

# **Hear our Voices – Meet our Needs:**

## Women and Health



National Women's  
Council of Ireland

Comhairle Náisiúnta  
na mBan in Éirinn

**REPORT FROM THE NWCI MILLENNIUM PROJECT**

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## **1. EXECUTIVE SUMMARY**

In January 1999, the National Women's Council of Ireland (NWC) initiated *Women Mapping the New Millennium*, a national research, analysis and action study. The research focused on six key areas of enquiry: women and health, poverty, work, education, violence against women and local development. The aim of the study was three-fold. Firstly, to provide women across the country with the necessary skills and opportunity to have their voices heard. Secondly, to obtain women's views on each area in order to inform the NWC's lobbying and policy strategies in the future. Finally, to explore and evaluate a model of participatory research and analysis which might form a basis for future ongoing research of this nature. This research could prove capable of assisting policy-makers and advisors, agencies, advocates, women and their communities with timely and appropriate information for policy formulation at local, regional and national levels.

This report presents the outcomes of the second of the above aims, that is, the views of the participants about women and health in Ireland.

### **1.1 RESEARCH METHODOLOGY**

The study was conducted using a Participatory Learning and Action (PLA) approach, which seeks to build bridges between locals at 'grassroots' level and policy makers at local, regional and national levels. Researchers who use PLA emphasise the fact that engaging in participatory research is a two-way learning process for all involved; that movement towards action is a central aim of the process; that a participatory approach can work equally well in urban and rural context, and that the techniques can be adapted and applied to a wide range of issues.

In the health component of the study, 30 facilitators engaged in research with 155 women across 8 counties, urban and rural.

### **1.2 HEALTH BRIEF**

It is recognised that there are many different understandings of health, well-being and illness which vary according to different socio-cultural factors. In order to understand the assumptions underlying health care planning and provision in Ireland, this study refers to the policy orientation outlined by the Department of Health and Children. The focus of the health discussion was to explore whether or not research participants believed that the aims and objectives of the *Plan for Women's Health 1997-99* (Department of Health and Children, 1997) have had an impact on their own health care needs and concerns.

Also presented in this report is a case study about the research done by the Irish Deaf Women's Group in relation to the health component of the Project. They have specific health needs in relation to being part of a linguistic and cultural minority. The experience of this group is instructive in raising our awareness of how minority groups' health needs can shape service provision in order to make it more open, flexible and effective for service users.

### **1.3 CONCLUSIONS AND RECOMMENDATIONS**

The following conclusions and recommendations from the health component of the Millennium Project are relevant to this concern.

#### **1.3.1 Conclusions**

- The results of the health component of the Millennium Project suggest that the Irish health system is not sufficiently decentralised or devolved, and that insufficient resources have been provided to implement enhanced services for women in their localities. In some areas services are provided and in

some they are not. Childcare was still an important health need across the country despite the commitment in the *Plan for Women's Health* (Department of Health and Children, 1997) to address this issue.

- The Department of Health and Children could use the four principles that guide health promotion policy in Ireland as a checklist for successful future implementation of the Plan for Women's Health (Ibid.). These principles are:
  - Re-orienting the health service to promotion and not just acute care;
  - Creating supportive environments in which to make healthy choices;
  - Strengthening community action - incorporating community development approaches to health promotion;
  - Developing personal skills through consultation with individuals about their needs (Department of Health and Children, 2000).
- Women across the country indicated that they could not access holistic health care, including alternative therapies, nor could they have all their health needs attended to in a one-stop shop, which was the primary 'completely unmet' need they identified. Thus, a biomedical model of care is still foremost in the Irish system. This is not in line with the Department of Health and Children's acceptance of the idea of health as related to social gain.<sup>1</sup>
- The use of a biomedical model is linked to the overlooking of social, cultural and economic factors in health. For example, participants in the health component of the Millennium Project gave evidence of negative experiences in their health care due to class and gender discrimination.
- The need for health information and education was seen as the second ranking unmet health need for participants in the Millennium Project. This indicates that the plan's commitment to increased availability and access to health information for women has not impacted upon the women involved in this research.
- There is a direct relationship between health policy and services, individual perceptions of health and well-being and the normative values of a society and culture. "Health care services, like other human service systems, closely mirror the deeply rooted social and cultural expectations of the citizenry as a whole." (Figueras et al., 1998). Participants throughout the country indicated that they did not feel the concrete effects of promises made in the Plan for Women's Health (Department of Health and Children, 1997). Thus, until those concrete changes are made, the Irish Government can be seen to uphold the subordinate status of women in Irish society. It may also be reasonable to assume that a tangible improvement in the state of Irish women's health may not be felt until the policies put forward in the Plan are more thoroughly implemented.

### **1.3.2 Recommendations**

It is recommended that the Department of Health and Children and other relevant departments and agencies, such as the Regional Health Authorities, and the Women's Health Council:

- Fulfil the promises made in the Programme for Prosperity and Fairness (Department of the Taoiseach, 2000), The Plan for Women's Health (Department of Health and Children, 1997) and The National Health Promotion Strategy (Department of Health and Children, 2000c) to consult with women about health services, their ethos and models of practice, and where they are needed.

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<sup>1</sup> The term "social gain" refers to the idea that health has social determinants, thus, improvement in an individual's health status can be a correlate to an improvement in their social status. There is a reflexive relationship between health status and social status.

- Commence initiatives to encourage the widespread distribution of free and accessible information about health, particularly for women's health issues. This may mean placing the information in settings where one would not normally find health information, for instance, in rural post offices. Other innovative ways of disseminating health information should be employed using a variety of media. Participants in the Millennium Project described needing health information on a wide variety of topics, but in particular they mentioned: holistic approaches to health; cancers; reproductive health, family planning and the menopause. Information should be relevant to women's life stages as illustrated in the results from the seasonal calendars.
- Incorporate research like the Millennium Project into the work of the National Health Information Strategy.
- Initiate further research to consult with women about gaps in health information provision, as well as their preferences for style, presentation and medium. Different topics and different age groups could necessitate different modes of delivery.
- Continue the decentralisation and devolution of health services, ensuring that administrative agencies and service settings are properly resourced, financially and otherwise.
- Provide awareness and sensitivity training at regular intervals to health care providers on issues of gender, ethnicity, sexuality, economic disadvantage and the relationship between social factors and health status.
- Ensure that health care providers are trained in effective communication skills and learn how to encourage client participation in their own health decisions.
- Provide free and accessible childcare, so that women can attend to their own health needs.
- Fund and resource women's groups working with older women, Traveller women, lesbians, refugee and asylum seeking women, women from other ethnic groups living in the Republic, women with disabilities and women who are living in poverty to do research about women's health issues. One of the most important areas of investigation would be the question of what 'being healthy' means to women in Ireland. This would allow for both a deeper and broader view of women's health in Ireland. Multi-method approaches should be used in any enquiry into health for women.
- Institute a wide range of reforms in services for carers in the country as advocated by the National Women's Council of Ireland (NWC) in its work with health representatives in the regional women's health committees (NWC 2000).
- Expand the range of care options regarding models of practice, particularly alternative therapies.
- Set up free and universal provision of contraceptives, fertility treatment and information about reproductive choice and STDs (particularly HIV and AIDS).
- Initiate inter-departmental and agency links with regard to women's health in the Republic in line with the above recommendations. For example, the Department of Health and Children should fulfil the promise made by the Minister of Health to collaborate with NAPS on establishing health targets,

measures and indicators. Health is an issue of human rights for women and should be addressed at a broad policy level.

## 2. INTRODUCTION

The National Women's Council of Ireland is a non-governmental organisation (NGO) currently operating as an agent of change<sup>2</sup> with and on behalf of women in Ireland facing a complex and rapidly changing society and culture. Over the past years, the work of the Council, coupled with that of other agencies and organisations, has achieved significant and life-enhancing change in ordinary women's lives. In 1998, approaching the third Millennium, and cognisant of significant shifts in the political, economic and social landscape in Ireland, the Council recognised that new models of partnership were rapidly emerging. This indicated the need, in turn, for new models of communication and information flow between people at local 'grassroots' level, policy makers and the NWCI as a social partner. In seeking to develop and explore such a model, the Council proposed its Millennium Project: *Women Mapping the New Millennium*.

### 2.1 WOMEN MAPPING THE NEW MILLENNIUM

*Women Mapping the New Millennium* is a national research, analysis and action project that seeks to foster a process of empowerment that "has the potential to radically redesign the current paradigm that continues to produce social exclusion" (Zappone, in Kirby and Jacobsen, 1998). It is a capacity-building programme that goes beyond the traditional notion of 'consultation' towards an active participatory experience of research, analysis and action.

The key objectives of the project are to:

- Design and explore an innovative model for forming national and local policy through direct participation by local actors;
- Provide women across the country with the training and capacity to conduct sustained social research and analysis;
- Encourage women to analyse the social and economic implications of their activities;
- Produce ongoing, up-to-date research on key experiences of women's lives – poverty, healthcare, work, etc.;
- Build towards sustainable development of initiatives at local level.

At time of publication, we have a partial picture as to the extent to which the last of these objectives was reached. It is the NWCI's task to take the results of the research into the national policy arenas to which it has access. This work is ongoing. An evaluation is planned for the future in which policy-makers will be asked as to the Millennium Project's effect on Irish social policy.

We have evidence that some, but not all, of the women involved in the project have fed the results of their research into their local policy-making arenas and/ or have initiated an action at local level as an outcome of their research and the skills gained through participating in the project. While this 'action' phase was built into the project, it was optional for facilitators and for a number of reasons, for instance, lack of time or lack of resources, not every group could progress action at local level. Also, groups may have started these initiatives long after the end of the project. A mail-out at close of the project asked facilitators to outline what ways they had used the skills gained through involvement with the project. These descriptions are available in the full reference report of the project available in the NWCI.

In many ways, the Millennium Project was a first step towards sustainable local action by the women involved. It represents the beginning of a developmental process. It illustrates the need for women to

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<sup>2</sup> Agents of change or 'change-agents' is a term commonly used in majority-world development planning to denote organisations (governmental and non-governmental), institutions (public and private), community activists and communities themselves, policy-makers and advisors, individuals and professionals (e.g., researchers, technical experts, etc.), who seek to foster positive change in people's lives at community, national and/or international level.

receive information, financial and training supports to pursue further projects which would enable them to investigate and challenge their environments.<sup>3</sup>

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<sup>3</sup> This issue is explored in more depth in, O'Reilly-de Brún et al. (2001). *The Millennium Project: Women Mapping the New Millennium Executive Summary*. Dublin: National Women's Council of Ireland.

## 2.2 RESEARCH AREAS

Six broad areas of research enquiry were identified via consultation with Council affiliates and advisory personnel:

- Women and Poverty
- Women and Health
- Women and Work
- Violence Against Women
- Women and Education
- Women and Local Development (rural and urban)

## 2.3 WOMEN AND HEALTH

Attempting to provide a single definition of health is highly problematic. Sociological, anthropological and feminist discourses in this area all point to the fact that there are many different conceptualisations of health, well-being and illness (McCluskey, 1997), among women and men within and outside of the medical profession. These different conceptualisations vary according to many factors, including socio-economic background, employment, gender, and culture (Ibid.). What is essential in this context, therefore, is to focus on the voices of the women involved in this research and how they view health and well-being.

In order to understand what underlying assumptions inform health service provision in Ireland, we have adopted as our reference point the approach taken by the Department of Health and Children to health planning and service provision. Although the Department did have an explicit bias towards ‘the curative and regulatory aspects of the health services and on the need to develop the acute hospital sector during the period from 1970 to the mid-1980s’ (Department of Health and Children, 2000a), this approach changed with the publication of the health strategy ‘*Shaping a Healthier Future*’ in 1994. This strategy was, in fact, ‘the culmination of a reappraisal of the health services which had commenced in 1986 with the discussion document *Health - the Wider Dimensions* (Ibid.). In 1997, the Department of Health and Children published *A Plan for Women’s Health*, which was directly informed by the 1994 strategy, and was the first such plan to be formulated among the member nations of the EU. Integral to this plan was the establishment of an advisory council, the Women’s Health Council, also the first of its kind within the EU.

*Shaping a Healthier Future* (Department of Health, 1994) signalled a significant change in direction, with its emphasis on the achievement and measurement of ‘health gain and social gain and its commitment to organise and manage the system as an integrated whole.’ (Ibid.) This report examines whether or not the 155 women involved in this research believe that this approach to health service provision has been manifested ‘on the ground’. Do health needs as articulated by the participants parallel those set out in the *Plan for Women’s Health 1997-99* (Department of Health and Children, 1997)? Do the participants perceive those needs to have been met and, if so, to what extent?

## 2.4 PARTICIPATORY RESEARCH APPROACH

Given this brief, what shape might our research take? How research is designed, and from whose perspective, radically informs the content and results of any research project, which, in turn, informs the policies developed in response to those results. The Millennium Project utilised an emic<sup>4</sup> approach and participatory methodology, which is described in detail in the methodology section of this report.

## 2.5 THE POLICY-INFLUENCING POTENTIAL OF THE MILLENNIUM PROJECT

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<sup>4</sup> To distinguish between the terms ‘emic’ and ‘etic’: etic research is conducted from the outsider’s perspective, while emic research takes the insider’s perspective on board as the framework from which to explore and understand the issue in question. The terms are drawn from anthropology (Goodenough, 1956) and were borrowed from linguistics. Emic research is also known as ethnoscience, the New Ethnography, ethnomethodology and componential analysis.

The Millennium Project has the potential to address several ‘audiences’ and therefore to influence policy at various levels. Intended audiences for the results and recommendations of this study include: the National Women’s Council of Ireland and its affiliate membership, policy-makers and advisors in key Government departments, NGOs, agencies, community groups and activists concerned with the issues which formed the research agenda.

