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**Summary Report of the Fourth Meeting of the  
UNAIDS Global Reference Group on HIV/AIDS and Human Rights  
23-25 August 2004  
Geneva, Switzerland**

## **I Introduction**

The fourth meeting of the Global Reference Group on HIV/AIDS and Human Rights was held in Geneva on 23-25 August 2004. The primary purpose of this meeting was to assess various approaches to documenting the effectiveness of human rights in the response to HIV and AIDS.

The discussions and recommendations of the meeting are summarized in the following sections of the report. The issue papers prepared for the meeting are listed in Annex 1 and are available on the UNAIDS website.

## **II Opening Remarks and Follow Up**

Purnima Mane, Director of the Department of Social Mobilization and Information, UNAIDS, opened the meeting. She introduced and welcomed the High Commissioner for Human Rights, Louise Arbour, thanking her for accepting Peter Piot's invitation to speak to the group. Dr Mane also thanked the Reference Group members for the time they have committed to the work of the group. She stressed UNAIDS' commitment to mainstreaming human rights into all of its efforts, and the timeliness of this meeting's agenda with the organization's current priorities and objectives. UNAIDS needs examples of successes in operationalising rights at the country level and she therefore welcomes this meeting as a necessary step in this regard.

The High Commissioner for Human Rights began her address by providing a global perspective on the state of human rights. She stressed the need to document both the effectiveness and the added value of a rights-based approach. She proposed several points to consider prior to beginning such an effort. First, the need to consider both the instrumental and the intrinsic value of rights-based approaches. The instrumental value is based on the assumption that a rights-based approach improves the effectiveness of HIV programming and is simultaneously beneficial in promoting human rights. Attention to the intrinsic value of human rights justifies their application on moral and ethical grounds. Both are necessary, and the tension between the two impacts on how rights are conceptualized within programming efforts and heightens the imperative to show the added-value of doing programming the human rights way. The High Commissioner concluded by stating that to demonstrate the added-value of human rights, it is important to take a long term view, particularly to show the benefits of participation and other areas which do not lend themselves easily to measurement. At the close of the session, following discussion with group members, the High Commissioner thanked the group and expressed her interest in the recommendations that would result from this meeting.

## **III Follow Up on Issues and Recommendations Raised in Previous Meetings**

Miriam Maluwa, Law and Human Rights Advisor, UNAIDS, gave an overview of follow up on areas discussed at previous meetings. She noted that the Guidance Note prepared by the Reference Group was being used to educate staff internally on HIV testing and counseling, and pointed to the UNAIDS/WHO Policy Statement and the Global Report that incorporated segments of the Reference Group's guidance on the same topic. The recommendations on HIV testing of the armed forces from the Reference Group's third meeting were forwarded to the UNAIDS Office on AIDS, Security and Humanitarian Response, in Copenhagen. She noted that UNAIDS is posting meeting documents and issue papers on the web site and the web site is being updated frequently.

## IV Sessions

### **1) What Constitutes a Rights-based Approach? Rationale, Objectives, and Areas of Focus**

This session was the first theme session of the meeting to launch discussions on how best to document the effectiveness of human rights in the response to HIV and AIDS.<sup>1</sup> To begin to consider what is understood to be a “rights based approach” in HIV and AIDS efforts, the presentation began by highlighting the growing number of debates as to whether attention to human rights have supported or impeded the success of HIV and AIDS strategies. The need to document the evidence of how the promotion and protection of human rights has had a positive impact on HIV and AIDS efforts exists, but the difficulty is in determining the proper criteria for making this determination. Numerous organizations and agencies use “rights-based approaches” in their work. How these approaches are defined and applied in practice is diverse. It was agreed there is a need to clarify concepts and approaches, and consequently provide tools and frameworks both for ensuring compliance with human right norms and standards in HIV and AIDS efforts, and documenting the ways in which this has had a positive impact on programming goals.

