DISABLED WOMEN’S PRIORITIES FOR ACTION

RESEARCH RESULTS
FROM THE INTERNATIONAL LEADERSHIP FORUM
FOR WOMEN WITH DISABILITIES
JUNE 15-20, 1997

Produced by The World Institute on Disability,
Tanis Doe, Ph.D., Researcher

WID
WORLD INSTITUTE - DISABILITY

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I. Executive Summary

The research conducted at the International Leadership Forum for Women with Disabilities used a Participatory Action approach. The purpose of the research effort was to identify major topics of importance to women with disabilities. In addition, the organizers and funders of the Forum wanted to explore with women with disabilities the specific issues selected for in-depth exploration at the Forum: education, employment, family life, health and reproductive issues, and leadership development. A Research Committee, formed of women researchers and people involved in the planning process, designed research which combined written forms, personal interviews, and focus groups. The results of this research will constitute urgent topics to be addressed through future research and training.

The specific research objectives were:

1) *To identify and prioritize the major research topics, and specific questions of importance to women with disabilities;*

2) *To develop an understanding of the specific factors of gender and disability in the areas of employment, education, health, and family life;*

3) *To explore and address leadership issues and related training needs for women with disabilities, using the data collected as a baseline;*

4) *To identify approaches and existing barriers to networking for women with disabilities and use this information as a basis for ongoing communication and tracking of networking activities;*

5) *To provide basic information to Forum participants in order that they can begin research efforts in their own countries, or enhance existing ones.*

This process of asking women with disabilities what was important to them, how they became leaders, and what action should be taken on issues of importance has resulted in a significant report which will be made available to all participants and interested parties.
Research Priority Areas

On the basis of responses that were given in interviews conducted at the Forum, as well as comments made in the focus groups that were held, we determined that the five priority areas for future research, training, and action are:

- Education;
- Economic Empowerment;
- Ending Violence Against Women;
- Access to Health; and
- Family Life.

Four issues for future research that were not the subject of focus groups nor themes of the Forum emerged from the interview responses of a minority of participants. These will be explored following the discussion of the five priority areas. The four issues are:

- Transportation;
- Housing;
- Technology; and
- Sports.

Recommendations

1. The original participant list of the International Leadership Forum for Women with Disabilities be expanded and maintained as a database that would be accessible in alternative media for women throughout the world to utilize.

2. Research proposals on the priority topics be prepared and funded appropriately through various national and regional mechanisms.

3. A web site and printed equivalent newsletter be created and made available to women's organizations, disability organizations, and individuals throughout the world, whose focus would be the priority issues, sharing information, coalition building, and leadership development.
4. Leadership training programs be established at international, national, and regional levels based on needs identified, and the learning materials for them be archived and made available to women who conduct the training.

5. A financial assistance mechanism and/or micro-loan system be developed to support women's initiatives and participation which specifically targets students, unemployed women, and women from developing countries.

II. Research Design

The research was designed to include women with disabilities at every stage and to reflect their views. Participatory Action Research¹ (PAR) differs from traditional research by empowering participants to be partners in the creation and legitimation of knowledge about issues that affect them. Traditional research separates the researcher, a trained professional, from the subjects, that is, the people being studied. This has often been perceived by people with disabilities as oppressive. One of the important elements of this research is the representation of voices and ideas that are often excluded from traditional research because they come from a minority of women, or are not part of a larger pattern.

The research conducted by women with and without disabilities at the Forum is intended to be useful to women with disabilities. Hopefully, the results of this research will guide future research efforts in productive directions.

The Research Committee coordinated four main research activities at the Forum. On the first day of the Forum, during registration, and throughout the week, women (and men) participants were given an opportunity to sign up to participate in research activities. In addition, they were given a brief written outline and a consent form which explained the process and their rights, and which gave them an opportunity to sign up for a copy of the report. These are essential steps in participatory research because people must know their

choices and rights, and must be protected from harm. Copies of the consent form and information page are included in the Appendix.

Interviews

Interviews are a research tool used in many disciplines to ask questions that are not easily answered in written form, or by survey. The ideas generated in interviews are often detailed and meaningful to the participant because the "words" used to express concepts are owned by the women. The members of the Research Committee encouraged women to participate in interviews on subjects of their choosing. Some women chose to discuss the themes of the Forum or the topics of the focus groups. Others chose to discuss issues which were not on the Forum agenda. Interview participants were asked general questions about leadership; then, they were asked to elaborate on the issues identified as important in their responses.

We audiotaped women during the interviews, or took written notes, which were then coded to protect each woman’s identity and which were later transcribed. While only three women signed up for interviews during the first day of registration, by the last day of the Forum we had interviewed 52 women with disabilities. We also interviewed three women who did not have disabilities. Approximately 100 of the more than 600 women participating in the Forum were presenters or were working as organizers. These women were not interviewed as part of this research effort. Therefore, the women interviewed constitute 10.4% of Forum participants. For a research effort like this one, 10% is a good sample. A copy of the interview script is appended to this report as Appendix A.

Focus Groups

A focus group is a group interview often used in research where people’s opinions are important. It is a qualitative method to seek out agreement, disagreement, and ideas in which the interaction between people in the group creates a dialogue and enriches the quality of information available. By following a script, the facilitator is able to set the tone for the topic and then allow the women participating in the group to develop their ideas
with each other. Copies of the focus group scripts are appended as Appendix B along with a brief guide to conducting focus groups (Appendix C).

We offered twelve focus groups on various topics for women and one focus group for men. The subjects of the focus groups paralleled the theme of the Forum on a given day. So, for example, on the day on which education was a theme, we offered a focus group on education. Several focus groups had more than fifteen delegates sign up to participate. On the afternoon of the first day, however, the focus groups on international development and organizational development were cancelled due to lack of participation. While this was disappointing, it is not unusual; focus groups are seldom easy to coordinate on short notice, and it often takes a great deal of effort to organize a group to attend a focus group in communities. This Forum was like a small community of over 600 women. By rescheduling the international development focus group for the second day, making announcements at the plenary, and through personal communication, we were able to conduct the focus group on this topic with twenty-seven women participating. For the remainder of the week, each focus group included between four and ten participants. A total of 67 people participated in focus groups, including four male participants and one male leader in the men’s group. Out of a possible total of 500 participants, this represents 13.4% of the participants. Participants were not asked to disclose their disabilities in the focus groups. Twelve of the women who participated in interviews also attended one or more focus groups.

**Research Workshop**

The Research Committee wanted the participants at the Forum to understand the research design and to contribute to our understanding of their needs by actively setting a research agenda. Over 50 women attended this workshop, and 42 evaluation forms were submitted at the end. During the three-hour workshop, the participants divided into groups of eight or ten to discuss the major research priorities for women with disabilities and the barriers to conducting this research. Members of the workshop panel joined the groups to act as informal facilitators.
In general, the ideas generated by this workshop reveal that the lack of financial and technical resources is creating barriers to conducting research on women with disabilities, and that negative attitudes result in a reluctance on the part of professionals and academics in recognizing disability studies as a legitimate field.

Research is needed on issues specific to women with disabilities around violence, development, and employment, as well as on the more general issues of public attitude, non-disabled allies, and accessibility. In particular, women identified a need for more training and information that would enable them to do their own research, which would then be recognized as valid and credible. Findings of the research workshop informed the research which comprises this report. Summarized findings are in Section VII.

**Evaluation Forms**

Although the primary purpose of the evaluation forms was to enable the Research Committee to assess the effectiveness of the workshops and of the Forum, we also asked questions to evoke responses for direct use in our research. Workshop evaluation forms included questions of intent: for example, after asking if the participant had learned anything new, the form also asked "What steps will you take to initiate this approach in your country?" By reading the answers to such questions, we were able to categorize and analyze actions and intended projects which came out of the Forum. Similarly, the end-of-Forum evaluation asked women what activities they are currently involved with in their communities. Their responses enabled us to collect data about community programs.

Participants were also asked to estimate the size of their networks, as well as to describe the impact of the Beijing conference on the status of women with disabilities. This data provides us with a "baseline" of information regarding women with disabilities in a number of countries in 1997. This data can be used now to help implement change by learning from others' experiences, as well as in the future by comparing the 1997 baseline with information collected in two years, or five years, to gauge possible change in the situations for women with disabilities.
The Research Committee received 457 workshop evaluations and 90 end-of-Forum evaluations. Some people completed more than one workshop evaluation, and some of the workshop evaluations were completed by people who also completed the end-of-Forum evaluation. Thus, these evaluations do not represent separate individuals; rather, they are raw numbers of evaluations. The priorities identified by women in their evaluations were combined with those mentioned in interviews to become the basis for this report. Additional activities or projects suggested by Forum participants are also included in this report.

Problems with Method and Analysis

It is important for any research effort to document mistakes and problems so that issues of bias and validity can be addressed. Three main problems associated with the methods we used in this research were: difficulty with audiotaping, problems with language use and response gaps.

All the focus groups and interviews were audiotaped; however, the sound quality of the tapes was not as good as it should have been, which made many of the sessions difficult to translate. Some audiotapes were accidentally shut off for a short time, and others had too much background noise. A few women with unfamiliar speech patterns had some of their words misunderstood or skipped in the transcription process. Women initiating research projects should attempt to make recordings as accurate as possible so that their data actually reflects what women have said.

Language use is always an important issue, especially when multiple languages are being used. Forum evaluation forms were provided in Spanish, French, and English. Interviews and focus groups were conducted in Russian, Spanish, French, English, and ASL; there was often hesitation or semantic differences between participants and interviewers. For future research, it is important to have language verified several times. Questions and phrases should be tested with native speakers of all languages used, both verbally and in writing. With such preparation, mistakes in language can be corrected before the final research is done.
There were two types of response gaps that caused problems for our research. The first type occurred when a participant filled out half of a form or left some questions blank. In such cases, we could not include all their input. The second type occurred due to a lack of response from particular types of participants. For example, we interviewed very few women under 25 years of age; we also interviewed very few women with cognitive or developmental disabilities. For future research, these problems can be minimized by testing forms before conducting the actual research in order to clarify potentially difficult questions, and by oversampling, or purposely seeking out under-represented populations, to help obtain better responses from those groups.

Despite these problems, the research that was conducted and the resulting analysis does represent an important source of data about the issues and priorities of women with disabilities. Women who did not participate in the research, or who did not attend the Forum, can read this work and can add to it by sharing their experiences and writing, researching, and training other people on these topics. We encourage women to learn from this project, and to use the resources suggested in the appendices to conduct their own participatory action research.

III. Introduction

Based on the various methods used to collect data at the Forum, this research reports on areas that are important to women with disabilities. Two words that have similar meanings are used to describe the areas: issues and topics. "Issues" are the main themes, such as employment, education, and family life. "Topics" are smaller pieces of information related to one or more issues, such as the lack of role models in leadership positions. The issues discussed in the focus groups were selected by the Research Committee to reflect the themes of the Forum.

The interviews were less structured, with prompts to allow women to address whatever topics they regarded as important. After the interviews were conducted, we were able to see how many women addressed each different issue. Many of the women interviewed spoke about the themes of the Forum, as did those in the focus groups: for example, issues
of employment, education, and violence. These issues have already been recognized as important to women with disabilities, so it is not surprising that they are well represented in the research results.

Some women raised topics which were not central themes of the Forum, nor did they fit neatly into our pre-selected issue categories. Attention must be given to these particular topics because a number of women mentioned them even though the topics were not included as part of the Forum’s pre-selected agenda. In addition, women in focus groups on one issue often raised vital concerns about other issues; for example, the women in the focus group on technology also had many opinions and ideas on education. In order to report on the priorities identified in this research, as well as to summarize the extensive data, two types of results will be reported. First, the priorities of the majority of women involved; second, the priorities of a minority of women involved.

When everyone is so passionate about their issues, it is difficult to decide which issues are most urgent. Three main factors were taken into account when reviewing the research data: how frequently the issue was mentioned, how urgently the issue was mentioned, and how Forum participants ranked the issues in relation to one another.

Frequency was determined by counting the number of times a topic was raised in various formats and situations, i.e. if it was mentioned in evaluation forms, in interviews, and in focus groups. By itself, the frequency with which a topic was mentioned does not determine urgency, since some people did not repeat a topic which had already been addressed; moreover, sometimes the perspectives of a small number of women are very urgent.

Urgency or emphasis placed on a particular topic was also considered in determining priorities. Even if only five women mentioned a specific topic (e.g., the identity of Latin American women), it may be seen as a priority when it is emphasized and commented on very strongly. This is a subjective judgment about the comments which can only be made after all the data has been read and the issues have been compared with each other.
Lastly, but not least importantly, was the ranking or priority that women themselves assigned issues. Women in focus groups, interviews, and in written evaluations were asked to identify major issues for the future and ways to make a difference for women with disabilities. These research findings are, in part, based on those rankings provided by the women who participated in the Forum.

All of the interviews, focus groups, and evaluations concentrated on women with disabilities. The data, however, spans a range of topics and touches on many issues. Using a "gender" lens and looking for issues of disability, all of the written records of interviews conducted, focus groups held, and evaluations submitted, were coded so that any comments that related to male and female differences, discrimination against people with disabilities or specific disability issues were flagged. This method of coding provides a sense of some of the specific gender and disability issues facing women with disabilities.

To treat all of the issue areas identified, we have compiled a brief report summarizing each focus group which can be found in Section VII. In addition, we interviewed three women without disabilities who self-identified as either a parent or service provider. We also held a focus group for men with and without disabilities which dealt with their role in the empowerment of women as leaders. The comments of these participants enrich the data with the perspective of non-disabled women and men. This entire report is supported with comments drawn from focus groups, evaluations, and the interviews. Where appropriate, we have supplemented the findings with added ideas drawn from academic and disability community literature.

**IV. The Research Analysis Process**

Women with disabilities can gain a great deal from learning how to conduct and report on research of interest to us. If we have a better understanding of our issues, we will be more able to act to implement change. Many good books are available for people interested in learning about ways to conduct research. In addition, we hope that disabled women can learn from the research process used in the Forum and explained in this report to conduct additional research.
The Forum is one example of how to conduct participatory research. The main concept underlying this model is that such research is done for, and by, the people who experience the problem which is studied. No single method works for every topic, but participatory designs allow for flexibility and data collection to suit the needs of the project and participants.²

Information was collected during the five days that the Forum was held. Most interviews lasted between 30 minutes and an hour. Focus groups lasted two hours. We made 62 audio tapes; handwritten notes were taken in the course of four interviews in which over 120 people participated. Over 540 evaluation forms were submitted, including 457 individual workshop evaluations and 90 end-of-Forum evaluations. The following process was used to begin analysis of this data.

**Organization and Preparation**

All of the evaluation forms and all of the audio tapes were collected and assigned a number so that we could refer to each response without using a name. This procedure protects the identity of women and men who participated. Evaluations of various workshops were organized in such a way that they could be summarized together. Interviews transcribed by hand were converted to text using a word processing program. All of the audio taped interviews and focus groups were translated to English and converted to text using a word processing program. This process took several people, who did translation and transcription, over 60 hours.

**Review of Data**

All evaluation forms, all interviews and all focus group transcripts were read by the research consultant. Themes that emerged were noted and specific comments were categorized according to one or more themes. After reading all the data, notes were written

directly on the printed versions of all the transcripts and then entered onto a computer for future reference. The transcripts and comments were then read a second time, using gender and disability as lenses to enable the researcher to pull out common themes. Each interview and focus group report was re-read and specific comments were noted. This process took more than 100 hours.

**Coding of the Data and Data Analysis**

All of the comments were marked with colored pens, with different colors corresponding to different issues. In this way, the issues of violence, employment, or family life, for example, could be noticed easily. After all of the interviews were color coded, the total number of comments about each issue was calculated with the computer. The total number of people who raised the issue in interviews was used to indicate how frequently each issue was regarded as a priority. Tabulating the actual comments, the issues that emerged and the gender/disability review, an analysis revealed which five issues were priorities for the majority of participants, and which were priorities for a minority of them. Since coding is subjective, this approach was a qualitative, rather than a quantitative, process.

