknowledged and addressed.

### **Target 9 – Violence & injuries**

*By the year 2020, there should be a significant and sustainable decrease in injuries, disability and death arising from accidents and violence in the Region.*

Gender-based violence constitutes a significant public health problem. It encompasses a number of different forms of abuse, including domestic violence, rape, sexual assault, childhood sexual abuse, trafficking, prostitution, sexual harassment and harmful traditional practices such as female genital mutilation.

Across the region between 20-50% of women have been subjected to one or more forms of abuse. Women and children are most at risk from men known to them (husbands, fathers, partners etc) rather than from strangers. Much of this violence is under-reported and under-recorded, yet its consequences for health and development are profound.

In addition to physical injuries, women who have experienced gender-based violence are at greater risk of problems such as chronic pain, disability, miscarriage and somatic disorders. Women with a history of abuse are also at increased risk for unplanned pregnancy, sexually transmitted infections, and miscarriage. The psychological and emotional sequelae of abuse are often manifested in the higher levels of depression, anxiety, panic attacks, substance abuse, eating disorders and psychiatric disorders amongst abused women. Suicide attempts are also more common.

The use of rape as an instrument of war increases women's vulnerability during times of upheaval and dislocation.

Women trafficked have no official papers and therefore they do not have access to health care in the countries where they are trafficked to.

Health services cannot act alone in seeking to eliminate such abuse but they have an important role to play. There is a need to collect data to accurately define the problem.

Training is required for workers to ensure that abuse is identified and responded to appropriately. Strategies to address violence should be incorporated into health policy and integrated into models of health care, for example in reproductive health programmes.

To eradicate gender-based violence requires challenging the structural inequality that gives rise to and sustains it.

### **Target 10 – A healthy and safe physical environment**

*By the year 2015, people in the Region should live in a safer physical environment, with exposure to contaminants hazardous to health at levels not exceeding internationally agreed standards*

The nature of women's work is such that they often find themselves in hazardous or health limiting situations, which can affect them or their unborn children. Traditionally, women tend to work in agriculture, food processing industry, chemical industry, X-ray departments and radiation and textile industries. In some countries, difficult socio-economic conditions have forced girls and young women who were previously in the school system to start work at a very early age in poor conditions for poverty wages. Workplace pregnancy protection and breastfeeding promoting at the workplace, are vital pieces of workplace legislation that need to be in place.

Women also make most of the consumer, energy and waste-related decisions in the domestic environment yet are often excluded from the public decision making processes that involve local governments or private businesses and, in general, have limited involvement in the development of environment and sustainability strategies. Local Agenda 21 highlights the need for women to be involved and many of the themes emerging from the Rio Summit - natural resource management, housing, social security, education, energy consumption, economic development and health related issues - lend themselves to integrating gender and environment perspectives in policy formulations. There is little evidence that this has happened and there is a strong need for Member States to examine both the links between their environmental and Health For All agendas and the extent to which women's needs are considered as part of this integration.

### **Target 11 – Healthy living**

*By the year 2015, people across society should have adopted healthier patterns of living*

There is evidence to show that women have considerable knowledge about the pre-requisites for good health both for themselves and their families and usually carry most of the responsibility for introducing health-promoting practices to their partners and their children. For many groups of women especially those experiencing poverty adopting healthier patterns of living is however a complex issue.

In many Member States some women are still denied access to a comprehensive range of nutritious foodstuffs and where they are available, women will often deny themselves in order to ensure that their families have an adequate diet. This may account in part for high levels of anaemia in some population groups and changes in the prevalence of non-communicable diseases such as heart disease. Obesity in women, which is a growing problem, can also be associated with poor diet.

Similarly, the time available to women for leisure and recreation is limited especially when they have families. Recommendations to take more exercise can be difficult to fulfil if there is no childcare available. Women are more likely than men to use public transport because of their lack of access to private transport. This may expose them to particular health risks.

### **Target 12 – Reducing harm from alcohol, drugs and tobacco**

*By the year 2015, the adverse health effects from the consumption of addictive substances such as tobacco, alcohol and psychoactive drugs should have been significantly reduced in all Member States.*

Across Europe there is a trend of increased smoking in women, particularly younger women and women of lower socio-economic status. This is in direct contrast to a pattern of falling consumption amongst men. Since tobacco-related diseases usually develop after smoking for a number of years, the results of this trend are only beginning to be apparent in the growing numbers of women contracting smoking-related cancers and heart disease. If this is to be reversed gender sensitive policies need to be implemented which take cognisance of the different factors influencing women's smoking e.g. stress, caring responsibilities, and actively seeks to support them in stopping smoking or in dissuading them from beginning. This is becoming more urgent since women are increasingly targeted by the tobacco industries, particularly in Eastern Europe.

This approach also has to be adopted in strategies to reduce alcohol consumption, which has also grown amongst women. Current services and programmes are male oriented and do not address the specific needs of women. Existing services should also consider the impact of male alcohol abuse on women as, for example, a contributory factor in relation to levels of violence and increasing family poverty. In responding to female drug abuse there should be measures to address some of the associated problems, such as the high prevalence of gender-based violence against women, and increased risk factors in financing their habit e.g. in relation to prostitution.

### **Target 13 – Settings for health**

*By the year 2015, people in the Region should have greater opportunities to live in healthy physical and social environments at home, at school, at the workplace and in the local community*

Women's and girls relationships to the key settings of home, school, workplace and local community needs to be understood if work in these settings is to fulfil its strategic potential. The way that houses and neighbourhoods are designed has tended not to meet the needs of

women even though these are often the principle domains of women's lives and women need to be actively engaged in policy and planning decisions if this situation is to be improved. The home may be a place of great risk to a woman's health if she has to experience domestic violence and it will therefore not be a haven or an opportunity to develop a supportive and healthy lifestyle. Disabled women have been even more excluded from the process of designing health promoting homes and environments. Where housing conditions are poor, women will be exposed more to the risks to health because of the greater period of time they spend in the home.

Health promotion in schools needs to enable both girls and boys to understand the impact of gender on their lives and the extent to which their differential roles in society may have both positive and negative impact on their health. In order to explore these issues in a meaningful way it may be necessary to provide gender-specific educational opportunities.

The workplace is another setting in which women can experience significant inequalities. Women's average income remains lower than that of men, women have fewer opportunities for career advancement, the introduction of family friendly policies which would allow women (and men) to combine work with their caring responsibilities is still variable across Member States and across organisations and in addition, the workplace can be a very threatening place for the many women who are exposed to sexual harassment.

The city and village policy makers can play an important role in improving women's health. Healthy City Projects offer a significant opportunity to raise the need for their different organisational partners to address women's health needs across a range of settings and it is essential that a strategic approach to the promotion of the health of women is made explicit in the plans and policies of each Healthy City partnership.