For example, since the beginning of the consultative process from which the *Plan for Women’s Health* (Department of Health and Children, 1997) emerged, the National Women’s Council of Ireland has acted in partnership with the Department of Health and Children and the eight women’s health committees around the country. We hope that our discussion of Irish women’s health will help to inform the ongoing health policy work of the Council, its affiliates and the health counterparts involved with the women’s health committees.

Through the Millennium Project, the Council has built considerable capacity within its affiliate membership (as outlined in the project objectives mentioned above). This enhanced capacity ought to further enable affiliates to address these issues at local, regional and national level, operating as agents of positive change.

Policy makers and advisors cannot develop viable policy in a vacuum. They require constant assistance from those who are the intended beneficiaries of the policies. At the same time, women cannot hope to improve their situation if their voices and expertise remains unsolicited and unheard; they need constant assistance from those who have the power and vision to seek that expertise and build it into healthy policy. A feature of the Millennium Project is the model it employs in order to bring women’s experiences, their needs, suggestions for change and potential solutions, into the heart of action and planning at local, regional and national level.

### 3. LITERATURE REVIEW

#### 3.1 THE STATE OF WOMEN'S HEALTH IN IRELAND

The life expectancy of Irish women has consistently exceeded that of men since at least 1950 (Department of Health and Children, 2000b), reflecting life expectancy patterns through the EU (Ibid.). The life expectancy for women born in 1995 was 78.6 years, compared to 73 years for men<sup>5</sup>. However, this life expectancy is still one of the lowest in the European Union (Department of Health, 1995).

In terms of externally reported health status, Irish women compare unfavourably to women in other EU member states:

- The standardised death rate (SDR) for Irish women aged between 0 and 64 years of diseases of the circulatory system are 42.4 per 100,000, compared to an EU average of 33.1.
- The SDR for ischaemic heart disease<sup>6</sup> for Irish women is 20.8, compared to an EU average of 12.7.
- Cerebrovascular diseases (including stroke) account for 10.6 deaths per 100,000 Irish women aged between 0 and 64, compared to an EU average of 9.1.
- In 1994, 29% of Irish women aged 15 years or over were regular daily smokers, compared to 28% of Irish men. This is the third highest rate recorded in the EU, beaten only by Denmark and the Netherlands.<sup>7</sup>
- This trend is repeated for the other major diseases affecting women in the EU, including cancer (of digestive organs, e.g. the colon and small intestine, and breast, lung and cervical cancer) and pulmonary conditions such as bronchitis, emphysema and asthma.<sup>8</sup> Together, cancer and cardiovascular disease accounted for 65% of all deaths in women aged under 65 years in 1990 (Ibid.).

All of this points to the fact that Irish women are at a considerable disadvantage compared to other women in the EU. However, there are some paradoxical findings emerging from the statistics gathered so far.

- Irish women perceive their health to be at a higher level than women in other EU member states (McCluskey, 1997).
- Irish women also have a low percentage of self-reported limited activity<sup>9</sup> due to chronic illness but a high rate of acute illness (Directorate-General for Employment, Industrial Relations and Social Affairs, 1997).

#### 3.2 THE BIOMEDICAL MODEL IN HEALTH CARE

'Western' approaches to healthcare are most often associated with what is known as the 'biomedical' model of medicine. This approach is rooted in an idea of nature 'conceived of in mechanistic terms, which led in biology to ideas that a living organism could be regarded as a machine that might be taken apart and reassembled' (McKeown, 1971). According to this model, illness is perceived as a failure of the 'mechanism' to work; in other words, a deviation from some undefined norm (Stacey, 1988).

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<sup>5</sup> Provisional figures, Demographic statistics, Eurostat, 1997.

<sup>6</sup> Ischaemic Heart Disease, otherwise known as angina pectoris, refers to chest pain arising from the heart, usually under the breastbone, due to an inadequate supply of oxygen to the heart muscle.

<sup>7</sup> HFA Database, WHO, 1994

<sup>8</sup> World Health Statistics HFA, 1994

<sup>9</sup> Limited activity means not being able to carry out normal tasks one was previously able to do.

However, no system is static, and Sarah Nettleton (1995) has argued that there has been an increasing movement away from the biomedical to other models in the 1990s for a number of reasons, including:

- Medicine's efficacy has been overplayed and over-professionalised, therefore non-medical people's healing skills have been appropriated and healing legitimacy wholly transferred to the medical profession.
- Biomedicine has failed to locate the body within its socio-environmental context and therefore fails to account for the social inequalities in health.
- Biomedicine medicalises normal physiological processes such as menstruation, childbirth and menopause.

What is regarded as legitimate medical knowledge is determined more by social and political processes than knowledge about health and illness per se. These processes act to perpetuate the dominance of the medical profession and the continuation of patriarchal systems of power in the medical profession (Ibid.).

### **3.3 FACTORS AFFECTING HEALTH STATUS**

The accusation that biomedicine does not take account of the wider socio-cultural context in which health and illness are situated has been borne out by research in this area. As Doyal (1995) says:

*“Inequalities in health between social groups are not simply inequalities in desired states of subjective well-being. They also represent objective inequalities in the capacity of individuals to play an active part in social and community life – to realise their own potential and to help others do the same.”*

Researchers have explicitly identified two main socio-cultural factors which impact on health status:

#### **Socio-Economic Status**

The publication of the *Black Report* by the National Health Service in Britain in 1988 (Black, 1988) confirmed widespread health differences linked to 'class' (Moore and Harrison, 1998), and Lynch et al. (2000) found a link between high levels of ill health and low socio-economic status.

#### **Gender**

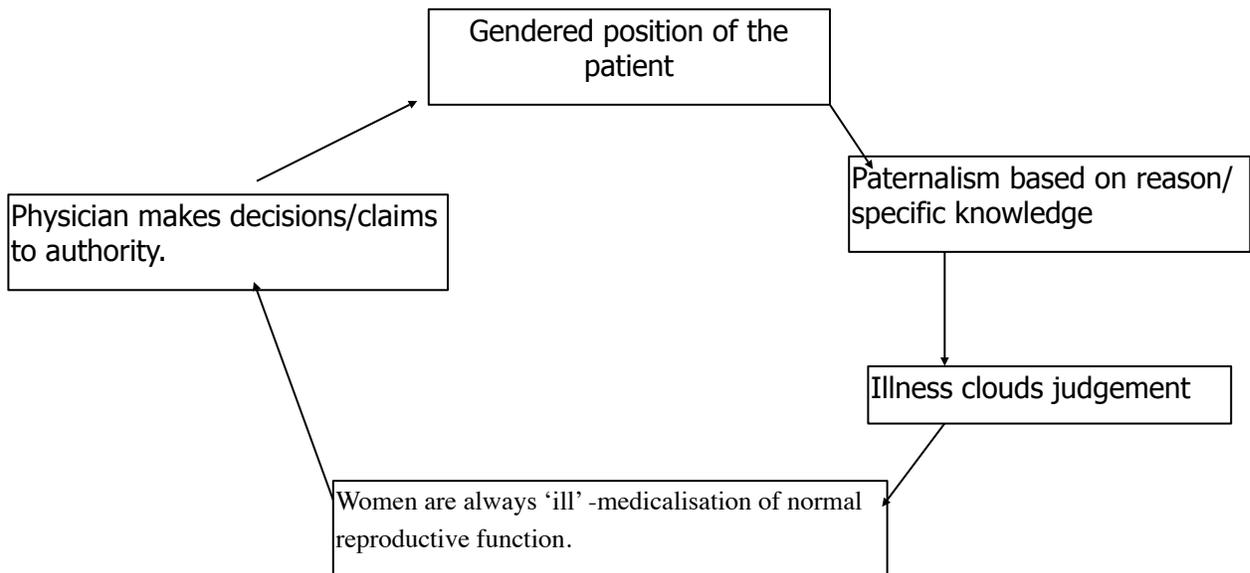
The impact of gender on health status is far-reaching and complex. Cohen (1994) has suggested that women bear the brunt of health problems related to poverty. He also noted that women from low socio-economic backgrounds were less likely to have a cervical smear or a mammography, and that breast self-examination was also less prevalent. The danger of a 'black box' scenario (as with poverty, in which women become invisible) has been highlighted by Arber (1990) who cautions against using the household as the unit of measurement in determining women's health status.

On the one hand, biomedicine has provided women with something that has empowered and liberated them in certain aspects of their lives, for example, with the provision of contraception. However, on the other hand, feminist writers such as Lorber (1997) and Kennedy and Murphy-Lawless (1998) have argued that women are doubly disempowered in the medical encounter by virtue of being both female and a patient at the same time. One example of this is the medicalisation of normal physiological processes such as pre-menstrual syndrome, menopause and childbirth.

### **3.4 GENDER, POWER AND KNOWLEDGE: THE ISSUE OF PATERNALISM**

Sue Sherwin (1992) has argued that "...the practice of medicine serves as an important instrument in the continuing disempowerment of women in society", and that in order to maintain this situation, a retention of 'specialised' knowledge is essential. This claim is justified through the construction of health and illness as part of scientific knowledge, rather than holistic, and therefore somehow outside the realm of everyday

understanding. This can therefore lead to the notion that it is more appropriate for medical practitioners to take on decision-making authority over the patient, which in turn leads to a vicious circle whereby the patient is maintained in a subordinate position:



It should be taken into account, however, that many medical staff fear to break the vicious circle due to fear of litigation and the fact that many doctors are judged on how closely they adhere to ‘accepted policy’. This reduces room for manoeuvre and negotiation, even if practitioners wish to do so.

There has also been an increasing awareness on the part of the medical profession that treatment approaches based on purely biomedical assumptions are no longer solely adequate. According to Stacey (1988), an increasing number of general practitioners are challenging the dominant paradigm and claiming to treat their patients as whole individuals and not collections of symptoms or ‘deviations from a norm’. As far back as 1964, there was some recognition that the doctor-patient relationship itself could be therapeutic (Balint, 1964).

Paula Baraitser, a Senior Clinical Medical Officer in the central family planning clinic in Norwich, has pointed out that “...in an attempt to increase patient satisfaction [in family planning clinics] there has been a move to increase doctors’ ability to communicate sensitively and effectively by providing consultation skills training in medical schools” (Baraitser, 1995). She also goes on to acknowledge the need to

understand how doctor-patient consultations are influenced by the sources of power and types of knowledge which both parties bring to the consultation (Ibid).

### **3.5 RESEARCH STRATEGIES IN HEALTH:**

Sherwin (1992) has argued convincingly that research in the health sector should be evaluated as to whether or not it will empower women or limit their ability to make informed choices about their health care. In order to involve women in determining their own health needs and how they would like these to be catered for, an understanding of their perceptions of health and illness, and acceptable therapies, needs to be obtained. Scambler (1991) has estimated that alternative medicine is growing five times as rapidly as biomedicine, and Di Matteo et al (1985) have documented the impact of doctor-patient interactions, service users' beliefs and their referral systems on health service utilisation, as have other researchers such as Becker and Rosenstock (1984), and Scambler and Scambler (1984).

In Ireland, a positive move would be to foster research approaches and methods which value local knowledge and enable women's voices to be heard by policy-makers, planners and managers. The biomedical model should be equated with others as culture-specific rather than perceived as representing the 'Truth' about health and illness.

### **3.6 HEALTH PLANNING AND POLICY-MAKING IN IRELAND**

Current policy in Ireland, and critiques of health promotion, both caution against the tendency to medicalise normal processes in women's bodies. As Daykin and Naidoo (1995) point out:

*“There is a need to develop policies and services which are accessible, appropriate and enhance the ability of women to resist the health-eroding pressures of their daily lives.”*

International governments and NGOs are currently attempting to develop and implement models of health care that eschew assumptions based on an underlying biomedical determinist philosophy. In Ireland, the recent reappraisal undertaken by the government of the health services completed in 1994 (Department of Health, 1994) and the release of the recommendations of the *Report of the Second Commission on the Status of Women* (1993), resulted in the publication of a *Plan for Women's Health 1997-1999* (Department of Health and Children 1997). During the preparation for this document, extensive consultation was undertaken with Irish women on health needs and issues.

The main aims and objectives of the *Plan for Women's Health* (Ibid.) reflect an increased awareness on the part of the Irish Government of the need to re-assess constructions of health, illness and well-being, and incorporate a broader view of what health and well-being actually mean. They are:

- To maximise the health and social gain of Irish women.
- To create a women-friendly health service.
- To increase consultation and representation of women in the health services.
- To enhance the contribution of the health services to promoting women's health in the developing world.

This plan was to be implemented between 1997 and 1999. While the shift in emphasis and new recognition of the specific needs of women in health service provision is welcomed, it remains to be seen whether these aims and objectives have been implemented successfully on the ground. It also remains to be seen if the needs as articulated by the participants in this project parallel those articulated in the plan. It is essential that government stay attuned to the opinions, needs and concerns of the women living in Ireland, who are the ultimate recipients of the care provisions outlined in the *Plan for Women's Health* (Ibid.).

## **4. METHODOLOGY**

### **4.1 INTRODUCTION: THE DEVELOPING RELATIONSHIP BETWEEN RESEARCH METHODS AND SOCIAL POLICY**

Research approaches and methods radically influence research content and, consequently, the policies designed in response to that content. Traditionally, research funding in Ireland has privileged large-scale survey-style research, and it has been a struggle to find support for smaller-scale qualitative research. The NGO sector has made strategic decisions regarding what type of research is necessary to support particular policy outcomes, but the salient question that remains is this: Is it the intention of social policy research to describe the current situation, to change it, or both? (Cantillon, 1998). What might small-scale predominantly qualitative research projects like the Millennium Project contribute to each of these objectives?

