

Global Forum for Health Research

HELPING CORRECT THE 10|90 GAP



BIAS FREE

The ***BIAS FREE*** Framework

A practical tool for identifying and eliminating
social biases in health research

Mary Anne Burke
Margrit Eichler

The *BIAS FREE* Framework: a practical tool for identifying and eliminating social biases in health research

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**A practical tool for identifying and eliminating
social biases in health research**



by

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Executive summary

This book presents the *BIAS FREE* Framework — a tool for identifying and avoiding biases in health research that derive from any social hierarchy. *BIAS FREE* stands for *Building an Integrative Analytical System for Recognizing and Eliminating inEquities*. The acronym is the statement of a goal, not an achievement. The *BIAS FREE* Framework suggests a pathway towards this destination. In this book we concentrate on biases deriving from three social hierarchies only: those based on gender, race and ability, and on the application of the Framework to health research, although in principle it is applicable to all types of research that involve human beings.

The Framework is “integrative” in that it aims to combine, co-ordinate and consolidate the various analytical lenses that have emerged from these various fields of study into a unified whole. It is also “integrative” in that it recognizes that health research is a global public good and that as such, all people have an equal claim to the health research process and its benefits, regardless of their gender, ability, race or other social characteristics, and works towards this end.

It is therefore premised on a rights-based understanding of health, which in turn rests on the following three basic relationships:

1. Health policies, programmes and practices have an impact on human rights.
2. Violations or lack of fulfilment of human rights have negative effects on health (physical, mental, social and spiritual well-being).
3. Health and human rights act in synergy. Promoting and protecting health requires explicit and concrete efforts to promote and protect human rights and dignity; greater fulfillment of human rights necessitates sound attention to health and its societal determinants. Paying attention to the inter-relationship between health and human rights may help to re-orient thinking about major global challenges to health and to broaden human rights thinking and practices.

While the *BIAS FREE* Framework is applicable not just to research but also to legislation, policies, programmes and practices, in this book the focus is on its application to health research in particular.

The following underlying criteria were used in developing the approach: that it be

- systematic and comprehensive;
- theoretically grounded;
- capable of providing a common terminology describing the various problems;
- applicable to biases deriving from any social hierarchy;
- free from privileging biases deriving from one type of hierarchy (e.g. gender) over those generating from another one (e.g. ability or race);

- capable of identifying intersections and compounding layers of biases deriving from different social hierarchies;
- applicable to research, legislation, policies, programmes, services and practices;
- applicable to any sector, e.g. health, education, justice, industry, transportation communication;
- applicable to all types of research, including one's own or that of others; and
- usable at all stages of the research process.

The Framework is open-ended, and defines concepts that have variable meanings in the relevant literatures by operationalizing them through a set of questions that alert the reader to the presence or absence of a bias that derives from a social hierarchy. The existence of social hierarchies gives rise to a tripartite set of problems that may play out in research. Efforts aimed at maintaining a hierarchy, give rise to the first of a tripartite set of problems identified in research. These are clustered in the *BIAS FREE* Framework under the heading of the Main Problem Type: *Maintaining a hierarchy*. The second set of problems arises when one's position on a given social hierarchy is not examined for its relevance, and ensuing differences are not accommodated. This set of problems is clustered under the Main Problem Type: *Failing to examine differences*. The final set of problems emerges when different groups are treated differently because of their position within a social hierarchy. This set of problems is clustered under the Main Problem Type: *Using double standards*. To identify all three types of problems, we have formulated a set of abstract questions with yes-no answers (see the Framework at the back of the book). Each of the questions has its own solution.

Failing to examine differences (the F-Problem) and using double standards (the D-Problem) are two sides of the same coin. The solution to the F-Problem consists of recognizing and accommodating existing differences by treating people differently, while the solution to the D-Problem consists of recognizing and eliminating unwarranted differential treatment. The F- and D-Problems are therefore mutually limiting. The touchstone that lets us decide which type of problem we are dealing with is whether *different* or *same* treatment reduces or reinforces an existing hierarchy.

Each of the questions comes with a set of sub-questions and answers. Various bias problems (which are operationalized in the questions) are:

H – Maintaining an existing hierarchy

H 1 Denial of hierarchy

H 2 Maintenance of hierarchy

H 3 Dominant perspective

H 4 Pathologization

H 5 Objectification

H 6 Victim-blaming

H 7 Appropriation

F – Failing to examine differences

- F 1 Insensitivity to difference*
- F 2 Decontextualization*
- F 3 Over-generalization or universalization*
- F 4 Assumed homogeneity*

D – Using double standards

- D 1 Overt double standard*
- D 2 Under representation or exclusion*
- D 3 Exceptional under-representation or exclusion*
- D 4 Denying agency*
- D 5 Treating dominant opinions as fact*
- D 6 Stereotyping*
- D 7 Exaggerating differences*
- D 8 Hidden double standard*

The Framework is based on a three-dimensional matrix consisting of the *type of hierarchy* examined (gender, race, ability, age, class, caste, religion, sexual orientation, etc.), the *component of the research process* relevant at any particular point of time (research proposal, literature review, research question and design, concepts, theoretical framework, research methods, data analysis and interpretation, conclusions) and the *particular type of bias problem*.

Extensive examples of all types of biases in all components of the research process are provided. Since no one is a member of only one hierarchy (i.e. a person may be a woman, black, and highly educated living in a high-income country with a good job, or may be a white man, disabled, living in a low-income country) the analytical process is iterative. Different ways of using the framework are discussed.

Foreword

The mission of the Global Forum for Health Research is to promote more research that focuses on the health needs of developing countries, the neglect of which has come to be symbolized in the expression ‘10/90 gap’. But to address the real health needs of poor and marginalized populations, attention is needed not only to the quantity of research but also to its quality and orientation. The commercial interests of the private sector may combine with disparities in wealth between countries to influence the public and private sector resources available for health research for development. In addition, the imbalance this generates may be further compounded by biases within the research that is conducted.

One important group of biases that arise in health research is associated with social hierarchies, including those based on ability, class or caste, gender, race or ethnicity, religion and sexual orientation. The existence of such biases may result, in the health research field, in research that is not only flawed but that perpetuates and reinforces health inequities. This may arise from the construction of a research process that is blind to the existence of a bias problem, that emphasizes differences when particular social groups should be treated equally or, conversely, that fails to address differences by treating distinct groups as if they were the same.

The *BIAS FREE* Framework is a new tool, developed as the result of a long-term collaboration between the authors. It can be used systematically to analyse research, either prospectively or retrospectively. It facilitates the clear identification of the presence of research biases due to social hierarchies and points to directions for their elimination.

We hope that this publication and the adoption of the Framework it describes will lead to wider and more systematic efforts to eliminate social hierarchy-based biases from health research, thereby improving the health of poor and marginalized populations and reducing health inequalities.

Stephen Matlin
Executive Director
Global Forum for Health Research

I Introduction

The intent of this book is twofold: first, to provide a tool — the *BIAS FREE* Framework — for examining and eliminating biases in health research that derive from social hierarchies; second, to present the theoretical underpinnings of the Framework.

The term hierarchy (literally: holy order) indicates a social system in which people are stratified on a continuum of economic, political and social power. Social hierarchies may be based on gender, ability, race, religion, geographical location, class, caste and sexual orientation, among other variables.

BIAS FREE stands for *Building an Integrative Analytical System for Recognizing and Eliminating inequities*. The acronym is the statement of a goal, not an achievement. The *BIAS FREE* Framework suggests a pathway towards this destination. In this book we are concentrating on biases deriving from three social hierarchies only: those based on gender, race and ability, and on the application of the Framework to health research.¹ The framework presented here is a work in progress, as emphasized by the first word in the acronym, building on the available scholarly work concerning sexism, ableism and racism, and the longstanding work and experience of the authors (Eichler, 1984, 1991, 1997b; Eichler, Reisman, & Borins, 1992; Eichler, 2002; Eichler & Burke, 2006; Burke, 1995, 1999a, 1999b, 1999c; Burke et al., 2003; Bach & Burke, 2002).

The Framework is “integrative” in that it aims to combine, co-ordinate and consolidate the various analytical lenses that have emerged from these various scholarships into a unified whole. It is also “integrative” in that it recognizes that health research is a global public good (Burke & de Francisco, 2004: 84), and that as such, all people have an equal claim to the health research process and its benefits, regardless of their gender, ability, race or other social characteristics, and works towards this end.

Rights-based approach

The *BIAS FREE* Framework is premised on the equal entitlement of all people to be treated with respect, and on the inviolability of human rights. The Framework derives from the understanding of health as a human right and uses a rights-based model of health and well-being. The Preamble to the WHO Constitution² sets out that, “[t]he enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition” (World Health Organization, 1948).

¹ The Framework can be applied to any subject involving human beings.

² The Constitution was adopted by the International Health Conference held in New York from 19 June to 22 July 1946, signed on 22 July 1946 by the representatives of 61 States (*Off. Rec. Wld Hlth Org.*, 2, 100), and entered into force on 7 April 1948. Amendments adopted by the Twenty-sixth, Twenty-ninth and Thirty-ninth World Health Assemblies (resolutions **WHA26.37**, **WHA29.38** and) came into force on 3 February 1977, 20 January 1984 and 11 July 1994, respectively, and are incorporated in the present text.

The rights-based model of health rests on three basic relationships:

1. Health policies, programmes and practices have an impact on human rights.
2. Violations or lack of fulfillment of human rights have negative effects on health (physical, mental, social and spiritual well-being).
3. Health and human rights act in synergy. Promoting and protecting health requires explicit and concrete efforts to promote and protect human rights and dignity; greater fulfillment of human rights necessitates sound attention to health and its societal determinants. Paying attention to the inter-relationship between health and human rights may help to re-orient thinking about major global challenges to health and to broaden human rights thinking and practices (Mann et al., 1999: 5-7).

Health (physical, mental, social and spiritual well-being) is fundamentally tied to human rights and social equality. In moving towards a broad definition of health focused on the well-being of people, WHO “helped to move health thinking beyond a limited, biomedical, and pathology-based perspective to the more positive domain of ‘well-being’...and radically expanded the scope of health, and by extension, the roles and responsibility of health professionals and their relations to the larger society” (Mann et al., 1999: 8).

The link between broad social inequities and inequities in health has long been recognized (Ferrie et al., 2002; World Health Organization, 1986) and is the current focus of the *WHO Commission on the Social Determinants of Health* (World Health Organization, 2006). Poverty and social exclusion also derive from social inequities, and are key risks to health (World Health Organization, 2006: 3-4). Addressing the underlying inequities that emerge from the maintenance of social hierarchies is thus central to addressing health inequities, poverty, and social exclusion.

The *BIAS FREE* Framework is designed to draw attention to the structural and organizational determinants of health, to assist in identifying biases in health research that derive from various social hierarchies, and in removing them, insofar as is possible.

The underlying theoretical framework draws on a long history of scholarly research related to the social dimensions of scientific knowledge, power and access to resources. Social hierarchies are built on the basis of gender, ability, race, class, caste, age, ethnicity, aboriginal status, geographical region, language, religion and sexual orientation, among others (Abberley, 1997; Blim, 2005; Munck, 2005; Ravaud & Stiker, 2001; Rothman, 1993; Shakespeare & Watson, 2001).

In every society, access to social goods, decision-making and economic and social well-being is shared unequally among all members depending on where they fit within the various social hierarchies (Desai & Johnson, 2005; Lenski, 1984; Shookner, 2002). Power structures within a society serve to reinforce and maintain the various social hierarchies, and the distribution of resources according to people's position within the various social hierarchies (Johnson, 2004).

In describing where people fit within a given hierarchy, and to facilitate our integrative approach to the various social hierarchies, we use abstract language applicable to all hierarchies. For example, we use the term “dominant group” to mean those at the top end of a hierarchy — those with the most power and ability to access and use the resources that accrue to them because of their position in a hierarchy. We use the term “non-dominant group” to mean those whose position is further down the hierarchy and who are not as easily able to yield power and access and accrue resources. The terms *dominant* and *non-dominant* are always understood in relation to each other, within a given socio-political context.

Historically, women, disabled people, and others belonging to certain classes or ethnic, racial, linguistic or religious groups have tended to be disadvantaged relative to men, to “non-disabled” people, and other dominant groups in their society (Rossides, 1997; Schriner, 2001). Membership

in more than one non-dominant group compounds the discrimination that people experience, and increases social, political, economic and other inequities.

A disabled woman living in a low-income country in Africa or Asia, for example, would likely have access to fewer social, economic and community resources than would a white able-bodied woman living in a high-income country. Her experience, however, might not be so different from that of a disabled Aboriginal woman living on a remote "Indian" reserve in Canada.

The problem of discrimination is compounded for disabled members of the lesbian and gay communities, disabled black people, disabled women and disabled members of other marginalised groupings... This is because in addition to disability they frequently experience other forms of discrimination such as heterosexism, racism, sexism etc. Thus, if a disabled person is also a member of one or more marginalised groups their experience of discrimination will be more complex and its consequences further disempowering. When explaining the outcome of disability, therefore, the likelihood of simultaneous oppression should always be considered (Barnes, 1992: 5).

Depending on which hierarchy is at work, people may experience both dominant and non-dominant status. For example, an African man may be in a dominant group relative to an African woman (gender hierarchy), and within African society experience a position of privilege. He may, however, also find himself in a non-dominant position relative to a white man (or woman) from a low-income country (hierarchy based on development status/race/geographical location), and experience social deprivation and powerlessness relative to those with higher status on the global stage.

Understanding that the logic of domination does not change across hierarchies, although it manifests in diverse ways across social hierarchies and contexts, enriched our understanding of the manifestations of biases derived from each of the hierarchies. This opened our eyes to similar manifestations in other hierarchies and allowed us to construct an integrative Framework for identifying and removing biases, to which we now turn.

II The *BIAS FREE* Framework

The *BIAS FREE* Framework is a systematic and integrative approach designed to identify biases that derive from any social hierarchy, such as those based on gender, race, ability, religion, geographical location, class/caste and sexual orientation, among others. Removing biases that derive from social hierarchies is a necessary but not sufficient condition for good research. There are other biases that derive from other sources, such as general methodological errors, that will not be detected using the *BIAS FREE* approach. This Framework will, therefore, make otherwise sound research better, but it will not overcome all problems. A project may, for example, be unbiased in terms of gender, race or ability hierarchies, but completely trivial or based on technically faulty presuppositions or unsound methodologies.

The *BIAS FREE* Framework is applicable not just to research but also to legislation, policies, programmes and practices. It is also transferable to any policy sector — not just health. It could be used, for example, in the education, justice or transportation sectors. For the purposes of this book, the focus is on applications of the *BIAS FREE* Framework in the health sector, and in health research in particular.

Criteria used to construct the *BIAS FREE* Framework

Any approach that aims to be integrative and comprehensive needs to meet some rather stringent criteria. In constructing the *BIAS FREE* Framework, the underlying criteria were that the approach needed to be:

- systematic and comprehensive;
- theoretically grounded;
- capable of providing a common terminology describing the various problems;
- applicable to biases deriving from any social hierarchy;
- free from privileging biases deriving from one type of hierarchy (e.g., gender) over those generating from another one (e.g. ability or race);
- capable of identifying intersections and compounding layers of biases deriving from different social hierarchies;
- applicable to research, legislation, policies, programmes, services and practices;
- applicable to any sector, e.g. health, education, justice, industry, transportation, communication;
- applicable to all types of research, including one's own or that of others; and
- usable at all stages of the research process.

The *BIAS FREE* Framework has been developed to help researchers and others recognize when biases exist, and to identify means to eliminate them. The Framework provides a set of questions aimed at discovering whether social hierarchies are at work in research, and if so, whether they are producing bias. The questions in the Framework probe the particular nature of the

problem so that appropriate solutions can be applied to the identified problem. Answering the questions at each step of the research will reveal whether social hierarchies are at work or not, and if so, whether or not they are producing bias. If hierarchies are not found to be at work, or if no bias is found, the researcher can proceed to the next stage of research. If bias is found, the Framework points to appropriate solutions the researcher may take to address the particular bias problem identified.

Development of the analytical questions

The analytical questions of the *BIAS FREE* Framework originated from questions developed while exploring the literature on sexism in research. For example, a critique might have been made of a specific study that dealt only with males but in which the conclusions were presented as universally applicable. The first step was to reduce the problem identified in the critique to a single statement (e.g. this article deals only with males but its conclusions are discussed as if they apply to both sexes) and then transform it into a question: Is information about males extended to females? Following this, an extensive review of the literature was conducted to find whether this formulation of the question would help us recognize the same problem within a different subject matter and discipline. The importance of abstract questions lies in the transferability that they allow from one subject area to another. If we were unable to find another example, the question was put aside until we found another example. If the question did help to identify problems, it was added to the Framework. The same approach was carried through with all other problems.

The next step involved the transformation of the gender-based questions into abstract language using the terms dominant/non-dominant group in lieu of male/female. Our sample question was thus transformed into the following formulation: is information about a dominant group extended to a non-dominant group without testing its applicability? From this abstract version, which is the version we are using in the *BIAS FREE* Framework, we translated it into various hierarchies: is information on whites applied to people of colour? Is information about people with normative bodies and minds applied to disabled people? The literature was searched again for examples concerning both racist and ableist examples in the literature. In the process, questions were formulated and reformulated many, many times.

