Report on the CCABA/ UNAIDS/ Global Fund "Road to Washington" meeting in Geneva – May 9-10 2011: Out of the box and into open spaces: Understanding what health systems are doing to address PMTCT and what families, communities and social systems can do to help

Background:

- CCABA is a collective of private and public foundations and re-granting organizations in the North and South. It works to improve the lives of children infected by and affected by HIV/AIDS, aided by key technical experts. Its membership comprises approximately 20 people who each represent their organizations, with the exception of two who sit as academic advisors. It is supported by one part-time staff. Collectively CCABA's funders and International NGOs have linkages to thousands of community-based organization. CCABA is therefore well-placed to make a substantial impact if the right key messages and models can be distilled from this process.

- Following two previous initiatives – the *Road to Toronto* and the *Road to Vienna*, CCABA is leading, with the cooperation and support of other organizations, the *Road to Washington*.

- On May 9-10 2011, 46 people gathered in Geneva for the first in a series of three meetingsorganized by the Coalition on Children Affected by AIDS (CCABA). Called *The Road to Washington: Mobilizing communities to create a supportive environment to help eliminate vertical transmission.* UNAIDS and the Global Fund were collaborators in this first meeting. See Appendix 2 for a list of meeting speakers and participants.

- The goal of the meetings is to narrow the gap between communities and the health sector to help achieve the targets for ending the vertical transmission of HIV by 2015 - reducing transmission to below 5% and achieving a 90% reduction in new paediatric infections).

- The goals of this first meeting were to understand the concepts and issues, to gain a better understanding of what is currently being done, and to better understand the gaps between community and the health sector. The second meeting will be a detailed review of what is being learned on the ground – presentations of promising programs and program models. The final meeting will focus on recommendations and future action, including the review of a draft synthesis paper to be launched at the IAS Conference in Washington and widely disseminated

- As one outcome of the meetings, CCABA is supporting a special issue of the Journal of the International AIDS Society (JIAS), also to be launched at AIDS 2012 in Washington DC. Papers published in the special issue will be drawn from those presented in the meeting series itself as well as from an open call being made in July 2011.

Presentations and Discussions

- Dr. Peter Laugharn, Chair of CCABA and ED of Firelight Foundation, opened the meeting by giving the background of CCABA and setting the context for this series. Dr. Gottfried Hirnschall, head of AIDS at the WHO also made welcoming remarks, noting that is an exciting time, during which people are converging around a common goal. He gave encouragement from the Director-General of WHO, Dr Margaret Chan, who is very committed to the targets of ending vertical transmission. Dr. Paul DeLay of UNAIDS gave greetings on behalf of Michel Sidibe and noted that he hoped we can get a serious commitment from delegates to the upcoming high-level meeting in June.

- Professor Linda Richter of CCABA (also from HSRC and The Global Fund), gave a presentation setting the context for the meeting topic. Key points included:
  - Community action is needed to avert the narrowing of PMTCT goals in the thrust to reach targets by 2015.
  - Leading up to Toronto, we talked about scaling up to meet the needs of all children affected by HIV/AIDS. Leading up to Mexico we highlighted poverty and the need for social protection. Leading up to Vienna, we concentrated on family-centred services.
  - Children are effectively a 'most-at risk population'. We've shifted from talking about orphans to taking *children in the epidemic*
  - The global efforts to end vertical transmission are the most significant and substantial commitment to children and families since the start of the epidemic. Although its alive with possibilities, we won't achieve even our narrow targets without significant mobilization of community action.
  - Communities can hold leaders accountable, advocate for comprehensive services, improve community knowledge and norms, and help key populations access services.
  - The OVC community is a massive work force – millions of people who have taken children into their homes, and provided children with support on a completely voluntary basis,. CBOs have deep penetration into community, but are cut off from PMTCT services in the health-sector vertical vice versa. *This meeting is about the possibility for establishing a relationship between the health services and community action*

- After introductory comments, meeting participants heard presentations from three panels. Panel 1 was on current PMTCT practice from the health systems perspective. Panel 2 was on lessons learned from research and practice on family and community supports that are working to end vertical transmission. Panel 3 was on strengthening community systems to support families, communities and health facilities to prevent parent-to-child transmission and improve the health of women and children**.** All meeting presentations are posted on http://www.ccaba.org/resources_geneva2.html