Many authors have demonstrated the inability of researchers using exclusively quantitative methods to attend to the “persistent requirement in social policy to understand complex behaviours, needs, systems and cultures” (Ritchie and Spencer, 1994; Cantillon, 1998; Hallett, 1996; Ruspini, 1999). As Irwin (1987) says, ‘Human behaviour and social existence is a subjective and wilful construction and requires drawing close to subjects in their natural contexts and understanding the fundamental human process.’ This ‘drawing close’ can best be achieved by using qualitative approaches because they provide “an opportunity, albeit briefly, to see the world from another person’s point of view” (Schein, 1995).

This is a lesson strongly reflected by what policy-makers in ‘developing’ countries in the majority world have learned: all the components of social policy – not just the technical and economic, but also the social and cultural – have to be taken into account (Kane, 1995). All the parties involved in research and policy-making - governments, sponsors, local people and external experts - have a unique perspective to contribute (Cernea, 1991). This holistic approach to research and effective policy-formation demands that we make the best possible use of available methods and techniques, and involve local people - in our case, women accessing health services - directly in the process of research, analysis and action-planning.

### **.2 FROM THE OUTSIDE IN, OR THE INSIDE OUT? CONTRASTING APPROACHES TO RESEARCH**

Research is designed and approached in two main ways, which contrast strongly in terms of perspective, method and therefore outcome. The more traditional approach, and the one with which most people are familiar, might be described as doing research ‘from the outside in’. This is called the ‘etic’ (see footnote #4) approach, and is reflected in the question: “What do I see these women doing/ how will I describe their experiences?” Such research is conducted from the perspective of professional ‘outsiders’, perhaps a team of researchers, or an organisation commissioning a piece of research. The framework for the research is decided in advance, and the ‘research group’ is usually perceived as a passive participant in the process.

Feminist research methodology is similarly focused on active participation of women and others in the research process ‘stemming from a concern that existing methodologies support sexist, racist and elitist attitudes and therefore negatively effect people’s lives (Holland et al., 1995).

The feminist research project proposes not a prescriptive, distinctly feminist set of methods, but a variety of methods employed with the objective of bringing women’s experiences from the margins to the centre. The objective, in terms of research outcomes, is the development of recommendations which position women’s interests centrally in policy debates and maximize their potential for implementation into policy and practice. As such the objectives of Participatory Learning and Action as a research strategy for this project

serve as an appropriate vehicle to place women and their concerns at the centre of the research process. The research strategy is outlined below.

In contrast, taking an emic approach means doing research ‘from the inside out’, and is reflected in the question: “What do these women see themselves doing/ how do they describe their experiences?” This approach sees the research group as expert in its own right, and takes that perspective on board, often placing it in positive articulation with other expert opinion. In emic research, the language and categories of analysis used by the group become the framework or lens through which the data is viewed and analysed, and the research group is involved in an active and participatory way throughout the research process.

#### **4.3 RESEARCH STRATEGY:**

##### **PARTICIPATORY LEARNING AND ACTION (PLA)**

The NWCI Millennium Project was designed to respond to the challenges and concerns we have noted, and a PLA (**Participatory Learning and Action**) research strategy was adopted. PLA techniques are capable of accessing both qualitative and quantitative data<sup>10</sup> and can be described as “a growing family of approaches and methods to enable local people to share, enhance and analyse their knowledge of life and conditions, to plan and to act” (Chambers, 1994c). PLA techniques also possess the necessary flexibility to explore issues of a sensitive nature, where ‘drawing close’ to women’s actual ‘lived experience’ of health/wellbeing is essential to making visible the complex realities of those lives. This research strategy provided the women involved in the project with tools to develop analytical frameworks that make sense of their experience and articulate their vision for a more positive future.

Key features of PLA include:

- giving credence to the insights and abilities of local people to share and enhance their knowledge of the issue in question;
- using emic research to elucidate the ‘insider view’ and uncover local categories of meaning and analysis;
- avoiding the kind of biases that have characterised much research done from the outsider’s point of view (Kane, 1995), and
- ‘handing over the stick’, meaning to actively encourage local participation and development of positive action planning.

This research strategy is now in use world-wide in organisations as diverse as UNICEF, Save the Children, WorldVision, Ipas and The World Bank.

#### **4.4 RESEARCH SCHEDULE**

**4.4.1 Training Programme:** Training for the Millennium Project took place in two distinct phases: Phase One training spanned March to October 1999 and provided practical training in basic PLA principles and techniques. Phase Two training spanned March to May 2000 and covered more fundamental issues in PLA.

An enormous amount of material was covered in each of the training sessions in groups where women had differing levels of knowledge about research and group facilitation. Since an aim of the project was capacity-building, participants did not have to have prior experience of any of the above. Facilitation skills

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<sup>10</sup> As a research approach, PLA remains open to the integration of conventional research methods and approaches. This allows PLA to inform other research strategies, for example, a tightly-focused qualitative PLA research project is capable of usefully informing larger-scale quantitative studies.

are extremely important in PLA research. Also important to the research is note-taking during research techniques. Both facilitation and note-taking were covered briefly in the training.

Feedback from the PLA facilitators<sup>11</sup> indicates that a number felt that they would like more training in facilitation and note-taking: *'[I would suggest] more in-depth training on bettering facilitation techniques – this is vital in both encouraging and energising a group to get to their full potential'* (PLA facilitator).

.2 **Research Schedule:** At the close of each of the 13 training programmes nation-wide, facilitation teams were invited to negotiate and choose one of the six topics as their 'national' issue (meaning it was being researched by other teams across the country). They were also invited to devise a 'local' topic of their choice ('local' meaning it could be a topic unique to the locality). In many cases, teams preferred to select another of the six issues for their local topic because it matched their concerns and those of their research groups. The information generated for the study on health, therefore, includes 9 'national' and 6 'local' issues.

Research was conducted over the period May 1999 – May 2000. Teams were provided with back-up support from one of four Millennium Project staff.

## 4.5 RESEARCH METHODS

The health component of the Millennium Project involved several processes:

- methods:
  - sampling;
  - research outlines and selection of data-collection techniques;
  - data analysis;
- putting appropriate monitoring and evaluation procedures in place;
- ethical issues.

### .1 Sampling

**PLA Facilitators:** The initial project design aimed to draw members from NWCi affiliate organisations to train 120 facilitators in teams of 2, giving us 60 teams nation-wide. In early 1999, the NWCi had 142 affiliates. All received information packs about the proposed Project and invitations to nation-wide Information Sessions. Project information was also made available via NWCi Panel Meetings and affiliates were invited to consider nominating women for inclusion in training. 41 affiliates responded, and from this number, 9 teams from rural and 6 teams from urban-based affiliates carried out research<sup>12</sup>. Counties Cork, Donegal, Kerry, Limerick, Monaghan, Galway, Roscommon, Wicklow and Leitrim were represented, as was Dublin West (x3), North Central and South Central. In all, 15 teams conducted research on the health component, with a total of 155 participants nation-wide.

**Research Participants:** Intensive qualitative study of a small number of cases can lead to valuable understandings about women's health needs and access to care. The sample of 155 participants involved in this study, therefore, is a non-probability purposeful sample<sup>13</sup>. The principle of selection is the researcher's

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<sup>11</sup> As the women involved were called after completion of the first phase of training.

<sup>12</sup> For reasons of confidentiality, participants were not asked for their address. It is therefore possible that although the facilitators may have come from an urban area, the women taking part in the research did not, especially in small urban centres. Therefore, we cannot give a precise urban/rural split.

<sup>13</sup> Types of purposeful sampling include: extreme or deviant case sampling, typical case sampling, critical case sampling and confirming and disconfirming cases (Kane, 1995).

judgement as to applicability (Robson, 1993). The value of non-probability sampling lies in the depth and quality of information generated in the research encounter.<sup>14</sup>

Facilitation teams gathered their research participants from within affiliate groups mainly via network sampling<sup>15</sup>. A basic criterion for selection was that participants needed to be able to speak from personal experiences of health-related issues.

#### **4.5.2 Research outlines and selection of data-collection techniques**

The NWCI Millennium Project Team engaged in a consultative process with affiliates, policy analysts, advisors and research consultants in the process of designing the research topics. Analysis of the data generated by this process, coupled with further input from the NWCI Policy Team, resulted in the identification of key foci for the health research component.

As one of the aims of Phase 1 was to provide data on a national scale, it was necessary to introduce some level of standardisation to the process. Therefore, a research outline comprising a range of PLA techniques and a sequence for their use was designed. Teams were asked to follow the outline closely in order to make scaling up and a level of standardisation possible. The specific questions addressed by each technique can be found in the results section of this report.

It is important to stress that PLA techniques function as a focus for discussion as well as an illustration of the discussion and analysis in which the group engages.

##### **4.5.2.1 'Women and Health' – range of techniques and sequence:**

- **Card Sort 1** was designed to enable participants to study a series of pre-prepared cards and decide whether all of these cards are relevant or whether some should be discarded.
- In order to access women's own ideas of what is necessary for health and well-being, participants were asked to add any extra cards they thought should be included via a **Brainstorming Exercise**. They were asked to consider these extra cards under the research question: 'What other key supports (needs) do you think necessary for women's health and well-being into the year 2020?' Participants could add up to 10 extra cards.
- Participants then proceeded to the **Seasonal Calendar**, taking all of the health needs cards and evaluating levels of intensity over the span of a woman's life.
- The next technique, **Card Sort and Direct Ranking**, was a two-part exercise, designed to access two different things:
  - Participants were asked to divide the 'needs' cards into 3 categories: 'adequately met', 'partially unmet' and 'completely unmet'. This identified which health needs and supports fell into which categories.
  - 'Adequately met' needs cards were set aside.
  - Then participants were asked to rank 'partially unmet' and 'completely unmet' needs cards in order of greatest to least importance for women's health/well-being. This produced two ranked sets of cards, where participants showed how important each need or support is in relation to the others (rank order).
- The final technique to be completed was a **Double Matrix**. It was designed to correlate needs for women's health/well-being and potential solutions. These solutions were divided into 2 categories,

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<sup>14</sup> As our study sample is not a probability one, we are not making claims for statistical representativeness or significance of our findings.

<sup>15</sup> Network sampling is, again, a type of non-probability sampling.

those that can be activated by participants themselves, and those that require outside assistance (for example, State funding).

#### 4.5.3 *Data Analysis*

PLA was developed for use primarily at the micro or local level, the level most often ignored in policy formation. Since the Millennium Project was national in focus, it required a scaling-up of the research approach. While scaling up has been achieved in many countries, the literature attests to its problems, mainly, meeting the challenge to maintain the integrity of the PLA process in terms of its context-specific value, while attempting to make key connections across groups at the macro level.

PLA analysis is usually undertaken on-site, is of an organic formative nature and is a collaborative effort by facilitators and participants alike (Chambers, 1994b and c). Due to the limited resources at the disposal of the research team and the breadth of the project itself, this approach was not feasible for this project.

Analysis of the returned research data was, therefore, conducted in-house. It is important to stress that this does not mean participants were completely removed from the analytical process; because many of the techniques are, in and of themselves, analytical tools, participants were involved in preliminary analysis at the local level. For example, by completing matrices and direct ranking, by conducting card sorts and creating seasonal calendars, the women in this study were analysing primary data as they generated it. They made analytical decisions about proportionality; they prioritised and categorised; they showed correlation and identified bases for action planning and policy development.

The main task, therefore, facing the Project Team was to design an analytical framework appropriate for dealing with ‘scaled-up’ PLA, where the analysis was to take place in-house. This framework would have to meet a number of challenges – it would have to:

- be able to cope with a considerable bulk of data;
- be able to represent as accurately as possible the voices of the women who carried out the research’
- be capable of presenting themes and categories that emerged across a number of research reports, while, at the same time, preserving the depth and individuality of distinct groups’ research material.

Data arising from PLA research is often a mix of textual and numerical data, each of which are interdependent on the other. Brewer and Hunter (1989) have pointed out that qualitative research in general is inherently multi-method in focus, and this use of what is known as ‘methodological triangulation’ (Janesick, 1998) is central to the strategies employed by PLA. Four techniques (card sorts, direct ranking, seasonal calendars and matrices) were utilised for the ‘Women and Health’ component.

Multiple analytic tools were used to deal with the different forms of data. An outline of the different methods used to analyse the techniques employed in ‘Women and Health’ follows below:

<b>RESEARCH TECHNIQUE</b>	<b>ANALYTIC TOOL EMPLOYED</b>
Background questionnaires	SPSS
Facilitator evaluation forms	SPSS
Card Sort #1	Microsoft Access
Brainstorming	Microsoft Access
Direct Ranking	Microsoft Access
Card Sort ‘Categories and Characteristics’	Microsoft Word
Seasonal Calendar	Microsoft Word
Matrices	Microsoft Word
Accompanying observation notes	QSR NUD*IST

Finally, PLA is fundamentally conceptualised and therefore designed as a holistic, interconnected research approach. The risk of indulging in multiple methods of categorisation is that one might “lose the particularity of particular cases” (Fielding and Lee, 1998), only to be left with “...a smoothed set of generalisations that may not apply to any single case” (Huberman and Miles, 1994). This danger was tackled by including a case study of the research carried out by one of the groups in this component of the project. This group represented a group of women with special needs specifically in terms of hearing, and it was felt essential that the special health needs articulated should be studied in their own right.

Because extended co-analysis was not feasible for the project, the team became aware of questions arising from the research that could not always be answered, for instance, when observation notes from facilitators did not expand on the emic concepts being used by groups or did not clarify decisions that were made during the techniques. Research is always somewhat unpredictable and questions will arise in the research that are as important as the rich descriptions of phenomena that are present in the data. In other words, the team did not expect to present the definitive voice on each of the six issues, but to employ a way of investigating the issues that could be improved and built upon in the future. The team understood that, “*no picture is ever complete...what is needed is many perspectives, many voices, before we can have deep understandings of social phenomena*” (Denzin and Lincoln, 1998). Thus, where appropriate, we have identified where information was not available and have made suggestions for future research.