If we found a problem that was not yet a part of our inventory, we added it and searched for examples in the other hierarchies. For instance, appropriation is a problem that comes from the anti-racist literature. After we had a formulation that seemed to work, we applied it to the gender and ability hierarchies. We had previously included a problem in the gender hierarchy known as "naming." An example of this is when women are identified by their husband's name, e.g. Mrs. David Smith. "Naming" was eventually eliminated as a category as it could be included under "appropriation".

This process of going back and forth among the hierarchies proved to be quite advantageous. Learning from the problems within each of the hierarchies opened our eyes to similar manifestations in other hierarchies, thus enriching our understanding of the manifestations of biases derived from each of the hierarchies. It also pointed the way towards an understanding that the logic of domination does not change across hierarchies, although it manifests in diverse ways across social hierarchies and contexts.

The open-ended nature of the *BIAS FREE* Framework

The *BIAS FREE* Framework is open-ended. If problems within any of the hierarchies are identified that are currently not part of any of the problems so far identified, a similar process could be undertaken and it could be added to the Framework. Similarly, other elements of the research process could be added. Most importantly, more hierarchies can be added, such as age, sexual orientation, class, caste, religion or geographical location.

Moving towards a common terminology

One problem in the literature on bias in research is that there is no uniformity in the meaning of the terminology used to describe the various bias problems, particularly across hierarchies. Good examples of this are the multiple meanings of “gender sensitivity” and “appropriation”.

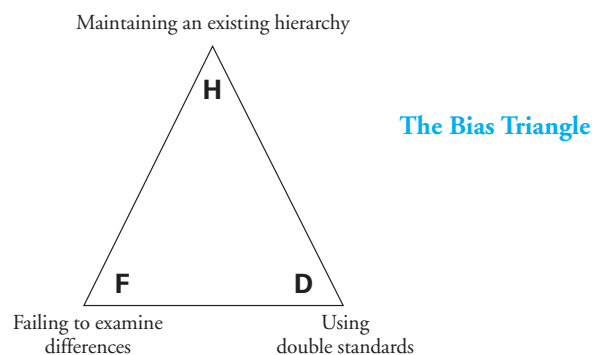
Clearly, it would be desirable to move towards a common understanding of the meaning of the terminology used for each problem. This is the reason for preceding each question in the *BIAS FREE* Framework with a concept. The question that follows is, in fact, the definition of the concept, and serves to identify the problem. This makes it easy to see exactly what is meant by each concept, to compare its definition to definitions used elsewhere in the literature, and to sort through some of the confusion of terminology in the literature.

The tripartite basis of social inequality and biases

Social inequality — and the biases that derive from it in research — are perpetuated through the maintenance of social hierarchies. The existence of a social hierarchy gives rise to a tripartite set of problems that may play out in research. Efforts aimed at maintaining a hierarchy give rise to the first of a tripartite set of problems identified in research. These are clustered in the *BIAS FREE* Framework under the heading of the Main Problem Type: *Maintaining a hierarchy*. The second set of problems arises when one’s position in a given social hierarchy is not examined for its relevance, and ensuing differences are not accommodated. This set of problems is clustered under the Main Problem Type: *Failing to examine differences*. The final set of problems emerges when different groups are treated differently because of their position within a social hierarchy. This set of problems is clustered under the Main Problem Type: *Using double standards*. To identify all three types of problems, we have formulated a set of abstract questions with yes-no answers (see the Framework at the back of the book). Each of the questions has its own solution.

Failing to examine differences (the F-Problem) and *Using double standards* (the D-Problem) are two sides of the same coin. The solution to the F-Problem consists of recognizing and accommodating existing differences, by treating people differently, while the solution to the D-Problem consists of recognizing and eliminating unwarranted differential treatment. The F- and D-Problems are therefore mutually limiting. The touchstone that lets us decide which type of problem we are dealing with is whether *different* or *same* treatment reduces or reinforces an existing hierarchy.

We have symbolized the tripartite nature of bias problems that derive from social hierarchies as follows:



1. Maintaining a hierarchy

All societies stratify people on the basis of gender, ability and class. Race is a stratifying factor in most societies. Caste is particularly relevant in India and related cultures. Stratification occurs on the basis of many other factors, including age, religion, language, geographical location, ethnic background, sexual orientation and physical appearance. No person is situated in only one hierarchy; everyone experiences stratification along more than one dimension. Where one is located on a hierarchy is profoundly consequential. Being white, male and having a normative body and mind are not neutral states of being. The issue is therefore to determine the effect of a hierarchy within a given context and seek to minimize it. In some cases, this will involve *different* treatment, and at other times, *same* treatment.

Placement on a hierarchy determines one's access to all types of resources, for example: power and decision-making; health; education; income; employment; and even the media (Barker, 2005; Blasiotti, Westbrook, & Kobayashi, 2001; Chen & Wellman, 2005; Denzin, 2005; Eichler, 1989; Lollar, 2001; Pfohl, 2005). This is somewhat modified by the type of society within which one lives. For instance, in a society with a socialized medical system, access to health care will be less stratified than in societies without such a system. Likewise, the tax and social welfare systems and community infrastructures are other mediating institutions that affect the degree to which access to resources is more or less differentiated.

Similarly, a hierarchy of power and access to resources exists on a global scale. This hierarchy of low-income countries (LICs), middle-income countries (MICs) and high-income countries (HICs) largely overlaps with a global stratification of people by colour — Japan would be one of the exceptions to this general rule. This hierarchy is exemplified by the extreme concentration of global wealth in a few countries and among a few people. In 1997, *Forbes Magazine* estimated that the world's three richest people had assets that exceeded the combined gross domestic product (GDP)³ of the 48 lowest-income countries; and that the world's 225 richest people had a combined wealth that was equal to the annual income of the poorest 47% of the world's people (United Nations Development Programme, 1998: 30). This global disparity in wealth is reflected in the global disparity in infant and maternal mortality and diseases of poverty (Evans et al., 2006; Sims, 2005).

One of the ways in which hierarchies manifest, as discussed earlier, is in knowledge and knowledge construction, including health research. Whenever researchers deny the existence of a hierarchy, such as that of race, gender or ability, they actually help maintain it (*denying hierarchy*). The same is true if views that are derived from acceptance of hierarchies are presented as normal or unproblematic, e.g. if an ability hierarchy is presented as a natural way of valuing people (*maintaining hierarchy*). Another way of maintaining hierarchies occurs when, intentionally or unintentionally, the perspective of a dominant group is adopted, e.g. non-normative body structures and/or functioning are automatically regarded as defects and burdens rather than as a variance from the norm and part of human diversity (*dominant perspective*).

Yet another form of maintaining hierarchies manifests when practices that restrict the human rights of members of non-dominant groups are presented as unproblematic (*objectification*). For instance, post "9/11", racial profiling of several non-dominant groups has increased steeply in North America. Failing to question such procedures objectifies members of the profiled groups. Another means by which hierarchies are maintained is *pathologization*. For example, people with Down Syndrome have a "naturally occurring chromosomal arrangement that has always been a part of the human condition" (Canadian Down Syndrome Society, 2003); however, people with Down Syndrome are often pathologized and denied a variety of rights because they are different from the norm (Burke et al., 2003).

Victim blaming is another way of maintaining a hierarchy. Whenever an abused woman is asked, "What did you do to provoke him?" a gender hierarchy is maintained. Similarly, an ability hierarchy is maintained when we situate disability in the individual rather than focus on removing societal barriers to the full inclusion and participation of disabled people. In a like manner, a race hierarchy is maintained when we fail to acknowledge the negative impact of colonialism on the behaviour of the colonized people and instead blame them for their situation.

Finally, *appropriation* is yet another form of maintaining a hierarchy. Colonial history is rife with the appropriation by the colonizers of lands, people, artefacts and cultural knowledge (Smith, 1999). And it continues today, as many traditional medicines are being appropriated under patents taken out by the pharmaceutical industry (Shiva, 1997). The practice of taking away a woman's name upon marriage and assigning her the husband's name instead is another instance of appropriation that is still taking place. In one Canadian province — Quebec — this was changed in 1981

³ GDP is used as a proxy for real disposable income (South Africa, 2004:27).

(Eichler, 1997a: 49). A woman retains her name upon marriage just as a man does. However, in most other parts of the country women still take their husbands' names, even though it is not a legal requirement.

2. *Failing to examine differences*

Failing to examine and accommodate socially relevant differences is the second type of bias problem. The anti-racist, anti-sexist and anti-ableist literatures have amassed a great deal of evidence concerning the failure to examine membership in a dominant or non-dominant group in contexts where it is of pivotal importance. The major form this problem takes is insensitivity to differences and treating people the *same* when they should be treated *differently*. This includes failing to look at and accommodate social differences *within* and *among* each of the hierarchies. In health research, this also includes the failure to look at and take into account biological differences between the sexes, or among people with different health conditions and/or non-normative body functions and structures.

A U.S. doctors' study made global headlines in 1989 with its landmark finding that preventive use of acetylsalicylic acid (Aspirin)⁴ —probably the most common medication in the world — reduced first heart attacks by 44% (Physicians' Health Study Website, 2005). Aspirin regimens quickly spread, as advised by doctors to at-risk patients, and self-prescribed by the wider public buying low-dose pills over the counter. Just as dramatic — and important — as the original finding was the news in March 2005 that the Aspirin promise was half empty.

The 1981 Physicians' Health Study was large-scale but used only male doctors as subjects — a cause for criticism that, according to one influential health commentator, eventually grew into a "crescendo of demands that clinical research must always be organized to account for the biologic differences between women and men" (Levin, 2005: 1366). The later, large-scale Women's Health Study found that Aspirin shows no preventive effect for first heart attacks in women, although it did show a preventive effect on first strokes for women, especially those over the age of 56 (Ridker et al., 2005). "This is the exact opposite of what we see in men," according to study researcher Paul Ridker, MD (Peck, 2005).

The Aspirin case is an illustration of how biases deriving from social hierarchies can manifest in health research and in public health. Not only did the original research study include only a dominant social group — men — but the same findings were applied to women (*overgeneralization*). By failing to explore potential differences by sex, the analysis was faulty, and led to faulty conclusions (*insensitivity to differences*). The assumption that what was good for the gander was good for the goose resulted in inappropriate therapy for the condition diagnosed in women.

A subtle way in which we may fail to recognize differences is in dealing with aggregate units in our analysis without taking the diversity within these units adequately into account. For instance, families, households, compounds, tribes, etc. are made up of people of different sexes, ages and abilities, and their interests may diverge in very significant ways (*insensitivity to differences*). A study in northern Ethiopia, for example, found that women are likely to spend more money on prevention of malaria than men in comparable households (Lampieri, Poulos, Cropper, Mitiku, & Whittington, 1999). Looking at consumption preference of various items by taking only household income into account would, therefore, be misleading.

Another way in which this bias expresses itself is in *decontextualization*, which happens when research that deals with a phenomenon with potentially different implications for dominant and non-dominant groups fails to examine these differences and treats people the same. An example of decontextualization would be a city-planning process that fails to recognize the needs of people who use devices to assist their mobility and, therefore, ends up with an infrastructure that is not

⁴ Aspirin®, first registered in Germany in 1899; today, it is a registered trademark of Bayer in Germany and in over 80 countries. The trademark was given up to the US, the UK, Russia and France in 1919 as part of the Treaty of Versailles, see <http://www.aspirin.com> and <http://home.nycap.useless/aspirin/index.html>

suitable for this group. This would include people in wheelchairs, babies in strollers, seniors with walkers and business travellers with heavy luggage on wheels. Decontextualization is among the most frequently encountered problems in research.

Oversgeneralization and universalization result from taking information about the dominant group and extending it to the non-dominant group without questioning its applicability. Any study that uses only one sex, one race or non-disabled people and presents its findings as if they were applicable to everybody is over-generalizing. A variation included under this heading involves statements that claim to be of universal applicability but in reality fail to take into account the situation of non-dominant groups. E.g. “The French revolution brought us universal suffrage” — but not for women. Or “The Canadian state supported the patriarchal family from the beginning of the 20th century to about 1970” — but not for male Chinese immigrants who were not permitted to bring their wives with them (Dua, 1999), nor for Aboriginal people whose children were forcibly removed to residential schools (Royal Commission on Aboriginal Peoples, 1996), or for disabled people who were put into institutions, prevented from marrying and forcibly sterilized (McLaren, 1990).

A different type of failing to recognize differences occurs when dominant or non-dominant groups are treated as homogeneous groups. Everybody belongs to more than one group. Whites come in more than one sex with different sexual orientations, abilities, class memberships, etc. People of colour may or may not have high educational attainment; they may be rich or poor; old or young; male or female; and so on. It is important to pay attention to the way in which the various hierarchies intersect (*assumed homogeneity*).

3. Using double standards

Double standards come in two forms: they may be open or hidden. The latter is, by definition, the most difficult type of bias to detect. There are many types of overt double standards. The most basic version involves different treatment of non-dominant groups where this different treatment reinforces their subordinate status. An example of an *overt double standard* is the conceptualization of race. It is only recently that whiteness has been recognized as a racial category, whereas people of colour have been racialized for a long time (Hurtado & Stewart, 1997: 299). A similar form of double standard is *under-representation or exclusion*. For a long time, women were excluded from drug trials because their hormonal cycles complicated the research projects — but the drugs so tested were then routinely prescribed to both women and men.

The companion piece to this type of double standard is *exceptional under-representation or exclusion* of members of dominant groups in contexts that are relevant to them but that are, for various reasons, usually associated with non-dominant groups. For instance, most research on reproductive health issues and on everything related to parenting is done on women, even though men have separate and different reproductive health issues and typically also have a longer reproductive span than women. Internationally, fertility is measured by the number of children per woman in childbearing years, leading to a scarcity of knowledge about male fertility and sexual behaviour.

Another form of bias is the denial of agency on the part of non-dominant groups, while dominant groups are often seen only as actors rather than as also acted upon. In particular, the health system — without justification — often treats disabled people as incapable of making decisions about their own lives and research is more often conducted about them than by them (*denying agency*).

Treating dominant opinions as fact is another expression of a double standard. Sometimes, the opinions of members of dominant groups about members of non-dominant groups are treated as facts rather than as opinions. For instance, in occupational health studies, sometimes only managers, rather than the workers, are asked about the effects of various working conditions on workers. While this may provide relevant information, it should not be taken as equivalent to the actual experience; that is information that can be supplied only by the workers

themselves. In historical research, it is important to note the source of information and treat opinions expressed by, for instance, an upper class male as his opinions only, not representing the actual situation of servants and women. If non-dominant opinions are the only ones being taken as fact, this too is a problem, and the solution would be to take the opinion of both groups as opinions.

A similar problem is treating stereotypes as if they were essential aspects of group membership rather than as socially constructed; for instance, when race is seen to be indicative of intelligence (*stereotyping*) (Rushton, 2000).

Another manifestation of a double standard is the tendency to exaggerate differences: by categorizing members of non-dominant/dominant groups into discrete groups rather than treating them as groups with overlapping characteristics. For instance, on average, men are taller than women. However, in almost any large gathering, we would find a very large overlap in size between the sexes. Rather than conceptualizing size as a dichotomous variable (men as tall, women as short), we need to think of size as a characteristic that has statistically a different distribution in terms of sex, but where the overlap is greater than the difference. This becomes theoretically important when dealing with less tangible character traits that are often used in the construction of Masculinity-Femininity scales, which use such character traits as independent, gullible, affectionate, self-reliant, etc. (*exaggerating differences*) (Eichler, 1980: 60-90).

Hidden double standards typically manifest when comparable phenomena pertaining to non-dominant and dominant groups are defined in such a manner that they are categorized and valued differently. To find hidden double standards one needs to look for non-obvious parallels. A classic example that falls within the gender hierarchy is our definition of work and productivity. It took decades of scholarly effort to establish that work comes in two forms: paid and unpaid. (For a more detailed discussion, see Concepts, p30).

Solutions to bias problems

The Framework has been designed to identify and eliminate biases that derive from social hierarchies and perpetuate social inequality and, in so doing, violate or prevent the fulfillment of human rights. It is embedded within a human rights perspective that presupposes equality as an underlying societal value and a commitment to equity as a pathway to achieving equality and ensuring that all people can enjoy their full human rights (United Nations, 1948). Where there is no commitment to this goal and its underlying values, dismantling social hierarchies may not be possible. Effecting social change under these circumstances will require much more concerted effort to bring about a shift in underlying values.

Eliminating biases due to social hierarchies is an enormous task — challenging existing power structures and long-standing cultural traditions and practices — and may take many years to resolve even when there is a commitment to equity and full and equal human rights. Concerted effort is required at many levels to map out fully these solutions, which may include changes in policies and practices at both broad macroeconomic levels and in intra- and inter-personal contexts, and involve diverse players in families, communities, organizations, governments and the international community.

The Framework is designed to assist in the process of eliminating inequities in health research so that people can enjoy their full and equal human rights to health. It distinguishes among a number of complex and interrelated problems, identifying the roots of the problems and pointing the way to appropriate and responsive solutions. The solutions vary depending on a diverse number of factors. Within research, some solutions are straightforward and relatively easy to implement. Others would require a shift in power that will not be brought about only through research.