- Appendix 1 provides a table with presentation highlights/key messages (apologies to presenters – any errors or misrepresentations are the fault of the report author)

Summary Messages from Participant Discussion

- The meeting produced a good review of evidence but there are some issues not adequately dealt with, namely:

    1. Gender-based violence and the degree to which women are put at risk through the involvement of men in PMTCT programs
    2. Adolescent sexual health and primary prevention of HIV
    3. Outreach by, and partnership with, faith-based groups working in sexual and reproductive health and PMTCT
    4. Social protection and how economic assistance could support demand for PMTCT
    5. Examples of models working specifically with key populations
    6. Integration PMTCT into maternal and child health and sexual and reproductive health
    7. Rural/ urban divide
    8. Clarifying the idea of scale-up versus replicability
    9. Programs that make the linkages by specifically attacking stigma

Conclusions:

- While there much that remains to be explored, there was agreement from participants that there is a strong role for community-based organizations, especially in terms of promoting demand for services and improving follow-up. We need:
    - more data;
    - more depth in terms of programmatic examples at the local level;
    - more discussion of strategies for funders to achieve wide-scale impact using their networks, which reach the multitude of community-based organizations that could help in the response;
    - strategies to work with health services in partnerships with communities;
    - better examples of how we can reach key populations with targeted responses and more work in breaking down stigma in mainstream services.

Next Steps

1. Produce meeting report and distribute
2. Post all presentation on http://www.ccaba.org/resources_geneva2.html
3. CCABA will plan for Meeting #2 in Addis Ababa, on December 1-2 2011. We'll engage with partners to develop a presentation list
4. CCABA will produce a short, attractively packaged pamphlet that could help all of our organizations to get out this basic information
5. We will send out a call for proposals for the special issue, starting in July in Rome 2011.

Appendix 1 - Presentation Summaries (with apologies to presenters - any errors or improper emphasis are the report author's alone)

Speaker	Selected key messages
Panel 1: Current PMTCT practice and how community groups and community action could help to prevent parent-to-child transmission and improve the health of women and children	
Dr. Lydia Mungherera, Mama's Club, Uganda (Session moderator)	• The answers lie in the community. Mothers in Africa use traditional birth attendants so we have to connect them to the health centres. • We have community cultural leaders – unless we work with them, we won't get anywhere. • Our approach must be family-based and must engage men.
Dr. Chewe Luo, UNICEF Headquarters Presentation title: *Casting a spotlight on community engagement in PMTCT services*	• If we do nothing, we'll have 367,000 new infections by 2015. Adding WHO guidelines, and other initiatives, we can get down to 79,000. Countries differ – in some, only a small proportion of women access services, so interventions have to reach out to them in the community • The way forward – we need to keep it simple. 4 issues: 1) We need to reach men more. 2) Optimizing and protecting HIV investments – PMTCT and neonatal interventions, 3) Infant feeding peer counselling support aligned to new WHO guidelines, and 4) community systems to improve follow-up support: Adherence for PMTCCT ARVs and clinic visits
Dr. Ryan Phelps, USAID Presentation title: *Post-partum mother-infant retention in PMTCT*	• Presentation of numerous studies showing loss to follow up (LTFU) in PMTCT programs and noted that this loss to follow up means that even the little treatment effectiveness data that we have is over-estimated. • When we go into the community and find mothers and children, we find out that we are over-estimating the number of children who actually end up becoming HIV-positive. • Key lessons from the data: 1) rural programs more challenging but we need more data, 2) LTFU increases over time, 3) coverage and health seeking behaviour go hand in hand
Ms. Gretchen Bachman, Office of HIV/AIDS, Global Health, USAID Presentation title: *Demand-side Barriers and Opportunities for Uptake of Pediatric HIV Testing and Care*	• There's so little data on the community mobilization side when you do a literature search. • All of the work the HIV/AIDS US Government has been doing for mothers and children now all fits into the "Global Health Initiative". We're trying to figure this out at the community level but think this is a positive thing for mothers, e.g. it's easier and less stigmatizing to get your child vaccinated on the same day that you get tested for HIV at the clinic. • Transport, food, medical costs, fear, stigma, lack of financial resources – these were the key hindrances to getting to clinics, to adherence. • Gave examples of incentive programs to help adherence, eg: text message reminders but we have to remember that rural women don't have good access to phones.
Dr. Nigel Rollins, World Health Organization Presentation title: *Current PMTCT*	• Outlined the confusion around infant feeding guidelines, the limits of the effectiveness of counsellors and nurses in the health care system • Championed the importance of seizing this opportunity, with simplified messages, and with communities' help, to improve maternal and child