#### **Target 14 – Multisectoral responsibility for health**

*By the year 2020, all sectors should have accepted their responsibility for health*

Any development of national and local infrastructures across sectors to promote health incorporating stringent accountability mechanisms needs to be gender-sensitive. Tackling women's health issues will have limited effectiveness without incentives and legislation to promote equal opportunities, anti-discrimination practices and women-friendly fiscal policies. The proportion of women in decision-making positions needs to be increased. Assessing the impact of policies and practices on the health of populations need to recognise where there are differential impacts on women and men. Specific women's health policies can provide the framework for increasing awareness and understanding of the factors which affect the health of women, shaping general policy development, planning and service delivery to improve the health of women, ensuring that there are structures within and across organisations which take account of the factors which affect the health of women and ensuring that the priorities identified by women themselves are addressed.

Foreign aid transferred across the Region and between Regions can play a powerful role in supporting health, social and economic initiatives which prioritise the health and well being of women. Targeting aid towards women does not just have a positive effect on women but supports families and communities as well because of the role that women play in relation to these key groups.

#### **Target 15 – An integrated health sector**

*By the year 2010, people in the Region should have much better access to family- and community-oriented primary health care, supported by a flexible and responsive hospital system*

There is often little recognition that the way the women and men use health care services can differ greatly which may have implications for the organisation of that health care. Women still have primary responsibility for the health of families and as such need access to both health and social care, which minimises the number of sites where they have to attend for services – a 'one stop' system. There is also some evidence to suggest that women face

inequality and inequity in accessing some forms of treatment especially for conditions such as heart disease, which is more prevalent in the male population.

Whether women's own specific health concerns may be dealt with through women-only health centres or in integrated health services is an issue of national policy decision. Women-only health centres may be particularly effective to identify unmet health needs especially in relation to different groups such as disabled women, and where there is a strategic function to inform practice within mainstream health and social care. Good quality maternity service provision that is integrated with general medical care at primary, secondary, and tertiary levels is something which women in some parts of the Region can almost take for granted. There is however an unacceptable level of variability across Member States that needs to be addressed.

### **Target 16 - Managing for quality of care**

*By the year 2010, Member States should ensure that the management of the health sector, from population –based health programmes to individual patient care at the clinical level, is oriented towards health outcomes.*

#### *Role of pharmaceutical industry*

#### *Relationship imbalance of power between clinics and women patients*

The development and adoption of internationally agreed indicators to measure health outcomes at population level has to incorporate a gender perspective. This will necessitate the recording and dissemination of sex and gender disaggregated statistics and the production of specific outcome indicators in relation to women's health.

The emphasis on consumer satisfaction and ensuring quality of care going beyond narrow clinical definitions will require a commitment and planned approach to mainstreaming gender within both policy and practice. Redressing this balance can be achieved through investigating and tackling inequities in the quality of care and inequities in accessibility of care. For example, there is evidence of differential access to diagnostic procedures and treatments in relation to heart disease. Similarly there are indications that gender divisions can be a causal factor in limiting the quality of care women receive. Power patterns within the doctor – patient relationships throughout medicine can often result in women experiencing medical encounters, which they find demeaning and which offer them little or no opportunity to exercise their own autonomy.

Measuring outcomes in terms of quality of care should include the degree to which women have been provided with appropriate information to allow them to make meaningful decisions about their health care. Ensuring the right to privacy and confidentiality are also key components in the delivery of services, which treat women with respect.

### **Target 17 – Funding health services and allocating resources**

*By the year 2010, Member States should have sustainable financing and resource allocation mechanisms for health care systems based on the principles of equal access, cost-effectiveness, solidarity and optimum quality*

The allocation of resources appropriate to need requires an understanding of the nature and extent of women's health problems to allow financial planning for health to be sufficiently comprehensive and for women's health to be sufficiently prioritised. Whether health care availability is dependent on National Insurance contributions, private insurance or through direct fee for service, women are likely to be penalised because of their generally lower incomes, the breaks they make in work-related contributions and their insurance status. Women's access to health care also needs to be separated out from their partner's insurance or income status. As a minimum, essential packages for women's health, antenatal, pregnancy, and birth care need to be secured from public funding. It may be

appropriate to link the availability of some packages to the workplace in order to improve women's access.

Funding of the health care sector and social sector is vitally important in terms of both women's health and employment opportunities because it is such a major employer of female labour.

### **Target 18 – Developing human resources for health**

*By the year 2010, all Member States should have ensured that health professionals and professionals in other sectors have acquired appropriate knowledge, attitudes and skills to protect and promote health.*

If gender-sensitive health plans are to be put into effective operation, the importance of educating health workers and policy-makers to understand better the importance of gender in their work cannot be underestimated. This should happen at all levels - undergraduate, postgraduate and continuing education.

Women comprise up to 70% of health care workers, yet are hugely under-represented within the higher professional levels. Addressing this gender imbalance within different staffing levels is an important element in any serious attempt to ensure gender sensitive health care. Increasing the number of women in decision-making positions in health care management & scientific and university training positions is central to a human resources strategy committed to progressing this aim. Within the governing bodies of professional and specialist associations there also needs to be more equal representation.

The lower status accorded nursing staff, which is predominantly female, contributes to the downgrading of their skills and value. Upgrading their status would be an important step towards recognition of their contribution to health care and perpetuates the division between them and physicians.

Social support to mothers after birth should be available.

### **Target 19 – Research and knowledge for health**

*By the year 2005, all Member States should have health research, information and communication systems that better support the acquisition, effective utilization, and dissemination of knowledge to support health for all.*

Research priorities are shaped by the prevailing social and political climate, and as such reflect the inequalities between men and women in society. Since the determinants of women's health have been recognised as stemming both from sex differences and gender differences, it is crucial that research is designed to address these issues. At its most fundamental level this requires the disaggregation of statistics by sex to provide a more complete picture of women's health status. The inclusion of sex and gender should be regarded as prerequisites for good science. Their omission can lead to problems of validity and less appropriate health care delivery. Historically, women have been excluded as subjects of research, which has implications for the applicability of data resulting from such studies. The quality of empirically based findings is dependent upon the extent to which they are genuinely inclusive.

Undertaking research that appreciates the differences in patterns of health and illness between the sexes is crucial. Some diseases are more prevalent in women while some affect men and women differently. The interaction of biological, genetic or immunological sex differences interacting with the complex construct of gender create health conditions, situation and problems that are different for women and men as individuals and groups. The inclusion of women in clinical trials should be ensured through close scrutiny of research design and funding allocation dependent upon the demonstration of relevance for both sexes where possible. There should additionally be greater recognition of the need for qualitative research methods to document and explore some of the more structural aspects of gender inequalities in health.