#### **4.6 DESIGNING APPROPRIATE MONITORING AND EVALUATION PROCEDURES**

An essential aspect of any research project is an evaluation component. This is especially true where the research aims to encourage people to become ‘stakeholders’ in the study and to facilitate participants in making their voices heard. To this end, a framework for on-going monitoring and evaluation was designed to give facilitators the opportunity to tell us what worked well and what could be improved. Multiple data sources were employed, including:

- Observation notes accompanying the returned research.
- Evaluations of training programmes.
- Facilitators’ comments at the ‘Gathering Day’ (this was an event organised by the team in February 2000 to gather facilitators together so that we could hear about their experiences of doing research).

Facilitators’ evaluation questionnaire (this was a questionnaire designed in order to obtain facilitators’ satisfaction with the research project as a whole).

#### **4.7 ETHICAL ISSUES**

For the health component of the research, facilitators were encouraged to remain aware that women providing information on any aspect of their lives are vulnerable in a number of ways. Facilitators were aware that researching these issues requires complete confidentiality. During training, several safeguards were put in place. Confidentiality guidelines were provided in the training manuals and discussed with facilitators, as was the need to respect boundaries and assure participants of their rights during the research process. Names of participants and names of affiliate groups were not mentioned in released material without consent. If data from one affiliate group was used during training or to be released, explicit consent for this was sought from the facilitators involved.

## **5. RESULTS**

### **5.1 RESPONSE RATE**

15 Groups completed research on 'Women and Health', 9 as their national topic and 6 as their local topic. Two groups were excluded from the cross-analysis of results, as they completed the research in a manner that did not conform to the standardised outline and was therefore not amenable to cross-analysis.

The geographical distribution of groups who engaged in research in this topic were as follows (for those included in the cross-analysis):

Dublin city and county: 4 groups

County Monaghan: 1 group

County Donegal: 1 group

County Roscommon: 1 group

County Galway: 2 groups

County Cork: 2 groups

County Leitrim: 1 group

County Wicklow: 1 group

### **5.2 SAMPLE PROFILE**

- The average age of the women who completed background questionnaires (respondents) was 42 years. Participants were asked to describe their current economic status by circling one value on a 6-point scale which consisted of: 1) extremely comfortable; 2) very comfortable; 3) comfortable; 4) not so comfortable; 5) barely comfortable, and 6) not comfortable at all.
- 53.2% of respondents described their economic situation as 'comfortable', and 22.8% described their economic situation as 'very comfortable'.
- 67.6% of respondents said they worked inside the home.
- 60.5% of the women said they worked outside the home, and
- 73.1% said that their work was paid.
- 15.2% of the respondents said they left education during primary school, 12.7% during secondary school and 12.7% after the Junior or Intermediate Certificate.
- 69.6% of the respondents said that they did have daughters. The average number of daughters per respondent was 2.

### **5.3 CARD SORT 1**

In consultation with the National Women's Council of Ireland, a list of pre-prepared cards was drawn up which reflected current opinion on priority health needs for women in Ireland. Participants were requested to decide how many, if any, of these cards should be discarded and to give any reasons they may have had for their decision.

These needs included:

- One-stop-shop for women's health;
- Women-friendly clinics in urban and rural areas;
- Respite and counselling support for women as 'carers';
- Access to counselling and mental health care;
- Easy access to women's health/well-being information;
- Equality in relationships between clients and service providers;
- Access to family planning;
- Access to fertility treatment;

- Holistic approach to health and well-being;
- Free breast screening;
- Free cervical screening;
- Improved maternity services.<sup>16</sup>

This parallels those areas of concern covered in *the Plan for Women's Health 1997-99*, (Department of Health and Children, 1997) although the plan goes into more detail on some areas. Below is a list of the target areas for women's health identified by the Plan:

- Information for health;
- Healthier lifestyles;
- Cardiovascular disease;
- Cancer (lung, breast, cervical, skin cancer);
- Promoting oral health;
- Childbirth and breast-feeding;
- Family Planning and reproductive health;
- Violence against women;
- Promoting mental health, with a specific focus on alcohol-related problems;
- Creating a woman-friendly health service (Ibid.).

Of the 13 groups who were included in this exercise, 10 retained all of the pre-prepared cards. Groups H2 and H3 discarded free breast screening, although neither specified a reason for this in their accompanying observation notes.

Group H4 discarded 3 cards. 'Easy access to women's health and well-being information' and 'Women friendly health clinics in urban and rural areas' were both felt to be covered by 'One-Stop-Shop for women's health':

*'Easy access to women's health and well-being information: when one woman said that this would be covered in one-stop-shops the group decided not to keep this card. Women-friendly health clinics in urban and rural areas...again the group felt that this need would be met in the one-stop-shop for women's health – so threw out the card.'*

'Access to family planning' was replaced with 'FREE access to family planning':

*'General belief that this was widely available, but consensus as to its need to be a free service, so changed to 'free' access to family planning.'*

- Overall, each card raised a number of important issues for the groups involved. All the groups felt that a **'one-stop-shop for women's health'** was very important and should cover all of a woman's health needs. Group H4 pointed out that an on-site crèche would be essential. *'All agreed that it would have a crèche.'* Group H8 pointed out that women-friendly health clinics are very important, especially those located in rural areas, in terms of familiarity and privacy:

*'[A] small country town would know if you went into [the] clinic. Everything provided so no-one would know exactly what you're going in for.'*

- The need for **respite and counselling support for women as carers** seemed to strike a chord with most of the groups. Group H9 stressed the fact that there is often no support for women when people

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<sup>16</sup> See Appendix 1 for the back-up sheet that accompanied these cards, explaining exactly what the research team meant by each card.

leave hospital, where they have had access to 24-hour care and return home. Group H5 felt that respite and support for women as carers was ‘virtually unavailable’. On the other hand, Group H13 said that in their area (Dublin) the service was improving for carers of children with special needs:

*‘...they will take the child and let you have respite or give you a holiday.’*

However, there did seem to be some confusion about the extent of support available, as another participant in this group felt that there was no organisation available to enable carers of people with amputations to take a break.

Group H8 said that the extent of respite care available was insufficient and that too often there was an assumption that mothers and daughters had an automatic duty to take on caring roles:

*‘...with handicapped children, respite for one week only, shouldn’t presume that once a mother/daughter, [you should] put up with your lot.’*

- **Access to counselling and mental health care**

The three groups who discussed this issue in their observation notes felt that there was a change in attitudes away from drug-based therapies for mental distress, or a denial of the legitimacy of mental distress, to a more accepting view of counselling and psychotherapy:

*‘With counselling [there’s] no anti-depressants’ (Group H4).*

*‘...the way we were brought up was to deal with our own problems...They were not looked at as needing counselling’ (Group H13).*

*‘Counselling [was] seen as weakness, flaw in character... [now] becoming more...acceptable’ (Group H8).*

However, when groups looked at the extent of service provision, feelings were much more mixed. Group H4 said there was difficulty accessing services, as *‘people didn’t know where to go.’* Group H8 felt that there should not be waiting lists for people trying to access counselling and that it is better to provide external rather than in-house services so as not to discourage potential clients. Group H13, however, did feel that there were easily accessible counselling services available in their area.

- **Easy Access to Women’s Health and Well-being Information**

Three groups recorded their discussions on this issue in their observation notes. Again, there was some contradiction between groups as to the range and current availability of such information. Group H5 felt that there was not enough

*‘...information, discussion and choice offered to a woman.’*

In contrast, Group H13 had a much more positive view – again they referred to the services available in their own area:

*‘Information leaflets [are] good...nurses from the [various] hospitals come to the family resource centre to give talks on women’s health.’*

This group said that the main stumbling block to the provision of information was in fact members of the Roman Catholic Church who had prevented talks on women's health:

*'a family resource centre in [name withheld for reasons of confidentiality] were not allowed to have a talk on women's health because the priest said family planning would be a part of it...[another participant] knew a group where a nun would not allow it.'*

However, it is important to note here that this should be taken as anecdotal and not as evidence that this is a systematic and widespread occurrence.

Group H8 saw information and education as essential for awareness-raising, to prevent people waiting for symptoms to appear before attending for treatment for potentially serious conditions, such as cancer. They also argued for more widespread dissemination of information:

*'Is information everywhere? Should be made available rather than having to make an appointment with GP.'*

- 6 groups discussed the issue of **equality in relationships between clients and service providers** in their observation notes. 3 of these felt that the attitude of the service provider was important in determining the quality of the interaction. Group H12 said that the friendliness of the doctor was essential:

*'...if women had a friendly doctor it would make all the difference.'*

Participants in Group H13 saw a link between women having children with them during a consultation and the doctor's attitude towards them:

*'...a mother cannot talk with the doctor when she has young children with her. Doctor's attitude: 'Why should he bother?''*

Group H14 appeared to hold a very negative view of levels of equality between clients and service providers, especially doctors, specifically in relation to lone parents:

*'Huge lack of sympathy and respect from doctors and some nurses especially to women. Manner very bad...particularly to lone parents.'*

Of the other three groups who discussed this issue in their observation notes, one (H4) discussed equality in terms of financial equality and the fact that some doctors take a different attitude to patients who use the medical card:

*'When I produce the medical card, there is an assumption and an attitude that I am not educated, that I know nothing' (Participant quoted in observation notes).*

Group H13 described a situation where levels of equality varied according to the institution and/or the particular practitioner attended (a quote here would not be appropriate as names and places are mentioned which would be prejudicial to those involved). The final group (Group H8) only mentioned this briefly in terms of the listening and communication skills of doctors during the consultation.

- **Access to family planning and access to fertility treatment**

Family planning was not discussed by any of the groups who supplied observation notes, perhaps because it was felt that it was self-explanatory and needed no justification for inclusion on the list. Two groups mentioned access to fertility treatment, both arguing that service provision in this country was insufficient and very basic.

- **Holistic approach to health and well-being**

Four groups expanded on their opinions about this issue in the observation notes. All supported the idea of an holistic approach to health, with even those who were reluctant to try alternative therapies supporting the right of women to choose the type of treatment they preferred:

*‘One woman spoke of her inability to be persuaded to try ‘alternative’, but still felt others should have the choice’* (Group H4)

Group H6 felt that many ‘biomedical’ doctors still did not support alternative approaches to treatment, while Group H5 did not agree with the placing of homeopathic remedies on prescription.

Group H8 believed that there was a lack of information available on holistic approaches to health:

*‘More emphasis on holistic approach if more information available. People wouldn’t only go to GP.’*

- **Free Cancer Screening** (Incorporating free breast screening and free cervical screening): There appeared to be different opinions about whether cervical screening was in fact available free of charge. While two groups (H4 and H14) said that sometimes participants had had to pay for a cervical smear test even when on the medical card, other groups said that, although a free service was available, uptake was restricted for reasons such as privacy:

*‘Free smear clinics but too many know you, don’t feel comfortable’* (Group H12)

lack of smear test centres:

*'Local doctor sends patients [elsewhere] for smear tests'* (Group H13)

and embarrassment:

*'Some women have hang-ups getting smear test done...'* (Group H8)

- **Improved Maternity Services**

Only two groups discussed this issue in their observation notes, and neither went into great detail. Group H14 pointed out the need for increased choice to be given to the mother before and after childbirth:

*'Maternity – more choice before and after baby.'*

The participants in Group H4 shared different experiences of childbirth, some negative and some positive, and concluded that 'while the service appeared to be mixed, overall the service could be improved.'

- **Summary**

Overall, as the majority of groups included all the pre-prepared cards provided, discarding none, it can be concluded that the health needs as outlined by the NWCI are relevant and important in the daily lives of the women who took part in this research.

#### 5.4 BRAINSTORMING – EXTRA CARDS ADDED

	REFERENCES	GROUPS
Education and information	19	7
Improve state services	12	9
Reproductive Health	11	6
Community Care	9	7
Child Care	8	7
Expansion of free medical care	7	6
Women and Care <sup>17</sup>	7	4
Abuse/Addiction	7	3
Counselling/Mental Health Care	5	4
Cancer Screening	4	3

The table above shows the list of additional 'needs' cards added by participants, by group and reference. Additional cards have been grouped together under 10 main headings for ease of analysis. As some groups created several different cards dealing with a common issue, these have been counted and the ranking of the headings is based on both the number of references and the number of groups who made those references. Topic number 1, 'Education and Information' is ranked number 1.

- **Education and information** has emerged as a significant issue for the groups taking part in this study. During the consultation process undertaken by the then Department of Health in drafting the Plan for Women's Health (Department of Health and Children, 1997), one of the strongest messages received was that Irish women felt that a lack of information restricted their ability to evaluate their own health and the health of those closest to them, making it difficult for them to make informed decisions about

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<sup>17</sup> [as carers of people other than children and as recipients of care]

their health (Ibid.). Unfortunately, it appears that there is still a perceived lack of access to education and information for the women involved in this project.

In the observation notes accompanying this exercise, many different points were raised about this issue. One was the impact that lack of education and/or information can have on women's health. The following quote from Group H9 illustrates this very clearly:

*'...education on women's health issues...is vital, women don't have smear tests done because of ignorance.'*

Another area mentioned by 2 groups was the need for more information and education on reproductive health and family planning, especially the menopause and teenage pregnancy.

A number of recommendations were put forward by groups on what could be done to improve access to education and information. Group H9 recommended that women educate themselves in order to be able to answer children's questions:

*'Women need to be more at ease about their bodies in order to explain and answer children's questions.'*

Group H6 also put forward a number of concrete recommendations:

*'A booklet in Q+A format written in simple terms would be important...An open health programme on TV would be extremely helpful...24 hour help-line necessary.'*

- **Improve state services**

The second most important issue raised by groups was the need to **improve state health care provision**, specifically the expansion of existing services and the decentralisation and devolution of power to current services so that women in rural and isolated areas can access appropriate health care. For example, Group H9 discussed the need for a *'...mobile unit for breast screening because Dublin is too far and transport is a problem.'*

- **Reproductive health**

This issue came third in order of importance. Two groups raised the issue of STD and AIDS awareness. Group H9 felt that clinics for STD and AIDS should be available locally, not just in major urban centres.