Speaker	Selected key messages
practice and how community groups and community action could help to prevent parent-to-child transmission and improve the health of women and children:	HIV-free survival. • We need a shared vision, a ready system and population, a mechanism to respond and develop solutions, and a system of accountability to track progress. • Shared evidence of good practice from Cuba, South Africa.
Dr. Karusa Kiragu, UNAIDS (Session summary) Presentation title: *Towards the elimination of new HIV infections among children: Working Together to Catalyze and Support a Prevention Revolution*	• Gave summary comments but also presented some information on the state of the epidemic as it relates to vertical transmission, and gave the case for why PMTCT, ie:. o 90% of children get HIV from mothers during pregnancy, childbirth and breastfeeding o HIV infection is more aggressive among children than adults; without intervention, half die by 2 yrs o In highly-endemic areas, children present for care much later, as late as ages 5-6 years o Mortality for children born to HIV+ mothers higher than children born to HIV- mothers even if the child is HIV-. o Elimination of MTCT is feasible; it is the ultimate value for money.
Panel 2: Lessons from research and practice on family and community supports for PMTCT: Visions for an expanded effort	
Dr. Christian Pitter, Elizabeth Glaser Pediatric AIDS Foundation (Session moderator)	EGPAF is working on several fronts: • addressing health-seeking behaviours in peer groups • enhancing household environments – getting to the women • working with local institutions to get to the structural barriers that exists • increasing ownership of health services by communities
Dr. Boshishi Mohlala, Imperial College London Presentation title: *Community-based & Family-centred Approach to Prevent Parent To Child Transmission of HIV*	• Outlined the Khayelitsha study on male involvement - found that the main barrier to male involvement was the health care facilities themselves. • When invited to the clinics (and they can get there), most men will get tested. Community mobilized to address some of the barriers to men. • Kenya study: Adjusting for viral load, vertical transmission was lower for those who brought men with, and those reported prior male HIV testing • Shift in paradigm needed - from MCTC to PTCT, from individual to family approach, from single intervention to continuum of care.
Ms. Gladys Mukaratirwa, Chiedza Community-based Orphan Welfare, Mutare Zimbabwe Presentation title: *Out of the Shadow and Into the Open - The Role of Community Based Organizations in the Support and Delivery of PMTCT*	• Ms. Mukaratirwa presented their program, a small CBO with roughly $50K/year budget, which includes a PMTCT program to 34 women in 14 villages. • Communities requested that Chiedza come up with programming option due to large numbers of child deaths. They are linking to the local Mission Hospital to extend treatment to the community. • They create community receptivity to messaging, advocate with local hospitals, encourage community members, sensitize community leaders. They work in collaboration with clinics and hospitals. • They sign an MOU with the ministry of health to ensure continuity of PMTCT from clinic to the community • challenges: 1) lack of confidence about the role of CBOS in working in the