**Emerging Themes**

We discovered some information about which we did not ask questions. Almost every woman was asked to identify the major issues for women with disabilities. If the answer was the topic of education for disabled girls, it was coded under Education; if the answer was insurance or universal health care, it was coded under Access to Health. When women were asked how we should empower women and girls with disabilities, diverse issues such as economic independence, better education, and mentoring were mentioned. Each answer to a single question was coded separately and given a value in itself, rather than being tied to the specific question. For example, a woman’s response to a single question could include her thoughts on a number of different issues; in coding the response, each separate issue would be counted rather than choosing just one. This method was used to acknowledge overlaps between issues, and the interconnectedness of some priorities.
Three new issues which emerged from the first 30 interviews were:

- Attitudes of women with disabilities and of non-disabled people toward disabled people and women.
- Role models/mentors/peer contact and the need for more visibility and connection among women with disabilities.
- Networking and leadership training (e.g., how to run a meeting, speak effectively to the public, write a grant, recruit women, change policy).

After noting these emerging issues in the first set of transcripts, new categories were used to identify similar issues or topics in the remaining transcripts and data. These three issues were apparent in a number of other areas: many women felt that role models are important whether they talked about employment, health, or technology. Similarly, many people felt that changing attitudes is important to affect issues of education, politics or accessibility. All of the comments relating to these issues were coded again to ensure that we captured these emerging issues.

**Report Writing**

Even with all the data analysis, re-reading and coding, there remained the difficult task of deciding what to report. A draft of this report was written using the Research Committee’s original objectives and proposal as a guide. In addition, the first draft included significant minority issues to reflect the “unexpected” information that we discovered. Since it is not possible to include everything participants said in this report, most general ideas have been paraphrased. However, some individual comments have been retained as illustrations, and such quotes or examples should be regarded as representative of participants’ remarks.

The first draft of this report was also edited to ensure that the language is clear, and that statistics are not overly complicated. The focus group reports were written in a short version so that they can be quickly digested. The first drafts of these were reviewed by the Research Committee, and subsequent drafts incorporated the comments of the Committee. The final version of this report was created to be distributed widely and in alternative formats.
V. Who participated in the interviews and focus groups?

Individual participants in interviews were mostly from United States (30 out of 52) and were mostly between 28 and 50 years of age. A few older women and a few younger women participated. Since none of the participants were directly asked about their ages, this assessment is based on comments made within interviews. The majority of participants (29/52) had physical/mobility disabilities. Twenty-two had other disabilities: five were blind or visually impaired, one was deaf, and three were hard of hearing. Four identified themselves as having learning disabilities, three identified as having developmental disabilities, three had health-related disabilities such as diabetes, sickle-cell anemia, and epilepsy, and three had psychiatric disabilities as their primary impairment. Twenty of the fifty-two women identified as having more than one disability, or more than one functional limitation resulting from a single disability. For a summary of these percentages, refer to the following table.

Table 1. Self-disclosed Disability Identification among Women in Interviews

<table>
<thead>
<tr>
<th>Disability Disclosed Number out of 52</th>
<th>Percentage of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility/ Physical Disability</td>
<td>29</td>
</tr>
<tr>
<td>Blind or Visually Impaired</td>
<td>5</td>
</tr>
<tr>
<td>Learning Disabilities</td>
<td>4</td>
</tr>
<tr>
<td>Hard of Hearing</td>
<td>3</td>
</tr>
<tr>
<td>Developmental Disabilities</td>
<td>3</td>
</tr>
<tr>
<td>Medical/health Disability</td>
<td>3</td>
</tr>
<tr>
<td>Psychiatric Disabilities</td>
<td>3</td>
</tr>
<tr>
<td>Deaf</td>
<td>1</td>
</tr>
</tbody>
</table>

NOTE: One woman said that she has a disability, but would not disclose which one on the principle that women should not need to ask each other questions about what type of disability they have. Three women identified themselves as either a mother, caregiver, or service provider.
In the focus groups, women were not asked to identify their disabilities but they were asked to identify from which country they came. A significant number were from the United States (29/67 or 43%), other participants came from North America, Europe, Africa, Latin and Central America, Asia and South East Asia, and Australia.

Fifteen participants in focus groups spoke languages other than English. Four participated in French, three used Spanish and three used Russian. Five women used either sign language or a sign language interpreter to participate. A check of sign-up sheets shows that twelve of the women who were interviewed individually also participated in one or more focus groups.

VI. Results from the Research

For each of the research objectives, the results have been reported in two parts. The first section under each topic discusses general findings based on the data; the second section summarizes specific suggestions provided by Forum participants.

Research Objective 1: To identify and prioritize the major research topics and specific questions of importance to women with disabilities.

Based on the interviews and focus groups, the top five priority areas for research, training and action are:

- Education;
- Economic Empowerment;
- Ending Violence Against Women;
- Access to Health; and
- Family Life.

Another four issues that were not the subject of focus groups or major themes of the Forum emerged from the interviews. These issues will be explored after the top five have been discussed. A minority of participants emphasized:

- Transportation;
- Housing;
- Technology; and
- Sports.

1.1 "Education is the Key"

A focus group on education was combined with one on international development. The participants felt that this combination was natural and useful because development and education can not be considered separately. Education was also identified as a priority in 80.8% of interviews conducted (42/52). Of the five priority issues, Education was the most frequently mentioned across all of the methods of data collection.

Women from every country, every class, and every background indicated that education is critical to the development of women and girls with disabilities. In addition, they noted that education is important at every level of development and for every population. For example, women specified that pre-school aged children must have access to education and that women elders must have access to it also. Literacy, basic education, and advanced or post-secondary education were all prioritized.

Education was linked by most women to independence, economic opportunity, political participation and personal growth. The topics raised with regard to education included access to physical buildings, real inclusion, gender equity in classrooms, equal opportunity as students and teachers, and accommodations and specific supports for students with disabilities. Accommodations and supports included: teacher's aids, assistive technology, interpreters, and alternative formats for materials. Women also mentioned that science and math education must be made more accessible for, and supportive of, girls and women with disabilities throughout secondary school, as well as at college and university levels. Many women said that education is a good way to promote self-confidence and to enable girls to recognize their own potential.

Women reported little or no recent progress in the area of obtaining education for women with disabilities. Most countries represented do not have universal education, so disabled children are not provided with funding or support to attend school. In some countries, literacy projects have been introduced, and some women are starting to help each other in
informal groups. However, receiving a better education is a top priority, for an inadequate education is a barrier to development, leadership and economic independence. A woman from Tanzania suggested:

"Empower women by giving them an education. Without being educated you cannot know how to manipulate what comes next. And then educate them to have income generating projects that can help them be economically strong."

For women in developing countries, women who use minority languages and women who immigrate to some developed countries, education is needed to ensure that they have the literacy and basic communication skills required to obtain appropriate rehabilitation and services.

Several women also commented on the need for educational materials about disability and about gender so that girls and women with disabilities will learn about identity, history and culture which impacts them.

Women referred not only to the education of people with disabilities, but also mentioned the need to educate non-disabled children, adults and professionals about disability. In fact, education was regarded as the key to attitudinal change and to increasing the opportunities for people with disabilities to participate in the mainstream.

The concepts of “women and disability” are constructed, in part, through societal attitudes and expectations, which are informed by experience and education (or lack thereof) and internalized. This link is important to make. In this research, women spoke strongly about the ways that education can be a tool to empower girls and women. They pointed out that education about disability must also be used to create an environment more conducive to expanding opportunities and inclusion for women with disabilities.

Women in developing countries believed that education could not be separated from development, that all development efforts must include education, and that all educational programs must be part of development. Women in more industrialized countries also argued that without education women could not participate in economic life, nor could they be socially and politically active in their communities.
Women agreed that education was a paramount issue. However, basic literacy and the opportunity to attend school was the immediate priority for some women, while women in developed countries focused more on equity and opportunities for further education. In an issue paper prepared for UNICEF on adolescence and disability, Nora Groce reported that UNESCO estimates indicate that literacy rates for girls and women with disabilities hovers close to 1%.³ Education needs to be universal and accessible to ensure that all disabled girls and women are able to participate in society. Many women considered this a fundamental human right.

**Research recommendations on Education**

- Distance education options using the internet, television, radio or correspondence, particularly for rural or isolated women.
- Curriculum development in the area of history of women with disabilities. Science and math appropriate for women with disabilities and literacy.
- Educational materials for girls around self-esteem, body image and peers so that they grow to understand that it is “okay” to have a disability.
- More, and better, physical resources such as ramps, technology, assistants for learning and appropriate equipment relating to disability access.
- Comparative outcomes for boys and girls with disabilities. Tracking success from various school models: mainstream and segregated. Analysis of success stories or methods that enable girls to continue their education.
- Understanding and accommodation within the educational system for girls with learning disabilities, mental health disabilities, and developmental disabilities.

**1.2 "Economic Empowerment is Essential"**

Economic issues were a close second in terms of frequency of comments. Forty out of 52 women interviewed raised this issue (76.9%), and one focus group was held on the topic as well. Although many women connected education to economic opportunity, other women focused specifically on participation in the economy. Similar to the comments made regarding education, economic opportunity and employment were seen as important at

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³ Nora Groce, "Adolescence and Disability: Issue Paper" Thematic Discussion on Childhood Disability Committee on the Rights of the Child, UNICEF Survey on
every level and for many different reasons. Women felt that once women were able to be financially independent, they would be able to purchase services and goods they need. Money, or a way of getting it on a regular basis, was seen as the main factor in successful independent living.

Poverty is an overwhelming barrier for women who live in developing countries; for some, this issue overshadows all other disability issues. Many of these women reported that they were struggling to get any money at all. Some spoke of disabled people who die because there is not enough money to feed them or to provide medical care. They were worried that children with disabilities were being killed or left to die because the families perceive that the child will not contribute to the family and they are unable to pay for the child's medical care. Others talked about dependence on family members and lack of independence.

The difference between needing money for subsistence and needing money for personal freedom was significant. Many women from more developed countries focused on ways to get more money than the standard "welfare" allowance. Women from Eastern Europe and North America who received small but regular pensions spoke about finding ways to increase their incomes beyond this bare minimum. Discussions around self-employment, income generating projects, and cooperative ventures were central. Although some of the North American and European women talked about employment in the mainstream, there was a general consensus that finding jobs was very difficult for disabled women in the current economy. One woman from Eastern Europe said:

"More money would help, because with money we could buy equipment, or transportation or just food. Even though it cannot solve everything, it can help us to live more independently."

Women strategized around options for income support and income generation. They also criticized the barriers to employment. Self-employment was seen as a positive option, especially in locations where it is almost impossible to find other employment. The two

Adolescents with Disability (Yale School of Public Health, 1997).
most popular types of income producing projects named in the research were wheelchair building/repair and micro-enterprise such as clothing, ceramics or crafts. Women were concerned that not enough of us are in business for ourselves, and that we have very little representation in the professions of media, medicine, and education which deal with our issues. Two women mentioned the lack of involvement of disabled women in trade unions and the labor movement, as well as the need to work together to achieve change since the number of women with disabilities in the workforce is small. One woman also noted that without women with disabilities in elected office and government jobs, we remain unrepresented at the decision-making level. Very few women were interested in the "quota" system or the North American affirmative action process. Instead, they focused on creating their own opportunities and finding other ways to earn money and achieve financial security.

Most women who responded to the question about economic development in the evaluation felt the situation had gotten worse in the last two years. Only three women described positive experiences with micro-credit or income generating schemes. Most were very concerned about income supports for women and felt disabled women were still among the poorest of the poor. In research undertaken using national statistics in the United States, Sharon Barnatt and Barbara Altman found that "all of the groups of female workers, whether with impairments or not, also earned substantially less than men in the general population-their incomes were 50%-61% of the income of that group."4 Women who are working at paid employment still face inequity in wage income.

In addition, it was noted that financial resources are essential for the survival of organizations as well as for individual survival. Groups need funding to advocate, provide services and assist women with disabilities.

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The problems surrounding employment and economic issues for disabled women need to be seen in the context of the political and economic climate of the country in which they live. Women noted the impact of different national factors such as natural disasters, war, economic crises, or political struggles, and recognized the ways in which these affect the economic progression of women with disabilities. These varying conditions mean that solutions offered in one country may not be appropriate in another, yet some model programs might work well when adapted appropriately.

Many women recognized that a large amount of the barriers to economic development are based on attitudes which devalue disabled people and women. Some believe that incomes for women with disabilities will not increase until support is provided for all women. Women commented that children with disabilities are not educated or given transition skills because they are not expected to work as adults. When children with disabilities become adults, they lack skills and training, and therefore they often cannot work. Many who do work are underpaid, exploited, and trapped in dead-end jobs with little room for growth. The problems are interconnected, but stem from a systemic devaluation of women and people with disabilities.

**Research recommendations on Economic Empowerment**

- Examine key factors in successful entrepreneurship and self-employment.
- Learn from other's experiences about "what works" and "what doesn't."
- Duplicate/replicate income generation and micro-loan programs.
- Train women to be home-based business owners or to run co-operatives.
- Evaluate various income support schemes internationally.
- Advocate for better income security policies in general, and consumer review of the social security formula for deductions for earned income in particular.
- Provide more women-positive job training and vocational rehabilitation that does not stereotype women's careers.
- Research types of accommodation, both technical and human resource, that would support women with all types of disabilities in the workforce.
- Develop employment opportunities in sciences, math, medicine, education and politics—and any other professional option women want.
1.3 "We Need to Stop Violence Against Women with Disabilities"

Despite the fact that there is still a great deal of stigma associated with violence, 61.5% of women mentioned this as a priority (32/52). Women from developed and less developed countries mentioned the issue at almost equal rates. The Forum focus group on this topic resulted in many suggestions for action, as did the workshop on violence. Women found that sexual violence against girls with disabilities continued at alarming rates, with little intervention from authorities. Physical and emotional violence against adult women with disabilities was also high on the agenda. The devaluation of women and girls in some families and societies was seen as an important factor. Lack of access to help increases the vulnerability of these women and girls. Forum participants talked about stopping the violence through education, legislation and enforcement, and also stressed the importance of support and intervention for survivors.

Several of the women from developing countries mentioned the connection between extreme poverty and violence. Passionate comments about why men batter and violate women touched on the stress and desperation facing all people in poverty. Women also connected health and education together with prevention of violence, and the need to make both educators and health care professionals aware of violence and women with disabilities. The issue of violence intersects with many others. A woman leader from Mexico said:

"There are no services for disabled women experiencing domestic violence. Many times the only means of transportation to a hospital is by taxi and there is no money in the house even to eat, there is no way to get a taxi to the hospital so many women do not even get to the hospital unless the nature of the violence is so severe that the neighbors intervene and take her. It is very much still a taboo and we have to take the cultural aspects into account. The way to intervene may be different in each country."

Research internationally and in North America confirms that women with disabilities are at least twice as likely to be assaulted as non-disabled women. Women in North American

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and European communities spoke about the "silencing" of victims and the lack of support in the disability community for survivors. Two women spoke about the rape of women in the military: one from the perspective of being in the armed forces and another as a civilian victimized during war. Both these and other women spoke of the effects of Post-Traumatic Stress Disorder and the long-term impact and disabling consequences of sexual violence and harassment on women.

The intersection of violence and other issues also relates to the devaluation of women and people with disabilities. In North America, assisted suicide, genetic testing, and euthanasia have raised issues about society's willingness to support the rights of people with disabilities to survive. Many countries still practice infanticide of disabled children, and children with disabilities are often malnourished, abused, and sexually exploited if they do live.