*'Sexually Transmitted Diseases, VD clinics and AIDS awareness are necessary and needed locally. Take women's health out of the cities into the rural areas.'*

Group H8 argued that there needs to be more awareness about the risk of STDs especially those that do not manifest physical symptoms:

*'More awareness of STDs...can get disease not even knowing about it, i.e. no symptoms to chlamydia.'*

Interestingly, Group H12 felt that differences in the quality of contraceptive services provided and the attitudes of GPs was a real problem for them:

*'O: We have our female doctor and she won't prescribe the pill, it's her religious belief.'*

*F: Girls go to temporary doctors when full-time doctors are off, and they can get the pill.'*

Prendiville and Short (1993) have documented the controversial and difficult struggle to obtain any real contraceptive services in this State, and point out that current service provision is still reliant on private organisations like the IFPA and Well Woman Centres, as well as GPs. Much has been written about how GPs' attitudes towards contraceptive health impacts on the quality of service they provide, if any.

- **Community Care**

Seven groups came up with 'needs' cards that were grouped together under Community care – these mainly referred to the introduction of staff and services to the local community to work on behalf of the community. Group H9 wanted to see a local walk-in health clinic rather than the referral system, although they did not elaborate further in their observation notes.

- **Childcare**

Although this issue was placed at number 5 in the ranking of overall headings in the above table, those groups that did mention it felt it to be extremely important to women's health, especially for those women working outside the home and lone parents. Group H4 strongly recommended the setting up of communal crèches in the community:

*'...there should be communal crèches where women can drop their children if they need to.'*

Participants also linked a lack of childcare facilities to the possibility and dangers of isolation:

*'Drop-in centres for mothers, get them out of the home'* (Group H8).

- **Women and care** was a closely linked issue, ranked at number 7. This heading included women caring for dependent adults, especially elderly parents, and also women trying to access care for themselves. Group H8 argued that there is a lack of recognition on the part of the State for mothers who stay at home and for carers in general. One participant in this group recommended 'a realistic payment for carers.' Group H4 pointed out that improved hospice care, or home care for women who are terminally ill, is needed without means-testing. They also recommended setting up a government department for the elderly:

*'Improved hospice/home care for women – no matter what their circumstances - for those women who are terminally ill...there should be a government department for the elderly.'*

- **Expansion of services on the General Medical Scheme**

Most groups who mentioned this felt that certain key services should be accessible to those on a medical card. These included dental care, eye care and ENT (ear, nose and throat) care, in addition to the free cancer screening covered by the pre-prepared cards.

- **Abuse or addiction**

Only three groups mentioned women and children experiencing domestic violence or having an addiction to substances as specific health needs. It was not clear why so few groups alluded to this issue. It is possible that both were not regarded as a health issue per se. However, those groups that did discuss violence against women and children or addiction to substances indicated that the service provided was patchy and relied very much on under-funded or voluntary organisations.

*'...there is nothing...in the north-west for women experiencing violence in the home, the nearest is Enniskillen and that is a different jurisdiction'* (Group H12).

- **Counselling/Mental Health Care**

Relatively few groups assigned additional cards to this issue, as it had been covered in the pre-prepared cards. Those who did talked about counselling in terms of specific situations where counselling is required, such as caring for elderly parents or people with special needs, and women and children experiencing domestic violence. A demand for the provision of free or funded counselling was also voiced.

- **Cancer Screening**

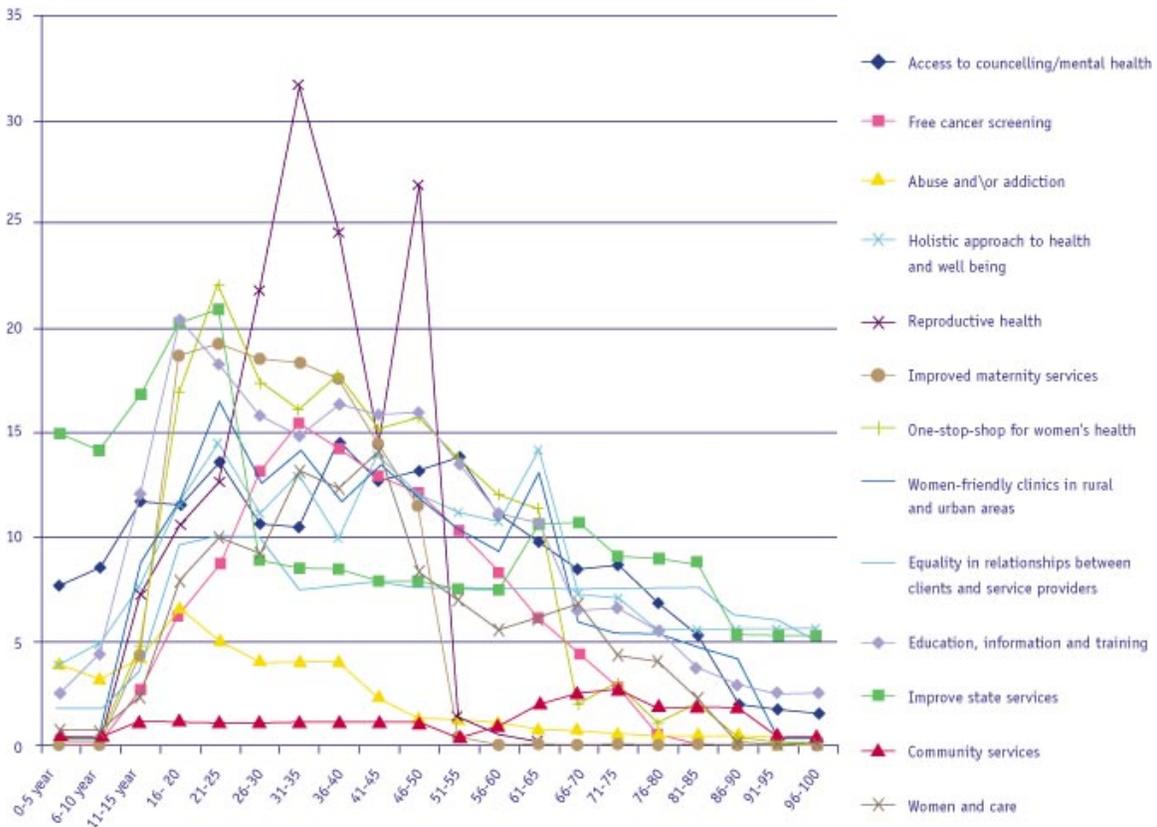
Finally, 3 groups (H1, H2 and H3) added extra cards dealing with the issue of cancer screening. All three emphasised the need to ensure that all forms of cancer screening were free. One group also

emphasised the importance of identifying families at high risk of developing breast cancer and providing free screening at an early age.

- **Summary**

Although the Department of Health and Children committed itself to working with others to pilot new approaches to disseminating information and good practice guidelines in order to render health-related information more accessible, this still arose as the most important health need identified by the women themselves.

## 5 SEASONAL CALENDAR



The chart above should be read by tracking each health need (coded by colour in the legend on the right) across from 0-5 years to 96-100 years, noting the peaks and troughs of each one.

The results of all the valid seasonal calendars submitted (10) were combined and an average was taken to obtain the combined trends for each health need identified. Some categories have been amalgamated to simplify the complexity of the data. **Free cancer screening** was expanded to include the pre-prepared cards **free cervical screening** and **free breast cancer screening**. **Access to counselling and mental health** also incorporated the items from the relevant additional needs category. **Reproductive health** now includes the pre-prepared cards **access to family planning** and **access to fertility treatment**. **Women and care** now incorporates **childcare** and **respite and counselling support for women as carers**, in addition to the categories originally covered by this heading.

The above graph illustrates a tendency for most of the health needs to peak in importance from the onset of adolescence (11-15 years) until ages 61-65. Certain categories would be expected to dominate within this age group such as **‘free cancer screening’**, **‘reproductive health’** and **‘improved maternity services’**. However, other needs not directly related to child-bearing or reproductive health also followed this pattern, such as **‘women-friendly health clinics in urban and rural areas’**, **‘one-stop-shop for women’s health’**, **‘education and information’**, and **‘expansion of free medical care’**, amongst others.

However, there were some significant exceptions to this general pattern. **‘Community services’** was assigned a low but constant value throughout the life-span until about age 61-65, when it showed a small increase in assigned importance before dropping again at age 90.

**‘Access to counselling and mental health’** stood out as being assigned relatively high importance throughout the life-span until its decline at around the age of 90.

**‘Improve state services’** is unique in that it is assigned a particularly high level of importance from age 0-5, peaks early between the ages of 21-25 and 26-30 and falls sharply until levelling off before climbing at age 61-65. It may be that women feel that current service provision is geared more towards meeting the needs of women of child-bearing, child-rearing age, and/or sexually active women than at other points in their lives, although further research would be necessary to investigate this further.

## 5.6 CARD SORT CATEGORIES AND CHARACTERISTICS

13 groups divided their cards into three categories:

1. Needs adequately met by current service provision;
  2. Needs partially unmet by current service provision;
  3. Needs completely unmet by current service provision.
- **Adequately met:** 4 groups identified needs that they judged were adequately met by current service provision. While there was no overall point of commonality, 2 groups indicated that ‘Access to family planning’ was currently ‘adequately met’.

Below is a table summarising the results:

### GROUP H4

- Family planning
- Supported breast-feeding
- Improved maternity services

### GROUP H2

- Access to counselling/mental health care
- Access to family planning
- Access to fertility treatment

### GROUP H5

- Availability without prescription of natural herbal remedies<sup>18</sup>

### GROUP H14

- Women’s needs not being met by the health promotion system overall
- Baby nurse gives good support

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<sup>18</sup> This group carried out their research before the decision in late 1999 by the then Minister of Health to ban the sale of St John’s Wort without prescription.

- **Partially met**

	<b>NO. OF GROUPS</b>
Access to Counselling and Mental Health	9
Improved maternity services	7
Free breast screening	6
Equality in relationships between clients and service providers	6
Access to family planning	6
Respite and Counselling Support for women as carers	6
Access to fertility treatment	6
Easy access to women's health and well-being information	5
Free cervical screening	4
Holistic approach to health and well-being	4
Women-friendly clinics in urban and rural areas	2
One-stop-shop for women's health	1

From the above table it is clear that the majority of groups felt that counselling and mental health issues were at least partially covered by current service provision. Improved maternity services also emerged as being partially met by 7 groups. The needs that fewest groups saw as partially met by current service provision were both to do with health care services that were specifically geared towards women; the 'one-stop-shop for women's health' and 'women-friendly clinics in urban and rural areas'.

- **Extra cards added (coded and categorised)**

Caution must be exercised when interpreting the results from this table as the rank order outlined above is affected by the number of groups who named these cards in the brainstorming exercise. However, it can be said that of the 7 groups who created cards coded under 'education and information', 5 saw these as partially met by current service provision. Of the 6 groups who created cards coded under 'reproductive health', 3 saw these as partially met. On the other hand, only 1 of the 7 groups who created cards coded under 'community care' saw these needs as currently partially met. This situation was paralleled in 'childcare'. Only 1 of the 4 groups who created cards coded under 'counselling/mental health care' felt that this need was partially met by current service provision.

- **Completely unmet**

	<b>NO. OF GROUPS</b>
One-stop-shop for women's health	10
Holistic approach to health and wellbeing	7
Women-friendly health clinics in urban and rural areas	7
Respite and counselling support for women as carers	5
Free cervical screening	5
Free breast screening	5
Easy access to women's health and well being information	3
Equality in relationships between clients and service providers	2
Access to fertility treatment	1

10 groups felt that 'one-stop-shop for women's health' was completely unmet by current service provision. Both 'holistic approach to health and well-being' and 'women-friendly clinics in urban and rural areas' were seen as completely unmet by 7 groups.

- **Cards added coded and categorised**

	<b>NO. OF GROUPS</b>
Child care	5
Reproductive health	4
Community Services	3
Free dental/eye/E.N.T. care	3
Cancer screening	3
Women and care	3
Improve state services	3
Education, information and training	3
Abuse/addiction	3

Of the 7 groups who created cards coded under ‘childcare’, 5 indicated that this issue was completely unmet by current service provision. Of the 6 groups who created cards coded under ‘reproductive health’ 4 considered it completely unmet. ‘Reproductive health’ refers to issues other than those mentioned on the pre-prepared cards, specifically health needs related to the menopause. All the subsequent health needs were designated completely unmet by 3 groups.

**Summary**

Health care needs dealing with environments and models geared towards the needs of women, such as ‘one-stop-shop for women’s health’, ‘women-friendly health clinics in rural and urban areas’, ‘childcare’ and ‘reproductive health’ were generally seen as having the least coverage by current service provision. ‘Counselling/mental health care’ and ‘education and information’ were seen as having partial coverage by the majority of groups.

## 5.7 DOUBLE MATRIX

Of the 13 groups who were included in the cross-analysis, 9 returned valid double matrices. In the Double Matrix, participants were asked to identify practical actions that could be taken to ensure that their health needs could be addressed in the health service arena and more broadly in the social policy arena. They generated these actions according to two categories: first, actions that they could do something about themselves with no outside assistance and, second, actions that require outside assistance.

When analysing the double matrices, only actions that were scored as interventions that addressed the pre-prepared health needs were coded and categorised. The wide range and complexity of the added cards did not permit their inclusion in the analysis of the matrices. The observation notes for the double matrices were not as detailed for that method as for some of the others in the health process. For this reason, only the range of actions specified and a description of what each type of action entailed are included without excerpts from the observation notes.