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	health domain, and 2) unwillingness of health workers to engage with Chiedza
Dr. Stanley Kiplangat, Christian Health Association of Kenya Presentation title: *Enhancing Uptake of Pediatric HIV Testing and Treatment in Kenya - Highlights from Baseline and Service Delivery*	• Conducted a study that identified barriers to accessing treatment, identified key constraints - cost, especially of transport, lack of awareness of service, denial, fear, stigma, provider workload. • Response: community outreach - key partners were identified, training of community health works and pastors. • In the health facility, they identified and addressed key constraints - mother-baby card stock shortages addressed, delays in receiving results etc.
Dr. Mitchell Besser, Mothers2Mothers Presentation title: *Enhancing PMTCT Services In Health Care Facilities: Supply and Demand Side Approaches*	• In the mere minutes per patient that they have, for nurses in Africa, the tasks that they have to accomplish have increased as we've improved the roll-out of ARV treatments. • Presented the model used by Mothers2Mothers. Mentor-mothers are engaged for up to two years – paid, and integrated into the health care team. National training curriculum – two weeks education. The site coordinator gets a 3rd week of training. • Active follow up has drastically improved results.
Ms. Kate Iorpenda, International HIV/AIDS Alliance & CCABA member (Panel summary)	• Summarized Panel 2 but also took the opportunity to present some of the work of SASO, an organization working in Manipur with people who use drugs (Shasikumar Singh was to present at the meeting but wasn't able to make it to Geneva) • Raised the issue that the word "elimination" triggers for key populations - discrimination and criminalization and the need to address structural barriers in order to get people into the PMTCT cascade.
Day 1 Wrap-up and Summary	
Mr. Peter McDermott, Children's Investment Fund Foundation	• Raised 5 points and led a participant discussion • 1. What is the goal and scope of the agenda for the elimination of paediatric AIDS (learn from the launch of the term "OVC" - the language of the targets is important). Typology - different contexts 2. Measurement - how do we know when we have succeeded? Goals, targets, indicators. The data is weak. Need more disaggregation. Need an operational research agenda. 3. Programmatic agenda - what should communities not be doing? What are they not good at? Need a sober reflection on the holy grail. What dilution effects occur? Can community interventions be nationally scaled with an evidence base (a) The community-facility interface is dysfunctional, stigmatising (b) Need to invest in fundamental capacities eg networks 4. The global agenda has been initiated. What is the accountability mechanism for the fund, coordination 5. Financial models need to be more rigorous, inclusive.Discussion: one doesn't get economies of scale with community-based programmes, as one does for example with prevention programmes. • Roles of the community - the first 3 roles Linda outlined in her talk have

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	high costs
Professor Lorraine Sherr, University College London & CCABA member Presentation title: *Recap - Mobilizing Communities*	• Presented a summary of Day 1 - issues raised: Background situation (HIV prevalence, health care starvation, crippling ratios, health care drain, demand greater than supply; VCT; Disclosure; Treatment/adherence; Engagement of communities; Good models and their evaluation, documentation, capture and roll out; Resistance to family centered approach; Marginalized communities • Are we paying lip service to community or is it *the* critical resource?
Panel 3: Strengthening community systems to support families, communities and health facilities to prevent parent-to-child transmission and improve the health of women and children	
Dr. Ade Fakoya, The Global Fund (session moderator) Presentation title: *Strengthening community systems to support families, communities and health facilities to prevent parent-to-child transmission and improve the health of women and children*	• Five things around community-based interventions are: 1) need to reframe our goals (don't make the same mistakes), 2) organize/ solidify the evidence base (identifying and filling gaps in knowledge), 3) simply the framework for community-based interventions (prioritizing for scale and effectiveness, 4) ensure there's adequate Funding, and 5) Measure and account • Need to include programs on stigma in our programs for community-based interventions
Ms. Ginna Anderson, International Community of Women Living with HIV & AIDS (ICW) Presentation title: *Vital Voices - Learning from the experiences and perspectives of people living with HIV to inform PMTCT programmes and health facilities/services*	• Presented findings on experiences and perspectives of PLHIV in accessing PMTCT and related services. • Findings: o HIV related stigma exists and was a barrier to accessing services o human rights violations o coercion from health providers o gender-based violence o supportive testing and counseling o safe conception and healthy pregnancies o couples testing and counseling o male involvement
Dr. Chukwumuanya Igboekwu, Physicians for Social Justice, Nigeria Presentation title: *Strengthening Community Systems to Support Families, Communities and Health Facilities to Prevent Parent-to-Child Transmission and Improve the Health of Women and Children*	• PSJ founded out of frustration with health system limitations – engaged with the communities to solve the problem. They mobilized and engaged the local governments. Thinking of name change to Physicians and Communities for Social Justice. • Raised the issue of the commitment and personal investment of health care workers and the need to support health care workers as they are part of the community and working under difficult circumstances.
Dr. Vernon Solomon, University of Kwazulu-Natal, South Africa Presentation title: *The role of health systems, families, communities and*	• We know a lot about barriers, and what is needed are useful frameworks, a process oriented approach, integrated approaches, and a non-negotiable emphasis on participation. • Presented and argued for a Clinical Systems Mentoring Approach (ICAP model) to help health systems and communities come together - come