Women showed concern that disabled women are still institutionalized throughout the world. The violence that takes place in institutions and in family homes has devastating effects on women with disabilities. In particular, women expressed concern for women with psychiatric disabilities and developmental disabilities who are raped in institutions, or who are raped and become depressed or disabled from violence and end up in institutions where they are re-victimized. A great deal of discussion took place about the role of the women's movement in ending violence against women and girls with disabilities; in particular, women emphasized that the women's shelters and services must incorporate the needs of women with disabilities.

**Research recommendations on Violence**

- Learn to identify victims by knowing symptoms and signs.
- Establish protocols for legal professionals to support women through the system.
- Develop therapeutic approaches to serving disabled women survivors.
- Create models of self defense and prevention strategies appropriate for disabled women.
- Establish crisis centers for and by women with disabilities and improve accessibility to all services.
• Train all levels of professionals to learn how to serve disabled women.
• Educate disabled women and the disability movement about issues of violence.
• Research violence-induced disability and post-traumatic stress.
• Develop training and professional standards for personal assistants around the issue of supporting survivors of violence and preventing violence.
• Increase self-esteem, empowerment and mutual support for women both before and after they experience violence so that they can live safely.

1.4 "Wellness and Health Should be Made Accessible for Disabled Women"

Twenty-six of the 52 women (50%) mentioned health in their interviews. Although there was no single focus group for the area of health, women in the four different focus groups on parenting, sexuality, violence and education made comments directly or indirectly relating to health and medical professionals.

A range of topics was raised under the category of health, but not all of them related to "clinical" health. Only a few women were interested specifically in research on preventing or treating disabilities. Most were concerned about maintaining their health as disabled women.

Women with disabilities are very aware of the need to access health services for medical problems unrelated to their disabilities, as well as very interested in knowing more about living successfully with their disabilities. In particular, women wanted to know about aging with their disabilities, having children, having sex, the effects of medication, and various medical interventions. The priority for most women is getting access to regular medical treatment, getting insurance, or being able to pay for services. For some women, a pre-existing condition makes it impossible to get insurance, for others there is no insurance available and there is no money to pay for health care. Some women who can afford health care, or who have insurance coverage, still find it difficult to locate appropriate and supportive health care.

Women cited lack of communication, lack of knowledge, and inappropriate equipment as major barriers. Many women were also concerned with depression, suicide, and mental health issues as they affect women with disabilities. Women mentioned the intersection
between violence and health, how some disabilities are caused by violence, and how some violence leads to depression and post-traumatic stress. Women with psychiatric disabilities were quite concerned about various medication and their side effects.

Women in developing countries mentioned health less often than they mentioned economics and education; however, those who did mention health tied it to poverty and rural living. Women in rural areas and those who were very poor had little access to health care. Women in developing countries mentioned vaccination against polio as an issue, as well as educating women about prenatal care and prevention of disability.

Access to health care was a priority because so many women were not able to obtain even basic medical services. Women in the cities, or those who have some financial support, have more chance of getting medical help. Many women from developing countries also felt that education is a key to health, especially when women must do their own self-care, and since prevention can reduce many of the common illnesses.

For women in Europe, North America, and Central America, access to screening for cancer, access to information about health promotion, and basic contact with medical professionals were all raised as priorities. Difficult experiences, lack of access, and attitudinal problems were ranked among the serious health issues for women with disabilities. Three women who were cancer survivors were concerned that many women with disabilities are not being screened and treated properly for cancer. Several women said they had trouble finding doctors who were sympathetic (had good attitudes) and who also had accessible offices and examination tables. Some women mentioned that doctors had mistreated them with errors in medication or lack of informed consent. One woman in a focus group advised other women to "shop around" until they found a supportive doctor.

In evaluations, women reported that there is increased awareness of our health issues and greater availability of family health education and support for community clinics than there was previously. Although there is still tremendous need for more awareness and access to health and health education, women are working in these areas and are trying to improve
the current situation. The ability to provide services and health information is tied to economic development and education for all women.

Research recommendations on Health

- Gather accessible, appropriate information about sexuality, reproduction, bioethics, and, in particular, new reproductive technologies.
- Examine how being disabled specifically influences risks of other disabilities and conditions.
- Research on access to prevention and treatment for cancer and AIDS/HIV.
- Research on accessible gynecological services for physically disabled women.
- Perform spinal cord research and explore the experiences of women with spinal cord injuries.
- Research on post-traumatic stress and violence-related health and disability issues.
- Research on bone marrow and treatment for people with sickle cell anemia.
- Develop training projects for professionals around sensitivity to disability and working with disabled women.
- Collect data on physical access for offices, hospitals, examining tables, and health promotion activities.
- Create a disability positive medical experience as well as a financially accessible medical system.
- Advocate for universally accessible medical services including prescription drugs, durable medical equipment, and services of rehabilitation professionals.
- Provide further education about polio vaccination and other prevention strategies in all countries and better prenatal education for mothers.
- Develop more consumer-oriented research on side-effects and impact of psychotropic drugs, and of other medications used by women with disabilities (in particular, how these drugs affect sex, reproduction, mental health, and mobility).

1.5 "Our Families Matter"

Twenty of the 52 women (38.5%) raised the issue of families as a priority during their interviews. Some raised the issue of their own families of origin (their parents); others spoke about being parents themselves, or about families of disabled children in general. Women had both positive and negative comments around the issue of families. Women with positive experiences of family said that having good family support was instrumental
in their empowerment and in the support of children with disabilities. Many women, particularly those from developing countries or those who had been neglected by their families, pointed to the need to focus on parents of children with disabilities. Women felt that changes to the family experience could make a difference in lessening the negative experiences and problems associated with poverty and shame.

In a national needs assessment of parents with disabilities, Berkeley Planning Associates reported that two out of five respondents reported having faced attitudinal barriers as disabled parents. About one-third of all respondents report that they have been discriminated against as a parent with a disability. Parents with disabilities particularly had problems with employment, recreation and transportation. This study conducted in the United States was the first of its kind and indicated a large number of unmet needs. The interviews and focus group discussions held at the Forum echoed these problems.

Women who were mothers, or who wanted to be mothers, spoke to the importance of family support, in the forms of relationships between adults, between adults and children, and among members of an extended family. Once again, poverty was raised as an issue where families could not afford to provide for a disabled child who might be regarded as a "burden." This image also was felt to cause a great deal of damage to the child as she grows up. Violence was also mentioned in the context of families, in particular, the importance of preventing isolation and stress that can foster violence.

Since disability is not usually intergenerational, disabled children are often raised by non-disabled parents who have no knowledge about disability or support for their unique needs. Adult women with disabilities feel they can help educate and support non-disabled parents of children with disabilities.

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Families are also important because of their unique capacity to instill children with a self-image and attitudes – either positive or negative. Almost half the women who spoke about families focused on the needs of young girls and wanted those girls to have a better family experience than they had. For girls to have feelings of self-confidence, pride and self-worth instead of shame, their families have to give them positive messages. When children become disabled as young adults, they have already internalized the values of independence, physical strength and beauty.

Mothers with disabilities felt it was important to be out in the public as role models for other girls, and for women to see that parenting was a possible role for them. When asked about the barriers to parenting as a woman with a disability, one American woman said:

"I think that the biggest issue is other people's expectations about your ability to be a parent, not so much your ability."

**Research recommendations on Family**

- Collect information on technical and physical adaptations for parenting with a disability (of particular interest to women from developing countries).
- Research on the needs and abilities of mothers with disabilities.
- Research on marriage, long term relationships, same sex relationships, and the impact of one or both partners having disabilities.
- Develop training for medical professionals who serve pregnant women with disabilities, including how to give women more choices in childbirth.
- Increase accessibility of childcare services for disabled women and their children.
- Conduct research on the bonding between parents and disabled children, and the impact of disability on family dynamics.
- Conduct research pairing parents of disabled children with disabled women to provide adult peer support for the families and adult role models for the children.

**1.6 Priority Issues of a Minority of Women Delegates**

The following issues are related to many other critical priorities raised by women at the Forum. Although some women gave these issues top priority, they were not ranked in the top five overall. The research reflects the fact that these issues were raised as important by a small number of women.
Transportation

Only 19% of the women interviewed spoke about transportation, but they felt that this topic was critically important. "More than the internet," one woman argued, "it is transportation that will reduce our isolation." "How can we be active participants in society if we cannot get from here to there?" echoed another. Women in developing countries and developed countries alike mentioned that transportation was a major barrier to social participation for women with physical disabilities. Transportation was also raised in the context of violence, and the ability of women to prevent or escape violence.

Transportation is linked directly to many other issues because without the ability to get around you cannot easily work, go to school, have friends, have a family, or participate in organizations. Problems associated with transportation included weather, safety, accessibility of public and private vehicles, and the cost associated with paying for transportation. For women in rural areas, and also in cities, being stuck at home due to inaccessible transportation was a major problem. One woman described her own "empowerment" as she learned to drive. At that point, she became independent, realized her dreams, and worked to meet her goals.

Housing

Housing is closely linked to the issue of transportation. Eight of the 52 women interviewed (15%) discussed housing along with the broader issue of accessibility. Four women identified housing as their major issue. Two women wanted to focus on universal design and building more accessible houses, and another two were interested in affordable housing, safe housing, and deinstitutionalization. One mother of a disabled adult woman felt it was critical for independent living of adults with disabilities for them to have "somewhere to go after the institution." For many women with disabilities, the family home is the only home they have ever known. Many women interviewed stayed with their families well into adulthood, even after marriage, because of concerns about accessibility.

Housing is also linked to poverty and employment. Many women living on welfare or pensions are unable to move or are unwilling to give up subsidized housing because of the
uncertainty of finding jobs or different housing situations. Housing was an issue for
college students, since most of them left their family homes to live in student residences
while in school. Housing appears to be a critical transition issue for people as they move
from family to independence, from school to work, or from institution to community.

There are not enough accessible homes with various options of independence and support.
For example, one woman had to choose between "an accessible, supportive housing choice
in a drug- and crime-infested neighborhood, and a barely accessible, dependent situation in
a middle class, significantly safer one." For many women with disabilities, violence is also
related to housing because many women report that they stay in violent situations due to
the lack of options for other living arrangements. Even some parents of disabled children
tolerate unhealthy environments because of the lack of options. Women with disabilities
who had better incomes or more secure employment found more choices in housing than
those without any income. Housing, transportation and poverty are also linked to levels of
independence, education and health.

Technology
A focus group on universal design and access was held in which five deaf and hard of
hearing women participated. Despite the popularity of the internet and other computer
oriented devices, technology was not a priority noted by the majority of women. Five of
52 women (9.6%) interviewed identified technology as a critical issue; three of these
women related technology to employment and health. One woman with a chronic
disability explained that the internet allowed her to work from home and reduce her
fatigue. She also found that many technical aids increased her independence. A second
woman related technology to her health, referring to her use of a respirator. She was
concerned that men are given more options for respiration than women and that once
medical technology is available (for men or women) there are policy issues around paying
for, maintaining, and servicing the equipment. The third woman spoke of basic wheelchair
technology and power wheelchairs. She felt that some women with disabilities are using
crutches or crawling when they really should be using wheelchairs, and that others using
wheelchairs are so disabled that they need power chairs. In her country, it is almost impossible to get wheelchairs even though mobility is critical to women’s employment and to their basic health.

Two other women focused on how technology allows communication to take place between disabled and non-disabled people. They pointed to captioning of movies and captioning of meetings, communication over the relay system, and real time video transmission over phone lines. These women felt that further research and development into technology would empower deaf and disabled people to be more active participants and leaders.

For all these women, funding is a key factor within the issue of technology, either as it determines actual choices of available devices, or by having third-party funders prioritize the funding of maintenance, repair or replacement of devices. Thus, this issue of technology is also tied to the broader issue of economic independence for all women.

Sports

There was no focus group and only one workshop at the Forum on the topic of sports, but almost 6% (3/52) of the women spoke passionately about the importance of sports for women with disabilities. One American woman was particularly convinced that sports were a way to regain self-confidence and social skills after an injury. She said that she was very depressed after sustaining a spinal cord injury, and sports gave her something to focus on and a way to meet other people. A woman from Mexico found that sports are a way to be a positive role model, to be active and to increase energy and self-esteem. Both of these women were actively involved in wheelchair sports.

A woman from Europe suggested that because many women have negative experiences with physiotherapy, exercise and the medical profession, they may tend to resist exercise and physical activity as adults. She felt that, depending on the type of disability and the associated fatigue level, some women with disabilities simply assume they can’t enjoy
sports. She said that women could use sports to achieve maximum health, to develop a positive attitude and to express a part of disability culture:

"the World Games for the Deaf, the Paralympics and the Special Olympics, are all opportunities for us to be successful and feel good about achieving our best."

**Research Objective 2: To develop an understanding of the specific factors of gender and disability in the areas of employment, education, health, and family.**

**2.1 "Women are Both Gendered and Disabled People"**

When asked if they "identified" as a woman with a disability, 48 of the 52 (92%) of the women interviews said that they did; some added emphatically, "of course" or "absolutely." No specific pattern of age or country of origin could be identified for these women. Several women added that although they currently identify as being disabled, they had often "passed" or pretended not to be disabled. Some felt that they had come to identify as disabled women through the process of being exposed to positive images and role models over time. Four women who stated that they did not identify as women with disabilities explained that they did not feel "handicapped" nor did they see themselves as disabled. Some saw themselves as "women first" or "humans." Three women interviewed did not identify as having disabilities: one is a mother of disabled children, and two are service providers and/or friends of people with disabilities. These three are not counted among the fifty-two; however, their comments were coded and included in the overall results.

Throughout the interviews and focus groups, women were given a chance to discuss their experiences and to prioritize issues of importance to them. They were also asked specifically to identify what makes their issues different from those of non-disabled women and men with disabilities.

Sexism was identified as a significant barrier by a majority of women. While men with disabilities have to face the same physical barriers, "they are still men after all;" therefore,
they benefit from their status and participate in the world as "gendered" men. Women from both developed and less developed countries were emphatic that women with disabilities face double jeopardy. One woman put it simply:

"We have the same problems as all women, compounded by prejudice, lack of education, lack of experience, and lack of mentors."

Transportation and housing were the issues least likely to be seen as different for men with disabilities and women with disabilities. The only difference that women mentioned in relation to these areas was safety, or threat of violence, because women need safe housing and safe transportation more than men do.

Women from some countries emphasized the very limited social roles available to women with disabilities, particularly with regard to marriage and family life. Other women emphasized limits in employment options and leadership opportunities. For example, a woman from India offers:

"In our country, men with disabilities are in a position so they can get married, but there are hardly any women with disabilities married because if someone in the family has a disability it becomes very difficult for the parents to arrange a marriage."

It would be simplistic to say that there was a North-South or East-West difference in the issues of gender roles among the Forum participants. However, there is a need to consider the contextual and cultural differences of women in various countries. According to women from some countries, disabled women fit traditional expectations of staying home, doing housework, and caring for children. Some disabled women from other countries did not have husbands or children, and thus went against the traditional role of women by going to work or being active as volunteers. Disabled women said that, as women, there are certain things they wouldn't do or would not choose to do; but, as disabled people, there are things they feel they are "not supposed to or not expected to do." There are both external and internal pressures on women with disabilities.

There was consistent concern that while some disabled men were succeeding in organizations or in the work force, women with disabilities lag behind. Other women commented that non-disabled women have been able to make many more social leaps
because they do not face the physical barriers of access. When asked about the differences between non-disabled women and women with disabilities in the area of sexuality, one African woman said:

"I would imagine it's not very different; we are both women. I wonder if the problem could be in education? I'm talking about schools and parents, attitudes that are cultivated when you are a child."