### **Target 20 – Mobilizing partners for health**

*By the year 2005, implementation of policies for Health for All should engage individuals, groups and organisations throughout the public and private sectors, and civil society, in alliances and partnerships for health*

Women obtain much information about health issues for themselves and their families from the media yet this information is often limited to a very narrow range of topics and is primarily focussed on women's reproductive health or portraying women in certain roles. Improving the role and impact of the media will only occur once the social model of women's health has become more widely acceptable, then enabling stereotypical representation of women to be challenged.

For many women, meeting together in informal groups, associations and self –help groups has often been a successful way in becoming involved in addressing their own health issues and sharing information. However, the informality of these groups typically means that they have operated outside official lines of influence and their ideas and knowledge have not been incorporated into mainstream theory and practice about health. They have also not been able to attract sufficient or sustainable resources to allow their work to develop.

In contrast more formal organisations and structures which have been identified as having a vital role to play in the promotion and advocacy of health will need to adopt a more gender-sensitive approach if they are to make any impact on improving the health of women with whom they come into contact.

### **Target 21 – Policies & strategies**

*By the year 2010, all member states should have and be implementing policies for Health for All at country, regional and local levels, supported by appropriate institutional infrastructures, managerial processes and innovative leadership*

To ensure that women's health is fully addressed and that women are genuinely involved in the process of Health for All, women must be involved in all aspects of strategy and policy development, and the female dimensions of those strategies and policies need to be accepted and adopted on a broad scale. There needs to be appropriate, realistic targets for change set which are then monitored and evaluated to gauge their impact.

## **6. A gender perspective on the Research Ethics Committee for Medical Studies: gender, drugs and recruitment of patients**

Margareta Söderström

*In 1996, I started to work as a scientific secretary at a research ethic committee at an university in Sweden. In this presentation I will discuss some of the experiences I had when introducing a gender perspective into the basis for forming an ethical judgement of a study-protocol.*

### **The organisational form of the medical research ethic committees in Sweden**

At first I will give a description of the research ethic committees in Sweden. Today, almost all human medical studies will be reviewed by a medical research ethic committee. The studies are reviewed both from an ethical point of view as well as from a scientific point of view(1). The ethical codes that are guiding the members in their judgements of the applications are stated in the Helsinki declaration(2) and the principal ethic codes are:

The principles goodness - to do good things

The principle of autonomy - the respect for person's integrity

The principle not to harm or hurt persons

The principle of justice

The patients/persons included in a study have to be able to make an informed consent to participate, and participation is on a voluntary basis. In some cases, persons are not able to give an informed consent to participate, for example unconscious patients, children, mentally handicapped persons and prisoners. Other forms of informed consent could then be used(1).

In Sweden there are seven medical research ethic committees. All are connected to the medical faculties at the universities. Each committee has around 15 members, of whom at least three are laymen (elected by the local political parties). The other members are elected by the medical faculty and are usually scientifically experienced persons, doctors or nurses or other health care professionals. Everyone has a stand in. The chairman, the scientific secretary and the administrator secretary are responsible for the daily work and the organising of the work in the committee. The committees usually have one meeting per month. Then the monthly collection of project applications are reviewed.

Today, there is no law but mere a recommendation to have your human research project reviewed by a research ethic committee. However, most scientific journals and research foundations imply an approval from the research ethics committee. In an official report from the government just finished, one suggestion is to start research ethic committees at all universities, the old as well as the new ones and furthermore at all faculties, thus not just at the medical (3).

In the committee I was affiliated to, around 50 research projects were reviewed every month. Almost 70 % of the projects were referred back to the applicant and some changes were requested. The most common cause for a referral back was the incomplete information to the patients. Most projects were approved as soon as the corrections had been made according the committees decision. Very few applications (1 to 2 per year) were not approved by the committee for various reasons. During this period, new problems due to the achievements in the field of genetics resulted in new ethical problems and some of those projects were rejected.

During the past years, the amount of work in the committee increased almost exponential. The increase may be explained by the time lag, between the start of a committee and the knowledge by everyone of its existence. Furthermore, an ethical approval of a project is requisite to either get a grant or to have your written article publicised in a scientific journal.

### **Approaching the gender perspective**

As soon as I started to work in the committee it was evident that more studies than I expected were actually performed on just males without obvious reasons. The diseases studied were almost equally prevalent in men and women. It could be discussed if it is a task for the research ethic committee to have any standpoint on that issue. One of the more experienced members of the committee had the impression that the medical scientific society will regulate such uneven distribution of study-populations by making studies on women and other groups later on.

During the 70ties, female scientist highlighted that more medical studies were actually made on men which could be hazardous for the health of women (4). At that time it was evident that the practice to exclude women from research studies had resulted in significant gaps in the knowledge of diseases that affect both men and women. Furthermore, during the 80ties and the beginning of 90ties the exclusions of women still were at hand and many of the important human health data generated by the modern biomedical research revolution are data on men. May I give you some examples: During the first 20 years of studies on health and ageing in USA only men were included in spite of the greater proportion of elderly women. Studies on Aids frequently omit women in spite of the fact that they are the fastest growing infected population (5).

Both men and women have the same right to be given the best possible care when fallen ill. However, if the increase of knowledge of diseases and therapies are based mainly on studies on men this could not be fulfilled. Diseases, symptoms put forward by women are still looked upon by the medical professions as diffuse, unclear and mostly psychosomatic and thus not understood. Just few years ago it was obvious that women with myocardial infarction had been miss-diagnosed, did not get the optimal treatment for their infarction, neither did they get the optimal rehabilitation and thus the mortality in myocardial infarction was higher in women than in men (6, 7). This discovery was made when women were included in studies of myocardial infarction and their symptoms explored (6).

### **How it started**

There are reasons to believe that Sweden has a great awareness of equal opportunities in most areas as well as in the scientific sector (8, 9). For that reason I thought it could be of interest to ask scientists in medicine, though still dominated by men, of their ideas and beliefs of not including females to participate in their medical studies on diseases affected by both sexes. Scientifically, a qualitative approach was chosen. Too soon an opportunity to start the study appeared by a telephone call from the public. A woman, who was very upset, phoned me (I do receive some telephone-calls from the public, but not very often). She had the same day read in the local newspaper an advertisement with the following text.

*Are you a man, between 25 and 59 years of age, with alcohol problem, then you could participate in a study with a new drug that could prevent your desire for alcohol.*

She had been in contact with the research team who said that the reason for women not being included was their hormones! They had got the idea that the hormones of women distorted the results of the scientists. After discussing back and forth she finally proclaimed that she did not want her tax money to be used for studies on men only.

As the project had not yet been reviewed and approved by the research ethic committee, the telephone conversation was retold at the following meeting. The argument of tax money was good enough and understood by the members of the whole committee. The committee decided then to return such application (refer back) with a request to the applicant to motivate the choice of their study population in a letter to the committee. At the same meeting two other projects were returned due to the same reason.