### 5.7.1 *Actions that could be carried out with no outside assistance*

A total of 59 actions were identified by the 9 groups who produced valid double matrices. Seven of those actions could not be categorised in any way. In all, 6 types of actions were identified across the 9 groups. They are as follows:

	REFERENCES GROUPS	
Educate ourselves	46	7
Raise awareness	40	6
Lobbying work	30	6
Women supporting each other	20	6
Accessing available options	9	5
Helping carers	5	3

- **Educate Ourselves**

The most popular action that participants identified as addressing the pre-prepared women's health needs was women educating themselves about health issues and options. This education could take place in a number of settings; a local library, in a doctor's office, or through classes. Groups also talked about women knowing their own bodies and doing their own research. The importance of this type of action is consistent with the finding that an important health need to women in the project was easy access to women's health and well being information. Participants also suggested that providers need to be re-educated.

- **Raise Awareness**

This category contains actions that have to do with women making others aware about the health needs of women. It also contains actions that have to do with women themselves becoming aware of, assertive and empowered about their own health issues. Some groups specified that they could start campaigns to teach women about health issues.

- **Lobbying Work**

The third highest scoring option that participants felt they could do something about themselves was lobbying various power groups to attend to the pre-prepared women's health needs. These groups included politicians and the health boards, but they also included the local TV station and town planners.

- **Women Supporting Each Other**

This category included actions that identified ways of women working together collectively to meet their own health needs. Ways to do this included forming support groups, sharing experiences and putting together courses for other women.

- **Accessing Available Options**

The fifth highest scoring action had to do with participants accessing health services that were already available in order to have the pre-prepared women’s health needs met. Options included taking an holistic approach to health, taking supplements, going for counselling and visiting the doctor or nurse and/or the local health centre.

- **Helping Carers**

Some of the participants came up with actions around supporting women who were carers with that work and were actions that addressed the health needs for respite and counselling support for women as carers and access to counselling/ mental health care.

### 5.7.2 *Actions that require outside assistance*

In all, a total of 87 actions requiring outside assistance were identified by the groups that produced valid double matrices. These were coded and categorised into 13 types of actions, with 8 actions that could not be categorised in any way. The 13 types of actions that were identified to require outside assistance were as follows:

	<b>REFERENCES GROUPS</b>	
Government responsibilities	64	5
Education and training options	48	4
New and improved general services	39	5
Specific local services	18	4
Family planning and fertility treatment provision	18	3
Financial assistance/funding	18	3
Mental health care provision	11	4
Services for carers	9	4
Accessing holistic health care	7	4
Cancer screening	7	2
Maternity services	6	2
Lobbying work	5	2
Domestic violence services	2	2

- **Government Responsibilities**

Actions were grouped under this heading where participants related actions that identified the State, Government or the Department of Health and Children as the site where a particular action should come from. This was by far the action that the majority of the research groups saw as addressing the pre-prepared health needs. Actions in this category ranged from funding and research to policy and legislation. An interesting facet of this category was an emphasis by participants on the Government legitimising the importance of women’s health needs. Clearly, groups felt that the State and the Department of Health and Children still had much to do in order to demonstrate a serious commitment to women’s health issues.

- **Education and Training Options**

4 groups came up with a range of actions that had to do with options for education and training around women’s health issues. This type of action ranked second in the 13 types identified. Women were not the only group that were to be in receipt of these options. 2 of these actions called for providers to be re-educated. A range of contexts, whereby women themselves could avail of education and training on health issues, were identified. They included media, antenatal clinics, schools and self-education facilities.

- **New and Improved General Services**  
 This category ranked third in the types of actions identified for which the participants require outside assistance. It includes calls for improved service provision at a general or national level and also new services with a national scope as opposed to new services that would vary depending on locality. 2 of the actions called for the provision of one-stop shops for women's health. Other groups called for new services such as mobile clinics and direct telephone links to staff in hospitals.
- **Specific Local Services**  
 Actions which fell into this category involved specific groups identifying actions that were needed in their locality. These were, for the most part, changes in or provision of services. An interesting facet of this category was that these actions were indicated by groups that were either in rural areas or disadvantaged urban areas, showing that marginalised communities are not getting the services that others are receiving, and they may also have needs that are quite specific because of their marginalisation, for instance, transport in rural areas.
- **Family Planning and Fertility Treatment Provision**  
 3 groups described actions that either called for accessibility to fertility treatment or the availability of family planning. With regard to family planning, participants identified the need for more clinics. The observation notes did not expand on this category.
- **Financial Assistance/Funding**  
 This category ranked equally to family planning and fertility treatment provision. 2 of the actions in this grouping had to do with expanding the scope of free services in Ireland from making all services free if an individual has a medical card to the provision of free health insurance for all.
- **Mental Health Care Provision**  
 4 groups came up with actions to do with provision of mental health care. For the most part, this meant the provision of counselling services. Actions dealt with rehabilitation programmes, preventative care, the need for more counsellors, further training for practising counsellors and an increased awareness of services that are already available.
- **Services for Carers**  
 9 references by 4 groups were made with regard to specific services provided to ease the burden on carers. Suggestions included increased options for care and financial rewards for carers. 1 group asked for more people to be trained in care for the disabled and the elderly. Another called for childminders to be registered.
- **Accessing Holistic Health Care**  
 Actions addressing the need for an holistic view of health and accessibility to alternative modes of care focused on the gatekeeping by difficulties of access arising from current gatekeeping practices by the State and allopathic practitioners.
- **Cancer Screening**  
 2 groups identified 2 actions to do with cancer screening. These were, "Mobile units in each county for free breast screening," and "Screening made available."
- **Maternity Services**

2 groups came up with 4 actions addressing the need to improve maternity services in Ireland, including availability of home birth services, access to support agencies for new mothers, provision of nursing facilities in public buildings and improved neonatal services.

- **Lobbying Work**

Various types of lobbying work were indicated with regard to a range of health needs.

- **Domestic Violence Services**

2 groups identified 2 actions to address the prevalence of domestic violence in the country and health service provision in response to it. The actions were: “Local refuge shelter,” and “More safe houses/funds.”

## 6. DISCUSSION

### 6.1 OVERVIEW

*The Plan for Women's Health* (Department of Health and Children, 1997) made provision for the creation of a woman-friendly health service. This was to be achieved through the implementation of the commitments in the Plan, gender-sensitivity training for staff, changes in opening times of clinics and the introduction of facilities for children at clinics. However, this study shows that women place high value on a range of new services, including: a 'one-stop-shop for women's health'; thorough restructuring of existing services, like 'women-friendly clinics in urban and rural areas'; attitudinal changes among mainstream health care providers; an 'increased acceptance of an holistic approach to health and well-being', and 'equality in relationships between clients and service providers'. This indicates that, while the *Plan for Women's Health* (Ibid.) promoted a vision akin to that expressed by the women in this study, it did not go far enough in terms of implementation. Participants' summaries demonstrate this through their descriptions of patchy health service provision and confusion to the extent of that provision on the ground. Adequate service provision and universal information about services were to be provided in the implementation of *the Plan for Women's Health* (Ibid.).

Nonetheless, it is clear that the women who participated in this project have many strong ideas about what actions could be taken to address the gaps in service provision, ideas encompassing State responsibility as well as the need for an upgrade in service provision. These women are not passive recipients of health care policy and service provision, but people who would like to be able to collaborate actively with policy-makers and service-providers to ensure continued improvement in standards of health care.

### 6.2 DECENTRALISATION AND VARIABILITY OF SERVICES

There may be a number of reasons why the directives in the *Plan for Women's Health* (Department of Health and Children, 1997) have not been directly felt by women around the country. First, Ireland is among the group of countries in the EU that spend the lowest per capita on health care for its citizens (Figueras et al., 1998). A plan for health necessitates adequate financing to accomplish its goals. To add to this, Figueras et al. (Ibid.) point out that in order to maintain a decentralised and devolved system, sufficient funds have to be injected into local administration and devolution. According to the participants in the health component of the Millennium Project, adequate decentralisation and devolution has not occurred. This can be seen in the importance placed by the research groups on the improvement of service provision and the adequate funding of community care across the country.

The *Programme for Prosperity and Fairness* (Department of the Taoiseach, 2000) has made a commitment to increased health spending and enhanced services, particularly for women and marginalised groups. In 1995, the Department of Health recognised that distance from services can be a 'major handicap for women on low incomes in rural areas' (Department of Health, 1995). However, during this study, carried out in 1999/2000, many research groups from a range of socio-economic backgrounds and both rural and urban areas placed strong emphasis on the need for a coherent policy of decentralisation and devolution. The Department's recognition of this problem needs to translate into concrete policies for decentralisation and devolution by the State, avoiding an over-reliance on under-funded voluntary workers.

The *Plan for Women's Health* (Department of Health and Children, 1997) specifically referred to reproductive health and maternity services, promising to ensure that these services would be provided as recommended. However, participants in this study present a picture of patchy and variable service provision and quality across the country.

In addition, the provisions for childcare in the Plan do not seem to have had a significant impact on the women who raised this issue. They state that the fundamental importance of childcare provision, and the issue of recognition and appropriate support for the caring roles that women take on in families and social life, have not been fully addressed as yet.

### 6.3 PARTNERSHIP, PROMOTION AND POLICY

Why has the implementation of the *Plan for Women's Health* (Ibid.) not been wholly and successfully implemented? We suggest that it may be due to the differing responsibilities of various Health Boards and the Department of Health and Children, and a lack of partnership between the two. There also seems to be some disjunction between health promotion activities outlined by the Department, the actual policies devised to direct health services in the country and the variability of needs in each health region. The *National Health Promotion Strategy, 2000-2005* (Department of Health and Children, 2000c) sets out the principles for health promotion in Ireland as identified in the *Ottawa Charter for Health Promotion* (World Health Organisation, 1996). Actions to improve the health of the nation should be made on the following five fronts (Department of Health and Children, 2000c):

- Building healthy public policy.
- Re-orienting the health service to promotion and not just acute care.
- Creating supportive environments in which to make healthy choices.
- Strengthening community action - incorporating community development approaches to health promotion.
- Developing personal skills through consultation with individuals about their needs.

These principles provide a helpful guideline for health promotion programmes. One objective set out by the *National Health Promotion Strategy* (Ibid.) is a review of the implementation of the *Plan for Women's Health* (Department of Health and Children, 1997). Data from the health component of the Millennium Project suggests that the principles of health promotion set out above could be employed as a checklist for implementing the priorities in the plan. The Department has devised a healthy policy for women's health in Ireland, but it has not adhered to the last four principles listed. Services addressing the needs that the women in this study identified as partially or completely unmet could be improved and specific services could be more thoroughly implemented via consultation.

A community development<sup>19</sup> approach would help to “ascertain the views of the public regarding their experiences of the health service” (Department of the Taoiseach, 2000), as well as attending to the geographic specificity of appropriate service provision models. The rank order of the ‘partially met’ and ‘completely unmet’ health needs show which services might constitute research priorities for the Department at national level. An ongoing process of consultation and qualitative research with women could assist in building a picture of how service providers could facilitate women to make healthier choices. This consultation process might also allow women to be active collaborators in the improvement of women's health care in Ireland. A conduit for doing this might be further investment in and consolidation of the Women's Health Advisory Committees by the Department of Health and Children via the Regional Health Authorities.

### 6.4 THE BIOMEDICAL MODEL IN HEALTH CARE

The findings of this study show that the biomedical model retains its primacy in Irish health care provision, although alternative models are clearly sought by participants. Women involved in the study consistently retained several key cards – *one-stop shop for women's health, holistic approach to health and well-being* and ranked them as the first- and second-highest ‘completely unmet needs’. The importance of *women-friendly health clinics in rural and urban areas* is also worth noting. In other words, women from around the country are saying that they are not receiving healthcare in which holism and consideration of social factors plays a role in their health and well-being.

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<sup>19</sup> The Women's Health Advisory Committees are currently engaged in consultation with service providers and the Department of Health and Children, in order to address such issues as information deficits, holistic health care and better family planning services. We welcome such consultation initiatives and hope that these are continued in the future.

Because they often perceived holistic approaches as embraced by the alternative or homeopathic therapies, women referred to these in their discussions about women-friendly health clinics. Women also referred to the idea that GPs could not provide holistic care and only those who practised alternative therapies could use such a model.

The need for information about each of the three needs outlined above was also highlighted in the research and will be examined in depth below. The continued use of the biomedical model as the primary model in the provision of health care, instead of as one among many, has implications concerning whether or not the *Plan for Women's Health* (Department of Health and Children, 1997) can be implemented. The one-stop shop for women's health and the need for an holistic approach parallel the Plan's policy for a women-friendly health service. Yet, women are frequently saying that these needs have not been met.

## **6.5 FACTORS AFFECTING HEALTH STATUS**

Participants described different ways in which life factors intertwined with their health needs. This is in part borne out by the importance of such needs as childcare, reproductive health, support for carers and the importance of women-friendly care. All this points to the ways in which gender affects health. Women, by social arrangement, represent the majority of carers in society and need childcare and respite support so that they can attend to their own well-being. The importance placed on such needs as holistic health care, the one-stop shop and reproductive health also point to the far-reaching impact of gender on health and well-being. Further research would be needed to expand on the quality of the services to ensure that women are not being doubly disempowered in the medical encounter.

Gender and other factors are never separate from each other in terms of determining health and well-being (Moore and Harrison, 1995). This interdependence of several different social factors has been illustrated in the observation notes from many of the groups who participated in research for this project, including ill treatment of lone parents by medical professionals and negative assumptions about medical card users. Displacing the primacy of the biomedical model and providing information have much to do with correcting the ways in which social factors impact negatively on the health status and experiences in the medical encounter.