Research in and of itself does not change societal structures, although the research may plant the seeds for change. The solutions to bias in research are located at the level of the research system rather than at a broader societal level. These include addressing bias in individual research

activities, and in the larger field of research, as a system, institution and source of knowledge, including research priorities identified by countries and the global community. Clearly those who control the research purse strings are in a dominant position within the global research hierarchy. Agencies that conduct or sponsor research can use the Framework to critically examine their own practices and implement significant changes. For individual (or groups of) researchers who may be recipients of grants or who conduct research independently, the arena for action and application of the Framework is restricted to the research project itself. Eradicating inequities from health research is of vital importance in reducing unnecessary deaths and suffering.

When dominance of one group over the other is in any way justified or maintained in research, the solution is to identify this as a hierarchy problem (*H problem*) and situate the problem within a human rights perspective in which equality is an underlying value. The researcher can point out the discrepancy between this value and the inequalities among groups of people that result from the hierarchy, and identify the various ways in which this biases research.

When the problem is that membership in a non-dominant/dominant group is not examined as socially relevant (*F problem*), the solution is to establish the relevance of such group membership within a given context. Once relevance is established, it requires that the differences are accommodated in ways that reduce the hierarchy.

When the problem is that members of dominant and non-dominant groups are treated differently, and where such differential treatment maintains a hierarchy (*D problem*), the solution is to identify the double standard and devise means to treat both groups the same. Examples of how this works out in research are presented below.

The nature of solutions also varies across the various elements of the research process. When conducting one's own research, the Framework can be used to alert researchers to the possibility of specific types of bias at any and all stages of their work, and to point to ways to avoid introducing biases of various sorts. It can also be used when reviewing the work of others. When conducting a literature review, for instance, a researcher might discover that within a certain sphere of research, little or no research has been conducted that involves a non-dominant group as research participant, and/or that most research on this non-dominant group has been conducted by a dominant group and from its perspective only (*H problem*).

Solutions to bias problems are multifaceted. While some aspects of the problem can be addressed directly through research, others require shifts in policy, societal values and attitudes that extend far beyond the scope of research. If during a literature review, a researcher discovers that a particular non-dominant group has been excluded from consideration, the solution would be to document and call attention to this problem, and ensure not to replicate it in his or her own research. For the granting body, the solution would be to identify biases within its granting processes that might perpetuate this kind of bias. It would need to examine the various stages of operations to see where the biases creep in, and address the problems as they are identified. It could use the Framework to look for biases within its Requests for Proposals (RFPs), funding criteria and research staffing policies, for example. Universities might look to their student admission, recruitment, and retention policies and practices, for example, to identify any biases that might lead to the training of fewer numbers of researchers from that particular non-dominant group and to influencing the composition of their teaching faculty. Governments might explore the biases within society that act as barriers for the full-participation of the non-dominant group along the many life pathways that would prepare them to be actively engaged in the research process.

Consequences of the failure to recognize the tripartite nature of biases

Much of the voluminous literature on sexist, racist and ableist biases tends to be restricted to only one or two of the bias problems identified in the Framework.

Gender hierarchy

The gender hierarchy is built on both sex and gender. Sex deals with the biological differences between females and males. Gender refers to the social construction of norms, values, attitudes, roles and behaviours attached to being identified as female or male, and are assigned not innate. These social constructions, and the social structures that reinforce them⁵ (March, Smyth, & Mukhopadhyay, 1999: 17-18), must be questioned whenever they have consequences for human rights, values and freedoms.

For the purpose of this book, we refer to the typical distinction between men and women with respect to sex and gender. While we recognize that sex and gender are not dichotomous variables, i.e. that a person may have biological characteristics typically associated with both males and females, may undergo surgery for sex change, or may have a transgendered identity, tackling these complexities is beyond the scope of this book. Merely adding in a reference to these individuals every time a reference is made to men and women would not do justice to the biases faced by people who do not fit the normative definition of male or female from a sex and/or gender perspective. While this analysis will not be covered in this book, we would encourage others to apply the Framework to do a full analysis of the problems that result from these biases.

Most of the literature and guides developed to deal with gender-based analysis (GBA)⁶ assume that the answer to *sex* and *gender* bias is *gender sensitivity*. Here we are dealing with a theoretical as well as a semantic problem. With respect to semantics, the current international parlance is that GBA solves the problem of gender bias.⁷ The term “gender-based analysis” suggests that it is enough to take *biological sex differences* and *social gender differences* into account, rather than to challenge existing gender hierarchies (that take different forms in different countries, times, ethnic and religious groups, etc.). The way in which *gender-based analysis* is understood, then, often identifies it with *gender-sensitive analysis*. The problem is compounded by the equation of gender with sex in much of the literature.

While many researchers are acutely aware of and concerned with the gender hierarchy, there are also many studies that present themselves as “gender sensitive” without reference to the gender hierarchy. *Gender sensitivity* is usually not explicitly defined, but rather is treated as a common-sense concept. It tends to be operationalized as: a) including women in the analysis; and b) asking whether there are different *biological* or *social* circumstances attaching to the situation of women and men that need to be taken into account within a given context.

While this is helpful as far as it goes, it becomes problematic when the context is taken as given. If we simply mirror the existing differences through gender-sensitive analysis (recognition of the biological and social differences between women and men) without questioning the hierarchy that gives rise to the social (not biological⁸) differences between the sexes, then we have failed to identify the hierarchy as problematic and thus have served to maintain it. This is an important point with relevance for both women and men.

The dominant gender hierarchy is a complex structure that affects men and women, girls and boys. Assigned gender roles usually disadvantage females and sometimes males. Worldwide, women tend to be responsible for housework and care for family members (Adkins, 1995; Agassi,

⁵ See Health Canada's GBA policy for distinction between sex and gender.

⁶ Kenya, Office of the President, & Gender and HIV/AIDS Technical Subcommittee of the National AIDS Control Council, 2002; Liverpool School of Tropical Medicine, 1999; March et al., 1999; Status of Women Canada, 1996.

⁷ An alternative is to identify the problem as sexist research and the solution as non-sexist research, which avoids the current dilemma. See Eichler, 1991.

⁸ Some biological differences are socially mediated.

1989; Arrighi & Maume, 2000; Baxter, 1997; Benéria & Roldán, 1987; des Rivières-Pigeon, Saurel-Cubizolles, & Romito, 2002; Hochschild, 1989; Major, 1993; Ross, 1987; Sanchez, 1993; Zuo & Bian, 2001). By contrast, men have historically been assigned the role of provider. A strict division of labour by gender has negative consequences for both women and men. Men who would like to participate equally in household work, including childcare, have a harder time finding support for such activities⁹ from their employers. Women experience more interrupted careers, financial insecurity and higher stress levels from role overload than do men.

Women often lack control over their physical and reproductive well-being, as is evidenced, for example, by the high rates of violence against women perpetrated by their partners (García-Moreno & France, 2001), unwanted pregnancies and high rates of partner-induced infection with HIV and other sexually transmitted diseases (STDs) among women (Fleischman, 2002). At the same time, within their communities, and both nationally and internationally, women have largely been excluded from other social spheres, wield little power in decision-making beyond the household and have less access to the world's resources than do men. This leaves women relegated to the household sphere and in a weak position to negotiate their entitlements to rights, equality, justice, health, dignity and respect, and to benefit from their contributions to society.

Boys are often socialized, from an early age, to “be a man”, not to show their feelings, and not to complain about how they are feeling. Violence and risk-taking behaviour are also often learnt from an early age. This plays out later in life as men fail to seek preventive health care and often engage in risky and violent behaviours, all of which is detrimental to their health.

To be sure, there are exceptions, and as the movement towards gender equality progresses, traditional gender roles are being questioned and some of the related inequities are being reduced; but, by and large, the predominant gender hierarchy results in women everywhere remaining disadvantaged relative to men.

There are infinite numbers of studies to show that to achieve the human rights of women leads, irresistibly, to the amelioration of the human condition without distinction as to race, sex, language or religion. God knows, that's what the world needs. It's sad, therefore, that in his report to the Commission on the Status of Women, whose meetings begin in two days time, the Secretary-General is forced to point out “that in no country in the world has women's full de jure and de facto equality been achieved.”
It's 2006. What a commentary on male hegemony (Lewis, 2006).

Thus, if we consider only the need for differential treatment, we will fail to note when double standards are at play and when, therefore, the *same* treatment (in research and in daily life) is necessary to reduce the hierarchy. We need to ask both when women and men (girls and boys) require *different* rather than the *same* treatment to achieve equal results as well as when it is necessary that females and males require the *same* treatment as the other sex to reduce historical as well as new forms of discrimination. Underlying this must be awareness that the problems stem from the gender hierarchy, and that the ultimate solution is the dismantling of the hierarchy. In the end, both women and men will benefit greatly from this.

Race hierarchy

There are, of course, many types of racism; it changes over time, place and with the socio-political system, etc. Current versions in North America, for example, include what has been called “democratic racism” that results from the retention of racist beliefs and behaviours in a “democratic

⁹ Consider the differences in maternity and paternity leaves (beyond the medical leave required by the mother) in many countries. (Fagan & Hebson, 2006).

society" (Henry et al., 2000: 19), and "aversive racism" — racial bias that manifests as a pro-white sentiment and "not simply anti-black sentiment that many traditional theories and measures have implied" (Gaertner et al., 1997: 175).

Much of the anti-racist literature focuses on, first, the existence and nature of a race hierarchy, and second, the need to recognize differences between people of colour and whites (as well as between different peoples of colour, and between "blacks" and Aboriginal people) and the need for different treatment to ensure equality. Much less has been written about double standards, relating to *different* treatment on the basis of "race" when the *same* treatment would be in order.

The global race hierarchy has been constructed primarily on the basis of skin colour, with people with "white" skin typically in the dominant position on the hierarchy, and people whose skin colour is variously described as "yellow", "red", "brown", "black" or "coloured", lower on the hierarchy, although their exact relationship to each other along the hierarchy may vary from culture to culture. Historically, however, other perceived "genetic" factors besides skin colour have been used to justify a racial hierarchy, such as in the case of Jews. On a national scale, racial hierarchies also exist, with superiority of one group over another based on skin colour (lighter is usually considered better), tribe, ethnic group, etc. Many atrocities have been perpetrated globally, and within nations, on the basis of race.

Over the years, various attempts have been made to measure racial differences to justify the supremacy of a particular race, and the rank order of the other races. This has included measurement of head circumference; brain size; IQ scores; muscle mass and density; reproductive rates; and a host of other measures (Rushton, 1991, 1992; Weber, 1992). Belief in the inferiority of races other than "white" historically has resulted in the denying of personhood, colonialization and whole-scale destruction of indigenous societies, and wide-spread discrimination, exclusion, persecution, elimination and other human rights violations on the basis of "colour" or other "genetic" differences perceived to be linked to race (Weitz, 2003). Similar beliefs with respect to particular ethnic or tribal groups have had similar effects within nations, such as evidenced by atrocities such as the genocides in Armenia (1915-1918) (Smith, Markusen, & Lifton, 1995), Germany (1941-1945), Cambodia (1975-1979), Rwanda (1994) (Human Rights Watch, 2006) and Bosnia (1992-1995) (Trahan, 2006), to name just a few.

Long-standing historical discrimination on the basis of race has left many peoples socially, economically, and politically disadvantaged relative to the dominant racial group within their society. It has resulted in extreme inequalities with respect to health, education, employment, income, political power, and other social disadvantage (O'Neil & Piron, 2003: 12-13). The black civil rights movement in the USA, work to dismantle Apartheid in South Africa, and Indigenous Peoples' quest for self-governance and settlement of land claims are all examples of rights-based movements to redress this historical discrimination.

There is debate today about whether race is actually biological — that many differences identified as "racial" are, in fact, the product of long-standing discrimination, genetic differences that have emerged within a small gene pool, and/or similar environmental conditions (Bamshad & Olson, 2003). Regardless, genetic predispositions to certain health conditions, or genetic differences in the metabolism of food, drugs etc. that are present in certain "racial" or "ethnic" populations, all need to be taken into account when dealing with the health of people. So too do the varying social conditions of people from "racial" or "ethnic" populations, especially when social disadvantages that negatively affect health are present.

Scholars who treat race as only biologically grounded rather than also socially constructed are criticized for practising race essentialism. Race essentialism exaggerates the differences between people of colour and whites, and fails to see both the internal variations among people of colour and whites as well as the commonalities between both groups (Jhappan, 1996: 17).

There are different meanings associated with the term "essentialism" in recent social science and cultural studies. Theories are typically branded as essentialist when they claim that these social distinctions [of gender, race and sexual orientation] have deeply rooted biological under-

pinnings, that they are historically invariant and culturally universal, or that their boundaries are sharp and not susceptible to sociocultural shaping" (Haslam, Rothschild, & Ernst, 2000: 114).

This focus on anti-essentialism has led to a specific quandary: is race still a meaningful category for scholarly analysis and political activity? This is parallel to the debate about whether it is still meaningful to use "woman" as an analytical category — and for the same reasons. Dei (2000) argues convincingly for the importance of recognizing race and race differences, and indeed asserts the salience of race, which he presents as a socially constructed category, stripped of all biological, inherent, and unchanging aspects.¹⁰

The tripartite *BIAS FREE* approach recognizes race as one of the bases on which social hierarchies are constructed. It also recognizes membership in dominant or non-dominant racial groups as socially relevant and in need of examination as an analytical variable. Finally, it recognizes that all people have equal entitlements to rights, equality, justice, health, dignity and respect, regardless of their race; and that to achieve equality with dominant racial groups, members of non-dominant racial groups may sometimes require *different* treatment to minimize the hierarchy, and at other times, the *same* treatment to resolve double standards. It also recognizes that, in relation to health, different treatment may be required in response to any differences in genetic, biological or social factors.

Ability hierarchy

The ability hierarchy has been constructed on the basis of a medical model of disability, in which people are assigned an order on the hierarchy on the basis of their biological structures and functioning in relation to species-typical normative structures and functioning. The focus is on abnormality, deficits and decrements in functioning (Üstün 2006). Position on the hierarchy is assigned in relation to measurable differences from the norm.

The 'medical model' of disability invokes a 'common-sense' definition of disability. Under this model, disability involves an observable deviation from biomedical norms and focuses on the abnormality of the body. People with disabilities are those who experience a significant level of physical, sensory or mental incapacity, which affects their life experience. Disability is conflated with impairment and incapacity, and is seen as an individual deficit. Medicine and rehabilitation are mobilised to overcome the consequences of impairment and to provide a basis for identifying those in need of support. Within the context of the modern welfare state, social security schemes may be introduced to compensate for the economic cost associated with impairment. The attitude to people with disabilities is, on this model, essentially paternalistic. It embodies the assumption that people with disabilities are in need of charity and care. Disability is conceptualised as an individual tragedy, and pity and concern are invoked. The consequence of viewing disability in this way is that people with disabilities are treated as outsiders. Adopting a negative view of disability, and people with disabilities, legitimises strategies such as relegating people with disabilities to institutions; sterilising them for eugenic purposes; or denying them citizenship rights. Such actions are considered to be appropriate responses to the social problems arising out of disability (Jones & Basser Marks, 2001: 8476).

¹⁰ Dei, like Jhappan and others, ends up using the concept of "strategic essentialism" — a term first coined by Spivak (Spivak, 1996). It seems that Dei's term of "race salience" achieves the same without the confusing use of the term "essentialism" in both a negative and positive sense.

Within the anti-ableist literature, there is much criticism of the biomedical model of disability and the prescribed solution to fix individuals so that they can appear, behave and/or function in a manner that approaches the dominant norm as much as possible. In response to the biomedical model, a *social model of disability* emerged as people claimed their entitlement to be equal members of society. The social model values the diversity of bodily structures and functioning and situates the source of disadvantage not in the individual, but in the environment and in social, political and cultural practices that disempower them and create barriers to their inclusion and full participation in society. “The social model rejects the individual deficit understanding of disability, which is exposed as a form of biological determinism, and disputes assumptions about the ‘inherent inferiority’ of people with disabilities as the cause of subordinate social status” (Jones & Basser Marks, 2001: 8477). From the perspective of this model, the solution is not the “cure” of the individual by doctors and rehabilitation specialists, but the “cure” by policy-makers of disabling and exclusionary policies, programmes and practices.

Within the literature, some disability rights activists have been criticized for omission of the body and the reality of the personal experience of impairment, pain and limitation. As Shakespeare and Watson (1996) argue, quoting Morris (1991), “We can insist that society disables us by its prejudice and by its failures to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to collude in our own oppression.” The denial of the personal experience of impairment is, the authors argue, a form of social or cultural essentialism. Within the disability movement, this essentialism is a point of tension. It is epitomized in the lack of clarity, the conceptual confusion and the failure to come up with consistent concepts to define disability itself.

Increasingly, there is movement towards a *human rights model* of disability¹¹. Recognition of disabled peoples’ entitlement to equality, dignity and social inclusion has gained widespread acceptance beyond the disability movement, and is the subject of an international convention on the human rights of disabled peoples agreed upon at the United Nations on 27 August 2006.