## **The first experiences with the written motives for not including women in medical studies**

Study 1. A study of a new drug that might reduce the desire of alcohol:

What were the motives?

1. Women cyclic hormones distort the results.
2. We do not have money to include women.
3. We have done a study on men before, and now we have to check the results on a new group of men.
4. Women are to be included later.

Study 2. A study with the title, "Abdominal fatness ....in man"

What were the motives?

1. Abdominal fatness more common among men.
2. Maybe we should alter the title to men instead of man.

A more specific motivation was then requested because it was mentioned in the application that abdominal fatness was common and a great problem (risk) for both men and women. The whole research group was then mobilised to articulate their motives.

1. We want to have polarity in the groups; fat against lean. It is easier to find that among a group of men than among a group of women.
2. The "scan" that will be used to measure the fatness may harm the female organs of reproduction.
3. In our planning of the study we have just considered scientific facts, nothing else.

Study 3. In this study food metabolism was to be further explored. The male medical students were given free food (special dinner) daily for six weeks, furthermore they had to keep the schedule and had venous tests taken a couple of times. They were rewarded with 3000 SV kroner (300 Ecure) when all their obligations had been fulfilled.

What was the motive?

1. To concentrate on a homogenous group of persons we will obtain a less wide distribution of the results.

All the studies were then approved by the committee without any change in the inclusion-criteria.

## **Analysing the motives of not including women in studies**

It was interesting to read all the motives written down on an official piece of paper during the coming two years. All the motives could be discussed from both a scientific and ethic point of view. But as the research ethic committee was no legal authority, sanctions at that point was not possible. One method was to document and analyse the motives trying to understand the phenomena. A parallel process was that it might give the scientist an opportunity to think of the problem in a practical way.

All the motives collected during the period were analysed in order to understand the ideas and beliefs of the scientist why they excluded women from their studies. The motives were analysed with a grounded theory approach. During this period 25 studies were included in the analyse. For most studies there were more than one motive for exclusion

## **Exclusion of women due to scientific reasons**

*Physiology and metabolism.* Several of the motivations had their origin from a scientific point of view. Women were excluded due to physiological reasons such as their cyclic hormones as well as their metabolism. There was a belief that the results found if women participated would give the scientist difficulties to interpret the results. "*The hormones derange the*

*results.*" This could be criticised such as taking a shortcut in the scientific process by avoiding difficulties -women. If the cyclic hormones are that important very few medicines or physiological tests are given/performed according to the time in the menstrual cycle. But the explanation could as well be a consequence of something completely different. In most pre-clinical studies male experimental animals are dominating and as a consequence much greater knowledge is achieved of the male physiology and metabolism.

*Methodology.* There exists a myth that men are more homogenous than women. But the variations among men are as great as among women. The second myth is about the difficulties to recruit women to medical studies. This could be due to the fact that in the clinic or laboratory there already exists a list of male patients/persons who earlier had participated in studies and willing to participate again. Then it is easy for the scientist to recruit them again.

### **Exclusion of women due to economic reasons**

To exclude women of economic reasons is just not acceptable today because women and men are considered equally valuable. I could not find any other reasons than the fear that the results could be difficult to interpret (because of the cyclic hormones) and thus waste of money. Another reason could be that the prevalence of a disease is lower among women than in men and for that reason it may enhance the time for inclusion enough women into a study. Time is money. This was (and is still) said for patients for example with myocardial infarction. Until now, the symptoms presented by women has not been understood by the doctors, so the researches had not been able to find women with symptoms of myocardial infarctions to the same extent as male patients (6).

### **Exclusion of women due to the gendered role of the researchers**

There still exists an idea of that the man is the norm for human beings. This is found both in written texts and in oral presentations. The scientist (and the medical doctors) are usually mentioned as a he.

Another myth is that women have a sex but men have not. There is seldom a need for protection of male reproduction organs but a lot of concerns for female reproduction organs.

### **The concern of women in clinical drug trials**

Many studies reviewed by the research ethic committees are clinical trials. In the drug statistics, more recipes are prescribed to women, especially in the childbearing ages compared with the number of recipes prescribed to men (8). But the number of women participating in clinical studies do not mirror this statistics.

Undoubtedly, the explanation for the exclusion of women is at least partly sexist. However, there is a more legitimate rationale for excluding women of childbearing potentials from the clinical trials, namely, the desire to protect pregnant women and their future offspring from miscarriage and birth-defects. The protectionist rationale has to be understood in its historical context, and is one reason to how research ethic committees was formed. There was a need for protection of human subjects which was made clear not only by the Nazi experiment but also the shameful episodes of the Tusage syphilis experiments (male black prisoners were not medically treated for their syphilis in order to be able to study the natural history of syphilis) and the experiments of injecting cancer cells into patients at the Jewish Chronic Disease Hospital. Added to this elevated concern for human subjects generally were the problem specifically to pregnant women who were given thalidomide and diethylstilbestrol (10)

### **Medical catastrophes have a great impact of women participation in drug research**

Taken the story of thalidomide. The drug was registered in 1958 as an over the counter medication for nausea in early pregnancy. After a while there was a shocking increase in the

number of children born without arms. Although the thalidomide disaster did not result from women participant in research, the experience had an enormous emotional impact that created an aversion to involving pregnant women and women of childbearing potentials to participate in drug research.

Similarly happened to diethylstilbestrol (DES). The synthetic hormone was given to women during the 40 and 50ties to prevent miscarriage despite evidence from large controlled studies that the medicine was not efficient. In the late 60ties an increased number miscarriages, stillbirths, rare forms of cancers in vagina and cervix were found among the daughters of the mothers who took DES. Public trust in science was shaken once again during a short time period and the protectionist attitude toward including fertile women into drug trials became further entrenched. Thus research involving foetuses and pregnant women is restricted but it is not banned.

Is it ethical to exclude women of childbearing potential from clinical trials to achieve maternal-fetal protection? Why exclude adult competent women, pregnant or not, in order to protect them from risks to their own health? Classifying pregnant women along with prisoners and children as a vulnerable population is offensive, as it suggest that pregnant women are incapable of weighing the risks and benefits and making informed and responsible decisions about participation in clinical trials (5).

A more plausible rationale for excluding women of childbearing potential is to protect their fetus. It could be discussed the incoherence that a society which tolerates abortion should adopt restrictive policies to avoid harming foetuses.

However, the goal of protecting children from being born with avoidable disabilities is perfectly legitimate. However, the exclusions of all pregnant women in clinical studies is an unnecessary blunt instrument to accomplish this goal. Most human studies do not pose a foreseeable risk to future children. The mere chance of risk does not justify total exclusions. Treating all women of childbearing ages as potentially pregnant does not reflect reality. Not all women are sexually active, many are perfectly capable of preventing unintended pregnancy. Since clinical trials may yield important health benefits to women generally, there is no reason to exclude women of childbearing ages from clinical trials.