This may speak to the minority model of disability and the issue of "essential" differences between men and women as well as the differences between disabled and non-disabled people. Most, but not all, of the interviews and focus groups included a specific question regarding the differences between men and women with disabilities, and non-disabled women and women with disabilities. However, all transcripts were read through a gender/disability lens to find issues relating to discrimination, and intersections of gender and disability even where such gender- or disability-related questions were not specifically asked.

The most frequently cited intersections of gender and disability were:

- child care/parenting;
- leadership roles in organizations; and
- violence.

Child care/parenting

One woman from Northern Europe perceived gender to influence the difference between men's issues and women's issues around disability. As she found in her research:

"Perhaps due to society's expectations, the issues with which people struggle vary according to gender. For example, all the men who were recently diagnosed (with Multiple Sclerosis) asked immediately about sex. They felt fundamentally threatened as men: more terrified of becoming impotent than of not being able to walk. Women were very concerned about whether or not they could take care of their families or do their jobs."

Women with disabilities experience their gender as being most influential when they are raising children. Women noted that men with disabilities and non-disabled men rarely take sole care of their children. In some countries, it is unthinkable for a man to hold an infant or to raise a child alone. Although there are exceptions to this rule, the majority of women
said that they were solely responsible for childcare and parenting duties. They also said that this was an area in which they felt discrimination from non-disabled men and women. Women at the Forum said that many non-disabled men and women disapprove of women with disabilities getting pregnant or having children, and fear that children of a disabled parent will somehow suffer or be damaged.

Women raised the point that although men with disabilities face discrimination in the workforce, women with disabilities are doubly disadvantaged in the workforce. When coupled with their additional role as parent, this puts an extremely important and difficult responsibility on mothers with disabilities who have to provide for their children both financially and physically. Single parenthood and poverty among women with disabilities were considered to be very gender-based.

**Leadership roles**

When asked about the differences between men and women with disabilities, a large number of women cited sexism and patriarchal attitudes as barriers. These women felt that men remain more likely to get leadership opportunities and to be in charge of events or organizations. This discussion focused on disability organizations rather than on mainstream organizations.

One American woman, who actively lobbies for legislative change, said that within an organization dominated by men, "they are acting like I am the wife and I am not. I am not the secretary or the mom." Other women found that disability groups in which they participate were made up largely of women. Some felt that men had trouble asking for help and rarely came to support groups or peer events, and that men were more often in leadership or administrative roles rather than actually participating. Women in developing countries found they were most able to attain leadership roles in women's sections or women's programs because the men did not respect them in "mixed" organizations.

Men who participated in a focus group discussion about differences in leadership styles between men and women felt that women are more democratic as leaders and tend to have
a more inclusive style of management. Some women felt that a lack of confidence, even when they had something important to say, kept them silent in meetings. Many women felt more comfortable talking with groups of other women. Some women commented that they experienced sexism in the disability movement from both disabled men and other disabled women. Two women gave examples in which other disabled women perceived them to be too domineering for women and had indicated that they should be more passive.

Again, in terms of countries and context, there were differences in standards and gender roles. Women from African and Latin American countries said that they are not seen as credible by men, so they have formed their own organizations. Women from North America found that while they could participate actively in mixed gender organizations, there are subtle rules regarding how a woman "should" behave.

Some women felt there is discontent and conflict within the disabled women's movement itself. Women who had worked with mainstream women's organizations believe that there is more opportunity to develop leadership skills in women-centered groups. Access to leadership roles and training was seen as an issue that is genuinely influenced by gender.

**Violence**

As previously mentioned, many women identified violence as a priority for future research. One of the strongest intersections between gender and disability was the vulnerability factor: being both female and disabled puts women in a higher risk category as potential victims of violence. Women from developing countries reported that while all women may be victims of abuse or rape, women with disabilities are raped more frequently and nothing is done about it. These women say that authorities turn the other way and families cover up acts of violence. Being disabled, being dependent, or being institutionalized multiplies the possibility that one will be assaulted as a woman.

The threat of violence is one area where women with disabilities clearly are more at risk than either women without disabilities or men with disabilities.
Power and economic issues were also raised in this context. It was widely felt that men have more power and more money, and that women are generally held in lower status and therefore are more easily abused.

*Intersections of Gender and Disability Oppressions*

Ablism and sexism work in concert to oppress women with disabilities. Almost all of the women felt that while they have many similarities with women in general, women without disabilities still do not really understand disability issues. Likewise, men with and without disabilities still do not have a deep understanding of sexism. About half of the women interviewed were working within the women's movement specifically to make changes in the attitudes of non-disabled women and to increase access to existing networks and services. A small number of women (five) worked almost exclusively with non-disabled women, and either had not or did not want to focus on disability issues. Some had only recently become involved with disability, and others did not want to restrict themselves to a disability focus. In contrast, one woman in a focus group felt that she had spent enough time trying to work with mainstream groups and now puts all of her energy into working with people with disabilities.

Almost all of the women (50/52) worked with disability-related groups and tried to raise women's issues within those groups. Some women noted that some organizations are reluctant to focus on women's issues because they are perceived to be exclusionary rather than for the benefit of all people with disabilities. Some women experience "internalized oppression" and do not want to focus on women's issues.

2.2 "Personal Empowerment Strategies Used to Deal with Barriers"

There was a high level of consistency among women with disabilities in their suggestions for personal empowerment strategies. When asked about becoming a leader, or about suggestions for newly disabled women, many women spoke about the "inner self." Many comments were made about "having a dream and going for it," "setting your sights high, even if you miss," "getting your own personal power," "having confidence and self-
esteem," and other suggestions involving internal personal strength. One participant offered this perspective:

"I think there are an awful lot of women with disabilities that just don't feel powerful at all, and they're just so bogged down with how to deal with their lives, they don't see how powerful they are.... Once we all get together and know that we're powerful, there is nothing going to get in our way."

For many of the women, the conviction that one can survive and thrive made all the difference. Although this attitude appears to focus on the woman herself rather than societal factors, almost all of the women who made these suggestions indicated that someone else had believed in them first before they had believed in themselves. A parent, friend, teacher, lover or role model who made a difference in their growth process was given credit for having shown these disabled women how to gain their self-confidence and pride. One young disabled woman commented that just meeting disabled adults taught her "what life with a disability could be about... the possibilities."

One woman from the United States who is now in the position to be this sort of role model to other women with disabilities said that when she meets a woman who has recently been diagnosed with a similar physical disability, she supports them:

"I try to share with them experiences, acknowledge where they're coming from and sort of let them know that it's not the end of the world to have acquired a disability. Maybe showing them ways of doing things that they hadn't thought of; letting them know that they're still women, that they're still worth loving, and living and being. That being disabled doesn't take that away from a person."

"Affirmations" are a very specific strategy that came up more than 20 times in the interviews and focus groups. Some women suggested using verbal "self-talk," and others suggested writing in journals or posting notes in the house. Another woman suggested having friends say positive things. From some of the women in developing countries, faith, confidence and will-power were seen as valuable to leadership and survival: these women advised "never give up," "keep going and keep trying," "be assertive," and "believe that you can do it and you will." A woman from Mexico cited Laura Liswood's speech about women political leaders. She said:
"You first must be able to visualize yourself and then it can become possible. Maybe I am too old now, but I believe, yes, I could be President of the Republic (of Mexico)."

In a similar way, believing in yourself means not believing society's images. One woman felt that what had empowered her was an ability to reject the limits imposed by others:

"I have said 'no' when people have said you can only go this far. If that could be packaged I'd share it with others."

It may seem surprising that so many of the women's strategies for empowerment are internal and not based on structural issues. Yet perhaps this should not be surprising, since women have been powerful advocates of using personal power for political purposes, and in many cases have to start by addressing their own needs in order to work for social change purposes.

The women participating in the Forum all expressed a great deal of passion, and made many positive and optimistic suggestions. The data clearly shows that these women are not unaware of the social forces working against them. Rather, they are conscious of these forces and fighting for equality despite the structural injustices.

Sexism, ablism, and other forms of oppression can be very divisive of movements for social change. Women at the Forum repeatedly called for increased unity and solidarity across disability types, across race and class backgrounds, across national borders, and across issue topics. Many women felt that "together we are stronger," "united we can win," or "we are more successful when we are on common ground." This was especially true when discussing the differences between disabled men and women, as well as between women with and without disabilities. Women commented on in-fighting in the disability community, discrimination against "less appealing disabilities," and conflict within the women's community. The strategies for overcoming barriers included working across differences and trying to unite women and men who share common interests.

However, not all women agreed with these suggestions. Some felt that women with disabilities should concentrate on issues of specific importance to them and should let the men work on their own issues themselves. Some women expressed frustration that they
had "tried enough" to teach non-disabled people about disability issues, and now focus almost exclusively on working within the disability community. Women of various ages, with differing life experiences, and from different countries expressed these "minority" views. One woman who was Deaf suggested that there are times when Deaf women need to be with other Deaf women only, and not be required to communicate with hearing women. She recognized, however, that there are times when it is important to come together across differences, saying:

"The difficulty is in accepting our differences, and knowing when to say, 'we need to be different and separate.'"

While issues of racism and discrimination experienced by women of color were not centrally located in this data, these issues were alluded to in other contexts. When women spoke of economic barriers, lack of education, or violence, they talked about double and triple jeopardy resulting from being a member of several minority groups. Women of color from North America were not well represented in the sample; in order to draw valid conclusions, further research must be conducted with this population. For Forum participants from Latin America and Africa, the major issues were economic and class oriented rather than ethnically defined. This is to say, women from these geographic regions expressed issues of ethnicity and culture in terms of class and access to resources.

**Research Objective 3:** To explore and address leadership issues and related training needs for women with disabilities, using the data collected as a baseline.

### 3.1 Leadership for Individuals and Change Strategies for Groups

When asked if they considered themselves to be leaders, all women in focus groups replied "yes," with the exception of two who said they were aspiring leaders, or leaders in training. Both of these women had previously attended the MIUSA training in Oregon. When asked to suggest traits, skills, or important attributes that leaders needed to have, women at the Forum offered a wide range of responses. The most frequently cited skills for leaders fell into the categories of:
• communication;
• technical skills; and
• teaching.

Half of the women mentioned the importance of being a good listener, being able to communicate well in writing, and being able to make speeches and articulate ideas. Technical skills necessary for effective leadership include the ability to write grant proposals, manage an organization, use a computer, and understand other specific topics in technology. Finally, women felt that leaders need to possess teaching skills in order to pass their skills on to others, to mentor and nurture younger women, and to transfer knowledge to large numbers of people and make that knowledge accessible. These leadership skills tie to the area of peer support and role models which will be discussed in section 3.2 below.

The end-of-Forum evaluations asked women what activities they were engaged in. A large number of women reported that they work in organizations and coalitions to increase awareness and implement policy changes. In addition, many women provide direct services to assist disabled women at the local level. In interviews, women were asked what they do to bring about change in the area of their work, and to identify what strategies are useful to support leaders and encourage networking. From their diverse set of answers to these questions, the women’s most frequently cited strategies fell into the categories of:
• media;
• legislation; and
• education/awareness.

Media

A large number of women spoke of using mass media, including newspapers, TV, radio and the internet to spread information and to implement social change. A focus group on communications and media also explored the issue of using media as a tool for social change. Some barriers in this area include misconceptions, the dominance of white able-bodied men in positions of power, and issues of access to information. Media promotion
was a strategy suggested for publicizing many issues including parenting, preventing violence, and employment of people with disabilities.

Legislation

Another large group of women mentioned the importance of influencing legislation and lobbying for change. Several of these women were politically active in parliamentary or political groups, or were members of interest groups that make proposals to the government. Another sub-set of women mentioned education about and enforcement of existing laws, and the training of legal authorities to effect change. Several of the suggestions revolved around UN documents, the implementation of the Americans with Disabilities Act, and basic human rights agreements throughout the world. Many women felt that getting national and international recognition for the basic rights of disabled women is essential to social change.

Education/Awareness

Educating for social change was the broadest category identified. Most women felt that, other than poverty, the biggest barrier is in current public attitudes towards disability, and their suggested strategies largely revolved around awareness of and education about disability issues. One European woman summarized the problems in education, employment and health care this way:

"I don't think we would be denied all these things if there was not a lot of these terrible, very deeply entrenched discriminating ideas in people's minds."

Many Forum participants are already involved in a variety of education efforts: some women make presentations in schools or rehabilitation hospitals, while some women in developing countries work with parents of disabled children and others work with non-disability related development agencies and international groups to increase awareness. Many of the women suggested that "legislation cannot change attitudes" and that education and personal contact are positive means to achieving social change.
Many women tied their leadership skills to the social change strategies. They felt that the ability to teach enables one to educate and change attitudes of the public; communication skills are useful for working with the media; and technical knowledge is essential for working with legislation and the law.

Strategies of increased education and awareness are not limited to non-disabled people. Disabled women also need to become more aware of positive attitudes about living with disabilities. The most frequently mentioned strategy of empowering women and young girls with disabilities was in providing exposure and access to other women with disabilities.

3.2 "We Need to See Each Other and Our Successes"

This section will focus on the issues of role models, peer support and mentoring. These constitute a priority area for several reasons. First, they were suggested as strategies for supporting newly disabled women and young women with disabilities. Second, they arose in the discussion of how to become a leader. Women with disabilities repeatedly referred to the need to prevent isolation and invisibility by exposing children and women to successful disabled women. The importance of having connections with other women with disabilities was raised in almost every interview and focus group, regardless of the topic of discussion. The need to promote mentoring and provide peer support was regarded as a priority in 96.2% of the interviews and focus groups. This figure does not include data from the focus group specifically on peer support and mentoring.

Isolation was identified as a barrier to leadership, and also as a barrier to basic self-esteem. Peer support is particularly important for women who share disabilities. One physically disabled delegate summarized:

"Networking is vital for young women and newly disabled women. Just learning from each others' experience..."

Women with less visible disabilities, such as learning disabilities and mental health disabilities, particularly mentioned their desire to meet other women like themselves. Sharing with people of the same experience and learning from role models or mentors with
more experience were named as critical factors in the development of women with disabilities.

**Peers**

Women with disabilities talked about the need to gather together as women who share common experiences. Some women used the internet as a way to reach across boundaries and barriers to get peer support; others formed small support groups on college campuses. Some women from developing countries created peer groups around issues such as income generation, parenting or literacy. Women from North and South, East and West all commented on the importance of talking with someone who shares similar characteristics. They also said it was beneficial to speak with women who had disabilities that were different from their own, and many women acknowledged how much they had learned from such relationships. The central factor throughout these discussions was that women need to have connections with others with experiences in common, enabling them to share information, to learn what resources exist, and to help minimize feelings of isolation and "otherness."

Younger women, particularly from the United States, voiced this lack of mentoring as a particular problem of mainstreaming. They felt that young girls with disabilities might go through school without meeting a disabled adult and, as a result, might not wish to identify as a disabled woman. Three young women interviewed, who were students in colleges, said they knew women with disabilities who did not want to be part of disabled women's groups or disability groups, and did not identify as being disabled. One of the women interviewed said she had felt this way herself, until she met more disabled women and read material about disability rights and feminism. A middle-aged woman who had a mild disability as a child agrees:

"I feel a little bit guilty about this: that when I was young, I was mainstreamed so much that I did not want to associate with other people with disabilities. I really was terribly uncomfortable with it. Now I identify strongly as a disabled woman and want other girls and women to be able to also."
Role Models

Women of all ages wanted more visible role models. They want to be able to look to models for their own success, and be able to say "If she can do that, so can I!" They also want more successful disabled women to provide models for the general public, so that such accomplishments will not generate surprise or inspiration, but so that people will be impressed with their achievements as women, as members of society, and as disabled people. Many women considered the speakers at the conference to be role models, and many women interviewed provided examples of well-known women with disabilities who had made a difference in their lives. One American woman commented that the blind woman who was a Member of Parliament in an African country had influenced her to set her own sights on political office. Women interviewed at the Forum were receiving significant exposure to highly accomplished women with disabilities. This had a large impact on them and they stated very clearly that they want more exposure to such examples. One woman suggested creating a multi-media show for girls with disabilities to show the history, experiences, lives and achievements of women with disabilities.