The human rights model starts from the point of view of the universal entitlement of all people to rights, equality and justice. People with disabilities, like all other people, are entitled to have their rights recognised and to be treated with dignity and respect. An inclusive theory of human rights takes the celebration of diversity and difference to be fundamental, and equality to relate to both the process itself and the outcome of that process. An inclusive human rights model does not accept formal equality as an appropriate standard nor does it accept that equalisation of opportunity will result in inclusion. People with disabilities can only have their human rights respected when society makes accommodations for difference not just when asked to do so but at every step along the way. This model does not elevate people with disabilities to a special status nor require that the primary identity of the person be that of a person with a disability. Rather, the human rights model proposes a fluidity of treatment and a flexibility in policy and practice. The needs of all people are to be equally acknowledged and respected such that accommodations will be made independent of status of the person (Jones & Basser Marks, 2001: 8477).

¹¹ For a discussion of models of disability see (Barnes, 1996; Jones & Basser Marks, 2001; Oliver, 1996; Rioux, 2003).

In keeping with this rights-based approach, the *BIAS FREE* Framework calls the ability hierarchy into question. It challenges the systems, structures and practices that have contributed to the discrimination, marginalization and exclusion of disabled people (Bach & Burke, 2002).

Benefits of an integrative approach to social hierarchies

Using an integrative approach to explore the nature of biases that derive from social hierarchies helps to identify some of the areas where existing anti-sexist, anti-racist and anti-ableist scholarly work have run into difficulty.

Exploring common roots of domination and social inequality

Bringing each of the hierarchies into a common framework has helped to shed light on common roots of domination and social inequality. A common manifestation of all hierarchies is a tendency to locate “the problem” in the individual and to construct non-dominant groups as pathologically different from the dominant group.

Rather than locating problems within the individual, the *BIAS FREE* Framework recognizes the hierarchy as problematic while, at the same time, acknowledging that personal experience is important — but without pathologizing it. The framework calls attention to the need at times to treat people *differently* to accommodate their differences and at other times to treat them the *same* to avoid double standards.

Correctly identifying the problem and needed solution

What happens if we fail to deal both with differences and similarities simultaneously? Typically we end up substituting one problem with another, or compounding the original problem. For example, to be eligible for disability benefits in the Province of Ontario, in Canada, disabled people must demonstrate that they meet certain criteria. In a recent study, one person recounted: “They said to my daughter, does she cook? And she said she has her own kitchen. And they said, if she can use her kitchen she doesn’t need a scooter.”

The authors of the report comment: “Because of her abilities in one area, she was ineligible for assistance to obtain the mobility device she needed so that she could participate in others” (Frazee et al., 2002: 77). In this instance the rigid set of eligibility criteria resulted in the disabled person being denied the support she needed for social participation. This is evidently a case of muddled thinking, lack of knowledge and failure of professional competence and judgement on the part of the persons making the assessment for supports and/or setting the eligibility criteria. Moreover, failing to consider and accommodate the needs of the disabled woman reinforces the social hierarchy and perpetuates social disadvantage and inequity for the woman. When this happens in a systemic way, such as in the case of system-wide eligibility criteria that are used over and over to deny people their right to accommodation, it is, very clearly, an example of a social hierarchy at work.

Examining both social and biological differences in a non-hierarchical manner

So far, we have looked at the gender, race and ability hierarchies, all of which are social constructions. However, there are also biological differences that must be acknowledged, particularly in health research. The current emphasis in the literature on *embodied knowledge* (Tomlinson, 1999) helps to re-introduce such differences in a non-hierarchical manner. The body has been called an “absent presence” (Schilling, 2003), of which we become aware consciously either through a process of reflexivity or because the normativity of a two-handed, two-legged etc. body is disrupted.

In other words, all knowledge is mediated through the body, whether the body meets normative standards or not. Acknowledging this helps to accept the diversity of body shapes and forms. As Lupton notes: “... claims which deny the biological characteristics of lived bodies may prove to be self-defeating if it means that women who are pregnant, undergoing in vitro fertilization, childbirth, breast-feeding or abortion, taking hormonal contraception, subjected to female circum-

cision, experiencing premenstrual syndrome, menstruation or menopausal symptoms are denied acknowledgement of the sheer physicality and inevitable social consequences of these uniquely female physiological experiences, some of which, like menstruation, pregnancy and childbirth, are universal across cultures” (Lupton, 1994: 25).

With respect to race, there are also some biological aspects that need to be taken into account in health research, such as genetic conditions (e.g. sickle-cell anaemia (Tapper, 1999)) that are more prevalent among specific racial or ethnic populations. On the one hand, they may require focused research on a particular condition; on the other, they may need to be taken into consideration in research that is not specific to these conditions, but where their presence may have a differential effect on results.

Biological differences are also relevant for people with non-normative body compositions, health conditions or impairments. For example, recent research has found that people with Down Syndrome have some protective factors against cancer (Hasle, Clemmensen, & Mikkelsen, 2000). Research to understand these factors could have benefits for others as well; but, this knowledge gives rise to serious ethical concerns that must be taken into consideration in the conduct of research.

Understanding intersections and compounding effects of biases

As already indicated, everyone experiences stratification in more than one social hierarchy. One may be disabled, male and white, or female and black with a normative body and mind, for example. To this, the many other hierarchies that are at present not considered such as sexual orientation, age, class, caste, religion, geographical location and so on can be added. Indeed, none of these statuses is ever experienced in isolation; each is mediated through the others.

The effects of being positioned in more than one hierarchy may not simply be additive, but may sometimes multiply. We therefore need to acknowledge and deal with the intersecting and cumulative nature of the inequalities stemming from various hierarchies. This requires a systematic, multidimensional analysis of the various biases and the forms they may take. An integrative approach facilitates this.

In research, the more dimensions that are added, the bigger the sample required. One cannot ever cover all hierarchies in every research study. The key is to acknowledge this in the study, identify which hierarchies are relevant within a given context, clarify which hierarchies will be addressed, and provide reasons for excluding the others.

Probing the nature of the problem

The *BIAS FREE* Framework builds from the three interconnected types of problems identified above. It provides a comprehensive set of diagnostic questions that will alert us to the presence of biases that derive from any form of social hierarchy. Questions are provided for each of the three main problem types. Further questions in the framework probe deeper to look at the nature of the problems. These questions allow us to recognize and to find solutions for *all* forms of biases derived from social hierarchies, not just one form. The various problems overlap but nevertheless have distinct characteristics.

It does not suffice simply to transfer questions derived from recognizing gender bias to, for instance, racist biases. One needs to take into account what forms racist biases take and how they differ from gender biases. Likewise, ableism presents its own unique problems. We have dealt with this issue by going back and forth between the three hierarchies in the formulation of theoretical questions that alert us to the presence of biases, and in the formulation of the solutions. Using the abstract terms “dominant” and “non-dominant” groups to refer to position on a social hierarchy, rather than names of groups specific to a particular hierarchy, e.g. men/women, non-disabled/disabled, allows shifting the focus back and forth to look at hierarchies that are organized along different axes (e.g. gender and race) as well as hierarchies that exist within a particular hierarchy.

Recognizing hierarchies within a hierarchy

Finally, there are hierarchies *within* each of the hierarchies. For instance, in the gender hierarchy, globally men are the dominant group (have a higher position in the hierarchy as evidenced by their ability to yield more power and accrue more resources than women); but among men there is also a clear global order, with white males from high-income countries typically being dominant over non-white males from low-income countries (as evidenced by the preponderance of white males in positions of power, wealth, access to resources like health, education, control over decision-making affecting global issues, and the relative social disadvantage of the majority of the world's non-white males, relative to white males, despite non-whites accounting for five-sixths of the world's population of men). Likewise, within a particular society, some groups of men will be dominant over others; while this may vary from country to country, ordering may be done on the basis of any number of hierarchies, for example, sexual orientation, number of wives, religion, tribal status, caste, etc.

While males are more dominant than females on the gender hierarchy, both are more dominant than people who do not fall within the normative definition of male or female. People who fit neither standard conceptions of male and female, nor ascribed gender roles, experience discrimination and social disadvantage in most societies, although there have been exceptions in some cultures. Among the Aboriginal Peoples of North America, for example, homosexuals and transvestites were assigned an honoured position within their community as shamans or healers (Trewartha, 1989).

Within the disability hierarchy, people with physical impairments are more dominant than people with psychosocial impairments (Deal, 2003), and experience less stigma and discrimination.

Types of applications

The major questions and sub-questions in the *BIAS FREE* Framework alert us to the presence of bias deriving from any social hierarchy and can be applied at any and all stages of the research process. The Framework also can be used to identify biases in legislation, policy, programmes, service delivery and practice; but these applications are not dealt with in this book. Each of these processes has a number of elements or stages, some of which overlap. Not all elements are always present in every research activity. For example, some types of research may not clearly distinguish between the research question, design and methods. Others may not have an abstract, a summary or policy recommendations. Some may not proceed on the basis of funded research proposals or calls for proposals. Qualitative research projects sometimes may not present hypotheses or use specific measurement instruments. The set of research elements listed below is not exhaustive — it is for illustrative purposes only. The list can be adapted as needed. The first list reflects elements of conducting research (Sage, 2005); the second list reflects elements of funding, managing and administering research programmes. For the purposes of this book, examples that illustrate applications of the Framework are limited to the various elements of conducting research.

Elements of conducting research:

- Research proposal
- Literature review
- Research question and design
 - Study purpose and rationale
 - Hypothesis
 - Description of population to be studied and inclusion and exclusion criteria
- Concepts
- Theoretical framework
- Research methods
 - Description of methods
 - Measures and measurement instruments
 - Recruitment of participants

- Data analysis and interpretation
- Conclusions
- Policy recommendations
- Communication of results
 - Title
 - Abstract/Executive summary
 - Literature review
 - Language
 - Analysis and discussion
 - Conclusions
 - Visual representations

Elements of funding, managing, and administering research programmes:

- Priority-setting
- Research protocols, including topics, nature of methods, staffing criteria, etc.
- Funding criteria
- Call for proposals
- Ethical guidelines
- Evaluation of proposals
- Guidelines for dissemination of results
- Evaluation of final product
- Communication strategy

Three-dimensional matrix

The *BIAS FREE* Framework has been designed as a three-dimensional matrix that uses a set of 19 diagnostic questions for exploring whether biases that derive from various social hierarchies are present in various elements of the research process, and a set of solutions for removing all biases uncovered during application of the Framework. The three dimensions of the matrix are:

1. Type of hierarchy (race, gender, ability, etc.);
2. Specific element of the process being examined (research proposal, literature review, methods, analysis, etc.); and
3. Theoretical questions that alert us to the presence of specific bias problems and to the appropriate solutions to remove the bias and resulting inequity.

Typically, when retrospectively reviewing published research, one would begin by identifying which hierarchy is at work, the main problem type and specific nature of the problem, and then whether the bias is at the level of a concept, the formulation of the research question and/or another element of the research process. When planning or conducting research, one begins with whichever research element best fits the current stage of the research process, and then proceeds as above.

A three-page version of the matrix for research applications is in the foldout pages at the back of this book. The questions and solutions from the framework follow below, and then we consider their application.

The *BIAS FREE* Framework

H – Maintaining an existing hierarchy

Question: *Is dominance of one group over the other in any way justified or maintained?*

Solution: Situate the problem within a human rights framework, in which equality is an underlying value. Point out the discrepancy between this value and the inequalities among groups of people that result from the hierarchy.

H 1 Denial of hierarchy

Question: *Is the existence of a hierarchy denied in spite of widespread evidence to the contrary?*

Solution: The existence of a hierarchy is acknowledged; its validation is questioned and rejected.

H 2 Maintenance of hierarchy

Question: *Are practices or views that are premised on a hierarchy presented as normal or unproblematic?*

Solution: Expressions of hierarchies are questioned and problematized.

H 3 Dominant perspective

Question: *Is the perspective or standpoint of the dominant group adopted?*

Solution: The perspectives of non-dominant groups are respected and accepted.

H 4 Pathologization

Question: *Is the non-dominant group pathologized when it differs from the norms derived from the dominant group?*

Solution: Challenge the norm and address the reasons given for pathologizing the group.

H 5 Objectification

Question: *Is stripping people of their intrinsic dignity and personhood presented as normal or unproblematic?*

Solution: Recognize that every human has intrinsic dignity and human rights that are inviolable and must be protected, and conduct the activity accordingly.

H 6 Victim-blaming

Question: *Are victims of individual and/or structural violence blamed and held accountable?*

Solution: Victims are not blamed; individual and/or structural violence is identified; and those responsible are held accountable.

H 7 Appropriation

Question: *Is ownership claimed by the dominant group for entities that originate(d) in or belong to the non-dominant group?*

Solution: Original ownership is acknowledged and respected.

F - Failing to examine differences

Question: *Is membership in a non-dominant/dominant group examined as socially relevant and accommodated?*

Solution: Establish the relevance of group membership within a given context. Once relevance is established, accommodate differences in ways that reduce the hierarchy.

F 1 Insensitivity to difference

Question: *Has the relevance of membership in dominant/non-dominant group been ignored?*

Solution: Relevance of dominant/non-dominant group membership must always be determined; group membership must be included as an analytical variable throughout the activity and only then can its relevance be assessed.

F 2 Decontextualization

Question: *Has the different social reality of dominant and non-dominant groups explicitly been considered?*

Solution: The context with respect to dominant/non-dominant group membership is explicitly examined and differences following from this are identified, analysed and taken into account.

F 3 Over-generalization or universalization

Question: *Is information derived from dominant groups generalized to non-dominant groups without examining if it is applicable to the non-dominant groups?*

Solution: Information about the dominant group is acknowledged as such and efforts are made to obtain information about the non-dominant group, or conclusions are limited to the dominant group.

F 4 Assumed homogeneity

Question: *Is the dominant or non-dominant group treated as a uniform group?*

Solution: Differences within dominant and non-dominant groups are acknowledged and taken into account.

D – Using double standards

Question: *Are non-dominant/dominant groups dealt with differently?*

Solution: Identify the double standard that leads to different treatment of members of dominant and non-dominant groups and how this maintains a hierarchy; then, devise means to provide the same treatment to both groups.

D 1 Overt double standard

Question: *Are non-dominant and dominant groups treated differently?*

Solution: Provide the same treatment to members of dominant and non-dominant groups whenever this increases equity.

D 2 Under representation or exclusion

Question: *Are non-dominant groups under represented or excluded?*

Solution: Non-dominant groups are included whenever relevant.

D 3 Exceptional under-representation or exclusion

Question: *In contexts normally associated with non-dominant groups, but pertinent to all groups, is the dominant group under represented or excluded?*

Solution: Dominant groups are appropriately represented in issues of relevance to them that have been stereotyped as being important only for a non-dominant group.

D 4 Denying agency

Question: *Is there a failure to consider non-dominant/dominant groups as both actors and acted upon?*

Solution: Examine ways in which dominant and non-dominant groups are both acting as well as acted upon.

D 5 Treating dominant opinions as fact

Question: *Are opinions expressed by a dominant group about a non-dominant group treated as fact?*

Solution: Opinions expressed by dominant groups about non-dominant groups are treated as opinions, not fact.

D 6 Stereotyping

Question: *Are stereotypes of non-dominant/dominant groups treated as essential aspects of group membership?*

Solution: Treat stereotypes as stereotypes, not as truths.

D 7 Exaggerating differences

Question: *Are overlapping traits treated as if they were characteristic of only non-dominant/dominant groups?*

Solution: Document both the differences and the similarities between members of non-dominant and dominant groups.

D 8 Hidden double standard

Question: *Are different criteria used to define comparable facts with the effect of hiding their comparability?*

Solution: Ask whether there might be a hidden double standard by looking for non-obvious parallels. One way of achieving this is by asking what form the phenomenon identified within one group might take within another group.

III Applying the *BIAS FREE* Framework to research for health

Applicable at any stage of the research process

There is no single best entry point when applying the *BIAS FREE* Framework to research. When we are dealing with our own research or research about which we have some control (e.g. the evaluation of a research proposal), we can use the Framework to identify and rectify problems before we get too far into the research. When we are dealing with research reports of projects already completed (e.g. publications), applying the Framework will alert us to the existence of a problem, thus alerting us to use caution in how we use such reports.

A particular research study may have several problems that manifest in different phases of the study. For an example, let us consider the Aspirin study cited earlier. The research methods were *gender insensitive* in that they failed to examine and account for differences between the sexes (F 1), the conclusions were *over-generalized* (F 3) from men to women, and the whole was derived from a male perspective (*dominant perspective*) (H 3) that contributed to ignorance about or indifference to the possible biological differences in response to a drug between men and women. Depending on where we start our analysis, different questions will guide us to the recognition of a problem. In other words, there is more than one way to approach the issue and sometimes more than one correct answer. The issue is, therefore, not to find “the” correct answer to a problem but to recognize that there is a problem and to deal with it appropriately.

Research into a particular health problem may point to the existence of biases not in the research process itself, but in legislation, policies, programmes, services or practices. Again, the important thing is to be able to pinpoint and name the problem. Addressing it may be beyond the scope of the research, but the research could point to a needed response at the level at which the bias occurs.