### **The hidden message in the written information to women of childbearing potential**

A very important piece of paper in a human medical study is the written information to the patients/persons. By reading such an information, it should in practice be possible to give an informed consent to participate in a study. In clinical trials, the following text passages address women of childbearing potential and may give the impression that women are not welcomed to participate.

*If you are a women of childbearing ages you can not participate.*

or:

*If you are a woman of childbearing age we demand a pregnancy test from you before the start of the study. Then at all the planned check-ups for participants in the study we have to control you with a pregnancy test. You have to have an officially approved method of birth control during the study period. If you do not have that, tell your doctor who will help you to get one.*

In a attempt to make the text more attractive and welcoming the women to participate it could be changed as follows.

*Women who are pregnant can not participate in this study because the effects on the foetus still are unknown.*

or

*If you are a woman of childbearing age you may participate in this study, if your personally method of birth-control is reliable. For your own safety, that a pregnancy has not started*

*before entering the study, we offer you a pregnancy test, that may be taken whenever you want to during the study period.*

### **Is it important to work with knowledge of a gender perspective in research ethic committees ?**

The question was brought up namely if the research ethic committees were prepared to have a gender aspect in their judgements of incoming applications. Together with the scientific secretary in the research ethic committee in another university of Sweden, a questionnaire was designed and sent to all the members in all the committees including their stand in(11). The following questions were asked.

- How do you define a gender perspective in relation to reviewing a research project ?
- Could you specify the risk and the benefit of such a review?

The response rate was 30 %, equally in proportion from all committees. A greater proportion of women answered the questionnaire. There were some who had no idea at all what this was about and there were members who had great knowledge of the problem. Some members expressed their beliefs that the quality of research would diminish if a gender perspective was put forward, that they consider themselves gender neutral in their judgements of projects. In contrast, some members had quite opposite ideas namely that which such gender aspects the quality of research will improve considerable. It was obvious that several members had as very vague ideas of gender perspectives in general. There was no great interest in learning more about the issue.

### **Did the actionstudy have any effect on the work at research ethic committees?**

What happened after this study, which was presented at several meetings? It was not easy for the researchers to put their arguments down on a piece of paper. Nobody had ever questioned their choice of study population. In some study-groups, this was discussed vividly and fewer applications were sent in with an unmotivated male study-population. Some of them learned new things, they did include women in their coming projects. Several scientist had never thought of the problem until asked. But for me, as a scientific secretary, it was really dangerous. In spite of the support from the department where I worked and the support from the chairman, who really learned something, my position was questioned. Thus, such actions/studies seem to be really dangerous for those persons who put up the gender-perspective on the medical research agenda.

### **The medical research council's new instruction to include "the representative study population "**

However, the Medical research Council proclaimed in the beginning of 1999 that the researchers have to motivate their choice of population as to sex(12). However, it was still appropriate to include a homogenous group of person.

### **Do the research ethic committees have any responsibility for the result of a research project?**

Yes, to some extent. Reviewing the scientific method chosen for the research question as well, could be a way to take responsible for a result. No scientific correct conclusion could be drawn from a study testing a new method in surgery without comparing with the old one. To do an in depth interview with 300 persons just seem to be waist of time and money. But the ethic committee has no influence of the choice of research questions. It is probably of some importance that most of the researchers are men. Their choice of research questions may as well focus on problems they think is important. So, the medical knowledge production are still favouring men.

The biomedical society is deeply rooted in positivistic research methods and lots of knowledge of diseases has been found with those methods. During the last years, an increasing number of research projects passing through the committee want to use

qualitative methods. It was in the beginning mainly women researchers who started to use these methods. To illustrate the frustration one scientist in the committee had when introduced to qualitative research methods "*not over my dead body could I approve a study without a control group*". This frustration for the unknown methods has changed. Today, most committees claim they need at least one member with a competence in qualitative methods.

### **Finally,**

to work in a research ethic committee as a woman scientist with a gender perspective is problematic. You need a lot of civil courage but still it is a dangerous work. There is a great risk for such persons to be excluded from the research society. Even if the medical research society do not benefit you for taking up the gender-aspects on research applications because, according to them, the changes in knowledge and attitude are done due to other reasons. Maybe an EU network of persons with a gender aspect on research ethic committees would be much more powerful. Economic incentives are powerful as well to change attitudes and behaviour.

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## 7. Women's bodies at mid life: Discourses on nature and culture

Johanna Esseveld

“One of the commonplace truths of contemporary culture is that people are born either male or female, and that these two groups of people exhibit differing characteristics related to their sexes across the life span... Yet how we understand these matters is subject to broad debate.” (Mary Gergen & Kenneth Gergen, 1995, p 191)

As Gergen and Gergen point out the relation between sex and gender, and previously between nature and culture, has inspired continuous debate in the social sciences. Two models are often counterposed to one another - either biological processes are seen as fundamental determinants of human behavior or behavior is seen as socially constructed. In the process a dichotomy is created between the biological and the social/cultural. A third position, the one I take, is that the boundaries between nature and culture are difficult if not impossible to identify in our contemporary mediated world.

In this article, I will show that dichotomizing nature and culture is not only unfruitful but is false. I will do this by looking at one particular stage in the life cycle, mid life or menopause, and how it is viewed through three discourses<sup>1</sup>: the medical, socialpsychological and the literary. My argument will be to show that these discourses, even though they differ in the emphasis given to the social/cultural and biological, have combined to produce what I would call the dominant narrative regarding women at mid life and menopause - the loss /decline model. In this model, the metaphors of progress and growth that are used to explain adolescence and early adulthood are replaced by metaphors that suggest the opposite. This means that the medical, socialpsychological and literary discourses cannot then be seen as separate but permeate each other. All include cultural interpretation and all relate to biological processes. Thus it makes little sense to speak about the biological and the social as separate entities. Each form part of a wider cultural narrative (Richardsson, 1990) to which individuals relate their – own and others – experiences.

### **Menopause as the result of biological processes; the medical discourse:**

“At the menopause everything that was granted the female being at puberty is taken back. Simultaneously with the process of genital retrogression, the beautifying activity of internal glandular secretion ceases, and the secondary sexual characteristics come under the aegis of the loss of femininity” (Deutsch, 1984, p 56)

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<sup>1</sup> Discourse is used in a sociological sense to refer to a class of texts. It refers to intertextuality and is also a concrete entity that is placed in an historical and social reality. (Chalaby, 1996)

Menopause was central to Helene Deutsch's writing on women at mid life. In the citation presented above, Deutsch suggests that menopause is a traumatic experience <sup>2</sup> for women as sexual beings. She also suggests that there is a connection between femininity and a woman's reproductive function. Loss of this reproductive function leads to a loss of femininity and to those characteristics connected to it, such as beauty. Deutsch also suggests that there are a number of bodily symptoms connected to menopause, such as "headaches, neuralgia, vasomotor disturbances, heart sensations, digestive trouble" (1984, p 59). In addition,

"Women's capacity for reproduction normally lasts as long as menstruation is regular. With the cessation of this function, she ends her service to the species." (Deutsch, 1973, p 476)

Cultural interpretations such as "...she ends her service to the species" in the above citation, are found in much of the literature on middle age and menopause in the field of medicine. Practitioners and scientists in the medical field often start from similar questionable social/cultural assumptions as the one mentioned above by Helene Deutsch and many draw similar conclusions. In much of this literature the emphasis is on *menopause*, a physiological process, and its negative effects on women. <sup>3</sup> Menopause is defined as a period of transition characterized through changes in hormonal production which ends in a woman being infertile.