Health care providers have been described as moral guardians of western culture (Lupton, 1996). Their modes of practice and styles of communication have the power to shape how women think about themselves and how others perceive them, especially those women who are most marginalised. For instance, as described in the literature review, women's physiological processes have been consistently depicted in medicine as abnormal in relation to male physiological processes. Thus, if doctors are not critical of the way in which knowledge shapes their interactions, women themselves may see those processes as negative. This could result in women being uneasy about their bodies. This was illustrated by one participant, who described how uneasiness about their own bodies could inhibit women from passing on health information to their children (see quote from Group H9 in section 5.4).

Political and ethical beliefs held by practitioners are also transferred in practice. This could limit a woman's access to proper care, specifically with regard to reproductive health issues and availing of contraceptives (see quote from Group H12 in section 5.4).

The results from the health component of the Millennium Project also show that women are not just asking for health needs that are specifically to do with the different biological health issues they experience. They are asking for such things as childcare, counselling and information about all their health needs in the widest context. The observation notes also support a critique of health care that fails to consider social exclusion as a factor in health. There is a danger that a description of women's health could be employed in

the Irish context that reduces that description to a limited set of health problems. Eckman (1998) says that focusing on certain health priorities for women and not acknowledging others has the effect of overlooking the ways in which social factors affect their health.

The *National Health Promotion Strategy* (Department of Health and Children, 2000c) sets out a very limited view of the health difficulties of Irish women. They are listed as: low life expectancy compared to the rest of the EU, heart health, smoking, maternal health (neural tube defects), mental health and infant feeding (Ibid.). This is in opposition to a recent commitment in the Dáil by the Minister of Health to develop health service interventions that are matched with the strategies in The National Anti-Poverty Strategy (Department of Social, Community and Family Affairs, 1997), with health targets, policy measures and performance indicators. The Department of Health and Children must maintain its commitment to improve the health of marginalised women.

#### **6.6 GENDER, POWER AND KNOWLEDGE, THE ISSUE OF PATERNALISM**

This trend is supported in the findings by the importance of the needs for *equality in the client/provider relationship, education and information and easy access to women's health and well-being information*. In the literature, these three aspects of health are linked to the paternalistic relationship between client and provider, where the provider retains decision-making power in the health encounter. When this type of relationship is maintained, a provider may assume that a woman does not 'know anything' and cannot make informed choices about her health. Although a trend for patient involvement in their own health care is on the rise in the EU (Figueras et al., 1998), women are still extremely vulnerable to negative health-care encounters.

The Department of Health and Children and policy-makers in general have much to do in encouraging the free distribution of health information that presents a positive image of women and respects diversity. This information should also be specific to the life stage in which women need it. As identified in the Seasonal Calendar exercise, some needs are important at the same level throughout the life course, while other needs peak and trough depending on life stage. Common information about these needs should be fashioned accordingly. Information needs identified in the Millennium Project include more information on cancers, reproductive health - particularly about STDs and HIV and the menopause. If this information is available, women are having difficulty accessing it. The recently established National Health Information Strategy could incorporate this research in order to inform its work on health information for women.

Easy access to information has the potential to break the cycle of paternalism in health care and to create a more equal playing field in the client/provider relationship. There are a number of aspects to easy access to health information for women. Firstly, information should be readily available and there for the taking - women should not have to ask a provider for it. Secondly, information should be placed in a variety of settings other than just health clinics and hospitals. For instance, one participant mentioned that rural post offices would be an ideal place for women to get health pamphlets. Thirdly, a number of different media should be employed to get health messages across to women.

More research needs to be done as to the types of information women need and how they would like to see it distributed. This is backed up by the results of the double matrix, where women suggested a number of settings where education and information dissemination could take place, for example, in local libraries, doctors' offices, or through classes. It should be noted that the high ranking of the need for health information and education also links to the wider issue of social justice for women. When women say they want information in order to make choices about their health, they may also be saying that they want increased power for self-determination. The wider context of women's health issues is explored in the next and final section.

The last three themes in this discussion are linked by three detrimental assumptions that Brems and Griffiths (1993) say underpin many of the programmes initiated around women's health, particularly in developing countries. They are: 1) that health can be separated from everyday life; 2) that women cannot say what they need for their own health and 3) that the biomedical model provides the answers to solving ill health. If the commitment to improving women's health is not evaluated for its real impact in Ireland, the same allegations could be levelled at Irish policy-makers.

## **.7 THE RELATIONSHIP BETWEEN POLICY, WELL-BEING AND THE STATUS OF IRISH WOMEN**

Health care reform is a process well-known to EU nations (Figueras et al., 1998). These reforms are shaped by a number of trends as well as by the fundamental challenge of deciding which reform principles fit a culture and society best. Health care reform principles have much to do with the way health and illness are defined in a culture and the ways those definitions are intertwined with broader socio-economic issues. Figueras et al. (Ibid.) have described a number of the trends informing the reform of EU health care systems and the policies that direct those reforms. They are:

- Dissatisfaction with and recognised inefficiency of centralised bureaucratic systems;
- Increasing interest in patient empowerment in their own health care;
- Increased patient involvement in clinical decision-making.

Each of these trends manifests themselves in different ways depending on the nation state referred to. Moreover, the ways in which health care services and policies directly affect the members of a country say much about the way life is in that country: "Health care services, like other human service systems, closely mirror the deeply rooted social and cultural expectations of the citizenry as a whole. A key indicator of society's normative values is the very nature of health care itself" (Ibid.).

The Department of Health and Children has indicated its adherence to the concept of health and social gain – that health has social determinants – in both the *Plan for Women's Health* (1997) and in the recent *National Health Promotion Strategy, 2000-2005* (Department of Health and Children 2000c). Health is described as a "resource for everyday life" (Ibid.). An important priority in Irish health promotion is the empowerment of people to make healthy choices, while being aware of the way in which social determinants limit or enable people to make healthy choices. The *Plan for Women's Health* (Department of Health and Children, 1997) also indicated an adherence to a similar ethos and a commitment to creating a more women-friendly health system. On paper, Ireland would be seen to value and wish to encourage the good health of Irish women. What the data from the health component of the Millennium Project show is that the principles of health reform espoused by Irish policy-makers have, at best, been implemented in a sketchy way, with high variability depending on geographic location. This is in evidence from the high number of health needs identified by women in the Project as being 'partially-' or 'completely unmet'. This finding is particularly borne out by the low number of 'adequately met' health needs of women involved in the project and the fact that there was only one common need that was perceived to have been met across the groups and their corresponding regions (see section 5.6).

The *Programme for Prosperity and Fairness* (Department of the Taoiseach, 2000) also reaffirmed the importance of implementing the strategies outlined in the *Plan for Women's Health* (Department of Health and Children, 1997), as well as commitment to: employing models of community and primary health care that are multi-functional; encouraging a patient-focused approach in the health care services and increasing health spending over the course of the programme. It also notes that the Women's Health Council is now properly resourced. It will be interesting to see if the ongoing evaluation of the Plan for Women's Health (Ibid.) being carried out by the Women's Health Council resonates with the feelings of the women in the Millennium Project.

By virtue of the fact that women in their local communities may not have felt any or very little of the changes outlined in the Plan (Ibid.) something can also be said about the value that Irish policy-makers are placing on the health status of Irish women. Community care can only be effective if it is provided with full funding and support by the Department of Health and Children. It is all very well to put the commitment to good health for Irish women down on paper, but if this is not felt in real and sustained ways by women themselves, then the Government is not sufficiently committed to improving the health status and related social status of women in Irish society. There is an interconnected relationship between health policies and services, health and well-being and the actual social status of women. Doyal (1995) defines the connection between health and the social status of women: “For those who wish to improve the situation of women, physical and mental health are...strategic issues. They are important goals in their own right, but they also provide the key to women’s effective participation in attempts to create a fairer and healthier society.”

Health policies and services are integral to this relationship because policies shape the way citizens and decision-makers think about and experience society, “These individual perceptions and experiences make and yet modify the material contexts of the areas. In turn, social and industrial structure, demographic characteristics and level and quality of service provision impinge on individual consciousness and well-being” (Eyles and Donovan, 1990). Our findings clearly show that the policies published by the Department of Health and Children have not been felt by the women involved in this study, pointing to the strong possibility that measurable changes in the self-reported health status of Irish women have not occurred. Until women for the most part are satisfied with the quality of their health service, a substantial improvement in the health of Irish women may not be seen. This is of the utmost importance to policy-makers trying to cope with Irish women’s low health status compared to the rest of the EU. Health is also an issue of human rights and should be a priority for the Government in terms of its commitment to women’s health in the Beijing Platform for Action.

## 7. CONCLUSIONS AND RECOMMENDATIONS

### 7.1 CONCLUSIONS

- The results of the health component of the Millennium Project suggest that the Irish health system is not sufficiently decentralised and devolved and that inadequate resources have been provided to implement enhanced services for women in their localities. In some areas services are provided and in some they are not. Childcare was an important health need across the country despite the commitment in the *Plan for Women's Health* (Department of Health and Children, 1997) to address this issue.
- In devising the *Plan for Women's Health* (Ibid.) the Government has created a healthy public policy for Irish women. This is one of the five principles by which health promotion should be guided in the Republic. By using the other four principles as a checklist for future successful implementation:
  - Re-orienting the health service to promotion and not just acute care;
  - Creating supportive environments in which to make healthy choices;
  - Strengthening community action - incorporating community development approaches to health promotion;
  - Developing personal skills through consultation with individuals about their needs (Department of Health and Children, 2000c);

The Department could make the changes to women's health care considered necessary by women in Ireland.

- A pluralist system of health care is not in evidence in Ireland. Women across the country felt that they could not access holistic health care, including alternative therapies, and have all their health needs attended to in a one-stop shop that was the primary 'completely unmet' need identified by participants. Thus, a biomedical model of care is still foremost in the Irish system, leaving women with the feeling that the wider context of their lives as Irish women is not recognised as impacting on their health. This is in opposition to the Department's commitment to the concept of health as related to social gain.
- Linked to the use of a biomedical model in health is the overlooking of the effects of social, cultural and economic factors in health. Women in the health component of the Millennium Project gave evidence of negative experiences in their health care due to class distinctions and gender. There is also a danger that a description of women's health could be reduced to a narrow range of health difficulties such as: maternal health, heart health, smoking, mental health and infant feeding (Department of Health and Children, 2000c). This would have the effect of excluding social factors as they relate to health/well-being.
- The need for health information and education was seen as the second ranking unmet health need for participants in the Millennium Project. This demonstrates that the Plan's commitment to increase availability and access to health information for women has not impacted positively on the women involved in this research. Easy access to women's health/well-being information has the potential to break the cycle of paternalism in health care. That is, it has the potential to create a more equal relationship between client and provider in health care interactions.
- There is a relationship between health policy services, individual perceptions of health and well-being and the normative values of a society and culture. Women throughout the country who were involved in this study clearly indicated that they had not felt the concrete effects of promises made in the *Plan for Women's Health* (Department of Health and Children, 1997). Therefore, it is reasonable to assume that a tangible improvement in the state of Irish women's health is not likely to occur until the policies put forward in the Plan are more thoroughly implemented.

## 7.2 RECOMMENDATIONS

**It is recommended that the Department of Health and Children and other relevant departments and agencies such as the Regional Health Authorities, and the Women's Health Council:**

- Fulfil the promises made in the *Programme for Prosperity and Fairness* (2000), *The Plan for Women's Health* (Department of Health and Children, 1997), and *The National Health Promotion Strategy* (Department of Health and Children, 2000c) to consult with women about health services, what and where they are needed, their ethos and models of practise. Consultations should employ a multi-method approach and qualitative methods should be acknowledged as strategies that are particularly useful in finding out about women's health issues (Brems and Griffiths, 1993).
- Commence initiatives to encourage the widespread distribution of free and accessible information about health, particularly for women's health issues. This may mean placing the information in settings where one would not normally find health information, for instance, rural post offices. Other innovative ways of disseminating health information should be employed using a variety of media. Participants in the Millennium Project described needing health information on a wide variety of topics, but in particular mentioned: holistic approaches to health; cancers; reproductive health and family planning; menopause. Information should be pertinent to women's life stages as illustrated in the results from the seasonal calendar technique.
- Incorporate research like the Millennium Project into the work of the *National Health Information Strategy*.
- Initiate further research to consult with women about gaps in health information provision and their preferences for style, presentation and medium. Different topics could necessitate different modes of delivery.
- Continue the decentralisation of health services, ensuring that administrative agencies and service settings are properly resourced, financially and otherwise.
- Provide awareness and sensitivity training at regular intervals to health care providers on issues of gender, ethnicity, sexuality and economic disadvantage, and the relationship between social factors and health status.
- Ensure that health care providers are trained in effective communication skills and learn how to encourage client participation in their own health decisions.
- Provide free and accessible childcare so that women can attend to their own health needs.
- Fund and resource women's groups working with older women, Traveller women, lesbians, refugee and asylum seeking women, women from other ethnic minority groups living in the Republic, women with disabilities and women who are living in poverty to do research about women's health issues. One of the most important areas of investigation would be the question of what 'being healthy' means to women in Ireland. This would allow for both a deeper and broader view of women's health in Ireland. Multi-method approaches should be used in any enquiry into health for women.
- Institute a wide range of reforms in services for carers in the country as advocated by the National Women's Council of Ireland (NWCI) in its work with health representatives in the regional women's health committees (NWCI unpublished, 1999), including free home help for carers, investment in

respite care, co-ordination of services for carers, a non-means tested Carer's Allowance, profiling the Homemakers Scheme and instituting uniform quality standards for all aspects of the caring services.

- Regarding models of practice, expand the range of care options, particularly alternative therapies.
- Set up free and universal provision of contraceptives, fertility treatment and information around reproductive choice and STDs (particularly HIV and AIDS).
- Initiate inter-departmental and agency links with regard to women's health in the Republic in line with the above recommendations. For example, the Department of Health and Children should fulfil the promise made by the Minister of Health to collaborate with NAPS on establishing health targets, measures and indicators. Health is an issue of human rights for women and should be addressed at a broad policy level.