The *BIAS FREE* Framework lists the theoretical questions we can ask of research by type of problem. However, when applying the Framework to research, one is more likely to proceed by research element rather than problem type, beginning with the research element applicable to the particular stage of a research project under way. Are researchers engaging in a literature review? In formulating the research design? In analysing data? Obviously, a different set of solutions to the problems that have been identified is possible and needed, depending on the specific element of the research process in which one is engaged. Selected examples using the questions posed in the *BIAS FREE* Framework are presented below, arranged according to the various elements of the research process. Examples are drawn from social hierarchies based on gender, race and disability, and occasionally from other hierarchies, to demonstrate the applicability of the questions within these differing contexts. Each of the identified problems is followed by a solution. The numerical designations of the questions in each of the examples below refer to the questions in the *BIAS FREE* Framework by their name and problem type.

Examples of the application of the *BIAS FREE* Framework to selected research elements

Research proposal

Gender Race Ability

Ensuring that bias does not creep into the research proposal itself is the first step to ensuring that research remains free of bias. A proposal is usually required when researchers apply for funding, although not all research projects require a formal proposal – for instance, if the research is unfunded. Whether or not a formal proposal is required, every piece of research begins with a hypothesis or question and a proposed course of action to investigate it. Calls for proposals can make it clear that proposals will be evaluated, among other things, on the basis of how well they include and pay attention to groups that are often excluded in research on a specific topic. This includes, for example, women in stress research (D 2), disabled people in almost any topic not specifically related to them (D 2), men in research on reproductive health (D 3), or race in studies that look at inequities in or financing of health research.

Researchers will need to demonstrate that they have contextualized the research for each of the groups studied by taking their circumstances into account in the formulation of questions (F 2), and that their analysis will likewise assess the relevance of membership in dominant/non-dominant groups and include it as an analytical variable. Promising projects that fail to do all these things can sometimes be remedied by drawing the attention of the researchers to these issues. While bias can also enter into research proposals in other ways, such as the inclusion/exclusion criteria for the population to be studied, the proposed sampling process, methodology and choice of research instruments, and in the data analysis, participant recruitment and communication and dissemination plans, they are addressed below as separate elements of the research process. Problems that may occur within a research proposal and within the research design that follow acceptance of a proposal are obviously closely connected — the major difference is in the time dimension.

Literature review

Research projects typically include a literature review as a first step. It is usually on the basis of such a review that decisions are made about whether or not to conduct a new study, how to design the study, and so on. Therefore, whenever a phenomenon under consideration affects both dominant and non-dominant groups within a given hierarchy, it is imperative to examine to what degree the literature deals with this fairly.

Gender

Literature reviews of specific articles or books involve — among other things — an assessment of whether or not they are free of bias. As such, it is necessary to ask the bias questions in reading and assessing each individual piece of literature. However, it is also necessary when conducting literature reviews to assess not only the adequacy of individual documents, but also the overall mix of documents. For instance, there is nothing wrong with single-sex studies as long as they clearly specify that they include only one sex. However, when the research is dealing with an issue that is relevant to both sexes — for example, heart disease — and study after study deals only with men, there is clearly a gender bias.

A good literature review, therefore, will consider not only whether individual studies do or do not have bias problems, but will also pay attention to and evaluate the overall mix. Literature reviews must therefore deal with what is available as well as what is missing within the field(s) surveyed. All three overriding questions need to be asked of the literature: Is dominance of one group over another in any way justified or maintained? Is membership in non-dominant/dominant groups examined as socially relevant and accommodated? Are non-dominant/dominant groups dealt with differently? If any or all of these problems are present, this needs to be explicitly pointed out. The identification of such problems provides an excellent jumping-off point for new research projects.

Gender Ability Race

For instance, most studies in stress research include male subjects only (Taylor et al., 2000). This is under-representation or exclusion (D2) in the research design. When the results are then over-generalized to women without examining whether they are applicable, we encounter a

different problem at the level of interpretation (over-generalization or universalization, F 3). If, when conducting the literature review, we keep asking ourselves whether the perspective of the dominant group (in this instance, males) is adopted, we would note that women have been largely omitted in this field of study. Exactly the same observation applies to the representation of disabled people and people of colour in many fields of research.

Accepting the findings as applicable to non-dominant groups without sufficient empirical evidence may lead to false conclusions and an inappropriate response to the group(s) excluded from the study. The solution is to note explicitly the imbalance in the literature, assume that, in the absence of empirical evidence, results are not transferable to the groups that have been excluded, and note the need for further research involving the excluded group(s).

Research question and design

The research question is the precise articulation of what one wishes to investigate. It often involves specifying the hypotheses (predictions about potential relationships and observations), and more broadly the overall question that the research process seeks to address. It is typically at this stage of the research process that the study purpose and rationale; and where applicable, the hypothesis and the description of the population to be studied; and the inclusion and exclusion criteria are articulated.

The term research design describes the overall approach to answering the research question and is most commonly used in the social sciences and natural sciences. While the terms “research question” and “research design” may not be used in the humanities, nevertheless, any research study will have a central guiding question and an overall plan of how to answer this question.

When retrospectively examining the research question and design in a completed project, all that can be done is to critique it if problems are present and to hope that this will lead to an avoidance of such problems in the next project. However, in prospectively planning or in conducting research, bias problems can be avoided. In the following, we provide some examples of problems and how they can be addressed in the overall approach to addressing the research question, and identifying the method(s) to be used in conducting the investigation and analysing the data.

If the study includes people who are located in different hierarchies, the existence of such a hierarchy needs to be acknowledged in the research design. A very basic way of maintaining a hierarchy is denying its very existence. Henry et al. call this problem “the discourse of denial”, i.e. the refusal to accept the reality of racism [and ableism and sexism] despite ample evidence to the contrary (H 1) (Henry et al., 2000: 26). The effect of such denials is to reinforce the hierarchy, since what is not accepted as existing cannot be effectively addressed.

Health issues of non-dominant groups, even in wealthy countries, typically get short shrift when it comes to expenditures on health research. For example, “[i]n a 1994 report, the Medical Research Council's Advisory Committee on Women's Health Research Issues estimated that only 5% of the Council's research funds went specifically to women's health issues. Exclusion of women from research results in problems of validity and important data gaps” (Health Canada, 1999: 15).

According to the World Health Organization, Saltman has argued, “One of the ways in which the existing health care system discriminates against women is in its focus on mortality: women's major health needs lie in improving morbidity rather than mortality” (World Health Organization 2000: 13).

By asking, “is the perspective or standpoint of the dominant group adopted?” (H3) it becomes clear that the research problem is, in this instance, defined from a male perspective. Women's life expectancy is longer than men's in most countries, but women experience higher morbidity. To deal adequately with women's health issues, some attention needs to be shifted from mortality to morbidity.

**Race
Ability
Gender**

Gender

Gender Ability The World Health Organization comments on the link between reproductive functions and psychiatric syndromes as follows:

It seems astonishing that issues such as forced sterilization, having one *[sic]* concerns dismissed or trivialized, not being asked for consent to invasive procedures or tests, being denied privacy or dignity when intimate gynaecological examinations are performed, having low or no access to accurate health information or to safe, effective and affordable methods of fertility regulation, safe care in pregnancy and childbirth and affordable means of preventing or effectively treating sexually transmitted diseases have never been seen to play a role in women's emotional well being. Inadequate reproductive health care and the violation of reproductive rights result in physical harm even death. Despite this, their psychological dimensions have been ignored, almost as if women's bodies and what is done to them had no effect on their minds and could be denied (World Health Organization, 2000: 25).

This makes a compelling argument that the research in this area is decontextualized (F 2) in the very way in which the research question is posed. On the other hand, by restricting themselves to commenting only on mental health consequences for women, the authors take the structural problems they enumerate as given, pathologizing women rather than the systems and structures (H 4). A more far-reaching approach would be to identify where concerted efforts could lead to a change in the structural factors that affect both the physical and mental health of women.

Gender There is much evidence that the gender hierarchy leads to serious problems in the design of studies, e.g., failing to take sex and gender into account (F1), excluding women from malaria research (D 2) (Heggenhougen et al., 2003; World Health Organization - Dept. of Gender Women and Health, 2004b). Similarly, we know that many illnesses — including tuberculosis (World Health Organization — Dept. of Gender Women and Health, 2004c); lung cancer and smoking (World Health Organization — Dept. of Gender Women and Health, 2004a); mental health problems (World Health Organization — Dept. of Gender Women and Health, 2004b) and others — manifest differently in females and males, and require different prevention, treatment and care strategies, all of which must be taken into consideration when designing and conducting related research.

Gender Looking at the opposite — the exclusion of men from research (D 3) — female contraceptives have been researched, produced and used for a long time, while male contraception is still in its infancy. A history of the World Health Organization task force on male contraception reveals how a number of factors coalesced to slow down the development of male contraceptives: companies did not see enough profit potential to assist in the development of drugs for sperm suppression in normal men. Also, gynaecologists and urologists “exercised a stranglehold on the treatment of male infertility and most appeared reluctant to support the development of methods for regulation of male fertility”, overall funding was limited, and medical graduates were reluctant to enter the new field of andrology, among other factors (Waites, 2003: 12).

Race Bias stemming from the race hierarchy has been shown to have a profound effect on how the research question and research design are formulated. Aboriginal peoples are often pathologized (H 4). A Canadian team of researchers notes: “Notwithstanding four hundred years of policies and practices of displacement and oppression, with the result that Aboriginal peoples exist at the bottom ranks of Canadian society, this resolution of the state of affairs continues to focus on Aboriginal people themselves” (Henry et al., 2000: 140).

Similarly, Smith, a Maori researcher, remarks that colonialists invented the "indigenous problem". "The 'indigenous problem' is a recurrent theme in all imperial and colonial attempts to deal with indigenous peoples" (Smith, 1999: 90). She argues:

A continuing legacy of what has come to be taken for granted as a natural link between the term "indigenous" (or its substitutes) and "problem" is that many researchers, even those with the best of intentions, frame their research in ways that assume that the locus of a particular research problem lies with the indigenous individual or community rather than with other social or structural issues. For example, researchers investigating poor health or educational underachievement among indigenous communities often focus on the community as the sole source of the problem and, because this is their focus, obviously fail to analyze or make sense of the wider social, economic and policy contexts in which communities exist. ... For many indigenous communities research itself is taken to mean 'problem'; the word research is believed to mean, quite literally, the continued construction of indigenous peoples as the problem (Smith, 1999: 91-2).

The effect of this approach is a pathologization of Aboriginal people (H 4). The solution lies in changing the research process so that research is designed and/or conducted by indigenous communities themselves about issues that are relevant to their health.

With regard to the disability hierarchy, a common problem in research is that research questions are typically framed to explore the effects of disability on education, income, employment, family status, housing, etc. Thus, having a disabled child is reported to result in high parental unemployment, family poverty and marriage break-up (UNICEF, 2005). However, when the questions are reframed to explore the effects of non-inclusive employment and family support systems, for example, on families with a disabled child, the failure of the system to adequately support the families becomes apparent and an entirely different picture emerges. While the first set of questions situates the problem in the child (H 4), the second calls into question the hierarchy that perpetuates disadvantage vis-à-vis disability. The solution is to look at disability (and other similar disadvantages) as both dependent and independent variables in the formulation of research questions.

Disability

Concepts

A concept usually indicates a general idea referring to a characteristic of an individual or group. In the context of this book, it is important to recognize the difference between biased concepts and biased language. In the case of concepts, we are not looking at the form of a word or sentence, but at the implied meaning of a word or set of words. The bias is not at the level of language or terminology; rather the bias is rooted in the definition of the concept itself.

Concepts cross-cut all the other elements of the research process and they may be biased in a complex and subtle way. Also, biased concepts can lead to biases in the formulation of hypotheses, research questions, design, analysis, conclusions, recommendations, etc. Identifying bias in concepts is one of the hardest things to do, and often takes the collective work of many people over a long period of time, such as in the case of "unpaid" work, referred to earlier. The solution is to use the Framework to identify the bias and the specific nature of the problem; then, redefine the concept to resolve the identified problem, ensuring that the new definition does not introduce a new bias.

One conceptual problem that is often seen erroneously as a language problem is the use of supposedly generic male terms — "man", "mankind", "he" (to describe everyone) — for general purposes. This is an instance of an overt double standard (D 1) — males and females are treated

Gender

differently in a way that maintains the hierarchy. The obvious solution to this problem is to use truly generic terms such as "human", "humanity" and "they".

The opposite problem is the use of general terms in situations when only one sex is considered, such as "the worker" or "voters" when dealing only with males. This is an instance of universalization (F 3); the concept suggests that women are included when in fact they are not. The solution, of course, is to use general terms only when the subject is, indeed, general.

The concept of work was cited above as an example of a hidden double standard (D 8). It is the equation of *work* with paid work and hence the exclusion of unpaid work from the definition of work that creates the bias, not the word itself. For a long time — and often still today — women who did unpaid work at home were described as "not working". It took the concerted effort of many feminist scholars in many countries to establish the notion that work comes in two forms: paid and unpaid — and that unpaid work is of very significant value, not only to individual people and households but to the economy of a country. The estimates of the value of unpaid housework vary greatly. A Canadian estimate pegs the replacement value at 41% of the GDP (Chandler, 1994). Using a different method of calculating value, an Australian estimate pegs it at 98% of the GDP (Ironmonger, 1996). American estimates fluctuate between 30% and 60% of the GDP (Folbre, 2001), and estimates from South Africa vary from a low of 11% of the GDP to a high of 55% - depending on the method of calculating the value (Budlender & Brathaug, 2004). It is clear that whatever the method used, unpaid housework is of enormous economic value.

The non-recognition of unpaid housework creates a host of problems. One consequence is that unpaid housework is seen as unproductive and hence as irrelevant to national budgets (Waring, 1988b). This systematically hides the unpaid work that women perform within households. For instance, when patients are discharged early from hospitals, this shows up as a cost saving in the budget. However, the care that used to be delivered by trained personnel within the hospitals is in such cases typically provided by women in the form of unpaid care work. The costs to women in terms of their own health, and sometimes their capacity to earn money, remain invisible as long as the work remains invisible (Bakker, 1998).

If we ask: "Are different criteria used to define comparable facts with the effect of hiding their comparability?" (D 8), we realize that paid and unpaid work are both work. The obvious solution is to recognize this and take it into account in research, and when setting budgets and devising policies.

Gender A different form of a hidden double standard occurs when a relationship is expressed from one side only. For instance, the concept of *polygyny* (= plural wives) is descriptively accurate but deals with the phenomenon only from the perspective of the man who has more than one wife (H 3). From the perspective of the women, "husband-sharing" would be a more appropriate term. To be inclusive, the solution would be to identify the phenomenon as plural wives/husband-sharing.

Gender In the health field, a similar example is the international definition of *fertility* that expresses fertility as the number of children born to a woman of childbearing age (D 3). This is an example of exceptional exclusion of men; and, correspondingly, we are much less well informed about male fertility than female fertility.

Race Sometimes research looks at patients' compliance with prescribed treatments. People in poor countries are often identified as *non-compliant* with prescribed medical treatments. A detailed case study of a young Haitian man who was labelled as "non-compliant" documented how he and his family made heroic efforts to comply with the treatment but that lack of money — in spite of the family having sold half of its land — distance from the medical center, coupled with inadequate transportation to it, and other such structural factors made it impossible for him to comply more fully (Farmer, 1997). This bias at the level of the concept of a "noncompliant patient" is an example of victim-blaming (H 6) as well as pathologization (H 4).

In occupational health studies, women and men with the same *job title* may be assigned to *different tasks* — a double standard (D 8) (Messing et al., 2004). Hence it is necessary to look at occupation codes in more detail and to determine the specific aspects of a job, rather than assuming that the same titles correspond to the same tasks.

Gender

The concept of *employability* uses a non-disabled population as a normative reference point, thus employing a dominant perspective (H 3). “People with disabilities may have to declare themselves ‘unemployable’ to get the support services, medications and devices they require” (Roche Institute, 1996: 86). The solution would be to develop new concepts such as *part-time employable* to serve the needs of some disabled people.

Disability

Theoretical frameworks

We adopt Warren’s definition of a theoretical framework as “a socially constructed set of basic beliefs, values, attitudes and assumptions that shapes and reflects how one views oneself and others. It is oppressive when it explains, justifies, and maintains relationships of domination and subordination.” Oppressive theoretical frameworks “are characterized not only by value dualisms and hierarchies but also by ‘power-over’ conceptions of power and relationships of domination...and a logic of domination” (Warren, 1993a: 257). Biases that come in at the level of the theoretical framework have the potential to result in biases throughout the research process, as hypotheses, research questions etc. all derive from the theoretical framework.

Smith notes that western academic researchers tend to theorize indigenous societies as:

Race

... a phased progression from (1) initial discovery and contact, (2) population decline, (3) acculturation, (4) assimilation, (5) ‘reinvention’ as a hybrid, ethnic culture. While the terms may differ across various theoretical paradigms, the historical descent into a state of nothingness and hopelessness has tended to persist.

This formulation is an example of a dominant perspective (H 3). In contrast, indigenous perspectives also show a phased progression, more likely to be articulated as:

(1) contact and invasion, (2) genocide and destruction, (3) resistance and survival (4) recovery as indigenous peoples. The sense of hope and optimism is a characteristic of contemporary indigenous politics which is often criticised, by non-indigenous scholars, because it is viewed as being overly idealistic (Smith, 1999: 87/8).