According to Emily Martin different metaphors existed in the medical sciences during different historical periods. In the medical model that evolved during the late 19 th century, different metaphors were used. In one, menopause was defined as a crisis which might bring on an increase of disease and in another Another again, ... In addition, she suggests that eventually a model in which women at mid life were regarded as more positive was replaced by a model in which menopause was interpreted in negative terms only:

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<sup>2</sup> She also suggested that changes during this so-called 'dangerous age' lead to a regression in women's sexuality. (Deutsch, 1984). Some people may react to my including Deutch who was a psychoanalyst under the medical discourse, I include her here, since she also had a medical degree and practiced medicine.

<sup>3</sup> See Evans, 1988, for an overview of this literature. Some of this research is also presented in the journalistic and partly autobiographical books on menopause written by Gail Sheehy (1991) and Germaine Greer (1991).

“What is the language in which menopause is described? In menopause, according to a college text, the ovaries become ‘unresponsive’ to stimulation from the gonadotropins, to which they used to respond. As a result the ovaries ‘regress’. On the other end of the cycle, the hypothalamus has gotten estrogen ‘addition’ from all those years of menstruating. As a result of the ‘withdrawal’ of estrogen at menopause, the hypothalamus begins to give ‘inappropriate orders’.” (Martin, 1988, p 42)

The descriptions given in medical and popular texts is that the system starts to ‘fail or falter. It is, according to Emily Martin this failure that puts menopause in a negative light. Central here is a connection to “*lack of production: the disused factory, the failed business, the ideal machine.*” (Martin, p 45). The problem takes on larger proportions than the one already presented in the citation by Helene Deutsch above, a loss of function.

“...our imagery of the body as a hierarchical organisation gives us no good choice when the basis of the organization seems to us to have changed drastically. We are left with breakdown, decay, and atrophy.” (Martin, p ...)

In addition to presenting negative metaphors of menopause, medical investigations have been carried out to find the symptoms connected to these physiological changes with the purpose of alleviating these. The psycho-somatic and psycho-social symptoms found ranged from headaches, hot flushes, heightened rates of heart beats, general nervousness to depression. Some - but not all - of the symptoms are more specifically connected to the cessation of menstruation. In all cases, there is a selective emphasis on menopause itself. Missing from most of these studies are comparisons across the life cycle. Longitudinal studies in which women at different age-groups are compared to each other, suggest that many of the symptoms medical researchers contribute to menopause were found amongst older groups of women. There is a general increase of depression for these age-groups in both sexes, where “... admission to mental hospitals increase with age in both sexes, but more steeply in women, with a peak in the climacteric group...” (Evans, 1984, p 55) This seems to indicate that it is difficult to separate symptoms of menopause from symptoms of ageing.

Missing from these medical studies are also the particular historical and cultural settings within which women’s experiences take place. Researchers who added the social and cultural dimensions were able to counter some of these earlier ‘myths’ of menopausal symptoms by showing differences in the experience of such symptoms in different groups and between women in different societies. J. Greene (1984) distinguished somatic, psychosomatic from psychological symptoms and found that women with less education, from working class environments and housewives were more vulnerable to somatic symptoms. In addition that:

“... it was women with pre-existing problems or long standing difficulties, such as marital dissatisfaction, problems in early development, financial and economic difficulties, who reacted most adversely during the climacteric.” (1984, p 212)

In the Scandinavian context, Tore Hallström (1973) found that those women who had serious psycho-somatic illnesses during menopause, all had significant problems in their relations with their children, problems at work and also low social status. He also found that mental illness in this age group of women (between 38 and 54) on the whole was not higher than mental illness in other age groups. Since then a number of other Scandinavian studies have supported his findings, suggesting that depression at midlife is less tied to biological events than to a change in social roles and status. Even larger socio-cultural context seems to play a role as well. In societies where the emphasis is placed on youth, where paid work is emphasized at the expense of caring work and where geographic and social mobility is

common, women who devote themselves to care work during the years their children are at home are likely to be at a loss after their children leave home (Bart, 1971).

*In the medical discourse on menopause*, the body and a woman's reproductive organs are given a central place. The body is presented in a particular way, as a biological organism that has lost something: its fertility. This loss is in turn related to other losses: the loss of sexuality - and loss of social role. Following from this, midlife is assumed to be experienced as a crisis and as a problem which are further intensified by a subsequent fear of one's impending death. Ageing, then, is not seen as a gradual process in which women actively participate through their awareness of and reflections on bodily changes and changes in social roles. Reflection is a cultural process which actively involves the subject in the understanding of these changes and even in preparation for their occurrence. The medical discourse differs fundamentally - assuming that changes occur and without engagement of the actors. In addition, the medical discourse sees menopause and the bodily changes connected to it as universally applicable to all women. Little attention is given to cultural and historical contexts.<sup>4</sup>

### **Middle-age - changes in social roles and self identity**

Similarly, in the socialpsychological discourse as well, emphasis is placed on the loss of social functions in the adult years. In this discourse, not only is it assumed that little happens after midlife, but also that "life ends with forty years and that there was little to do except waiting to be pensioned and death." (Orville Brim, 1976).

This aspect of the discourse was most clearly expressed in the so-called disengagement theory of Cummings and Henry (1961). In short, this theory suggests that individuals prepare themselves for death through a slow process of disengagement from society. This process of disengagement cannot be avoided since death is unavoidable. According to their account, the process is universal and not relative to a particular society or a particular group in society. Disengagement is seen as part of the unavoidable and universal preparation for death. The authors recognize some individual differences in this process due to personality characteristics and biological make-up. The notion of disengagement is based in a traditional gender division of labour and is suggested to start with retirement for men and when the children leave home for women.<sup>5</sup>

Different streams can be detected in these studies and theories on middle-age. There have been studies attempting to account for what happens at mid-life in general. Some of the explanations offered base themselves either on male populations and/or emphasize that what is central to men in changes of identity and social roles during middle-age. (See Erik H. Eriksson (1959), Robert Gould (1978) and Daniel Levinsson (1978). In a few studies men and women are compared at midlife (Neugarten, 1968). In this literature midlife is seen as a period of taking stock, self-reflection and changes in identity as a result of this.<sup>6</sup>

Levinson further develops Erik H. Erikson (1959) model where different tasks are connected to different phases of life and that subsequent phases are impaired when earlier phase-related tasks are not resolved. While Erikson suggests stages of 'early adulthood' and 'adulthood' and 'mature age', his main emphasis is on child development. Levinson on the other hand focusses specifically on early adulthood and the middle years of life. From his

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<sup>4</sup> Studies that take into account the social and cultural context in which women act however, indicate that the social and biological interact with each other. See e.g. Greene (1984) and Hallström (1973)

<sup>5</sup> There seems to be a problem in this theory in that processes of ageing are confused with the process of dying. The cessation of certain social roles, such as paid work and parenting, which are part of a process of ageing, are interpreted as part of the process of dying.