Rights-based approaches have officially or unofficially been endorsed by UNAIDS and its cosponsors. Efforts to review the effectiveness of rights-based approaches are needed to reassess and evaluate how human rights can best be integrated in the current and changing contexts of the HIV and AIDS epidemic. The goal is not to justify the application of human rights but to begin to clarify the concepts and methods used in rights-based approaches and identify how to highlight and document their effectiveness. Although human rights are recognized as important on legal and moral grounds (the intrinsic value of human rights), work is needed to show effectiveness at the practical level (the instrumental value of human rights). A member commented that what has been described as a “backlash against human rights” in parts of the HIV and AIDS community may perhaps more accurately be explained as feelings of disenchantment when it was recognized that human rights were not the magic bullet to alone make programmes effective, and that this effort may help to address this disenchantment.

Discussion then addressed the need to clarify what we, as a group, mean by a rights-based approach. There are multiple definitions in place and even as flexibility adds value to the way these approaches can be used, it can lead to confusion. A member noted that before collecting evidence of effectiveness, it would be important to communicate the usefulness of human rights in simple language that programme managers can understand. The “language of human rights” currently used is difficult to understand and as a result, its utility on the ground can be questioned. This becomes a particularly difficult issue in countries and contexts where the concept of a “rights-based approach” is non-existent, for example there are no words in Spanish for “rights based approach” (as opposed to human rights in general). Several possible definitions of a rights-based approach were discussed.

Several members noted the tensions that arise between the intrinsic and instrumental values of rights. It was agreed that it is in fact possible to show the added value of introducing human rights in a policy or programme that has thus far neglected rights, applied illegitimate restrictions, or violated human rights. The group agreed that the failure to define the content of rights-based approaches in ways that are useful needs to be further explored and a conceptual framework put together to address the different contexts and challenges. There was agreement on the need to validate rights-based approaches both at the intrinsic and instrumental levels.

### **2) What Constitutes a Rights-based Approach? Definitions, Methods, and Practices**

The session began by reviewing how various UN agencies, donor governments and international NGOs have defined rights-based approaches and used them in their work.<sup>2</sup> The presentation then highlighted some general observations about rights-based approaches, focusing in particular on the differences between using a rights-based approach to work to strengthen legal accountability and using a rights-based approach as a part of programming efforts. While consensus appears to exist on language, all agreed that discerning the differences in how this plays out in practice is key.

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<sup>1</sup> Please see Issue Paper: “What Constitutes a Rights-based Approach? Determining Rationale, Objectives and Areas of Focus for Our Work.”

<sup>2</sup> Please see Issue Paper “What Constitutes a Rights-based Approach: Definitions, Methods, and Practices.”

The Human Rights Based Approach to Development Cooperation – Towards a Common Understanding Among UN Agencies (‘The Common Understanding’)<sup>3</sup> was then presented. The Common Understanding called for comprehensive integration of human rights into all aspects of programming efforts. As of August 2004, an interagency plan of action to strengthen efforts at the country level has been adopted by 23 agencies and it is hoped that this plan of action will keep clarifying a common approach in putting the Common Understanding into practice. There has been widespread adoption of this understanding by UN agencies, however implementation appears to be at different stages.

The discussion raised several points. One member noted that it is important in reviewing rights-based approaches of different organizations to take into consideration the political climate and leadership at the time policies were instituted, as this may explain strengths and weaknesses in the definitions, as well as shed some light on how they may play out in the future in supportive or less supportive environments. In reviewing the Common Understanding, it was noted that applying this document as a framework to conceptualize rights-based approaches for HIV and AIDS efforts may require adding some key components such as principles of confidentiality.

The discussion then turned to whether the differences in rights-based approaches that “mainstream” human rights into programming efforts and rights-based approaches that “prioritize” rights in programming should be considered. It was agreed that many lessons could be learned from the failures and successes in “mainstreaming gender”, where mainstreaming had at times resulted in a loss of attention to gender because the principals were not sufficiently understood by those responsible for implementation. It was agreed that human rights should be systematically considered in all programme efforts. Agreement is needed not only on a framework but to be able to show how to integrate rights in practical terms. It was recognized that an approach that prioritizes rights would be necessary in order to document effectiveness. This is not likely to be possible when taking mainstreaming as the approach of choice.

Members concluded that the Common Understanding is very useful even as for purposes of the group’s work; other approaches would also be considered. It was agreed that the core principals referenced in the Common Understanding are key to HIV and AIDS work, and that discussions will fully engage with these core principles.