Perhaps the strongest (but not most frequent) call for role models came from minority and marginalized women. Women with developmental disabilities, Latina women and African American women were among those who spoke most passionately about their need to "see themselves," and to have role models or examples that enable them to believe that it is possible to succeed. Although many women in the interviews were able to identify influential women, a large number said they did not have role models but wished that they did. A small minority said that they currently act as role models to younger women, despite the fact that they themselves had not had role models available while they were growing up.

Mentoring

This is a very specific form of support that involves one leader with experience working one-on-one with an aspiring leader or person with less experience. This mentor-mentee relationship is often sustained over a long period of time and is usually connected to career
development or occupational choices. For women with disabilities, particularly women in academic and professional fields, there is a sincere desire to have more formal and informal mentoring. Mentoring can also be a way of learning about ways to live as a woman with a disability. One woman who kept her disability a secret finally found the "shame to be draining;" when she did acknowledge her disability she reached out to other recently diagnosed people to support them. Another woman spoke of "giving back" and being a mentor to younger women with disabilities.

Both younger and older women called for more mentoring. One of the biggest concerns was that the knowledge and skills developed by women with disabilities is not being passed down to the next generation. An older woman in a professional position from the United States said:

"It's harder to lead when you think that you're doing it alone and that you are the only one meeting those challenges. These kinds of workshops where you meet other people who are doing the same things in other countries are very helpful, very empowering."

This sort of knowledge about life as a disabled woman can not be found in textbooks or seen on television, so it needs to be communicated personally. Many women also mentioned the need to develop specific skills in areas such as disability rights, accessibility, technology, writing, budgeting, and public speaking. Women felt that while training programs should exist, many of these skills are best developed through the extended intensive contact that mentoring provides. Women from developing countries did not use the word "mentoring," and a few of the Spanish speakers had trouble with translation of this word; however, they did recognize the need for established leaders to work directly with emerging leaders in order to train them for future roles.

In a focus group on communication, a woman from the United States used the comments of a Forum speaker to make her point:

"Laura Liswood, the filmmaker, said 'change moves from the unthinkable, to the impossible, to the inevitable. ' What you couldn't even conceptualize becomes inevitable. We have to see our lives this way, we have to imagine what we think is impossible and then find the path to make it real."
Women noted that the path is neither clearly marked nor always accessible, so we need to fight to establish our chosen path every step of the way.

*What are the training needs of women with disabilities?*

There are two categories of needs, listed here in descending order of frequency with which they were mentioned. The first list is of materials that women said they need (from most to least important); the second list shows specific skills training they want. These lists combine responses given in interviews, focus groups, evaluations and workshops.

**Materials:**

- information on gender issues (particularly reproduction, violence, and parenting) that includes the perspectives of women with disabilities;
- books written by disabled women;
- lists of names and addresses, phone numbers, services, interests of women with disabilities from the conference and other networks;
- accessible written or taped materials about disability and/or women;
- books with women with disabilities in prominent roles;
- courses, distance education, and syllabi about women with disabilities;
- web sites and internet accessible materials about women with disabilities;
- technical equipment (such as computers, modems, printers), and disability related devices (such as tables that adjust, screen readers, braillers, and tape recorders).

**Skills training in:**

- writing proposals, writing budgets, developing project designs;
- cross-disability sensitivity, accessibility issues, and equipment;
- fundraising, money management, and accounting;
- public speaking, writing media releases, producing newsletters/videos/radio programs, and effective use of mainstream media;
- languages, basic literacy, and advanced writing skills;
- how to apply specific techniques for doing research, lobbying and education;
- use of technology, computers, internet and equipment;
- working with groups, counseling and personal relationships;
- training design, and implementing community development projects;
• overcoming internal conflicts within organizations.

**Research Objective 4: To identify approaches and existing barriers to networking for women with disabilities and use this information as a basis for ongoing communication and tracking of networking activities.**

### 4.1 What is the System of Networking Like Now?

Isolation was named as a major barrier to networking, and peer support as a strategy for removing this barrier. Many women also named the problem of information gathering, or the absence of information, as a barrier. This was particularly true for women with low incidence disabilities, and women in rural areas or developing countries. In interviews and evaluations, women identified lack of financial resources, technical knowledge, equipment and staff time as additional barriers to networking. One of the suggested strategies was getting in touch with other organizations that might have more information, more resources, or more contacts. Women know that they are not alone if they can reach out and access other women who will share their resources and information.

The internet is one resource that can connect people to each other, but only a small minority of the world's population has access to it. The research done in this project demonstrated that a small number of women are using the internet for networking. Of sixty-one women who answered the question about electronic mail, 37.7% had no access to it, and 37.7% used email to reach only 1-20 people a month. Email has the potential to bring people from great distances together on-line and provide access to libraries and sources of information that would not otherwise be possible. Despite the economic and technical barriers that women with disabilities face in getting a computer and using the internet, email can be a positive strategy to build networks between disability organizations as well as to promote communication between individual women with disabilities.

For organizations to have contact with women, they need to have a method of direct communication. The most common methods currently in use are by mail, newsletter and telephone. Some groups use regular mail to send notices or newsletters, others have a system of phoning the membership to alert them to particular issues. An incoming
telephone line can be accessed by interested women to obtain information from the organization. Of the 63 women who answered the question about use of mail and phone for networking, 13% said they reached between 101 and 500 women per month using the telephone, and 11% reached between 101 and 500 women per month using mail and newsletters.

Many of the women who participated in the interviews and focus groups are actively involved in more than one group. Some work with both disability and women's organizations; others work specifically with groups of disabled women. One of the strategies for networking is working in coalition. By sitting on advisory boards with other women, or by contacting other organizations, women can reach more people. Responses from the Forum evaluation revealed that 21% of respondents were able to reach between 101 and 500 women through organizational and committee contacts over a period of a year. Fourteen percent were able to reach over 5,000 women through this method. The only method that reached more people per year was the mass media; 17% of the women responding used mass media to reach more than 5,000 people a year. Although organizations using mass media reach a larger number of people, they often are able to convey only a very general promotional or educational message.

For networking to be effective, it must create a two-way exchange of information. This exchange empowers both organizations and people. Networking has both quantitative and qualitative components. The quantitative aspect of networking, based on numbers the women provided, was the size of the network that women had developed using various means of communication. The qualitative component of networking concerns the effectiveness, or outcomes, of the networking. Women with disabilities wanted more networking, with better and more consistent communication strategies.

Although some women did not understand the question about networking on the end of Forum evaluation, the women who did answer gave us a baseline about the level of networking among them. We should compare this baseline with data collected in the future to see if the network has expanded or changed. The data collected about the size of the network does not provide information about the effectiveness of networking methods. This
is another topic that should be pursued in future research. Since women prioritized the education of the public, the empowerment of younger women with disabilities, employment, violence prevention, and family issues, research should be undertaken to examine the impact of networking strategies on the status of these topics.

In evaluation forms, as well as in interviews and focus groups, women indicated that they want more conferences like this Forum, where they can meet other women leaders face to face. Moreover, women also want to be able to communicate in the time between events of this sort. Many women suggested distributing a list of delegates with names and addresses. While Forum organizers provided such a list before the end of the week, many women wanted a more detailed and organized database with references to skills, interest areas, and services. A database of this sort would provide a valuable resource tool; for example, a woman developing parenting education classes for blind women in one country might be able to locate and connect with a woman who has skills or experience with a similar project in another country.

4.2 "We Need a Unified Movement"

This section examines the issues of working and building alliances with women without disabilities, with men with disabilities, and of working in a cross-disability environment, as well as the suggestions women had for such situations. To reduce isolation, increase opportunities, and develop leadership, women with disabilities must be successful in their own organizations and also learn to work with other groups effectively. When asked how they network and cooperate with other organizations, women often responded that they are members or volunteers with these other groups. Sometimes women from different organizations shared financial resources or space, but only saw each other at meetings or public events.

Responses to questions about working with men with disabilities were mixed. About half of the women interviewed (25/52) felt they had no problem working with men; slightly more than half (27/52) said they had experienced some difficulties. The women generally worked with men on disability related topics that were of interest to both men and women.
Often, women stated feeling more conflict or discomfort when working with men on issues that were particularly important to women. In fact, one woman felt quite comfortable focusing solely on women's issues and leaving men's issues to men.

Women generally had more positive experiences working with non-disabled women than with disabled men. However, 25/52 women mentioned that they spend most of their time in mainstream organizations or working on issues that affect all women, with an emphasis on disability issues that are not specific to disabled women.

These women also noted that they usually need to educate non-disabled women colleagues about their specific needs, such as how to make meetings accessible, in addition to advocating for the general needs of disabled women for services. For example, one woman from Latin America said:

"I first have to explain that I can't read the print they give me, so it needs to be read aloud or put on tape. Only after I deal with all the access to the meeting can I raise the issues of disabled women to services or programs for women."

To ensure that social change will take place, women with disabilities must develop ways to work with non-disabled women and with disabled men. In addition, we need to work on issues specific to disabled women, including recognizing and appreciating the diversity of disabled women within our groups.

A few women talked about conflict within disability groups, and the challenges of working in a cross-disability environment. Half of the women interviewed said they found it difficult to work with women whose disabilities were different from their own. This is mainly due to lack of knowledge or access. Women in developing countries, where only one group is available to serve all people with disabilities, were most likely to report that their groups were cross disability. Some women spoke of educating themselves about issues of other disabled women, and others talked about the need to slow down and accommodate women with disabilities within organizational processes. The strategies offered by women with disabilities interviewed, and by the men in the focus group, are also applicable to working in cross disability settings.
Suggested strategies for working together

- Build on common ground, shared values and goals, respect for differences.
- Meet in shared locations, learn to exchange resources so that all groups benefit from the relationship.
- Learn about each other, educate each other, and adjust individual and group attitudes.
- Share information, be open with knowledge, and support other groups in their goals.
- Act as role models and mentors to each other across differences in gender and disability.
- Allow space and time for activities for disabled women only.
- Form alliances with other marginalized groups, including racial and linguistic minorities, as well as with movements seeking social justice, such as groups supporting gay, lesbian and bisexual rights, labor rights, civil rights, environmental protection, and peace.

Research Objective 5: To provide basic information to Forum participants so they can begin or enhance research efforts in their own countries.

One of the purposes for including detail on the research methods used in developing this report is so that other women can use similar methods to conduct research. The appendices of this document include all the scripts that were used, the evaluation forms and consent forms, and a brief explanation of how to facilitate focus groups. A reading list of materials (in English) is also included to help women get started collecting data relevant to the needs of their own country or region.

Several women who participated in interviews and focus groups were students or graduate students pursuing their own interests in disability research. All women are encouraged to further their education and to consider research as a career option.

VII. Workshop and Focus Group Reports by Topic

Workshop on Disability Studies: Research Priorities and Barriers

Discussion Summary
Women with disabilities who are also members of an ethnic minority can choose to analyze their issues primarily on the basis of either ethnicity or disability. There was discussion around using a purely ethnic minority model versus comparing or integrating that theory with disability studies perspectives. Women also commented on issues of using cross cultural and cultural studies model for diversity in American colleges, and the resistance to including disability status within diversity programs.

Participants raised the problem of getting funding to do research, and how to convince the government to give money when they do not even recognize the situation of the disability population. A woman stated that in developing countries, research is still conducted primarily from the medical perspective on the etiology and course of "disease," rather than examining how our lives are affected by the experience of disability.

Barriers to conducting research:

- Segregation of disabled people and issues of disabled people;
- Lack of funding to support research;
- Lack of financial resources and information on how to get funding;
- Disability not seen as a valid topic;
- Resistance to doing research for fear it would expose needs- and become costly and publicly embarrassing;
- Lack of access to existing information about disability studies;
- Lack of reliable information about disability, disability research;
- Lack of qualified and supportive disabled people and researchers;
- Communication barriers for Deaf people and researchers;
- Leadership and role models lacking for Deaf community;
- Lack of information resources to conduct research;
- Difficulty in actually collecting the data, finding participants, giving them access and identifying people.

Some suggested resources and strategies included:

- Read the journals and existing material in various disciplines and write your own criticism;
• Work with other groups doing current research to ensure your questions are asked and access is provided to the data collection;

• Talk to funders, use existing data via the internet and the library to support your needs and build coalitions with international groups;

• Read and use results from the Forum research to develop your own research agenda, research and action to meet your needs;

• Bring disability perspective to the sciences as well as the humanities, and ensure that a civil rights/social model is used to understand our situation and needs;

• Understand that disability issues can be incorporated into reproduction, employment, health, parenting, awareness and almost all women's studies or cultural studies.

Priorities for research as suggested by participants

• Create a developmental theory from a disability perspective (like Erikson's from birth to death but from our point of view).

• Learn how to find disabled women participants for research, get them to participate, provide them with access.

• Investigate issues of caregivers and family members with disabilities and their needs, including respite care and stress.

• Examine violence against women of many types: caregiver violence, domestic violence, sexual/physical abuse, institutional abuse, etc. relationship between abuse and disability and gender.

• Participate in health care partnerships with professionals and caregivers.

• Work towards having a standardized sign language and communication in developing countries.

• Improve access to literacy and education for deaf people.

• Improve parenting and reproductive health education for deaf children and adults.

• Examine factors associated with becoming or not becoming an ally of the disability rights movement.

• Investigate factors for successful employment.

• Identify the bias or the current philosophy in existing research.

Focus Group on Peer Support and Mentoring

There were three women participants and a facilitator. The countries represented were Costa Rica, the United States and Bermuda.
Discussion Summary

Leaders in the disability movement need to be able to work in groups, to facilitate groups, and to work with people individually. In order to achieve systems change, leaders also need to be able to work with the government and larger organizations. Communication skills are vital in order to convey messages clearly and forcefully. Activism is important whether it consists of writing letters, demonstrating, or taking other initiatives to make change happen.

Women in this focus group identified the need for financial resources and economic security for disabled people as part of the struggle. As is obvious, organizations need funding to provide services, and individuals need money to live. One of the priorities then is creation of income-generating projects so that disabled women develop the resources for self-support.

At the individual level, women need to have self-esteem and believe in themselves first, and then need to develop social skills to work with other women. Personal growth goals and specific strategies for survival are priorities for disabled women. As one woman stated:

"We first have to unlearn the negative messages and then support each other as women."

Families were considered critical in how women form their self-image, and it was recognized that each individual woman has her own unique experience. The woman from Costa Rica worked with both parents of disabled children and disabled mothers to ensure that children and mothers have access to information and services. The women stated that support networks and peer contact are essential for women to develop confidence and positive images of themselves.

Women spoke about the need to be inclusive around all the different disabilities, races, cultures and age groups. A basic requirement is to work within each community to be inclusive and provide access to services. A lot of the logistics around access take a long time and financial resources. One barrier noted was a resistance to coming together as
disabled people because of the pressure to integrate and be part of mainstream society. Another woman noted that they were told by men that they did not need to have a separate women’s group. A third woman described the peer support of people who live together in a group home who have naturally come together to support each other.

There is a felt need for more one-on-one mentoring and services that are directed at improving the skills of individual women and girls with disabilities. Some programs designed for students or youth could be adapted to meet the needs of women with disabilities, and some programs for women in general could be made accessible for all disabled women.

Recommendations

- Eradicate sexism and discrimination on the basis of disability, particularly the attitudes of non-disabled people towards women with disabilities.
- Provide families with support so that they meet disabled adults, and so that disabled children can have older role models.
- Develop more networking opportunities for women with disabilities to meet peers and mentors, and to use these to support their leadership and personal needs.