Erikson’s typology of human development, when applied to disabled people, relegates such people permanently to lower stages of development, because the model assumes that a child must master the most salient stages of the lower stage before moving on to the next stage. Gartner et al., drawing on the work of Gliedman and Roth (1980) argue:

Disability

Thus, for example, the child’s mastery of bodily functions, which is central to resolving the second stage’s issues of autonomy versus shame and doubt, remains an open issue for the adult person with a disability who either lacks bladder control or is dependent upon an attendant (or a family member). Thus, ‘there is an “infantile” quality to the way he [*sic*] must assert his mastery over his body. Like the young child who must call on his mother [*sic*] for help, the

physically handicapped person must sometimes relate to his own body by means of another (able-bodied) person'...[In addition]...the typology does not well address the great precocity that many persons with disabilities display in their interpersonal behaviour (Gartner, Lipinsky, & Turnbull, 1991, footnote 5, pp. 25-26).

This is another example of using a dominant perspective — the norms derived from the dominant group are applied to the non-dominant group without questioning their relevance (H 3). The effect of this is pathologization of the non-dominant group (H 4). Biases at this level are extremely difficult to remove, as the dominant group has a stake in perpetuating its view of the world. In many cases, all one can do is to point to the inherent bias and offer a different more valuing framework as a new analytical paradigm, and demonstrate the differences that result when a different paradigm is used. If people are genuinely interested in equity and social justice, demonstrating, for example, how the original paradigm violates the human rights of the non-dominant group may help to stimulate interest in moving towards a new paradigm.

Research methods and data-gathering

Research methods encompass the procedures used to answer research questions. Many factors influence the choice of method(s). Primarily, the nature of the question being asked determines which research techniques would be most appropriate. Surveys, experiments, secondary data analysis, participant observation, in-depth interviews and focus groups are all examples of research methods.

Data-gathering or collection refers to the procedures that have been developed for the study (in-depth interviews, surveys, etc.) to collect information in a systematic way.

Research methods — like any other set of tools — can be used for various purposes. While they themselves are neutral, they can, unfortunately, be used in a biased manner. Bias can enter into research methods at many levels, including in data collection forms such as survey questionnaires, measures and measurement instruments used, and type of analytical methodology, recruitment of participants, etc.

Data collection forms

**Sexual
Orientation
Race
Gender
Ability**

Intake forms in hospitals can be regarded as a form of research questionnaire. These forms will usually be based on assumptions about family structure. Typically, forms require information about the patients' mother and father. This can result in problems for some people. For instance, in Canada same-sex marriages are legal. When a same-sex couple has or adopts a child, children may have two mothers or two fathers. The forms do not allow for this reality (F 1). Similarly, in Aboriginal families, a tradition of "adoption — whereby children live with another female relative (aunt or, grandmother) is common" (Stager, 2004: 22). Indeed, "custom adoptions" whereby a grandparent or other close relative informally assumes responsibility for the upbringing of a child are also legal in Canada. The lack of consideration of these types of families is an instance of failure to take differences into account on the basis of sexual orientation and Aboriginal status (F 1). Among children in care, disabled children are over-represented. In such cases, a guardian would have to sign the form — another reality that the current forms do not accommodate (F 1).

The solution is simple: revise the forms by asking for Parent 1 and Parent 2. The intake person can then identify each parent as mother, father, grandmother, guardian, aunt, etc.

Measures and instruments

Disability

The Disability Adjusted Life Year (DALY) is a statistical tool that combines in one measure the time lived with illness and disability and the time lost due to premature mortality, based on the assignment of numeric values and weights to different states of disability and ill-health. One

DALY is defined as one lost year of “healthy” life. The burden of disease is defined as the gap between current health status, as measured in DALYs, and an ideal situation where everyone lives into old age free of disease and disability (World Health Organization). It is based on values assigned to a measured degree of “functioning”, without considering – indeed expressly excludes as being irrelevant – extraneous factors such as gender, and overall environments within which people live.

When the health of disabled people and non-disabled people is measured using the DALY, disabled people will nearly always score more poorly than non-disabled people. This is because by definition, DALYs a) assume a “reduced value” of lives lived with a disability; b) use the term disability interchangeably with ill-health; c) assume that living with a disability represents a net drain on society; and d) assume that individuals with a disability suffer an existence that lies somewhere between living and an anticipated premature death (H4) (Groe, Chamie, & Me, 1999).

Methods

A particular statistical method called *discriminant item analysis* is used to simultaneously study differences between two or more groups of objects with respect to several variables. It is a useful technique when used appropriately. However, when used inappropriately it results in exaggerating differences (D 7). An example would be a study that asks male and female subjects to agree or disagree with a number of statements, subsequently eliminates all statements on which there was no differentiation in responses by sex, and goes on to draw consequences with respect to all women and men, based on the presentation of completely polarized results.

Adjusting scores on the basis of sex is justified if an effect that is being measured is a direct effect of sex; but, if used incorrectly, it may hide differences in the situation of males and females. For instance, a review of studies of carpal tunnel syndrome found that all the studies reviewed adjusted for sex — without asking whether female workers were more likely than male workers to engage in work that leads to this problem, which is in fact the case (Messing, 1998: 74 + ft. 1, p. 208). This is an overt double standard (D 1) — *different* treatment when the *same* treatment would be appropriate. However, the double standard is in effect quite well hidden, since few people are likely to read the footnotes that alert readers that the scores had been adjusted. This example illustrates that even overt double standards sometimes may be extremely difficult to detect.

Unit of analysis

A similarly subtle problem occurs when there is a discrepancy between the unit of analysis and an observation (F 1). Often, the family or the household is taken as the basic unit of analysis, disregarding that typically households include people of different sexes and ages, with different positions, needs, desires, etc. As previously mentioned, a study in northern Ethiopia found that women are likely to spend more money on prevention of malaria than men in comparable households (Lampieri et al., 1999). Taking only household income into account, when looking at consumption preference, is misleading. We also need to know who is making the financial decisions.

Similar problems around the unit of analysis emerge when talking about care provision. As patients are discharged from hospitals, they often require follow-up care, which is provided “by the family”; however, given the global division of labour by sex, the people most likely to deliver this care are women, not men — with sometimes significant consequences for the health and well-being of women (F1).

This problem takes a different slant when women are discharged from hospital and in reality there is no one other than themselves to provide the care (F2) (Seymour-Smith & Wetherell, 2006; Shambley-Ebron & Boyle, 2006). Indeed, the women providing the care may be disabled themselves — a fact that often is not taken into account in research or policy (F 4).

Gender

Gender

Ability

Research participants

Gender Race Ability

When identifying research participants — both those conducting the research and research subjects — bias can be introduced. *Assumed homogeneity* (F 4) occurs when dominant or non-dominant groups are treated as homogeneous groups when, in fact, they are constituted of diverse people. The solution is to recognize the diverse make-up of such groups and give proper attention to it. As noted, we are also likely to find hierarchies *within* the gender, race and ability hierarchies.

Race

A comprehensive review of experimental psychology reports, spanning more than 75 years of research, found: "Save a minuscule subset [of] ... experimental psychology reports, including over 90 percent of the research on race, indicate[d] no race of experimenter". Instead: "The subjects' racial status, skin color, degree of 'white blood', racial psychology, or attitudes eventually gained primary consideration. In the end, the vast majority of race of experimenter studies have been about the *other*, not the self of the investigator" (Morawski, 1997: 13/4). This is a very serious methodological concern (F1). Essed has argued that interviewers of colour have privileged access to information about racism experienced by people of colour. "Unlike many (White) social scientists, I took their [women of colour] accounts of racism seriously and showed genuine interest in the "ordinary" events of everyday life. This attitude allowed me to ask the interviewees to qualify specific statements and to go into details without inducing defensive reactions from their side. In other words, being an insider provided a rich base for tentative probing, which is valuable in exploratory research" (Essed, 1991: 67).

Race Gender

The solution, of course, is very simple: control for and report the race (and sex and other relevant characteristics) of all participants in the research process — from interviewers to subjects — and reflect upon its significance. One difficulty, of course, is to get a good operational definition of race.

Data analysis and interpretation

Data analysis and interpretations involve the sorting and summarizing of research findings. Different techniques are used to analyse results, depending on the type of research. Some techniques are designed to maximize insight into a data set, uncover underlying patterns in the data, extract important variables, detect outliers and anomalies in the data, test underlying assumptions, develop models and determine optimal factor settings. Data analysts may use any of these approaches, or a mix of different approaches to their data, depending on the research methods employed. For example, in field research, participant observation may involve classifying observations into categories, while in survey research it would involve computer-based sorting, conducting statistical analyses, summarizing, describing, and inferring from the data.

While the analytical techniques in and of themselves may not be biased, bias can enter into analysis in a number of ways, for example in underlying assumptions about relationships, in the selection of variables for analysis, in the focus on one set of variables over another, and in the overall interpretation and presentation of results.

Gender

The following example from the gender hierarchy exemplifies why taking differences into account in the analysis of research results is so important. Version A is adapted from a Finnish study (Heiskanen et al., 1991), version B is our rewrite using the information supplied in that study.¹²

¹² For a longer version of this example, see (M. Eichler, 1997b).

Version A: Understanding research on violence without a *BIAS FREE* approach

About one person out of ten was the victim of a violent act or threat of violence during 1980. In 1988, one person out of 12 was a victim. In 1980, almost half (46%) of the victims had a least two such experiences; in 1988 the proportion of such victims was 45%. The victim in both years was most likely a young single man.

The relative number of people who were victims of incidents that resulted in restricted activity had also fallen between 1980-1988, but only slightly. The decreased number of experiences of violence was most accentuated among the youngest men in the category of street violence.

An exception from the overall decreasing trend was work-related violence. This had become more common among women most active in the labour force (aged 20–44). Among men, the number of such experiences had fallen.

In 1988, the incidence of family violence remained similar to figures for 1980.

Version B: Understanding research on violence with a *BIAS FREE* approach

A comparison of women's and men's victimization

All forms of violence

	Men	Women
1980	58%	42%
1988	53%	47%

While men were slightly more likely to be victims of violence than were women, this difference decreased between 1980 and 1988. In 1980, 58% of all victims were men and 42% were women. In 1988, 53% were men and 47% were women. The typical male victim experienced violence on the street. The typical female victim suffered violence from a family member in her own home.

Both women and men experienced a relative decrease in small group violence and street violence and an increase in family and other violence. Although the proportion of violence that was work-related almost doubled for women, the single most important category for women remained family violence. This accounted for 27.5% of all violence experienced by women.

A comparison of the consequences of violence for women and men

All forms of violence

	Men	Women
1980	3.4%	3.6%
1988	2.7%	5.1%

The most telling indication of gender differences concerned the gravity of the consequences. Between 1980 and 1988 the number as well as the proportion of male victims who suffered incidents resulting in at least one day of restricted activity fell from 12,440 or 3.4% of all victims to 7,146 or 2.7%. Female victims, however, experienced the opposite trend. The numbers of women who experienced restricted activity following an incident of violence increased both in absolute numbers as well as in relative numbers, from 9,533 or 3.6% of all female victims in 1980 to 11,974 or 5.1% in 1988. Not only were women more likely to be victims of violence in 1988 than they had been in 1980, their likelihood of suffering restricted activity as a consequence had almost doubled.

Thus, a higher proportion of the violent incidents was directed against women in 1988 than in 1980. The likelihood that such incidents would result in reduced activity had increased in both absolute and relative terms for women, even though there were fewer female (and male) victims in 1988 than in 1980. In other words, the acts of violence had become more violent.

Version A versus Version B

Very different messages emerge from the two versions. In Version A, the typical victim is a young single man. In Version B, the typical male victim is a victim of street violence and the typical female victim is a victim of family violence. In Version A the likelihood of a victim experiencing restricted activity had slightly decreased. In Version B the likelihood had decreased for men but increased for women.

In Version B the statistics clearly demonstrate that violence is a gendered experience, in that violence is rooted in social conditions, behaviours and attitudes and plays out differently in the lives of men and women. It is a sign of the quality of the publication that the data provided were detailed enough to allow us to re-compute and re-analyse the conclusions. Had the study not collected data by sex, (i.e. been completely gender-insensitive) we would not have been able to examine gender differences in the experience of violence among women and men. On the other hand, the study does not identify the sex of the perpetrator and, therefore, we cannot explore gender issues related to perpetrators in our re-analysis of the data.

Class Turning to a different type of problem, opinions expressed by members of a dominant group about members of a non-dominant group are sometimes treated as facts rather than opinions (D 5). For instance, in studies of occupational health, managers sometimes are asked about the experiences of workers. While the managers' views may be an important part of the overall picture, they should not be taken as representative of the actual experience of workers. To cite just one example, a study of workers in electronics factories in Thailand found that workers do not wear protective gear. Management interpreted not wearing protective gear as the workers' failure. However, as the workers explained, when "we have a big order to meet and the pressure is on, they [the protective gear] slow you down and there is a sort of group agreement not to wear the stuff so that we can all work quicker" (Theobald, 2002: 20). It turned out that managers had been the ones to put on the pressure for speedier production.

The solution is to note the managers' opinions in assessing occupational health risk as their opinions and to compare and contrast them with those of the workers.

Race Failure to examine differences sometimes occurs when comparing attitudes of whites and people of colour towards medical professionals (F 1). "For many racial and ethnic minorities... preferences for treatment are often difficult to separate from mistrust of health professions that stems from racial discrimination and the history of segregated and inferior care for minorities..." (Smedley et al., 2003: 131). Studies that fail to take this into account sometimes contrast "preferences" with racial discrimination as competing explanations for health care disparities, rather than recognizing that the preferences themselves may be shaped by past experiences. The solution is to contextualize the situation by taking such factors into account.

A recent critique of Transcultural Nursing Theory (TNC) points out: “TNC texts implicitly legitimise whiteness as a politically neutral identity position from which to interpret race difference” (H 1) (Gustafson, 2005: 16). They do so by assuming equality of opportunity and by failing to acknowledge the complex histories of colonized and marginalized peoples and the privileges that accrue to whiteness (Dei, 2000). Inequality between nurses of colour and white nurses then can be attributed to individual inferiority or inability to integrate into the dominant society (H 4) (Gustafson, 2004).

Studies on sexual violence that fail to disaggregate data on the basis of disability miss one of the major axes along which people are victimized. Most studies on sexual violence fail to include disability as an analytical variable, even though research that does focus on disability has “found that people with disabilities are more likely than others to be subjected to acts of violence and abuse...” (Rioux et al., 1997: 203). This is an instance of insensitivity to difference (F1), as disability status is not included as a relevant analytical variable.

In data analysis, there can often be a tendency to write up the results in a way that pathologizes people who differ from the norm (H4). For example, rather than describing the different ways some people communicate, alternate modes of communication are pathologized and treated as deficits and abnormal.

Conclusions

Conclusions are drawn on the basis of the analysis of the findings and results of the research. Typically, they describe what was learnt, provide an evaluation of the research and its shortcomings, make recommendations that ensue from the research and give directions for future research.

Biased conclusions can result if the analyses on which they are based were biased, or if certain aspects of the results are ignored or swept aside. In the Finnish example, cited earlier in this book, Versions A and B demonstrated how a re-analysis of the data using a *BIAS FREE* approach could have resulted in very different messages emanating from the study concerning the gendered experience of violence.

The solution would have been to remove the bias from the analysis and rewrite the conclusions. This, in fact, was done in a Tanzanian study of the impact of user fees on access to health care (Manzi, Mbuyita, & Urassa, 2003). The original conclusions were drafted on the basis of analysis that was gender-biased. When an application of the *BIAS FREE* Framework pointed out the problems in the study, one of the members of the research team took the paper back to the original research team. The team then wrote a voluntary supplementary report focusing on the gender aspects that had been missed (such as the exclusion of women from community governance structures and gender differences in expenditure patterns), and they are discussing recommendations to be added to their report. These preliminary results were reported at *Forum 9* of the Global Forum for Health Research in Mumbai, India, in September 2005 (Mbuyita, 2005).

Policy recommendations and practices

The *BIAS FREE* Framework can be applied to policies and policy development in a manner parallel to the way it is used in research, although the elements of these processes are somewhat different. We are dealing here only briefly with policy recommendations that derive from research.

Disabled children are often deprived of important resources that would aid their development, because they are subjected to practices that view an ability hierarchy as normal and unproblematic (H 2). For instance:

Ability

Ability

A focus on investment in healthy child development that uses a set of norm-referenced indicators to measure that a child in the 0-6 age group is ready to learn ignores that many disabled children may never be able to meet “age appropriate” physical, motor development, language skills, etc. If failure to meet these benchmarks by children who, for instance, move or communicate in different ways then results in these children not being eligible for certain early childhood services because they are seen to be unable to benefit from such an investment, this results in excluding these children (Bach, 2002: 18).

Maintenance of the hierarchy (H 2) thus leads to exclusion (D 2). The solution to this biased policy is to shift the focus from one of strict age-related developmental stages to an understanding that each child has a unique developmental path. This includes “unique ways of realising different developmental tasks whether they be managing communication and interacting with others, developing personal identity, moving from adolescence into adulthood” (Bach, 2002: 19).