### **3) Review of Approaches Used by Major Organizations to Assess the Effectiveness of HIV and AIDS Programming**

Paul De Lay, Director of Monitoring and Evaluation, UNAIDS, presented the history of HIV and AIDS monitoring and evaluation<sup>4</sup> leading up to the current interest in putting together human rights sensitive HIV and AIDS indicators. In the 1990s, there was a first attempt to standardize HIV and AIDS indicators and more specifically prevention indicators. These indicators tended to “piggy back” on existing data, with a lot of testing of indicator sensitivity, cost, and feasibility. In 2000, the UNGASS Declaration of Commitment committed countries to more serious reporting of their responses to HIV and AIDS and thus helped move the M&E agenda forward. Currently, the UNAIDS Monitoring and Evaluation department is investing in health information systems (HIS) and increasing its focus on building capacity at the country level. De Lay explained that although the indicators produced are effective, they still do not sufficiently capture both human rights and advocacy issues.

As there are different reasons to collect data and different ways that this strategic information can be used, a key emerging concern is becoming how to present data to different stakeholders (governments, civil society organization, media, the community, etc.) He noted that similar to the challenges faced when speaking of a “rights-based approach”, organizations understand and use the terms “monitoring and evaluation” (M&E) differently.

De Lay presented an overview of different logical frameworks for monitoring and evaluation.<sup>5</sup> He described many of the indicators currently in use which allow governments to collect information, for a

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<sup>3</sup> “The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies (‘Common Understanding’)” (outcome document from an Interagency Workshop on a Human Rights based Approach in the context of UN reform 3-5 May 2003).

<sup>4</sup> Please see Issue Paper “Review of Approaches Used by Major Organizations to Assess the Effectiveness of HIV/AIDS Programming.”

<sup>5</sup> Please see PowerPoint presentation “Review of Approaches Used by Major Organizations to Assess the Effectiveness of HIV and AIDS Programming.”

variety of needs including project specific and reporting and accountability. He raised several critical points to consider in any efforts to bring human rights into HIV and AIDS indicator work:

- the M&E toolkit is moving away from addressing health issues in a vertical fashion and going towards monitoring and measuring disease indicators in a multiple and interconnected fashion.
- There are key categories of information or “datastreams” and efforts are now moving towards collection of strategic information which looks across datastreams. Human rights cuts across these streams.
- Core indicators for national use have been expanded but none reflect human rights issues per se.
- The National Composite Policy Index will be updated and there is an opportunity to ensure the additional human rights sensitivity of these indicators.
- Reporting is a critical process for addressing human rights concerns. Reporting obligations through UNGASS, API, Global Fund, PEPFAR and “3 by 5” all provide ample opportunities for follow up and analysis from a human rights perspective.
- The politics of M&E have to be taken into consideration particularly in countries that want to deny or suppress the severity of their epidemic. It is very difficult to collect data on marginalized populations, track resources or monitor service delivery. There is also selective evaluation of data – people choose the information they want. Human rights may raise additional concerns and this must be recognized and addressed in any efforts to move forward.

De Lay concluded his presentation by introducing the work of the Monitoring and Evaluation Reference Group (MERG). He noted that MERG vets and approve indicators, and collaboration between these two reference groups will be important as human rights sensitive indicators are further developed. He also noted that M&E staff will be sent to countries to support them in their M&E efforts and these trained staff will be key in moving the agenda forward.

In their discussions, the group noted that at the political level, for human rights indicators to be used by governments within countries, the promotion and protection of human rights has to be a stated goal by UNAIDS and its partners in and of itself. With respect to technically how this work should move forward, it was suggested that process and outcome indicators would need to be looked at for human rights sensitivity. Reviewing each in turn and then looking at gaps in these processes and potentially constructing indicators to bridge those gaps might be a very useful effort. NGOs and civil society groups are important actors to collect data to bridge these gaps and to shed light on qualitative aspects not apparent through the use of quantitative data. The distinction between human rights indicators and human rights sensitive indicators was discussed and it was agreed that potentially every indicator should be tested for human rights sensitivity. In conclusion, it was agreed that the work on indicators could proceed along three themes:

1. Analyzing existing policy, programme, and impact indicators through a human rights lens.
2. Sensitizing HIV and AIDS indicators that already exist to human rights concerns.
3. Creating new indicators which set out deliberately to capture human rights concerns.