Focus Groups on Education and International Development (Combined)

Eighteen women and one facilitator participated in this group. Six other women participated in a separate group since the room became full. The large group included women from Canada, the United States, Zambia, Panama, Great Britain, Switzerland, Yugoslavia, Russia and Indonesia. The smaller group included women from Korea, the Philippines and El Salvador. In addition, a group of three French-speaking women from West Africa were interviewed.

Discussion Summary

Leadership requires a willingness to take risks, to be a pioneer and to speak to people who know nothing about the issues, to spend time educating people and to be a lone voice in the crowd. Leaders need to have good networking and communication skills, and to be able to get to know people and get messages across to the public and to organizations. Leaders
need to have a vision, to identify their goals clearly, and then have the ability to reach their goals. In many countries, disabled leaders need to have basic management skills, and learn how to write project proposals and administer programs to meet their goals.

Education is very difficult to obtain for many children who are kept at home in developing countries. It is critical that communication access be available so that people with communication impairments can learn the curriculum. For example, in some countries there are few hearing aids and no comprehensive sign language. As a result, children who are deaf or hard of hearing do not get an education and cannot learn to read or write, and therefore cannot communicate. There is generally a lack of education for disabled girls who are encouraged to stay home.

Technology can assist in empowering people who are isolated. For example, women with mental health disabilities who have access to the internet have been able to build a national and international network. Although many countries do not have the wiring or the funding for this, the internet is becoming more accessible and can be used for distance learning and gathering information. Education, in a broad sense, is the basis of development- not just school based education but skills and training needed for general development.

Several women were graduate students or trained teachers and were concerned about finding employment in the field of education. There is still serious discrimination against disabled professionals. The resultant lack of role models causes a problem for younger students who are considering their futures and need to envision themselves in various careers. We need more teachers with disabilities in the school system.

Discussions also focused on women's concerns that they will not be able to marry or find a good job, and that they will remain dependent on family. Education is seen as a way to be more independent. Even some women with a college education are still not able to get jobs.

Vocational rehabilitation is seen as being gender biased in that women are steered towards fewer and more feminized professions while men are given more options. Funding for education is limited for women if they have demonstrated that they can be "housewives" as
opposed to being trained for professions or blue collar careers. The level of education that is funded is often inadequate. The job market today requires higher degrees and more training to be competitive, but the vocational rehabilitation systems do not usually fund higher degrees. Women acknowledged that many girls do not yet have access to primary and secondary education, but stressed that access is required at all levels to achieve economic equity.

Because of the importance of education, it is critical that development agencies prioritize women with disabilities within all programs. Many programs for development exclude disabled people by omission, and women's programs do not always make services available for disabled women. There are now efforts being made to educate development agencies, to tell them that disabled women are part of the target population and not a special population.

For development, both in United States and other countries, organizations need to develop income generating projects so they are not dependent on government assistance. Because of the funding relationship, it is also a concern that organizations remain advocates and not servants of the government. There need to be more creative ways to fund our projects so that we can do our work without strings attached. Women thought it was extremely important to have exchange of expertise and knowledge so that countries can learn from each other, but to also see unique situations that are based on cultural and historical experience.

Peer support is an important way to develop skills because we can learn from each other's challenges, successes and failures. Lack of role models and lack of mentoring has been a problem for women in the United States. In disability organizations and in women's non-governmental organizations, there are few disabled women leaders. There is concern that most of the leaders are men or non-disabled women.

Recommendations

- Ensure that all development agencies budget for disability related services and provide access for disabled participants in their programs.
• Provide universal and free education for disabled girls.
• Expand vocational options for girls and women with disabilities by funding higher education.
• Hire more teachers with disabilities in the school system, particularly women.
• Develop training in leadership and management skills for women with disabilities to improve effectiveness in advocating for their rights as disabled people and women.
• Organize ways to bring together women with disabilities to support each other and also to take part in women's and disability organizations.
• Respect cultural differences but also prevent human rights violations.
• Encourage international and inter-regional exchanges for training and technology transfer.

Focus Group on Employment and Economic Development

The group had eight participants and a facilitator. The countries represented included the United States, Russia, England and one other unidentified country.

Discussion Summary

This focus group started out speaking about the career development and employment options for women with disabilities, but soon focused on entrepreneurship and income generating projects. Despite the fact that many women still want traditional jobs, with a basic salary, regular work hours and benefits, many women considered self-employment and cooperative or group income generating projects to be a positive solution to current barriers to employment.

Discrimination is still commonplace in hiring practices, both against women and against disabled people. Some women felt it has gotten worse, while others see some progress. One woman noted that in educational careers women have a good chance of being teachers, but that most of the senior administrative jobs are taken by men. There are still additional barriers for women with disabilities even in fields dominated by women. Women noted that unemployment is highest in the United States among women of color with disabilities.

Examples of successful businesses were discussed and the group suggested that women need a plan, or an understanding of the factors which contribute to successful businesses, to
avoid failure in their own businesses. Some women knew of mentorship or training programs for young people or entrepreneurs that could be adapted to suit the needs of women with disabilities. The woman from Russia noted that an exchange project and collaboration with an American organization, World Institute on Disability, had helped them to develop their business plans and become more economically self-sustaining.

The key to the income producing projects seems to be finding a market where there is a profit to be made. In addition to using the skills of disabled people or training them to use new skills, there are opportunities within the existing market to buy and sell or deliver services differently in a way that makes money for the organization. Selling clothes, pottery or food may be examples of income generating programs that provide both employment, income and experience for disabled people.

Women also spoke about discrimination at the banks and the inability to get loans. There was an example given of a micro-loan program offering revolving short term loans for small businesses. Women mentioned the income support program for self sufficiency in the United States which helps people establish a business or become employed. Women mentioned that computers and the internet are making home based businesses more feasible for some women, and that technology, while expensive, can be empowering.

Recommendations

- Lobby for tax credits or tax based system of encouraging employers to hire disabled people; give disabled people tax benefits for employment related expenses.
- Train business people, employers and educators about the rights and abilities of people with disabilities.
- Eliminate barriers to transportation and buildings so that more people with disabilities can work in the mainstream.
- Create a national and international awareness campaign to promote the employment of people with disabilities, including the businesses run by disabled people.
- Develop mentorship programs and training so that women with disabilities can learn how to start their own businesses, and network with other women owners.
- Seek out micro-loan and sustainable grants for income generating projects.
- Identify what works and what doesn't for small business or entrepreneurship.
• Guarantee jobs for disabled students graduating from professional programs so that teachers, doctors, counselors or other professionals with disabilities will be given jobs and can act as role models and support to disabled consumers.

Focus Group on Violence Against Women with Disabilities

There were nine people in the focus group and two facilitators. Countries represented included Sweden, Australia, United States, Zimbabwe, Uganda, Mexico, and Canada.

Discussion Summary

Leadership requires many skills and resources, including information and research. This information can be used as a tool for lobbying and teaching service providers. On the more personal level, women also need a network and support system for survivors of sexual abuse and violence. At the individual level, women need to believe in themselves and to develop strengths, and then share this with other women in a sense of sisterhood.

Legal support is needed to help women going through the court system, and training is needed to be culturally sensitive to the issues surrounding rape and domestic violence for consumers in different countries. Women suggested that perhaps legal and police officials could be specially trained so that some advisors would know how to deal with women with disabilities in appropriate ways.

One of the major issues raised was the economic condition of poverty and the resulting frustration which leads to violence in poor countries. The financial needs of the community must be addressed, and information should be widely disseminated to the public about the link between violence and poverty. Public attention to the issue of violence against disabled women needs to be done in a sensitive manner so that disabled women are not further exploited or made more vulnerable.

One strategy for supporting victims is working with women's organizations and disability groups to raise awareness among both populations about the vulnerability and needs for support among disabled women. Using the media for public education and training of service providers will help raise awareness of the needs and issues. Only a small number of countries have succeeded in having disabled women's issues around violence addressed by
women's organizations, but more countries are now beginning to network and educate. In particular, improving accessibility of shelters and refuges for battered women was mentioned. Counseling services that are now available to non-disabled women could also be expanded and offered to all women with disabilities.

A significant difference between disabled and non-disabled women in the area of violence is the physical inability to defend against assaults and/or the inability to disclose the assault. There is a significant problem around girls and women with disabilities being assaulted by fathers or family members but being afraid to speak about it. Even when trying to collect information about the nature of violence, many women do not want to disclose their experiences. Again, it was emphasized that intervention and prevention must take cultural issues into consideration.

Recommendations

- Develop a system to recognize the signs and symptoms of women who are victims so that we can offer support, and so that the doctors will recognize the results of and reactions to violence.
- Produce a video or media campaign to educate women about their rights and how to escape from violent situations, including access for blind and deaf women. Provide a phone number to call for more information.
- Train professional staff such as lawyers, police, doctors, counselors and sexual assault or domestic violence workers to ensure they can meet the needs of women with disabilities. Work with the women's movement to be sure we are part of their agenda.
- Work to secure funding for physical access so that transportation, housing and support services are provided to women with disabilities if they are using the social services related to violence (this might include sign language interpreters, special vans or equipment in shelters).
- Establish a peer support network for and by women with disabilities to give strength to survivors, to develop training and services and to spread awareness about the problem and strategies to solve it.

**Focus Group on Parenting and Health**

This focus group had six participants and a facilitator, including people from the United States, Hong Kong, Zimbabwe and Great Britain.
Discussion Summary

The women all had similar experiences with physicians not knowing very much about pregnancy, child birth and disabilities. Even the women who had adopted children found it frustrating that doctors did not know what to recommend or had uninformed opinions on parenting options. The women had all experienced some resistance from family, professionals or friends to the idea of them being pregnant or having a child. One woman recommended that each woman should seek out a doctor who is supportive and willing to become informed. Although there were many barriers, the women felt most of the barriers were in the attitudes of others and not resultant from their disabilities themselves.

One woman explained that she did the "emotional carrying" of her children because the physical exercise was too straining for her. Another woman talked about how she did educational and emotional caregiving while her husband did more of the physical tasks. The women exchanged ideas on adapting baby and child care techniques.

In terms of division of caregiving, most of the women felt that mothers are usually given more responsibility than men. However, their experiences had been positive in that male partners took on their share of support in the relationships and co-parented. One woman with a non-disabled husband also used neighbors or caregivers to help, partly to ensure that her husband did not do all the physical work. Women were very concerned that there be enough money to support the family. Income and employment were urgent issues, especially relating to providing for the children in tangible ways. One woman suggested that mothers become funded to do home based or income generating businesses as a source of income.

Health and education were two other areas prioritized by the participants within the parenting focus group. The women agreed that these need to be free and universal. The group had many positive experiences with their children and felt that their children were better able to cope with difference because of the experiences of having a disabled parent (or two). One woman shared a story which revealed her non-disabled child had fully expected to get her own wheelchair one day. Another explained about how her children
played with her braces or walked like her yet did not want other children to make fun of how she walked. One woman suggested that all mothers need to "work to be as good in family life as we are in professional lives."

Recommendations

- Establish free, universal education and health care.
- Provide training to all doctors, health educators and midwives about disability.
- Create accessible services for women who are pregnant or parents.
- Teach disabled women how to be parents and teach parents of disabled children about disability.
- Distribute better and more information about being pregnant and having a disability.
- Investigate equipment and ideas for accommodating different disabilities while parenting.

Focus Group on Sexuality and Reproduction

This focus group had only four people including the facilitator. One woman was from Namibia and three were from the United States.

Discussion Summary

Leadership involves taking initiative and having the will to act. The ability to listen and communicate are vital to making groups work and reaching goals.

On a personal level, the issues of sexuality can involve physical discomfort, fatigue and pain as well as the effect of some medications on sexuality. One woman felt that sexuality was not an issue to her because she was not married, and does not plan to marry. One lesbian woman described facing more disability-based discrimination than homophobia because she has very positive self-esteem and supportive community around her sexual orientation.

There seem to be fewer problems of getting into an actual doctor's office than in getting informed health-related services. Some doctors are simply unable to answer questions around medication, long term prognosis or even diagnosis. Women with chronic illnesses
can be a challenge to the medical profession because it is often unclear what is wrong and what can be done. One woman had a supportive, informed doctor who had explained her options around surgery for fibroids and gave her full information and choices on the issue of child bearing.

Issues of attitudes around sexuality were discussed, including the perception that women are not really sexual if they have a disability. One woman suggested that people are still shocked by the thought of a disabled lesbian in a wheelchair. Another woman felt that most men would not be attracted to a disabled woman because of a fear they would have to take care of them. She added that men tend to be intimidated by professional women, and a professional disabled woman might be even less attractive. Some men are also uninterested in women who are not willing to engage in extra-marital sex.

Moral, religious and personal beliefs come into play with sexuality, and women's self-image is heavily influenced by early childhood experiences. When discussing whether or not sexuality is different for women with and without disabilities, the participants agreed that essentially it is the same, but said:

"Because of the messages [disabled women] get, they think they won't be seen as attractive or potential sexual partners, and the very real experience of being rejected is different."

Both women and facilitators discussed strategies of changing attitudes and supporting women as sexual beings. The strongest recommendation was to use the media and to increase the visibility of a variety of disabled women role models in community events, in mainstream women's groups and in disability groups. It was also seen as important to give women a chance to meet each other and discuss their lives and strategies. Too often women are isolated and don't know other women with similar experiences. More education and awareness building about chronic illness and disability, and specifically about sexuality, is needed in all countries because it is still considered such a taboo topic.

Recommendations
• Make accessible information about sexuality and reproductive health available.
• Increase visibility of women in various roles.
• Create more opportunities for women to come together to discuss their issues.
• Encourage media attention and campaigns to increase awareness for the general public and for disabled women.
• Improve education and awareness for medical professionals and educators.
• Work for universal access to buildings and services so we can be active members of society.

Focus Group on Communication and Media

There were six women in this focus group and a facilitator. One woman was from Mexico and the other women were from the United States.

Discussion Summary

Leadership for women with disabilities, as for all women, requires a willingness to assert oneself and to bring together diverse groups and find common ground. Many leadership skills concern building relationships between groups and individuals, as well as basic communication skills. Abilities in raising funds, developing programs and creating messages that can be understood widely are also necessary.

Almost all the women spoke of a turning point in their lives when they "came out" or self-identified as having a disability, realizing that they had rights and that these rights were being violated. The issue for some women was not the visibility of their disability, but their own identification as a person with a disability. One woman said that knowing people who had faith in her and who took the time to show her how to do things made a difference. She explained that most of those people were men, because most of the technical people in the field of communications are men, but some strong women played important roles in sharing their skills and giving her confidence.

Women spoke about the fact that only a small portion of people with disabilities are actually active in disability rights organizations. Accordingly, only a fraction of women with disabilities identify as being disabled. Even strong women leaders who become
disabled sometimes are not willing to become publicly identified with the disability movement. This is based in part on the fears, stereotypes and negative attitudes about disability that are still widely held by society in general as well as by some people with disabilities.

An on-going forum for women with disabilities is needed to provide exposure to the different issues of numerous groups. Work should not be done in isolation. Inclusion is an important part of our development so that all people with disabilities are part of the movement. Access needs must be met to allow us to participate with each other and in the mainstream. Particularly in journalism and media, where power and influence are still primarily held by conservative white men, we need to have opportunities to be represented.

A wide range of media issues need to be further developed. On many fronts, the disabled community and women with disabilities need to be able to communicate effectively with each other and with the public. The group stressed that the use of language is very powerful, as is the way images are used to represent people with disabilities. The women felt that mainstream media should be informed of more positive ways to portray disability, and monitored for negative representations of disabled people.