<sup>6</sup> See Esseveld, 1988 for a presentation of the different theoretical models of middle age.

perspective, the middle years involve a period of crisis and self re-evaluation, a period also in which an earlier work/career life style is replaced by greater investment in family and private life.<sup>7</sup> Changes in time-perspective - from time left to time since birth - are also taken up. Bernice Neugarten (1976) however suggests that chronological age alone cannot be used as a marker for major life events. Instead, she suggests that chronological age (or life time) needs to be combined with historical and social time. Neugarten also disagrees with Levinson on what 'midlife' entails. Where Levinson emphasizes midlife crises, Neugarten suggests that midlife consists of a normal, gradual change in an individual's time perception, a change that is structured through age norms and life contexts and not chronological age:

"Middle-aged people look to their positions within different life contexts - the body, the career, the family - rather than to chronological age for their primary cues in clocking themselves. Often there is a differential rhythm in the timing of events within these various contexts, so that the cues utilized for placing oneself in this period of the life cycle are not always synchronous." (Neugarten & Datan, 1974, p 274)

Some individuals are 'on time', others may be 'off time' and others again may be on time in relation to some norms and off time in relation to others.

According to Neugarten (1968) the content of middle age also differs for women and men. For men middle age is perceived in relation to paid work while for women it is tied to changing relations in the family. For men midlife is also more closely tied to biological bodily events, such as changes in health, than for women. Her conclusions are based on interview studies with middle aged men and women in which she found that men more often than women referred to biological changes:

"The most dramatic cues for the male are often biological. The increased attention to his health, the decreased efficiency of his body, the death of friends of the same age - these are the signs that prompt many men to describe bodily changes as the most salient characteristic of middle age...Changes in health and in sexual performance are more of an age marker for men than for women. Despite the menopause and other manifestations of the climacterium, women refer much less frequently to biological changes or to concerns about health." (Neugarten & Datan, 1974, p 279-280)

There are also studies that account specifically for women at midlife. It is in these studies in particular, that the negative consequences of middle age are emphasized. This is apparent for example in the literature on the so-called empty nest syndrome. One assumption in this literature is that children leaving home and the subsequent loss of social function will lead to a crisis in women's lives. The loss of biological function - loss of menstruation - as described in the writings of Helene Deutsch is here replaced by loss of a social function - loss of mothering role. Again, the emphasis is placed on the negative effects.

According to Pauline Bart, in societies where the emphasis is placed on youth, where paid work is emphasized at the expense of caring work and where geographic and social mobility

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<sup>7</sup> Levinson's results may be applicable to men (although Rossi questions whether this is true for black and/or working class men), they cannot be applied to women's adult life without some amendments. Most women's lives during the early adulthood years do not center around paid work and career alone. A more common pattern for women is an uneven employment history - which may include a withdrawal into the home or working part-time to combine paid work and care work. In the three-phase model of women's adult life, developed by Alva Myrdal and Viola Klein (1956) women chose different solutions to ever existing conflicts between work for pay and care-work at home at each of these phases. Their second phase coincides with middle-age and reverses the shift in emphasis from work to care given by Levinson.

is common, women who devote themselves to care work during the years their children are at home are likely to be at a loss after their children leave home. In her study on depression amongst middle-age women, Pauline Bart found that mothers who were 'overly' involved with their children had the highest rates of depression. She also found differences between different groups of women:

"Women who have overprotective or overinvolved relationships with their children are more likely to suffer depression in their postparental period... Housewives have a greater rate of depression than working women... Middle-class housewives have a higher rate of depression than working-class housewives... The patterns of black female role behaviour rarely result in middle age depression. Often the 'grannie' or 'aunti' lives with the family and cares for the children while the children's mother works; thus the older woman suffers no maternal role loss." (Bart, 1970, p 109-112)

*In these sociological-psychological texts*, the emphasis is on women's and men's social roles and identities. All emphasize middle age as part of a longer process of development. With the exception of Neugarten, for whom the interrelation between body, identity and social roles is centrally placed, changes in the body are missing from these approaches. The body, here understood as a biologically entity - man or woman - only plays a role in so far as it is the basis for these gendered identities and social roles. For women, which in the medical discourse was understood as biology (reproduction, sexuality, pregnancy etc) is here re-defined motherhood and wifehood: ie social roles.<sup>8</sup> Similar metaphors are used to describe changes in social roles. Loss and negative consequences such as depression and isolation are central even here. Thus, making it possible to incorporate this dominant social psychological discourse under the loss/decline model.

#### **Middle-age in literary texts:**

"She spoke of death and compared midlife with the second half of a football match, 'the game' she said, 'decided long ago, is coming to an end. Short of breath and sweating, shaking in every part of their bodies the players move up and down the field while they wait for the sound of the whistle. Even if I myself am active at center field', she told him, 'I may not be able to play till the end. It's possible that I will be taken off the field.'" (Beryl Bainbridge, 1977)

The woman talking is middle aged (although her exact age is never given) and the man she is addressing slightly older. He answers her by saying that he no longer lives in the here and now, nor does he look ahead, but instead reminisces about the past.

In this passage from the novel *Injury Time*, a number of commonly held stereotypes about middle age can be seen: the idea that there is little to look forward to; that there is little or nothing new to learn; that active involvement in the world is replaced by a 'just being in the world' and that one has little control over what happens. Death takes an important place in one's thoughts. In addition, the bodily images presented in the passage resemble that of the symptoms attributed to a menopausal and ageing person. Beryl Bainbridge who was forty-odd years old when she wrote these words is not alone in this view on middle age, I will argue. Much of contemporary literature contains similar images. Often these are only presented in passing, e.g. in a recent book by Toni Morrison as "Adults hope that life begins at 40 - but the great anxiety is that it ends there."