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## APPENDIX 1. WOMEN AND HEALTH BACK-UP SHEET

Please use the following notes to clarify the needs/supports described on the 12 pre-prepared cards for the Women and Health Research Statement. If your group asks you for an explanation of any of the issues, it is important that you use all or part of these explanations only so that they are standard across all the groups working on the Women and Health Research Statement.

- 1. One-stop shop for women's health** – a one-stop shop would be a health clinic or health centre where a woman could have all her health needs attended to. For instance, she would be able to see a family practitioner for general health needs; a counsellor, psychologist or psychiatrist for her mental health concerns; a homeopathic or complementary practitioner for general health needs; a masseuse for touch therapy or a variety of other alternative practitioners. A woman would also be able to have breast and cervical screening in this one-stop shop.
- 2. Women-friendly health clinics in rural and urban areas** - refers to the lack of women-friendly health clinics in rural and urban areas. The term 'women-friendly' embraces many factors. A clinic would be 'women-friendly' if it had flexible opening hours, could send out staff for home visits, and if it had an in-house crèche and crèche worker. The group can think of other aspects to this but if they do, have them write them onto separate cards.
- 3. Respite and counselling support for women as 'carers'** (of people with special needs, people with disabilities, partners, children, the elderly, etc.) – this need acknowledges that women do most of the community and home care for people who are not able to do self-care for themselves. Women who do this caring should have access (time-wise, financially and so forth) to support for and time-off from their heavy workloads.
- 4. Access to counselling/ mental health care** - 'access' to this need means access in the broadest sense of the word. That is, if a woman needs to find counselling/mental health care, it should be close to her geographically, it should be free or subsidised and it should be 'women-friendly,' with all that that concept embraces. There should also be more information about counselling/mental health care, its availability and choices around it.
- 5. Easy access to women's health/well-being information** – again, 'access' is meant in the broadest sense of the word in terms of ease of finding the information, increased production of health/well-being information and free provision of that information. The information itself should be free of sexism and should provide all the options around different women's health needs. It should also be respectful of the differences among women in terms of class, ethnicity, sexuality and ability.
- 6. Equality in relationships between clients and service providers** – aspects of equality in relationships between clients and providers include: clients and providers being on a first-name basis; clients would give fully-informed consent to procedures and prescriptions; clients would be offered all the choices and information available to them around their health needs, not just what is convenient for the provider; clients would be able to arrange exactly how they would like to manage their own health, the providers would not make those decisions for them; and providers would be respectful of the backgrounds of their clients, that is, if their client was gay or from a specific ethnic group, they would be sensitive to how background might affect a client's needs and would never be judgmental about that.

7. **Access to family planning** – again ‘access’ is in the broadest sense of the word, particularly around choice. For instance, when a woman goes to a provider for birth control, she may not always be told of all the options available to her. True access to family planning would ensure that a provider would be required to share all the birth control options available with her/his client. Access would also mean that these options would be widely available or that there would be no limits on obtaining them; for instance, if a woman has a medical card, she has a restricted choice of contraceptive methods ranging from certain types of the birth control pill and condoms. She would not be covered for an IUD or diaphragm, for example.
8. **Access to fertility treatment** – ‘access’ here is meant in the broadest sense of the word with particular emphasis on the financial aspects of getting fertility treatment, as well as the idea that women should be able to have fertility treatment regardless of financial position, marital status, sexuality, class, ethnicity or ability.
9. **Holistic approach to health/well-being** – often in traditional medicine (i.e. hospitals, doctors, specialists etc.), the mind is separated from the body and not seen as connected. For instance, stress could cause a physical reaction, but because stress is meant to be ‘in your head’, a provider might treat the mind and not the body. Holistic health care means that mind and body are treated together, not separately. An holistic approach to health/well-being for women would also mean that all the aspects of their lives would come into an investigation of their health/well-being because a woman’s social reality can affect her health.
10. **Free breast screening** – means that screening for breast cancer would be paid for by the State.
11. **Free cervical screening** – means that screening for cervical and endometrial cancers would be paid for by the State.
12. **Improved maternity services** – the components of improved maternity services would include improved ‘access’ to services already in place, but would also include increased options in services, for instance, that the option to have a home birth would be supported by the medical profession and could be easily accessed if a woman chose to do so. Also, that there would be respectful and equal relationships between women and maternity service providers.

## APPENDIX 2: CASE STUDY: THE IRISH DEAF WOMEN'S GROUP

### A2.1 INTRODUCTION

The standardised research outline for 'Women and Health' was not capable of fully reflecting the experiences of The Irish Deaf Women's Group, who had specific health needs in relation to being part of a cultural and linguistic minority. In addition, they experienced unique challenges in dealing with research techniques and processes during the Millennium Project. This fact has significant implications for the future design of PLA projects for groups who have special needs related to deafness. The experience of this group is also instructive in raising our awareness of how minority groups articulate their specific health needs in order to enable health services to become more open, flexible and effective for service users.

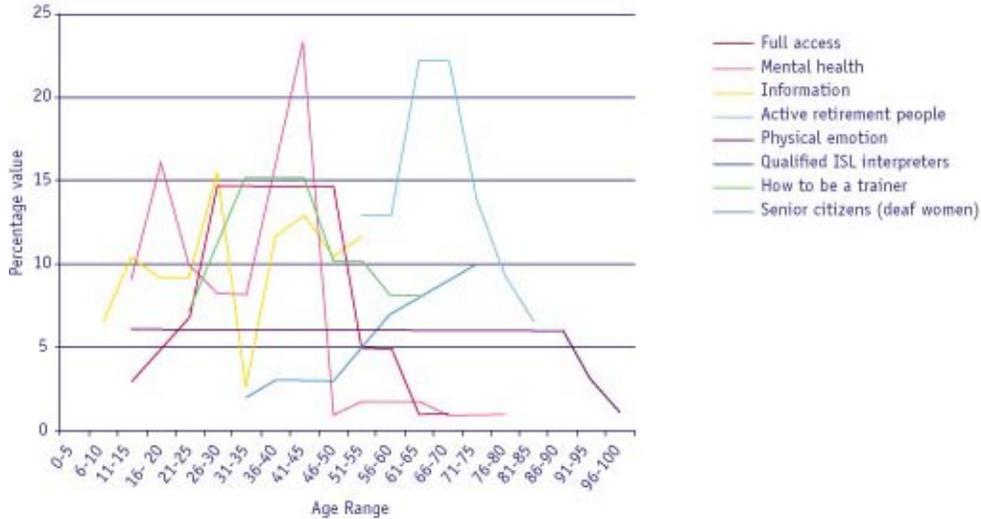
### A2.2 BRAINSTORMING – IDENTIFYING KEY HEALTH NEEDS

The group created a set of 13 'health needs' cards through a Brainstorming process:

1. More awareness of deaf women's needs required, especially around delivery/post-delivery health issues and services for mother and child.
2. Pregnancy – inability to participate in group discussions due to lack of availability of Irish Sign Language (ISL) interpreters.
3. Lack of information generally about ante- and post-natal care.
4. Ante-natal classes – cannot afford to pay for interpreter; lack of choice re male/ female doctors available to women on medical card.
5. Giving birth can be made more difficult by lack of finance for interpreter.
6. Attending out-patient departments - hospital staff and administration do not take account of specific needs of deaf women.
7. Lack of privacy and dignity in family planning clinic.
8. Feel uncomfortable having smear tests – *'no confidence in nurses while they are busy'* and no interpreters available for General Practitioners.
9. Re: hormone replacement therapy – older women need adequate information in relation to changing health needs.
10. Re: media – lack of subtitles reduces access to information; insufficient coverage of health issues.
11. Re: genetic modification – serious lack of information – *'deaf people are always the last to know about importance of health needs.'*
12. Re: alcoholism – lack of information; lack of ISL counsellors.
13. Re: abuse – lack of awareness of needs of deaf women in relation to rape and/or domestic violence.

The group 'bundled' these 13 health needs into the 8 categories represented below in the Seasonal Calendar, and evaluated their levels of intensity over the span of a woman's life.

## A2.3 SEASONAL CALENDAR – KEY HEALTH NEEDS ASSESSED ACROSS THE LIFESPAN



(Please note: ‘Physical emotional’ and ‘Qualified ISL Interpreters’ follow the same trajectory in this diagram, and therefore the lines indicating these two needs across the lifespan overlap and appear as one.)

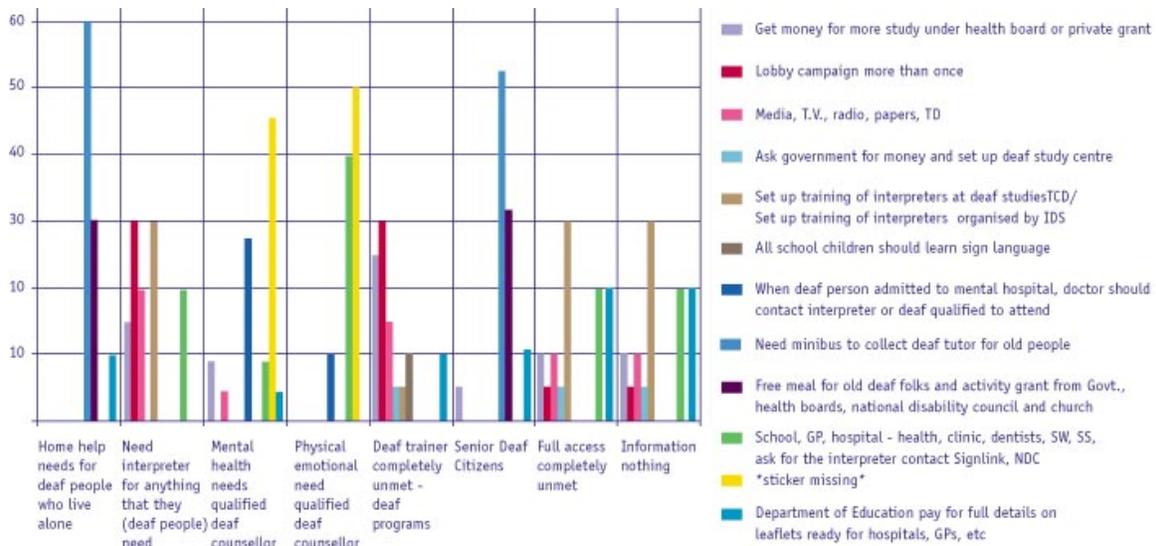
- **‘Full access’** now incorporates the need to hire interpreters for the deaf at all healthcare provision centres (rape crisis centres, hospitals, GP surgeries, cancer and gynaecology centres);
- **‘Mental health’** emphasises the need for ISL-qualified or deaf mental health counsellors and psychiatric staff;
- **‘Information’** incorporates all the areas previously indicated where information is unavailable due to barriers in communication. The group advocated the use of videos with sub-titles to supplement women’s health leaflets;
- **‘Active retirement people’** is the ‘hormone replacement therapy’ card renamed;
- **‘Physical emotional’** represents the interdependence between physiological and emotional aspects of health and well-being – incorporating the need for accessible counselling;
- **‘Qualified ISL interpreters’** emerged as one of the key areas of concern for the group – more qualified interpreters would lead to more access to information and equality;
- **‘How to be Trainer’** refers to how deaf people might act as trainers in education, healthcare, counselling and careers;
- **‘Senior Citizens (deaf women)’** overlaps with ‘active retirement people,’ but focuses on the need for general supports for older women: wheelchairs, ‘meals on wheels’ and so on.

The Seasonal Calendar indicates how certain health needs, for example, ‘Active Retirement People’ and ‘Senior Citizens’, are clearly linked to the later years of the lifespan, while ‘Information’ and ‘Mental health’ are associated with earlier years (5-55), with a dramatic peak at the 40s. ‘Full Access’ scores highly

across the years from 26-50. Similarly, high scores for ‘How to be Trainer’ fall into a narrower age band, from 31-45. Two needs, ‘Physical Emotional’ and ‘Qualified ISL Interpreters’ are presented as equal in importance across the lifespan.

#### A2.4 MATRIX – POSITIVE ACTIONS TO HELP ADDRESS IDENTIFIED HEALTH NEEDS

The group felt that none of the health needs cards were adequately met by current service provision and proceeded to create a matrix, naming actions that would help to address their health needs.



The graph above shows the relative scores for each action according to each of the health needs listed by the group. Each vertical grid represents one of the key health needs identified by the group. Each solution identified to address key health needs has been given a certain colour bar and may address more than one health need. Thus, the solution ‘need minibus to collect deaf tutor for old people’, addresses the needs, ‘home help needs for deaf people who live alone’, and ‘Senior Deaf Citizens’.

The trend towards emphasis on the need to increase provision of ISL interpreters and recognition of the importance of ISL emerges once again in the findings of this matrix, with 3 of the top 4 scoring actions having some connection with the availability either of ISL interpreters or qualified deaf staff in health care provision.

From the observation notes, it appears as though this theme is closely linked with the increased participation of deaf people in mainstream society:

*‘...nobody hears our scream. Problem is over barrier – our needs, frustrations. Interpreter would solve from [problem] 1 to 7.’*

#### A2.5 KEY EVALUATION COMMENTS

Finally, in relation to the challenges this group faced using the PLA process, their evaluation included the comment that:

*‘Video would be perfect solution to solve this problem. Too much hassle by writing.’*

Facilitators could re-run the video to catch signing they missed during sessions, enabling them to make more complete and extensive observation notes, Although the project was described as ‘time-consuming’ and frustrating at times, the group also recognised within the process a potential for their particular voices to be heard:

*‘We feel that the only way [this project] will be important [will be] because the Millennium Project will pass [it] on to the Government. It is our first step to do [something] like this and our turn to shout the message loud. The Millennium Project is of central importance to the women’s deaf group. We appreciate their moral support to help us to go on with [the] project by providing the interpreter’s feel costs/patience.’*