Role models and mentors seem to be absent from major media organizations, and the women at the Forum could name few professional journalists who were women with disabilities. The lack of women in visible roles on television, on the radio and in print media is a big barrier. More availability of training in technical careers would enable girls and women with disabilities to choose electronics or media careers, and there should be a demand for representation in appropriate roles to reflect the diversity of the community. Such role models would provide positive messages to young girls and women with disabilities, encouraging a greater sense of self-esteem and allowing women with disabilities to see themselves as potential participants in the media industry.

Recommendations

- Increase representation of disabled women in the media; as journalists, actresses, professionals, producers, technicians, etc.
- Develop more mentoring and support for younger women to encourage them to pursue careers in media.
- Provide positive images and stories about disability rights from a cultural perspective that tells our stories.
- Encourage women with disabilities in leadership roles to identify themselves with the movement and support our issues.

**Focus Group on Technology and Universal Design**

There were four women in this focus group, and a facilitator from the United States. All the participants were either deaf or hard of hearing and came from Switzerland, Russia and the United States.

**Discussion Summary**

Leaders were seen to be people who are good at relationships and are able to network. Someone who can express the problems of people and share it at another level could be a leader. Communication and learning how to negotiate the system are part of leadership because you have to be able to interact and deal with various systems and individuals.

Notably, all of the participants interested in technology were deaf or hard of hearing. Issues of technology and universal design do not have a clear gender focus, but the women discussed some technology issues specific to women with disabilities. Primarily, they were concerned with women and girls being discouraged from pursuing technological or scientific careers, or of being afraid of science and math. There are very few role models for girls interested in careers based on science or math; for women with disabilities there are even fewer.

The women agreed that all technology is important for the future, whether or not it is disability related. Women need to be able to deal with changes in technology and learn how to use tools to achieve their goals. Wheelchair building and repair, hearing aids and computers were all given as examples of technology that women with disabilities need to understand. Even email and the internet are tools that will help women to network and access information, go to school and maybe even get a job. Language training on computers was another example of how the technology could benefit women.
Several women thought that attitudes present the main gender bias for women using technology. They pointed out that parents treat disabled girls different than they treat disabled boys, just as non-disabled girls and boys are encouraged in different ways. One woman thought that, as a disabled girl, she was expected to remain dependent; but that if a son had been born deaf then maybe the parents would feel a conflict between expectation of male independence and the expectation of dependency based on disability. Women felt that more responsibility is expected out of women, noting that women often need to prove themselves better than average to succeed while men can get away with being mediocre.

Women brainstormed about the kinds of technologies they wanted and came up with ideas such as videophones, translation devices from signing to speech or signing to text, ways of using the internet for disabled people, accessible captioning for movies, telephone compatible hearing aids and automatic transmission from microphones to hearing aids in conferences and meetings. Universal design needs to take all types of disabilities into consideration. If the principle of universal design is truly implemented, then it should serve both men and women, but sometimes people do not build structures with women in mind.

Recommendations

- Develop more role models and encouragement for girls and women to enter careers in science and technology.
- Improve education on the potential of technology for networking and supporting women.
- Reduce stereotypes and myths around disability and gender.
- Implement more appropriate universal design world wide.
- Develop of technical aids with consumer input to meet consumer needs.
- Increase accommodations for employment and education to enable people with disabilities to work from home, telecommute, and take advantage of distance learning.

**Focus group for Men: Men as Allies to Women in Leadership Roles**

Four men with disabilities and a male focus group leader participated. All were from North America.

**Discussion Summary**
Traditionally, women have been seen as having different management styles than men. Men perceive that women are more inclusive and democratic in management, consider a wider perspective, place less emphasis on hierarchy, and take longer to make decisions. Men thought that men tend to be less verbal and faster decision makers. It was also suggested that men are more abstract in conceptualizing solutions while women are more personal and oriented to interpersonal solutions. The men suggested that men need more training in how to listen and empathize, and that men can benefit from studying how women manage and make decisions. They also felt that men and women could teach each other the different styles in order to have the flexibility and capacity to use both styles.

One of the issues raised was the lack of role models for women developing as leaders. Men felt they could help by making existing leaders more visible. Men also felt that education is the key to leadership for women, and that women need to be trained as leaders throughout the education system, from elementary school through post-secondary. They emphasized the need to be trained within mainstream leadership programs rather than exclusively within disability-oriented training.

The men in the focus group identified that changing men's attitudes is the greatest obstacle toward helping women with disabilities realize their own leadership potential.

Recommendations

- Assist access and support for women in achieving formal education at a professional level.
- Encourage women's access to leadership courses in public schools and communities.
- Create a model of equity in professional fields, using the American Association for the Advancement of Science as an example.
- Men should adopt a philosophy of affirmative action and lobby for it at every opportunity.

VIII. Conclusions and Recommendations

One of the main goals of this research was to create an "Agenda" for research in areas of importance for women with disabilities. There were many opportunities for women to
discuss their issues, and within the context of the research itself, there was a great deal of agreement on what is important. However, the issues themselves were not the only topics noted. Another important factor were the opinions that women with disabilities held about research and about services.

All of the women who suggested research questions or projects for women with disabilities wanted to ensure that women with disabilities would also have access to the results. There was a great deal of cynicism around the use of research to empower women with disabilities. Women made it clear that they wanted to have research that helped them and that was accessible to them. Services and projects for them, including training, also should involve women with disabilities in significant ways. There were many women who felt that women with disabilities should be coordinating and delivering most of the training and doing the research. Other women felt they wanted help from experts who might not have disabilities, but still wanted disabled women to retain control over the process and outcomes.

Some women in interviews and focus groups were not able to formulate a specific research question, but did identify activities that they felt would help improve the lives of women with disabilities. Most of these suggestions have been categorized under training and projects, but some require substantial research to be realized. In every situation, the research could result in materials that could be used to empower women, the public and professionals. In almost every suggested training or service, some research will be needed to create the materials or provide the service. Training, services and research are not mutually exclusive, and should be taken together as mutually supportive parts of a larger goal.

**Identified Research Questions**

The following specific questions emerged from the input of participants at the Forum.
Education

- curriculum development in the area of history of women with disabilities, science and math appropriate for women with disabilities, and literacy;
- learning materials for girls to improve self-esteem and body image, so that they grow up to understand it is okay to have a disability;
- comparative outcomes for boys and girls with disabilities, tracking success from various school models (mainstream and segregated), and looking at success stories or methods that enable girls to continue their education.

Economic Opportunity

- finding key factors in successful entrepreneurship and self-employment;
- learning from other's experiences of "what works" and "what doesn't;"
- evaluations of various income support schemes internationally;
- consumer review of the US social security formula for deductions for earned income, and better income security policies in general;
- research on accommodations, both technical and human resource, that would support women with all types of disabilities in the workforce.

Violence

- ways of identifying victims/survivors by knowing symptoms and signs;
- protocols for legal professionals to support women through the system;
- therapeutic approaches to serving disabled women survivors;
- research about violence-induced disability and post-traumatic stress;
- successful prevention and intervention strategies that can be duplicated.

Health

- more research to look specifically at how being disabled influences risks of other disabilities/conditions, on secondary disabilities and on access to prevention and treatment for cancer and AIDS/HIV;
- research on accessible gynecological services for physically disabled women;
- basic spinal cord research and questions about the experiences of women with spinal cord injuries;
- research on post-traumatic stress and violence related health and disability issues;
- bone marrow and treatment research for people with sickle cell anemia;
• more consumer oriented research on side effects and impact of psychotrophic drugs and other medications on women with disabilities (in particular how they affect sex, reproduction, mental health and mobility).

Families

• information on technical and physical adaptations for parenting with a disability (of particular interest to women from developing countries);
• more research on the needs and abilities of mothers with disabilities;
• research on marriage, long term relationships, same sex relationships and the impact of one or both partners having disabilities;
• research on the bonding between parents and disabled children and the impact of disability on family dynamics;
• research pairing parents of disabled children with disabled women, and using adult peer support for the families and adult role models for the children.

Suggested Training and Services for Women and Girls with Disabilities

These suggestions are drawn from information gathered through all forms of data collection at the Forum, both evaluation and research.

Leadership and Support for Leaders

• make current women role models more visible, and distribute information in many media: posters, books, web, video and audiotapes;
• develop mentoring programs and find connections among women with disabilities to support emerging leaders and existing leadership;
• conduct specific hands-on leadership training at many levels.

Training on:

• being a mentor, running peer support groups and recruiting new women;
• writing proposals and budgets, developing project designs;
• understanding cross-disability sensitivity, accessibility issues and equipment;
• fundraising and money management, accounting;
• public speaking, writing media releases, producing newsletters/videos/radio programs, and effective use of mainstream media;
• applying specific techniques for doing research, lobbying and education;
• educating men about women's issues and women about disability issues;
• working with groups, counseling and personal relationships;
• training design, implementing community development projects;
• overcoming internal conflicts within organizations.

**Education**

• languages, basic literacy, advanced writing skills;
• free, universal education for all girls and women with disabilities;
• more and better physical resources such as ramps, technology, assistants for learning and appropriate equipment relating to disability access;
• distance education options using the internet, television, radio or correspondence, particularly for rural or isolated women;
• understanding and accommodating learning disabilities, mental health disabilities, and girls with developmental disabilities in the education system.

**Economic Empowerment**

• more women-positive job training and vocational rehabilitation that does not "stereotype" women's careers;
• employment opportunities in sciences, math, medicine, education, politics, and all the professional options women want;
• duplication/replication of income generation and micro-loan programs;
• training women to be home based business owners or to run co-operatives;
• vocational training programs and access to options for technical careers.

**Violence**

• models of self defense and prevention strategies appropriate for disabled women;
• crisis centers for and by women with disabilities and better accessibility to all services;
• training for all levels of professionals to learn how to serve disabled women, and also for disabled women and the disability movement to learn about violence issues;
• training and professional standards for personal assistants around the issue of supporting survivors of violence and preventing violence;
• self-esteem, empowerment and mutual support for women before they experience violence, and as survivors to continue to live safely.

**Health**

• more accessible, appropriate information about sexuality, reproduction, bioethics and, in particular, the new reproductive technologies;
• training projects for professionals around sensitivity to disability and working with disabled women;

• physical access for offices, hospitals, examining tables and health promotion activities;

• creation of a disability positive medical experience as well as a financially accessible medical system;

• universally accessible medical services, including prescription drugs, durable medical equipment and services of rehabilitation professionals;

• further education about polio vaccination and other prevention strategies in all countries and better pre-natal education for mothers.

Families

• medical professionals to be better trained to serve pregnant women with disabilities, including giving women more choices in childbirth;

• childcare services to be more accessible for them and their children;

• train women with disabilities to be better parents through education;

• train professionals to support women with disabilities as parents;

• train parents of disabled children to nurture and support their children and give them positive self esteem.

Transportation

• accessible, affordable public transit and parallel transit;

• co-operative or communal transit;

• creating and distributing wheelchairs and other mobility aids.

Housing

• providing more accessible housing for families and singles;

• more universal design of all housing;

• more financial assistance to support independent living and make options for deinstitutionalized people with disabilities.

Technology

• use technology, computers, internet and equipment;

• make more computers and internet access available to the public;

• provide assistive technology and rehabilitation equipment.
Sports

- increase the visibility of women with disabilities in sports;
- provide more opportunities for recreational and athletic participation;
- support women's sports and integrated disability sports for women with disabilities.

Networking

- create and distribute an international database with names and information on contacting women and organizations by interest, country and specialization;
- provide electronic access to literature, training materials and resources through the internet or other accessible media system;
- communicate between women's groups and disability groups through a newsletter or bulletin to increase awareness of disabled women's issues internationally;
- hold regional, national and international events more regularly to involve all levels of women leaders;
- involve more young women and women from marginalized communities, and build coalitions to develop a stronger base;
- provide toll-free telephone access to women for information in various languages, and support rural women in getting information they need;
- participate on many "issue" related committees, organizational boards and conference planning groups to insure that disabled women's voices are heard in our own organizations, disability organizations and women's organizations;
- encourage each member of the network to share their experiences and knowledge with at least one newly disabled or young woman with a disability to bring new women into the network.

Recommendations

- That the original participant list of the International Leadership Forum for Women with Disabilities be expanded and maintained as a database that would be accessible in alternative media for women world wide to access.
- That research proposals on the priority topics be prepared and funded as appropriate through various national and regional mechanisms.
- That a web site and printed equivalent newsletter be created and made available to women's organizations, disability organizations and individuals world wide to focus on priority issues, sharing information, coalition building and leadership development.
- That leadership training programs be established at international, national and regional levels based on needs identified, and learning materials be archived and made accessible to women delivering training.
- That financial assistance mechanisms and/or micro loan systems be developed to support women's initiatives and participation, specifically targeting students, unemployed women and women from developing countries.
IX. Appendices
APPENDIX A: Interviews

Most interviews are audio taped so that they can be transcribed. However, with deaf women, it might be useful to video tape or take notes. If a person has a voice that is difficult to understand on audiotape, hand written notes are also useful. Even if you are audiotaping it is important to take notes in case there is a mechanical failure.

The following is the script we used for the interviews at the Forum. Not every question was asked of every person. Some interviews were very long, and others quite short. You may use this as a starting place to determine questions that might be appropriate to ask women in your community.

A. Start with the general questions about leadership then move to priorities and strategies and perspectives on the specific priority areas.

1. Quick warmup: What country are you from?

2. Describe your disability (ies)

3. Do you identify yourself as a woman with a disability?

B. Are there experiences in your life that were critically important to you becoming a leader?

1. An event, a meeting, a conference, a problem, a course, a mentor?

2. Briefly describe how you came to be a leader.

3. Describe what you think could make a difference to young women and newly disabled women in becoming empowered.

C. Describe some of the goals you have for yourself and women with disabilities in general. What services, training or information would help you and other leaders to achieve your goals?

D. What are the major issues you feel are the most important now? Describe these issues in your own words.
E. Relate the rest of the interview to the issues she identifies as important.

1. If you had a grant/budget so that money was not a problem, what research or activities would you like to do?

2. What programs or policies would you focus on to make a difference for women with disabilities?

3. Why are these so important?

4. To explore topics a bit more, use generic prompts:
   - You mentioned ________, could you tell me more about your experience with this issue and why it is so important to you.
   - For women with disabilities, is ________ (issue) different than for women without disabilities or for men with disabilities? How? Please explain.

F. What are some organizational or networking strategies that women with disabilities use to address the barriers?

1. How are you "making changes?"

2. If you could change just three things within the next 5 years that would improve the lives of women with disabilities, what would those three be?

3. How have you accommodated or dealt with the "cross-disability" issue of having people with a range of disabilities?

4. How have you worked with men with disabilities?

5. How have you worked with women without disabilities?

G. When you leave this conference, what kind of follow up to the training and research would you like to see in this area______? Anything else you want documented before we close?

H. Wrap-up: Thank her for participating, remind her that copies of the final report will be available if she signs up for one or writes later.
APPENDIX B: Focus Group Scripts

The main body of this script is what we expected the focus group facilitators to use but within each topic there were also specific questions relating to the themes of the Forum.

A. Welcome everyone, we will try to keep this under two hours. I know you are tired from the Forum. The organizers of the Forum wanted to take the opportunity of this international gathering to ask questions and collect information from women with disabilities. Your answers will not be attributed to you personally. We will be audio taping the discussion and later transcribing all the focus groups and interviews. Then we will analyze the comments and produce a report which we hope will be useful to you. This focus group will discuss your experiences within the context of the issue of ____________.

B. Let’s start with a general concept of leadership. Can we go around the room and have people give their name and answer these questions:

1. Do you think of yourself as a leader?

2. Name ONE skill you think is important for a leader to have and use. Don’t be afraid to repeat something someone else already said if it is important to you.