Simone de Beauvoir explicitly wrote about middle age in *The Second Sex* (1949/1970) and continued to write about the middle and later years in life in her biographical novels and

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<sup>8</sup>See Esseveld (1997) for an analysis of adult identity in which women's relations to and interpretations of their bodies is given a central place.

books: *The Prime of Life* and *Old Age*. De Beauvoir's reflections on changes in her own body provide an important element in these descriptions:

"One day I said to myself: 'I'm forty!' By the time I recovered from the shock of that discovery I had reached fifty. The stupor that seized me then has not left me yet... I often stop, flabbergasted at the sight of this incredible thing that serves me as a face... When I was able to look at my face without displeasure I gave it no thought, it could look after itself... I loathe my appearance now: the eyebrows slipping down towards the eyes, the bags underneath, the excessive fullness of the cheeks, and that air of sadness round the mouth that wrinkles always bring... when I look, I see my face as it was, attacked by the pox of time for which there is no cure." (Quoted in Germaine Greer, 1990, p 281)

Beauvoirs reflections are partly autobiographical, although in *The Second Sex* she relates her own reflections to a wider audience by suggesting that these reflections on bodily changes and a sense of loss is inscribed in women's collective narrative (Richardsson, 1990). Middle age she furthermore suggests is a crisis for all women. In a life cycle perspective it contains a continuation of earlier crises - closely connected to changes in the body - and differs from the changes across the life cycle for men:

"Each period in the life of a woman is uniform and monotonous; but the transitions from one stage to another are dangerously abrupt; they are manifested in crises - puberty, sexual initiation, the menopause - which are much more decisive than in the male." (De Beauvoir, 1970, p 541)

Striking also is the close connection between heterosexuality and this loss of femininity in women. The following citation suggests that this midlife crisis is also due to men's loss of interest in their partners' bodies:

"Long before the eventual mutilation, woman is haunted by the horror of growing old... she has gambled much more heavily than the man on the sexual values she possesses, to hold her husband and assure herself of his protection, it is necessary for her to be attractive, to please... What is to become of her when she no longer has any hold on him? This is what she anxiously asks herself, as she helplessly looks on at the degeneration of this fleshly object that she identified with herself. She puts up a battle. But hair-dye, skin treatments, plastic surgery, will never do more than prolong her dying youth. Perhaps she can at least deceive her mirror. But when the first hints come of that fated and irreversible process which is to destroy the whole edifice built up during puberty, she feels the fatal touch of death itself." (de Beauvoir, 1970, p 542)

The nature/culture distinction and its gendered hierarchy reappears in her text. A connection is made between women's biology and femininity while no such connection is made between men's bodies and masculinity. The processes are described differently as well. For men a gradual process of ageing occurs while for women ageing is more disruptive and occurs through crises:

"Whereas man grows old gradually, woman is suddenly deprived of her femininity; she is still relatively young when she loses the erotic attractiveness and the fertility which, in the view of society and in her own, provide the justification of her existence and her opportunity for happiness. (De Beauvoir, 1970, p 541)

A close connection between individual and cultural narratives is given through the expression "in the view of society and in her own" in the above citation. While it is possible to interpret deprivation of femininity in the above citation in different ways: as an attempt to signify the construction of woman as the other and thus as an attempt to deconstruct the cultural

narrative about women and femininity in Western society, what is interesting in relation to the argument made here is that the metaphors 'decay' and 'loss' of the two discourses presented above reappear in her text. Even the metaphor of crisis reappears. Contrary to the other discourses, de Beauvoirs text emphasizes the interrelation between biology, social. In her text, the body is viewed by the woman, reinterpreted through the eyes of others - men, society - and in turn internalized by women.

In a more recent book *The Change. Women, Ageing and the Menopause* by Germaine Greer (1991) many of the above mentioned aspects connected to menopause and middle age are taken up as well. Like Simone de Beauvoir, Germaine Greer moves between discussions of own experience, women's realities, myths, metaphors and scientific discourse. Her text is more ambivalent/contradictory than deBeauvoirs however. On the one hand Germaine Greer attempts to present menopause in a more positive light - as a turning point that can lead to individual growth and as such follows more closely some of the socialpsychological literature presented above. But there are also parts in which she presents the negative effects with reference to own and other women's personal experiences and with the help of scientific studies. Here, as before with deBeauvoir and Bainbridge the relation between menopause and impending death is given a central place:

"At menopause as never before a woman comes face to face with her own mortality. A part of her is dying. If she has been encouraged all her life to think of her reproductive faculty as her most important contribution, the death of her ovaries will afflict her deeply. Nothing she can do will bring her ovaries back to life. The grief of menopause affects every woman consciously or otherwise. The feeling that one's day has passed its noon and the shadows are lengthening, the summer is long gone and the days are growing ever shorter and bleaker, is a just one and should be respected. At the turning point the descent into night is felt as rapid; only when the stress of the climacteric is over can the ageing woman realize that autumn can be long, golden, milder and warmer than summer, and is the most productive season of the year."  
(1991, p 142)

In these *literary texts*<sup>9</sup> within which middle age plays a role, the interrelation between nature and culture replaces the earlier either/or (biological, social) perspectives of the medical and socialpsychological texts. Changes in identity and processes of ageing are here closely linked to physiological changes in women's bodies. It should be pointed out that opposed to the medical and social psychological discourses however this popular culture discourse brings in reflection. Unfortunately these reflections assume that the changes during women's mid lives are interpreted primarily as negative and in turn connected to metaphors of loss and impending death. Thus this discourse can be contained under the loss/decline model. The three discourses on women and midlife presented here, all take into account the interrelation between body, identity and social context. However each place different weight on these three aspects. In the *medical texts*, emphasis is placed on physiological changes in the body and the symptoms that may occur during menopause (a biological process) and the subsequent loss of reproductive function. Such symptoms and their negative consequences are given priority, while cultural contexts are largely absent here. In social psychological texts, identity and social roles are placed at the center of the analysis and physiological changes are not explicitly mentioned. In much of this literature the adulthood years - including middle adulthood - are seen as a period of change in which individuals continue to learn and develop. There are differences associated with gender however in the meaning given to middle age. For men, it is seen as a period of growth and development while for women the emphasis is placed on loss and decline. Loss is here defined differently than in the medical texts - as a loss of social functions, as e.g. mothering roles and not through

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<sup>9</sup> I am aware of the problem in my choosing texts that supports my argument. My contention is however that these can represent the discourse.

biological changes. The work of Neugarten with its focus on the interrelation between changes in body, identity and social norms forms an exception here. While the literary texts offer a more reflective subject - middle age for women is still seen as a period of crisis, loss and decay.

These discourses combine to produce a dominant cultural narrative in which mid life for women is seen as a period of loss and decline. It is this narrative and model which 'frames' much of common-sense and everyday understandings. However, I believe that the actual experiences of women can generate a basis for reflection and understanding (a collective narrative) that may transcend this cultural narrative. Thus while this cultural narrative may still be dominant and a narrative we have to relate to - it is not dominating.

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