#### ***4) Review of Assessment of HIV and AIDS Strategies that Explicitly Include Attention to Rights: Prevention***

The objective of the session was to consider the different ways in which rights-based approaches have been interpreted in HIV prevention.<sup>6</sup> The presentation began by providing an overview of the history of HIV prevention efforts, summarizing current thinking and practice. It described the theories and practices of HIV prevention as terrains for wide practical, scientific, moral, and ideological debates; recognizing however that most can now agree that there are multiple factors which must be addressed to prevent the spread of HIV. Three categories of approaches to prevention were proposed and examples presented of each: programmes that happen to be consistent with human rights; programmes that are deliberately rights-based; and programmes that clearly violate human rights norms.

The discussion produced some important points for consideration. One member pointed out that where “violations” of human rights are associated with positive public health outcomes, analysis has to be done to distinguish between a “violation” and a permissible and legitimate restriction of rights. Application of the Siracusa Principles can help ensure that the action chosen is the least restrictive alternative.

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<sup>6</sup> See Issue Paper “Review and Assessment of HIV/AIDS Strategies that Explicitly Include Attention to Rights: Prevention.”

The group reviewed the Common Understanding and agreed that, in the context of HIV prevention, this definition may be too narrow. A focus on international norms and standards may be too restrictive and broader lay definition of rights used in social campaigns and programmes may lead to more effective action. Practitioners may need the flexibility allowed by lay interpretations to build effective programmes. This flexibility does not take away from the need to be precise in the application of human rights principles to HIV and AIDS efforts to avoid confusion and over generalizations, but the discussion did demonstrate the value of human rights beyond the strict application of legal norms in HIV prevention efforts.

It was suggested that it might be useful to put together a “toolkit” that would include a list of questions and responses that may be used to assess the application of rights in specific situations and contexts. This could be done by addressing efforts by programme or by issue (e.g. MTCT, premarital testing, etc.).

The prevention discussion also raised several points on the value of indicators for these efforts. One member suggested that perhaps rights sensitive indicators could ensure the accountability of government for HIV and AIDS actions. For example, instead of asking governments to report merely on the portion of their budget spent on prevention efforts, governments could be asked to disaggregate their budgets based on prevalence in their countries, and to offer the largest share of resources to address the situation of the most vulnerable sectors of the population.

#### ***5) Review of Assessment of HIV and AIDS Strategies that Explicitly Include Attention to Rights: Treatment, Care, and Support***

The members of the group were pleased to welcome Alex Ross, Advisor to the Assistant Director General, HIV and AIDS Tuberculosis and Malaria, WHO, who was invited to speak to the group on the status of 3 by 5 and in particular how human rights are being addressed by the initiative. He began by explaining that 3 by 5 was the result of the work of activists calling for more treatment, the falling prices of drugs, the creation of the Global Fund, and the Director General of WHO making HIV and AIDS his political priority. He then proceeded to give a comprehensive overview of 3 by 5, emphasizing that the 3 by 5 initiative was conceptualized with recognition of the ethical and rights aspects of scaling up, such as how to ensure sustainability once you put people on treatment. The most important outcome indicator to measure the progress of the initiative is of course how many people access treatment. He noted, however, some of the difficulties in ensuring accurate numbers on both methodological and political grounds.

Members raised several questions and encouraged the 3 by 5 team to review the guidance submitted by this group in regards to HIV testing and counseling. Concern was raised as to why there seems to be a focus on ethics only and not human rights in the 3 by 5 initiative, and it was suggested that they perhaps put more focus on human rights issues.

The group then focused on rights-based approaches in the context of treatment, care, and support.<sup>7</sup> Latin America was presented as a case study in demonstrating how the law has been used to help ensure integration of human rights in HIV and AIDS efforts and how this has evolved through the years as a means to address complex situations resulting from inequality and discrimination, particularly in access to services and treatment. Examples were presented of the application of rights in the jurisprudence, legislation, regional declarations and national strategic plans for HIV and AIDS and this was discussed highlighting how important it is to look not only at language but at how these documents are implemented and play out in practice. While there is a lot of experience in using legal instruments in pushing for access to treatment, this alone does not result in people being able to access the treatment they need. Difficulties arise in implementation and follow-up even when there is good law.