C. This focus group is going to touch on some issues of leadership within the context of the topic ....

- international development and developing projects
- communication, media, video, internet
- organizational development
- education literacy
- peer support/mentoring
- sexuality and reproduction (could also touch on health)
- violence (touch on health)
- family life/parenting
- employment/income generation
- technology access, universal design
- men and the issues of women with disabilities
.....then we will ask specific questions about the issues facing women with disabilities in this area. At the end we will look at possible strategies and successes in resolving these issues.

Lastly, we will try to discuss ways to help you as leaders to implement the changes in these areas you feel are important. The discussion will flow from questions I will ask, but you should feel free to speak at any time in response to issues raised by other women as well.

Are there any questions? Does everyone have their communication needs met? translation, interpretation, volume etc?

(BE SURE TO DEAL WITH THESE EARLY- remind people of your own needs: to speak slowly or use voice instead of raising hands, to wait for interpreter, etc.)

D. Many groups want to achieve specific goals of inclusion or equality, but we are struggling with how to do this. What services, training or information would help you as a leader to achieve your goals?

1. How do you think women could best be trained for leadership roles?

2. Are there experiences in your life that were critically important to you becoming a leader? An event, a meeting, a conference, a problem, a course, a mentor? (allow women to discuss their experiences)

3. What are some organizational or networking strategies that women with disabilities use to address the barriers?

4. How are you "making changes?"

E. In the area of ______(communications, education, etc.), we would like to know what you see as the priority issues – both positive factors contributing to success and existing barriers which limit opportunities.

1. What are the specific factors that women with disabilities face which are different from what men with disabilities face?

2. What are the specific factors that women with disabilities face which are different from women who do not have disabilities?

3. What information do you need to know to help women with disabilities progress in the area of ______(communication, education etc)?
4. If you had a grant/budget so that money was not a problem, what research would you like to do?

5. Do you have a success story of achieving a goal you want to share?

F. Then use prompts from each of the various topics

1. Development and Developing Projects
   
   - Are women with disabilities involved in development activities in your country/region?
   
   
   - What have been the successes and the failures in your experience?
   
   - How have you integrated disability issues and accessibility into existing programs or proposals?
   
   - Are women with disabilities able to take advantage of projects that are offered to the general public? To women? To disabled people?
   
   - What are some of the reasons for exclusion?
   
   - Are there development projects or special efforts made to focus on women with disabilities themselves? Describe examples.

2. Communication and Media
   
   - Give some examples of representations of disabled women in the media.
   
   - What actions are being taken to increase our participation and representation in the various media forms, print, radio, TV, books, etc.?
   
   - What level of access do women have to technology, to media, to the internet and computer training?
   
   - How are women with disabilities communicating other women with disabilities? with other women? with other disabled people and organizations in general?
   
   - Are phones/radio/print/alternative formats etc being accessed by women?
• In your country, what are the main barriers to women with disabilities accessing the media and communication strategies?

• What can be done to increase the participation of women with disabilities in communication activities?

3. Organizational Development and Leadership

• What kinds of organizations are you active in? disabled women’s groups? women's groups? disability based groups, cross disability groups, caucuses within these types of groups?

• What strategies are being used to bring disabled women’s issues to the agenda of these organizations?

• How have you been able to raise funds and solicit support for your activities?

• Any suggestions about recruitment of members and volunteers— in particular, women with disabilities?

• Any experience developing coalitions or encouraging allies with other movements?

• What are some of the barriers to women with disabilities developing their own organizations, and/or becoming leaders in existing organizations?

• What strategies can be used to empower disabled women’s groups and women with disabilities individually?

4. Education and Literacy

• How does literacy or illiteracy impact on women with disabilities' opportunities?

• Do women with some disabilities do better or worse? Which disabilities? For example do women who are blind have less access than women who use wheelchairs, or is there any access at all?

• Describe what you see as priority or problem areas facing girls with disabilities who are now in the school systems.

• What are the issues for women with disabilities getting an education or a post-secondary education?

• Are there policies or programs that work? Or should be changed? Describe...
• How can getting an education impact on women with disabilities' leadership potential? her self-esteem? her independence?

• What are some of the strategies to address adult education for the many women who are over school age?

5. Peer Support and Mentoring

• Do you have a peer support program or individual mentoring program for women with disabilities? Describe.

• What are the "ideal" conditions for making such a program work?

• How can we ensure that women with disabilities, and girls growing up with disabilities, have access to other women to support them?

• What are some of the barriers making it difficult to develop mentoring or peer support? Do you use independent living centers?

• Is there a central location for gathering?

• Is isolation or distance a problem? Are there other options: telephone, writing, internet, meetings?

• What are some of the advantages or benefits of having peer support?

• For leaders with disabilities, what qualities or skills makes a good mentor?

• What skills can young women and women of all ages learn from other women with disabilities, to empower themselves?

• What are some successful strategies to implement programs or informal systems of peer support and mentoring?

6. Sexuality and Reproduction (and health)

• As women with disabilities, what are some of the key issues around sexuality for you?

• What problems do you encounter gaining access to information or services relating to your sexuality?

• Are there programs or successes you want to share about women with disabilities and sexuality? Books, media, courses, groups, events, conferences, any ideas at all relating to this topic?

• What are some of the key issues related to reproduction, which is sometimes, but not always separated from sexuality?
• What problems do you encounter gaining access to reproductive information, family planning, medical services, support etc?

• What examples are there of positive and useful services that are accessible and have made a difference for women with disabilities?

• What specific needs do women with disabilities have around reproduction that are not being addressed by the current health system? (Note here: it may be possible to discuss genetics, and the issue of abortion but I think it's best to see where the discussion takes you first- so be prepared to discuss it if there is a question or comment raised about it- i.e. Is there differential access to abortion, or pressure to have an abortion when the mother has a genetic or even non genetic disability, etc.)

• What kinds of organizing strategies or actions can women with disabilities undertake to address some of these issues you have mentioned?

7. Violence (health)

• Do you feel that violence against women is being adequately addressed within the organizations you are involved with?

• What are some of the major contributing factors to violence against women with disabilities in your opinions?

• What can be done to prevent violence?

• What can be done to intervene during violence, to both stop it and to support victims?

• What kind of services and action are needed to support survivors of violence in the days, months or years after their assaults?

• What are some of the secondary disability and health issues that affect women who are victims of violence, or survivors of abuse?

• What are the primary access barriers for women with disabilities?

• What systemic changes are needed within justice and legal systems?

• What services can women with disabilities access now?

• What can the health care/medical system do to respond better to women with disabilities needs before and after they are assaulted?

• How can we improve access to these and other services in the future?

8. Parenting/Family
- In your country or region, how are women with disabilities treated by medical professionals when seeking health care around parenting and pregnancy?

- What are the major health needs for women with disabilities?

- Are women with disabilities the primary care givers in families? What are the strategies that work to address these needs in your experience?

- For both children and adults with disabilities, what supports are there for family life development, including issues of violence, adoption and marriage?

- What are the problems or barriers to getting support for families with members who have disabilities?

- From your experience how important is family to women with disabilities?

- What services or training would help women with disabilities to increase their empowerment and independence in families?

9. Employment/ Income-generating Projects

- Are women with disabilities actively involved in work force or economic development projects? as leaders? as participants?

- Are there successes or failures for income generation that are useful for women with disabilities to learn about?

- What are the key factors which make a project successful- for a coop, a workshop, or any type of income generation program?

- Why are women with disabilities not more fully integrated into the paid work force?

- What are the structural barriers to participation? Disincentives...

- Are employment programs designed for disabled people accessible and supportive of the needs of women with disabilities?

- Are employment programs designed for women accessible to and supportive of the needs of women with disabilities?

- What kinds of supports do women with disabilities need that are different from non-disabled women, or from disabled men?

- What strategies can be used to increase employment opportunities and reduce barriers to employment for disabled women?
10. Technology Access and Universal Design

- What are some of the priority issues facing women with disabilities as they relate to technology and universal design?

- Describe any specific barriers that affect women with disabilities as opposed to men with disabilities, or women without disabilities.

- Describe any successes or projects that you feel have addressed technology and access issues for women with disabilities. How can other women with disabilities also achieve these goals?

- In terms of accessibility, and designing for accessibility, what are some important factors for women with disabilities that will increase access?

- In both high tech and low tech environments, women with disabilities can be included or excluded in the use of technology. What strategies can be used to encourage and support women with disabilities in accessing technology, including computers, the internet, environmental controls etc.

- What can organizations and groups do to ensure that women with disabilities have access to developing technology and the implementation of universal design?

G. If you could change just three things within the next 5 years that would improve the lives of women with disabilities what would those three be?

1. How would you go about trying to implement those changes?

2. What programs or policies would you focus on?

3. For activities or programs in your region/country, what do you think are the most important questions to answer?

4. How would start collecting information on these issues?

H. All the strategies and ideas we have generated will be useful to other women who get this report. Before we close, let’s look at our own needs as leaders, and as women with disabilities.

1. What can be done to empower women leaders with disabilities so that these social change goals can be reached?
2. What would you like to see as a model or ideal leadership program for girls and women with disabilities?

3. What strategies have been effective for you to increase self-confidence and self-esteem, both in yourself and in other people you know?

4. Where have you gotten your skills from? Courses, life experiences, other women, mothers, friends, etc.

5. Have you used role models or mentors? Peer support or circles of support?

6. Lastly, what follow up would you like to see come out of this Forum, from its workshops, the research, the networking...?

I. Either re-cap or simply allow women to add any last comments. Usually time is running out by now but it's important to give people a chance at the end to bring up any additional thoughts. Lastly, be sure to thank every woman, remind them how important their comments are, that copies of the report will eventually be made available, and that we hope they will be able to make use of it.
APPENDIX C: How to Conduct a Focus Group

Who do you invite?
Most focus groups are made up of people who share some similar characteristic. They are all within a certain age, they are all working at a similar job, or maybe they all have disabilities. You should invite women to a focus group who share some characteristic related to the topic. For example, if you are researching parenting, you might want to invite all mothers with disabilities. If you are researching transportation, perhaps invite all people who are having trouble with the services and/or who have found a way to use the services. People in a focus group do not need to have the SAME opinions. You want a range of experiences but it is important that they share some specific characteristics relating to the topic.

Size and Length
Some focus groups are best kept small. If it is a very detailed or serious personal issue, a focus group of approximately five people can work well. If you are talking more about general public issues, a larger group of ten to twelve can be managed. Most research projects which use focus groups conduct more than one focus group meeting. You might do five focus groups with five people each, or four focus groups with eight people each. People get tired after about an hour of talking and the quality of participation often falters if the group continues for a longer period of time. With a large group, you need to budget at least 15 minutes per person and include time for you to give instructions. A two hour focus group with 10-12 participants usually will be limited to five major questions and about 4 or 5 prompts. A smaller group could discuss a few more questions within the same two hour time period. Always pilot your questions by actually asking them and timing them with a small group so you know if there are too many, not enough, or some questions that do not work well.

To encourage women to attend and to reward them for their participation, you should try to offer an incentive. This could be information, a copy of the report, cash, food, a snack, a
bus ticket, or some other type of gift certificate. Remember to thank the women and answer any of their questions before they leave.

**Basic Structure**

1. Warm up/introduction, confidentiality comments 10 minutes

   Puts women at ease and sets tone for the focus group. Each woman should perhaps go around and comment early so that everyone has a fair chance.

2. Major issues are named 5 minutes

   This lets them know ahead of time what topics will be covered, so if they have something to comment on they know it’s coming

3. First question is put out 15 minutes

   The group is freely able to answer (not going round in order). Based on the response to the first question, two or three prompts are used to focus the answers- trying to elicit examples etc. For the Forum research, this question will be about general leadership and social change, but could be about any research subject.

4. The second question is usually the meat of the focus group 40 minutes

   The warm up and first question are used to get people talking and feeling comfortable. This second question starts to get at the “meat” of the focus group, and so should be directly about the research topic: employment, health, etc. Almost 40 minutes is probably spent on this question, with about 4 or 5 prompts to help bring out more details about the topic from the group. The facilitator tries to give everyone a chance to speak and allows discussion to flow from questions on the floor as well as the questions in the script. Keep the pace moving so that people are always participating.
5. The third question is usually about follow up/training/what if. 20 minutes

After discussing the issue in detail, the facilitator now wants some solutions. This question is often harder if people do not have concrete ideas. Use prompts about training, research, services, social change etc and see what comes up.

6. The last question returns the focus to the beginning 15 minutes

This last round of questions is again related to leadership, and tries to bring the discussion full circle by reminding the women that they are the leaders, and that their needs must also be met in order to further the issue at hand.

7. Closing whatever time is left

This is not always done, but sometimes the facilitator tries to summarize the discussion or recognize what was said and ask for last additions or clarifications. Otherwise the group is thanked and the group interview ends.
APPENDIX D: Consent Forms and Evaluation Forms
Participation Consent Form

Your participation in any of these research activities is completely voluntary. We encourage you to volunteer for a focus group or interviews and to complete workshop evaluations and/or the final evaluation. Your name will not be connected to any of your comments or answers. We plan to audiotape the focus groups and interviews for accurate recording. The information we collect will be analyzed and reported, and you can request a copy of the report for your own use once it is ready for publication. We hope that by asking questions we will better understand how to support leadership and empowerment for women with disabilities. Our focus on topics of priority to you will also reflect the needs of women with disabilities for further research, training, and action. Evaluation responses help us improve our ability to meet the needs of participants and provides valuable feedback to presenters, organizers and funders. Your input is extremely valuable in setting the agenda for the future. If you have any questions about the research process or use of the information we collect, please do not hesitate to ask a Research Committee member.

To participate in these activities, we would like your permission and statement that you understand the confidentiality of your comments. If you need this explained to you again, please do not sign until you are fully able to understand.

1. I, _______________________________ (print your name) understand that my participation in the research activities at the Forum is voluntary and that I may withdraw at any time. I also understand that my name will not be used with my comments or answers. I understand that the data collected, including my comments, will be made public after it has been analyzed.

2. Signature: ___________________________ Date: ___________________________

3. If you know now that you want a copy of the results, you may indicate your name and address below. This page will NOT be filed with any of the research data, and so will not associate your name with your responses. If you prefer, you may write to us later to request a copy of the results.

Name: ____________________________________________________________

Mailing address: ____________________________________________________

Format: _____ English _____ English large print _____ Braille _____ Audiotape _____ Diskette (preferred type: __________________________ )

_____ Other (Specify: __________________________ )
INDIVIDUAL WORKSHOP EVALUATION

Title of Workshop: ____________________________________________

Your feedback is very important to us. Please take a few minutes to complete this evaluation of this workshop. If you need more room, use the back of the form. If you need assistance, please ask one of the volunteers/staff. This form is also available in Spanish and French. Thank you.

Please check the most appropriate box for each statement:

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<td>1. The workshop gave me valuable new information</td>
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<td>4. My objective for attending this workshop was reached.</td>
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<td>5. The workshop format was conducive to an in-depth exchange of views and information.</td>
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5a. If the workshop was not conducive to an in-depth exchange, why not? Please check all that apply:

☐ Presentations were too sophisticated
☐ Presentations were too basic
☐ Insufficient language skills
☐ Too many people in workshop
☐ Too little time
☐ Other, please specify: ____________________________
6. What I liked most about the workshop: 

7. What I liked least about the workshop: 

8. Did you learn about some project or approach that is applicable to your country? Please describe: 

8a. What steps will you take to initiate this approach in your country? 

9. Other comments: 

10. Please check one of each below:

☐ Disabled  ☐ Female  ☐ Government  ☐ NGO
☐ Non-disabled  ☐ Male  ☐ Other, describe: 

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APPENDIX E: Helpful References for Conducting Research

WEBSITE TO CHECK OUT  http://www.cstoolbox.com/


To order this publication, please contact:

The world Institute on Disability, 510 16th Street, Suite 100, Oakland, CA 94612
Tel. (510) 763-4100, Fax (510) 763-4109, TTY (510) 208-9493