Disabled people often have decisions made on their behalf by professionals, parents, medical staff, social service organizations, etc. sometimes against their expressed wishes. This is an example of denying agency at the level of policy (D 4). By contrast, the disabled peoples’ movement defines “independent living” as “being in control of one’s life” (MacFarlane, 2004: 189). Thus, the solution to denying agency in this case is to respect disabled peoples’ *human right* to self determination and to decision-making about the things that affect them, and to support them in their decision-making.

Gender There are clear gender patterns in diagnoses given by doctors. For instance, women are more readily diagnosed with psychological and psychiatric illness than are men who present with similar symptoms, while men with somatic and physiological complaints receive quicker diagnoses than do women (Kolip & Hurrelmann, 2004: 20-21; Leo, 2001).

This is an instance of an overt double standard (D 1) — the failure to give the same treatment. The solution is to devise checks so that women are tested equally for somatic and physiological illnesses, and men for psychological and psychiatric illnesses.

Gender
Race
Ability
Poverty Decontextualization (F 2) may lead to hidden double standards. For instance, user fees for health services may seem fair on the surface — ie. everyone pays the same. In fact, however, user fees discriminate against the poorest segments of society (in which women, children, homeless people, marginally employed people, and people on disability and other types of pensions typically predominate). For instance, Yoder (1989) documented that the introduction of or increase in fees for services in Swaziland resulted in declining attendance at government health facilities frequented by the poor. It also resulted in lower rates of immunization against childhood diseases (D 8). Similar findings were reported from Tanzania (Manzi, Mbuyita, & Urassa, 2003).

This problem can be identified by asking: “Has the different social reality of dominant and non-dominant groups explicitly been considered?” Once such differential effects have been identified, the solution might consist of either abolishing user fees or introducing a graduated system in which people pay according to their means.

Communication of results

Authorship and other forms of credit

Historically, there are many examples in which authorship of jointly authored pieces of work has been claimed only by a member of a dominant group; this is appropriation (H 7).

Gender After the advent of the feminist movement in the 1970s, a number of male anthropologists whose wives had done half the fieldwork started publishing their work under both names. For instance, Yolanda and Robert F. Murphy describe the fieldwork they conducted 20 years earlier as follows:

Most of our days were spent by Yolanda among the women and Robert among the men. She sat with the women in their houses, worked with them in making manioc flour, went with them to the gardens, bathed with them, and helped them take care of the children. When she was not with them, one or more women were usually in our house. Mundurucú women are eminently gregarious, and she soon became included in most of their activities (Murphy & Murphy, 1974).

They reflected on the process when they wrote a joint book about Mundurucú women. At the time, the fieldwork resulted in an MA thesis for Yolanda, and a slew of publications for Robert (cited in Murphy & Murphy, 1974).

Occasionally, professors use their students' work without giving any credit to the students. The same appropriation takes place when supervisors in research organizations or government departments identify themselves as authors in cases where the work has been carried out by their subordinates.

Professional Status

Title

It may seem trivial to examine titles with respect to bias; but, in fact, this is a very important issue. Bias takes on special importance when dealing with titles. In just a few words, the title conveys the focus and applicability of the research. As well, it is important to ensure that language and concepts used in the title are not biased.

Today much of the literature is accessed via computer searches that check for particular words or word combinations. It is difficult to assess whether a reference is relevant or not when the titles are not sufficiently specific. Much literature still takes a middle-aged white male with a normative body and mind as reference point; often enough, studies that include only such people are couched in general terms. If the study is about women or girls, it is more likely that our attention will be drawn to this in the title. The same applies to race in countries with populations that are primarily of European origin, where race is specified in the title only when the study deals with non-white people.

When looking at titles, one of the questions we ask is: "Has the relevance of membership in dominant/non-dominant group been ignored?" (F 1) If we then apply it to the gender hierarchy, we would be alerted when a vital part of the information about the study is omitted in the title. For example, a review of 1,041 articles in 17 English-language, addictions-specific journals found that males were much more likely to be included in the studies than females. "In 45.0% of the studies with 80% or more of male or female subjects, there was no indication in either the title or the abstract that the study was a single-sex study or was based mostly on one sex" (Brett, Graham, & Smythe, 1995: 29).

Gender Race

The obvious solution is to identify the sex (and race) of research participants in the title.

Studies that deliberately screen out specific groups, e.g. disabled people, as is often the case, (see, for instance, Bittman et al., 2003), should include in the title that they are dealing with a non-disabled population only.

Disability

Abstract/Executive summary

Abstracts and executive summaries are one of the main communication tools for disseminating the results of research. Given that a lot of information is accessed today via computer searches on keywords, it is important to be specific as to the applicability of a given study. This will usually

require specification of the particular group that was the focus of the study. Failing this, a lot of time and effort will be wasted in going through the literature that is inappropriate for specific purposes.

Gender
Race
Ability

The same points as are made for titles apply, even more strongly, to abstracts and summaries of all types. It is frustrating to read a study, summarized as studying 205 people, without being told their sex, race and/or other salient characteristics.

Language

Bias in various languages has received a great deal of attention. For the purposes of this book, we will restrict ourselves to biases in the English language. English has been criticized for being sexist, racist and ableist, and considerable efforts have been made to overcome these problems. For instance, a number of guides to non-sexist, anti-racist and anti-ableist language have been developed (see below).

However, guides concerning non-sexist language usually address two problems that we have discussed under the rubric of concepts. We did so because both practices become problematic through the meaning attached to a concept, rather than being located at the level of language. We are referring to the practice of using sex-specific terms for general situations (the generic “he” – D1) and the practice of using general terms for sex-specific situations (e.g. talking about all citizens when only men have been considered – F3). The latter also applies to other non-dominant groups, such as people of colour and disabled people, when they are excluded from consideration, but this has not been noted.

Gender

One manifestation of sexism in language is a non-parallel use of terms or grammar, such as when men are referred to by their last names (Mr. Smith) and women by their first names (Jane) — an obvious double standard. Similarly, dealing with women in the passive voice and men in the active voice, as is often the case, is another example of a double standard (D 1). The same treatment for both sexes easily solves this.

Further, women or girls are sometimes described in derogatory or objectifying language (H 5 Objectification). An example would be a speech by the President of the Pacific Coast Obstetrical and Gynecological Society in which he shared his thoughts concerning surrogacy. He offered his sympathy to “barren women” who are condemned to remain childless, and put forward as a solution to their problem disembodied “uteri” who will produce, in a number of ways, children for these women. These “normally functioning uteri of ‘off-duty’ gestational specialists” would help “women who seek the bliss of motherhood” (Eichler, 1994: 193). While the “barren women” are seen as women, the women who would bear the children are not there as persons at all — although it is they who would carry all the risks associated with childbearing. This language may also carry over into research on infertility and its treatment.

Race

“...[I]n everyday language — ‘whiteness’ is associated with overwhelmingly positive connotations, while ‘blackness’, in *Roget’s Thesaurus*, has no fewer than sixty distinctly negative synonyms, twenty of which are related to race” (H 5) (Henry et al., 2000: 57). There are several attempts to develop guides to non-racist language, such as the British Sociological Association’s 1997 anti-racist language guide.

Ability

There are also guides dealing with disability and ableist language. The British Council of Organizations of Disabled Persons (BCODP) has listed 11 disability-related stereotypes in the English language. These include portraying the disabled person as pitiable and pathetic, sinister and evil; as a burden; as an object of violence or ridicule; as *curio* or *super cripple*; as sexually abnormal; as incapable of participating in community life; and as their own worst and only enemy (H 5). Among this array of negative depictions, BCODP lists the stereotype of disabled person as “normal”, which in effect denies the whole experience of disability (F 1) (Barnes, 1992).

Visual representation

As with language, visual representations can carry powerful messages about dominant and non-dominant groups. Visual representations may include: actual pictures, such as photographs; reproductions of paintings; cartoons; and charts and graphs.

The size and placement of images should correspond to the actual importance of the group within the given context. This point is relevant not only with respect to pictures of people, but in particular with respect to graphs.

A content analysis of psychology texts for gender bias found that photographs depicted negative stereotypes of women and men in traditional gender roles:

Ability

For example, in a review of psychology texts... women were presented in photographs as mentally ill or as passive participants in psychological research, e.g., looking on while a male investigator conducted an experiment. Males were more often depicted as therapists or researchers (Leo, 2001).

IV Theoretical framework and concepts

Pervasive inequalities

Pervasive social inequalities have negative health consequences and contribute substantially to global health inequities and the "10/90 gap" in health research.

Mirroring these inequities, in health research itself there is an imbalance globally in how resources are applied. The 1990 Commission on Health Research for Development...estimated that less than 10% of the world's resources for health research (which totalled US\$ 30 billion in 1986) were being applied to the health problems of developing countries, where 90% of the avoidable burden of ill-health was to be found. Since then, the expression '10/90 gap' has become a symbol of inequity in global expenditures on health research and, while global health research spending has more than tripled, a large imbalance remains (Burke & de Francisco, 2005: vii)

Power structures and the generation of knowledge

One of the ways in which power structures manifest is in research and knowledge generation of all types. Explorations of knowledge, science and medicine and their inter-relationships, and of how to identify "expertise" in these domains date as far back as Plato (Plato, 1986). One of the best known formulations in this tradition comes from Karl Marx who stated that what is accepted as knowledge represents the ideology of the ruling class (Marx & Engels, 1932). With the advent of feminist scholarship,¹³ scholars turned their minds to disentangling the many ways in which male dominance has shaped our understanding of how societies work (Hess & Ferree, 1987), what constitutes science (Harding, 1986; Harding & Hintikka, 1983; Herschberger, 1948), and how research itself is a product of social relations that are deeply informed by a gender hierarchy (M. Eichler, 1991; O'Brien, 1981; Sherman & Beck, 1979; Sydie, 1987; Tamm, 1989). Sexism is embedded in the very language and concepts we use (Klein, 1997; Lapointe & Eichler, 1985; Spender, 1980; Waring, 1988a).

Partially in reaction to the feminist literature that presented gender as the single most important social hierarchy, the anti-racist literature developed arguments that racism had parallel effects on scholarship (Anzaldúa, 1990; Bhavnani, 1993, 2001; Commonwealth Secretariat, 1999; Essed, 1991; Fine et al., 1997; Henry et al., 2000; Jhappan, 1996; McClintock, 1995a, 1995b; Mohanty, Russo, & Torres, 1991; L. T. Smith, 1999).

¹³ The feminist and anti-racist literatures on these topics are enormous. The citations provide only a few selected examples.

Disability studies began to engage in a similar process of critique in the late 1970s in response to continued institutionalization, segregation, medicalization and eugenic practices, such as enforced sterilization of disabled people. With the emergence of critical disability studies, academics, researchers and activists began to focus on the social model of disability, on the removal of barriers to participation and societal inclusion, and on notions of oppression, identity and human rights (Abberley, 1997; Albrecht, Seelman, & Bury, 2001; Barnes & Mercer, 1996; Bergum, 1996; Davis, 1995; Eichler, Reisman, & Borins, 1992; Frazee et al., 2002; Thomson, 2002).

Rights-based model of health

A rights-based model of health emerged with the 1948 World Health Organization definition of health. It offers a framework for understanding the conditions needed to create and sustain health that is applicable to all people, regardless of their social status or condition. It rests on the following three basic relationships:

1. Health policies, programmes and practices have an impact on human rights.
2. Violations or lack of fulfilment of human rights have negative effects on health (physical, mental, social and spiritual well-being)
3. Health and human rights act in synergy. Promoting and protecting health requires explicit and concrete efforts to promote and protect human rights and dignity; greater fulfilment of human rights necessitates sound attention to health and its societal determinants. Paying attention to the interrelationship between health and human rights may help to re-orient thinking about major global challenges to health and to broadening human rights thinking and practices (Mann et al., 1999: 8).

Logic of domination

By logic of domination we mean “a structure of argumentation that provides the moral premise that superiority justifies subordination” (Warren, 1993b: 257). This is the aspect that is common to all “isms” of domination—sexism, racism, ableism, classism, heterosexism, ageism, etc. The basis for superiority is variously identified. Warren, from whom we have adapted this argument, uses rationality as the distinguishing characteristic that allows the human domination of nature and the female identification with nature that result in male superiority. The logic of domination applies equally when being white is regarded as superior to being of colour, or having a normative body or mind superior to being disabled. In other words, the basic conceptual interconnection among all systems of oppression is the logic of domination (Warren, 1987, 1993a, 1993b). The *BIAS FREE* Framework is premised on this conceptual interconnection.

Values and objectivity

A question that arises within this context is the issue of objectivity. Feminist, anti-racist and anti-ableist literatures are sometimes charged with being non-objective, since they are openly committed to improving the situation of disadvantaged groups. This type of criticism derives from a particular understanding of the meaning of objectivity. (For a more extended discussion of the objectivity debate, see Eichler, 1997b). There are multiple meanings associated with this concept. Two prominent interpretations equate objectivity with value freedom and/or emotional detachment.

As Max Weber pointed out a century ago, research is never value free (Weber, 1977). Minimally, the decision to conduct research in a given area reflects a value judgement — that the subject under research is worthy of being researched and having human and other resources dedicated to this purpose. Failure to conduct research in a given area also reflects a value judgement that it is not worthy of similar investments. This is an important point given the huge inequities in health and health research, symbolized by the expression “10/90 gap” in health research.

The issue of “emotional detachment” is likewise based on a misperception. Facts and statements do not become true or false because their proponents are emotionally involved or

uninvolved. In fact, it is questionable if it is ever possible to be completely emotionally detached. The position of privilege enjoyed by members of the dominant groups contributes to their own sense of emotional comfort. They typically fail to recognize this, as it is part of their “normal” experience. Challenges to the status quo thus can be seen to disturb the emotional¹⁴ comfort of the dominant group and may partially explain why there is often resistance to change. Likewise, those in the dominant group typically see those who challenge the status quo as being “emotionally charged”. This is often used as a reason to invalidate the concerns of those seeking change.

Objectivity as property of a scientific community

More importantly, however, these interpretations treat objectivity as an individual property rather than as the property of a scientific community.

Longino argues that the goal of objectivity is “to block the influence of subjective preference at the level of background assumptions involved in observation and inference, as well as the influence of individual variation in perception at the level of observation” (Longino, 1993: 265). Objectivity requires minimally four criteria¹⁵ that must be satisfied for it to become possible: 1) Recognized avenues for criticism; 2) Community response; 3) Shared standards; and 4) Equality of intellectual authority.

This requires that avenues for the presentation of criticism be the same as those for “original research”. Mere tolerance for criticism and dissent is not sufficient for objectivity; instead, critics must play a role in shaping the views of an objective community. This means widening the scientific community by including people with experiential expertise as acknowledged members of the community. This requires that all stakeholders participate in critical discussions and that the assumptions that govern their group activities remain logically sensitive to it.¹⁶ This is well captured by the disability community’s slogan: “Nothing about us without us” (DPI Solihull Declaration, 2000).

To allow for such a process, there must be some shared elements. These can include substantive principles and an understanding of what counts as knowledge and social values. Individuals must acknowledge the relevance of such standards to the evaluation of cognitive practices in their community of inquiry. Such standards must be open to criticism by appealing to other standards.

This requires that arguments must be evaluated on the basis of the agreed upon criteria rather than on the status of the person(s) making them. Not only must a community treat all its acknowledged members as equally capable of providing persuasive and decisive reasons, it must take active steps to ensure that alternative views are developed to be robust sources of criticism. In other words, not only must dissenting voices *not* be discounted, but they must be actively cultivated (Longino, 1993: 266-268). “Knowledge and objectivity, in this view, are identified as the outcomes of social interactions and, hence, are located not in individuals but in communities” (Longino, 1993: 268).

The mere aspiration of objectivity must not be mistaken for being objective. This allows us to understand the contribution that feminist research has made to making research more objective. Adding the voices of anti-racist, anti-ableist and other equality-seeking scholars and activists in a central manner is a necessary step to obtain objectivity in health research.

**Recognized
avenues
for criticism**

**Community
response**

**Shared
standards**

**Equality of
intellectual
authority**

¹⁴ In a like manner, such challenges may also disturb the economic, social and political comfort of the dominant group.

¹⁵ The following draws heavily on Longino (1993). Adaptations and some additions were made by the authors.

¹⁶ This is in line with the Global Forum for Health Research’s approach as stated in the Foreword of *Mental and neurological health and the millenium development goals* (Matlin, 2004).

Social construction of knowledge

Epistemologists and sociologists have long explored the construction of knowledge (Harding, 1986; Harding & Hintikka, 1983; Keller, 1985; Keller & Longino, 1996; Sydie, 1987). Sociology of scientific knowledge studies social influences — including prevailing values and beliefs — on scientific knowledge in particular, and conversely, the influence of scientific knowledge on society. One of the key findings of this long-established field of inquiry is that research tends to reflect power structures within society. This has been formulated within sociology as follows:

- All knowledge is socially constructed.
- What is accepted as a dominant ideology is the ideology of the ruling group.
- There cannot be such a thing as value-free science.
- The perspectives of people, including their insights into the workings of society, vary systematically with their position within that society.
- Objectivity is maximized to the degree to which disadvantaged groups are able to contribute to knowledge generation (Adapted from Eichler, 1985).