The group recognized that the application of a rights-based approach in this discussion had focused on law and policy, while the session on prevention used programmes as its entry point. It was noted that there appears to be a more conscious utilization of legal approaches to human rights in treatment efforts than in prevention. The group recognized that law and programming provide different entry points for bringing rights into HIV and AIDS work – whether with respect to prevention or treatment – and that any efforts to produce guidance on rights-based approaches will need to take both

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<sup>7</sup> See Issue Paper “Review and Assessment of HIV/ AIDS Strategies that Explicitly Include Attention to Rights: Treatment, Care, and Support.”

perspectives into account. Members noted that the integration of progressive realization is a key component of rights-based approaches generally, and treatment efforts specifically.

#### **6) Review of Assessment of HIV and AIDS Strategies that Explicitly Include Attention to Rights: Impact Mitigation**

This session reviewed HIV and AIDS strategies that incorporate human rights in the context of impact mitigation, primarily in the area of children orphaned by AIDS.<sup>8</sup> The presentation distinguished between legal and programmatic approaches and provided examples in each area. The group used the example of impact mitigation for orphans to discuss the risks faced when duty bearers are not legally accountable under international human rights law for their actions. Government engagement is relatively limited when it comes to HIV and AIDS orphans, and NGOs find themselves the primary actors in this aspect of the response. Where governments are supportive, their roles are generally limited to creating an enabling environment for the work of NGOs. In addition, either parent or any public authority can claim to be acting “in the best interests of the child” with little accountability, because it is assumed they are doing the right thing. The group agreed that accountability for both state and non-state actors would need to be considered in any framework of rights-based approaches to be presented, and that the examples raised in the context of impact mitigation shed light on important areas for future work.

#### **7) Monitoring a Rights-based Approach: Key Issues and Suggested Approaches**

This session explored issues and approaches relevant to monitoring the application of a rights-based approach in the planning and implementation of HIV and AIDS strategies. Key issues in assessing rights-based approaches were presented, including 1) whether the primary focus should be on processes and/or impact? monitoring and/or evaluation?; 2) what levels of assessment are relevant to any monitoring discussion; 3) whether the purpose of monitoring should be national capacity building or an international watchdog function; 4) how to avoid redundancy or contradiction (internal, and across cosponsors) in information collection; 5) how to build on existing information and collect and analyze existing and new data from other sources, and finally 7) how to use the range of information collected for action. The group discussed each extensively in turn, and several points of concern emerged.

It was agreed that effective monitoring of rights-based approaches would likely require that existing indicators be tweaked to make them more sensitive to human rights. Any proposed framework would need to involve monitoring policy, programmes, and practices with the clear objective of ensuring consistency with human rights norms. It is still to be determined whether the emphasis of monitoring is best placed on violations of rights; promotion of rights; or the impact of including human rights in programming efforts. Since not all instances of interventions can be monitored, regardless of area of emphasis, key areas of focus would need to be identified. Consideration would need to be given as to whether it is preferable to focus on a relatively small number of existing data sets and suggest options for their tweaking, or provide a human rights analysis of existing evidence.

Participants then engaged in an exercise that served as a first step in beginning to conceptualize thinking on monitoring and evaluation of rights-based approaches.

It became clear from discussions that a determination would need to be made as to whether the ways in which rights would be used in monitoring would be grounded in their legal definitions, or simply used as signals to alert people as to issues to be considered. It was also discussed that while UNAIDS is focused on monitoring at the national level, human rights call for attention to differentials within a country. It was agreed that efforts were needed to make certain that the framework was constructed to ensure enhanced efforts at the national level, rather than to draw attention to violations of rights after they occur.

Collecting and analyzing existing and new data from a range of sources was identified as an important step. Members agreed that it may be useful to compare and analyze information from different sources. The group reinforced however, the need to build on existing processes and information, rather than to reinvent the wheel or operate independently. A suggestion was made to look into establishing third party sources to validate information. This could include independent collection of

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<sup>8</sup> Please see Issue Paper “Review and Assessment of HIV/AIDS Strategies that Explicitly Include Attention to Rights: Impact Mitigation.”

data by NGOs and other civil society actors on similar indicators such as the UNGASS core indicators.

As the group concluded discussions on issues and approaches to monitoring rights-based approaches, attention turned to translating information into action. It was agreed that empowering stakeholders to know how to use the rights-related information would involve capacity building in human rights more generally, not only with respect to the use of indicators.

#### **8) Next Steps: Conceptualizing Thinking around Collecting Evidence**

This session focused on concrete tools which could be proposed based on the group's deliberations. Members chose a few priority areas of work along two broad themes, construction of human rights and/or human rights sensitive indicators to be used in programming efforts, and collection of information on existing rights-based approaches to HIV and AIDS (and potentially on the implications of violations of rights on the effectiveness of HIV programming), in order to document the effectiveness of rights-based approaches.

#### **V Closing Remarks**

Purnima Mane closed the meeting. She noted that the policy, programme, practice framework discussed by the group is likely to be very useful. She noted that UNAIDS will be very interested to work with the group to produce products that illustrate the positive role of human rights, and that UNAIDS Best Practice Series may be an appropriate venue to showcase this work. She urged the group to engage with UNAIDS over the coming year to address emerging issues, and assured members their recommendations will be taken seriously.

## **ANNEX 1: Issue papers and supporting documents prepared for the fourth meeting**

**What constitutes a rights-based approach? Definitions, methods, and practices**

[http://data.unaids.org/Topics/Human-Rights/hrissuepaper\\_rbadefinitions\\_en.pdf](http://data.unaids.org/Topics/Human-Rights/hrissuepaper_rbadefinitions_en.pdf)

**What constitutes a rights-based approach? Determining rationale, objectives and areas of focus for our work**

[http://data.unaids.org/Topics/Human-Rights/hrissuepaper\\_whatconstitutesrba\\_en.pdf](http://data.unaids.org/Topics/Human-Rights/hrissuepaper_whatconstitutesrba_en.pdf)

**Review of the human rights content of frameworks to assess the effectiveness of HIV/AIDS programming**

[http://data.unaids.org/Topics/Human-Rights/hrissuepaper\\_reviewapproaches\\_en.pdf](http://data.unaids.org/Topics/Human-Rights/hrissuepaper_reviewapproaches_en.pdf)

**Review and assessment of HIV/AIDS strategies that explicitly include attention to rights: prevention**

[http://data.unaids.org/Topics/Human-Rights/hrissuepaper\\_prevention\\_en.pdf](http://data.unaids.org/Topics/Human-Rights/hrissuepaper_prevention_en.pdf)

**Review and assessment of HIV/AIDS strategies that explicitly include attention to rights with a focus on Latin America: treatment, care, and support**

[http://data.unaids.org/Topics/Human-Rights/hrissuepaper\\_treatment\\_en.pdf](http://data.unaids.org/Topics/Human-Rights/hrissuepaper_treatment_en.pdf)

**Review and assessment of HIV/AIDS strategies that explicitly include attention to rights: impact mitigation**

[http://data.unaids.org/Topics/Human-Rights/hrissuepaper\\_impactmitigation\\_en.pdf](http://data.unaids.org/Topics/Human-Rights/hrissuepaper_impactmitigation_en.pdf)

## ANNEX 2: Participants the fourth meeting

### **Attendees**

#### *Reference Group Members*

Sofia Gruskin, Chair

Mabel Bianco  
Edgar Carrasco  
Anand Grover  
Ralf Jürgens  
Michael Kirby  
Ruth Macklin  
Felix Morka  
Jeffrey O'Malley  
Martin Scheinin  
Daniel Tarantola

#### *Invited Speakers*

Louise Arbour, United Nations High Commissioner for Human Rights

#### *Observers*

Maria Luisa Silva, Office of the United Nations High Commissioner for Human Rights

#### *UNAIDS Secretariat*

Paul De Lay  
Miriam Maluwa  
Purnima Mane  
Peter Piot

#### *Reference Group Secretariat*

Shahira Ahmed

### **Apologies**

Geeta Rao Gupta  
Mark Heywood  
Meena Saraswathi Seshu  
Mary Ann Torres  
Jim Welsh  
Beatrice Were