Biases in health research

Generally, biases are well hidden. Careful systematic analysis is needed to uncover them, as they are often part of taken-for-granted basic assumptions accepted by the majority of researchers. It is, therefore, not easy to identify biases and even harder to convince researchers to avoid them. The identification of biases that derive from social hierarchies, and how they play out in the various elements of the research process, enables researchers to see how their research could be improved by removing the biases. The *BIAS FREE* Framework helps illustrate how biases operate, allows researchers to “see” differently, and points to solutions for reframing their work to remove identified biases.

Research that is biased is, by definition, bad research. The following examples demonstrate how biases deriving from various social hierarchies can result in biased research.

We know that biases in the way we research health problems can literally be deadly. One of the best-known examples of biased medical research concerns heart attack symptoms. For a long time, coronary research concentrated on males, hence symptoms identified were those typical of males with the result that when women presented with different symptoms, they were less likely to be diagnosed as suffering heart attacks. Failure to diagnose led to inappropriate treatment and resulted in higher mortality rates for women. Fortunately, these differences are by now well known and some corrective actions have been taken (Turek, 2000).

A review of the literature found that African-Americans with coronary artery disease and acute myocardial infarction “are significantly less likely to receive appropriate cardiac procedures or therapies” (Geiger, 2003: 426). This “does not reflect problems of primary access to health care” since the studies are based on “persons already *in* the health care system” (Geiger, 2003: 426).

Looking at the intersections between race and sex, several studies found that when white and black female and male patients presented with the same symptoms physicians varied in their diagnoses and prescriptions to the detriment of people of colour, mediated by sex. For example, in one study that used videotaped actors who displayed the same symptoms of cardiac disease, white and black male and white female “patients” were referred to catheterization at about the same rates (90%) but black females were significantly less likely to be recommended (Smedley et al., 2003: 11).

In contrast to the biases in research on the basis of gender and race, it is the *lack* of research on how to overcome biases on the part of medical professionals that may be deadly for disabled people. There is evidence that disabled people are often under-treated for their medical problems (Asch, 2001; Peat, 1997). In some cases, this is because they are not seen as worthy of medical interventions as has been the case for many years, for example, for people with Down Syndrome (Kmietowicz, 2001). In others, it may be because their symptoms are not recognized or that the attending physician has difficulty communicating with the person to ascertain the nature of the

problem. People who have difficulty expressing themselves verbally and who are in pain sometimes exhibit behaviour that is deemed to be inappropriate, overly aggressive, etc. They may be diagnosed as mentally unstable and in need of restraint. Rather than recognizing pain as the source of their agitation and treating it, medical professionals sometimes wrap the patients in straitjackets and commit them to mental institutions. Left unattended, the medical problem causing the pain (stomach ulcers, obstructed bowels, etc.) continues to progress, leading to a worsening of the medical condition and in some cases to premature death (Ouellette-Kuntz, Garcin, & Lewis, 2004; Wolbring, 2001).

These examples demonstrate the gravity of failing to remove biases. To avoid biases in health research, with their sometimes-fatal consequences, we need to identify and remove biases that derive from all types of social hierarchies.

V Conclusion

Historically, people have experienced much harm because of biases deriving from social hierarchies. In health research, this is in direct contrast to the ethical principle of “do no harm”. Health and human rights are inextricably linked, yet inequities in health and health research persist on a global scale.

The examples provided in this book convey the scope and the gravity of the problems and underscore that some of them are of life-and-death importance. Achieving real improvements in global health and reducing inequities in health and health research are dependent on more widespread and systematic recognition and removal of these biases.

We offer the *BIAS FREE* Framework as a tool for uncovering and eliminating biases in health research that derive from social hierarchies, and for operationalizing a rights-based approach to health and health research. Our book highlights the theoretical underpinnings of the Framework, the logical connections among the various hierarchies, the biases derived from the hierarchies and how they manifest in research.

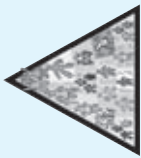
We recognize that it is never easy or quick to eliminate biases that derive from social hierarchies given their structural and systemic nature; however, asking the questions presented in the framework alerts us to the presence of biases in previously reported research, and to the potential for biases when planning or conducting research. The solutions provided point the way to removing the biases. Sometimes, putting the corrective measures into action will be straightforward and easy to accomplish. At other times, concerted and co-ordinated efforts by the various stakeholders involved in the research may be needed. Identifying the problems and the required solutions will assist greatly in this process.

Failure to address biases in research that derive from social hierarchy will contribute to the persistence of global social, economic and health inequities. Research that fails to address these biases cannot go unchallenged as biased research is, by definition, bad research, and ultimately bad for health.

THE *BIAS FREE* FRAMEWORK for Research

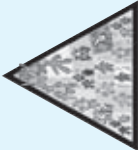
TYPE OF HIERARCHY	MAIN PROBLEM TYPE	NATURE OF PROBLEM	SOLUTION	RESEARCH ELEMENT
 <p>Gender Disability Race/Ethnicity Age Class Caste Socio-economic status Religion Sexual orientation Geographical location Health status (among others)</p>	<p>H - Maintaining an existing hierarchy</p> <p><i>Is dominance of one group over the other in any way justified or maintained?</i></p> <p><i>Situate the problem within a human rights framework, in which equality is an underlying value. Point out the discrepancy between this value and the inequalities among groups of people that result from the hierarchy.</i></p>	<p>H1 Denying hierarchy: Is the existence of a hierarchy denied in spite of widespread evidence to the contrary?</p>	<p><i>The existence of a hierarchy is acknowledged; its validation is questioned and rejected.</i></p>	<ul style="list-style-type: none"> • Request for proposals • Research proposal • Literature review • Ethical review • Research question/hypothesis • Research design • Description of population to be studied • Staffing • Concepts • Theoretical framework/model • Research methods/instruments • Recruitment of participants • Data analysis and interpretation • Conclusions • Policy recommendations • Identification of audience • Abstract/Executive Summary • Language • Visual representations • Communication of results
		<p>H2 Maintaining hierarchy: Are practices or views that are based on a hierarchy presented as normal or unproblematic?</p>	<p><i>Expressions of hierarchies are questioned and problematized.</i></p>	
		<p>H3 Dominant perspective: Is the perspective or standpoint of the dominant group adopted?</p>	<p><i>The perspectives of non-dominant and dominant groups are respected and accepted.</i></p>	
		<p>H4 Pathologization: Is the non-dominant group pathologized when it differs from the norms derived from the dominant group?</p>	<p><i>Challenge the norm and address the reasons given for pathologizing the group.</i></p>	
		<p>H5 Objectification: Is stripping people of their intrinsic dignity and personhood presented as normal or unproblematic?</p>	<p><i>Recognize that every human being has intrinsic dignity and human rights that are inviolable and must be protected, and conduct the activity accordingly.</i></p>	
		<p>H6 Victim-blaming: Are victims of individual and/or structural violence blamed and held accountable?</p>	<p><i>Victims are not blamed; individual and/or structural violence is identified; and those responsible are held accountable.</i></p>	
		<p>H7 Appropriation: Is ownership claimed by the dominant group for entities that originate(d) in or belong to the non-dominant group?</p>	<p><i>Original ownership is acknowledged and respected.</i></p>	

THE BIAS FREE FRAMEWORK
for Research

TYPE OF HIERARCHY	MAIN PROBLEM TYPE	NATURE OF PROBLEM	SOLUTION	RESEARCH ELEMENT
 Gender Disability Race/Ethnicity Age Class Caste Socio-economic status Religion Sexual orientation Geographical location Health status (among others)	F - Failing to examine differences <i>Is membership in a non-dominant/dominant group examined as socially relevant and accommodated?</i> <i>Establish the relevance of group membership within a given context. Once relevance is established, accommodate differences in ways that reduce the hierarchy.</i>	F1 Insensitivity to difference: Has the relevance of membership in dominant/non-dominant group been ignored? F2 Decontextualization: Has the different social reality of dominant and non-dominant groups explicitly been considered? F3 Over-generalization or universalization: Is information derived from dominant groups generalized to non-dominant groups without examining if it is applicable to the non-dominant groups? F4 Assumed homogeneity: Is the dominant or non-dominant group treated as a uniform group?	<i>Relevance of dominant/non-dominant group membership must always be determined; group membership must be included as an analytical variable throughout the activity and only then can its relevance be assessed.</i> <i>The context with respect to dominant/non-dominant group membership is explicitly examined and differences following from this are identified, analysed and taken into account.</i> <i>Information about the dominant group is acknowledged as such, and efforts are made to obtain information about the non-dominant group or conclusions are limited to the dominant group.</i> <i>Differences within dominant and non-dominant groups are acknowledged and taken into account.</i>	<ul style="list-style-type: none">• Request for proposals• Research proposal• Literature review• Ethical review• Research question/hypothesis• Research design• Description of population to be studied• Staffing• Concepts• Theoretical framework/model• Research methods/instruments• Recruitment of participants• Data analysis and interpretation• Conclusions• Policy recommendations• Identification of audience• Abstract/Executive Summary• Language• Visual representations• Communication of results

Eichler & Burke 2006

THE BIAS FREE FRAMEWORK for Research

TYPE OF HIERARCHY	MAIN PROBLEM TYPE	NATURE OF PROBLEM	SOLUTION	RESEARCH ELEMENT
 <p>Gender Disability Race/Ethnicity Age Class Caste Socio-economic status Religion Sexual orientation Geographical location Health status (among others)</p>	<p>D - Using double standards</p> <p><i>Are non-dominant/ dominant groups dealt with differently?</i></p> <p><i>Identify the double standard that leads to different treatment of members of dominant and non-dominant groups and how this maintains a hierarchy; then, devise means to provide the same treatment to both groups.</i></p>	<p>D1 Overt double standard: Are non-dominant and dominant groups treated differently?</p>	<p><i>Provide the same treatment to members of dominant and non-dominant groups whenever this increases equity.</i></p>	<ul style="list-style-type: none"> • Request for proposals • Research proposal • Literature review • Ethical review • Research question/ hypothesis • Research design • Description of population to be studied • Staffing • Concepts • Theoretical framework/ model • Research methods/ instruments • Recruitment of participants • Data analysis and interpretation • Conclusions • Policy recommendations • Identification of audience • Abstract/Executive Summary • Language • Visual representations • Communication of results
		<p>D2 Under representation or exclusion: Are non-dominant groups under represented or excluded?</p>	<p><i>Non-dominant groups are included whenever relevant.</i></p>	
		<p>D3 Exceptional under representation or exclusion: In contexts normally associated with non-dominant groups, but pertinent to all groups, is the dominant group under represented or excluded?</p>	<p><i>Dominant groups are appropriately represented in issues of relevance to them that have been stereotyped as being important only for a non-dominant group.</i></p>	
		<p>D4 Denying agency: Is there a failure to consider non-dominant/dominant groups as both actors and acted upon?</p>	<p><i>Examine ways in which dominant and non-dominant groups are both acting as well as acted upon.</i></p>	
		<p>D5 Treating dominant opinions as facts: Are opinions expressed by a dominant group about a non-dominant group treated as fact?</p>	<p><i>Opinions expressed by dominant groups about non-dominant groups are treated as opinions, not fact.</i></p>	
		<p>D6 Stereotyping: Are stereotypes of non-dominant/dominant groups treated as essential aspects of group membership?</p>	<p><i>Treat stereotypes as stereotypes, not as truths.</i></p>	
		<p>D7 Exaggerating differences: Are overlapping traits treated as if they were characteristic of only non-dominant/dominant groups?</p>	<p><i>Document both the differences and the similarities between members of non-dominant and dominant groups.</i></p>	
		<p>D8 Hidden double standard: Are different criteria used to define comparable facts with the effect of hiding their comparability?</p>	<p><i>Ask whether there might be a hidden double standard by looking for non-obvious parallels. One way of achieving this is by asking what form the phenomenon identified within one group might take within another group.</i></p>	

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Testimonials

The *BIAS FREE* Framework: A practical tool for identifying and eliminating social biases in health research

by

Mary Anne Burke and Margrit Eichler

An unusually sensitive, subtle, and incisive tool that can have immense value for self-critical reflection and transformation. Much of its power lies in its ability to be applied to a variety of issues in any context.

Richard Jordi, Industrial Health Research Group, University of Cape Town, South Africa

I have done so many research activities and write many reports. After learning the *BIAS FREE* Framework, I wish I could ask back all the reports I have written and submitted to various areas for re-writing because I see obvious biases.

Selemani Mybuyita, IFIKARA Research Centre, Tanzania

I used to work or do research and think that I am *BIAS FREE*. After attending this course I have found out that I was not. The course has opened my mind. I know now where I went wrong, how and why. The *BIAS FREE* Framework should be used by all those who are truly addressing health rights, equity and social justice issues. I thank you.

Mwajuma Saiddy Masaiganah, People's Health Movement, Equinet, Tanzania

I have witnessed how the said Framework if used properly can make medical research more bias-free.

Joseph Mwanga, National Institute for Medical Research, Tanzania

Understanding the manipulation of the *BIAS FREE* Framework can lead one to reduce scientific biases in research at all stages of writing either articles or proposal for funding purposes.

Williams Makunde, National Institute for Medical Research, Tanzania

The Framework has made me look at articulating articles, scientific or general in a much broader perspective. In a sense it has really added value to my analytical skills.

Ssanyu Nyinondi, IFIKARA; Tanzania

By using this tool, researchers and policy-makers will systematically question individual and societal bias and will, therefore, be able to inform decision-makers with clear, objective findings. The *BIAS FREE* Framework will revolutionize research and science policies. A major step towards justice.

*Lorraine Touchette, Senior Policy Advisor,
Science and Technology Community Management Secretariat, Government of Canada*

The *BIAS FREE* Framework crystallizes thoughts around the existence of biases and is an invaluable tool to my students for uncovering biases in the debate of issues and in their own approach to the issues. Furthermore, this tool is very useful to equity-seeking NGOs. Members of the Ad Hoc Committee involved with writing the UN Convention on the rights of disabled people were very impressed by the *BIAS FREE* Framework and its potential. I know many disabled people and policy makers who are already using the tool.

*Dr. Gregor Wolbring
Dept. of Biochemistry and Molecular Biology Faculty of Medicine University of Calgary, Canada
Adjunct Assistant Professor for bioethical issues, Faculty of Education, University of Calgary.
Founder and Executive director of the International Center for Bioethics, Culture and Disability*

That 'power structures within a society serve to reinforce and maintain the various social hierarchies' may be undisputed, however, the fact that they are manifest across the economic spectrum and the uncertainty about what can be done has teased educators, researchers, and policy makers for decades. Finally, we now have a practical tool that is meticulously constructed, rigorously underpinned by theory, well referenced, and is challenging... Biases in the way we research problems can be a matter of life or death, biased research is bad research, this text is long overdue. The authors highlight the gravity of failing to remove biases and emphasise the need to remove biases that derive from all types of social hierarchies. They consistently direct the reader to the structural and organisational determinants of health thus minimizing the pathologisation of non-dominant members of society. Although the text focuses on the health sector and on health research in particular, the Framework is transferable to any policy sector and across legislation, policy development, programmes and practices as well as research. Please read and use!

Margaret Sills, Academic Director Higher Education Academy Health Sciences and Practice Subject Centre King's College London

I think you've produced an extremely important, practical and much-needed document that is going to be of significant use to researchers and policy makers. As I read through it, I was continually applying its methods and questions to my own on-going work and found the use of your template extremely useful in identifying possible gaps and oversights in my methods, research questions and analyses. From the point of view of someone (like myself) who is sympathetic to the approach you've developed and, particularly to the project, ie. the need to promote and seek equality and non-oppression for vulnerable populations, this Framework will be a very useful tool... It so clearly illustrates how bias operates and how applying the *BIAS FREE* Framework allows us to "see" differently and the very material consequences that follow from this.

Roxanne Mykitiuk, Associate Professor of Law, Osgoode Hall Law School, York University, Toronto, ON

The *BIAS FREE* Framework provides a useful tool for the identification and elimination of bias in health research. The utility of The *BIAS FREE* Framework goes beyond the specific context of health research and extends to human subject research generally and to the policy and law reform contexts as well... Drawing on the insights of feminist scholarship and critical race and critical disability scholarship the authors highlight the importance of identifying the values that underlie research and go on to deconstruct the concept of scientific objectivity noting that "the mere aspiration of objectivity must not be mistaken as satisfying the conditions of objectivity... The *BIAS FREE* Framework is posited on the equal entitlement of all people to be treated with dignity and respect and on the inviolability of human rights and it uses a rights-based model of health and well being. In speaking of equality the authors make it clear they are referring to equality of outcomes not simply equality of opportunity... Finally I would like to congratulate the authors on the development of a very important and useful tool for examining and eliminating the biases that derive from social hierarchies and one which while framed in the context of health research will have a broad application in other areas.

*Lee Ann Bassar, Associate Professor of Law, La Trobe University, Melbourne, Victoria, Australia;
Adjunct Faculty, MA (Critical Disability Studies) Faculty of Graduate Studies, York University, Toronto ON, Canada*

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