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social systems in PMTCT	from a history of mentorship in HIV programme implementation, WHO, ICAP and others. • Difference from Clinical Mentorship was outlined - teams can be mentors, mentorship happens outline the management line, etc. • has the potential to improve quality and strengthen the service and the system
Ms. Olive Edwards, Jamaican Network of Seropositives Presentation title: *Creating an enabling environment for more meaningful involvement of people with HIV within self support groups and HIV positive women's networks*	• Presented the history and model of JNS, which is a peer-support model. • Spoke about how they have supported their members in their intersection with the health system.
Dr. Stefan Germann, World Vision International (Panel summary)	• What came out from the sessions is that we need to reframe the discussion from the perspective of human rights. • Confusion still exists on where the health system ends and the community systems begin • Recommend that collectively we have a 1-pager that outlines the role of community systems strengthening along the continuum of community care • On the funding, we need to make a stronger case that strengthening community strengthening is essential to getting results in health • It would be good if we had some simplified metrics in terms of community outcomes.
Meeting Wrap up, Summaries, Discussion, Next Steps	
Dr. Lydia Mungherera, Mama's Club, Uganda	• Let's not forget the children • the answers are in our community • need to keep mothers alive to keep children alive
Dr. Robin Jackson, UNAIDS	• Do we need to talk about replicability or do we need to talk about scaling up. • We haven't talked about the rural/ urban divide • integration – we didn't hear much about integrating PMTCT into MCH etc • Social protection • The Global Plan – there are a number of orgs that are part of the Global Task Team, that are putting together the Global Plan and presenting it at the High-Level Meeting. There are four components to it: Frame it, campaign it, do it and account for it. I'd encourage you to put some of it in the plan
Dr. Linda Richter, CCABA/ HSRC/ The Global Fund	• Reminded us that this meeting is about what CCABA can do, and reminded us of CCABA's reach to thousands of small CBOs through its funder members • We met here, said, who are you? Do you want to hold hands? And now we will be moving on to our 2nd meeting just before ICASA. We leave this with a couple of topics still to be explored: 1) gender-based violence, 2)

Speaker	Selected key messages
	what is the evidence of implications for broad-based social protection for programs doing PMTCT, 3) link to primary prevention – what does it mean to be somebody who's able to prevent HIV, 4) what are the boundaries, what is community? • What can CCABA contribute given our goal re: children and therefore our goal to keep parents alive and happy. There are quite clear roles for them. We need all of our CBOs to disseminate some key points –that PMTCT can be effective, that treatment for children is effective, that breastfeeding is important • Could the foundations in CCABA produce a short, attractively packaged pamphlet that we could help all of our organizations to get out this basic information. • How can CBOs encourage women to attend ante-natal programs as early as possible? How can they also encourage the participation of men? How can they establish buddy and mentor groups? • Is it possible to get together with EGPAF, USAID, UNICEF to begin to talk beyond this room about getting a proposal in through one of the CCMs to the Global Fund in one of the high-prevalence countries that would draw community and health together.
Dr. Shirin Heidari, Journal of the International AIDS Society Presentation title: *Special Issue: Mobilizing communities to create a supportive environment to help eliminate vertical transmission*	• Pleased to be part of this effort and provide a platform through a new special issue. Best practices, models, and lessons learned. • Encouraging original research articles for this special issue. Innovative approaches/ models that are making a difference. • Operational research is important • Timeline estimates: - Call of abstracts – deadline for submission of 1 page abstract by September 2011. Submission of paper by end of December. Peer review in Jan-Feb 2012. 1st revision in March, 2nd revision April. May-June production and publication.
Dr. Peter Laugharn, CCABA/ Firelight Foundation	• Presented a calendar of activities from now until Washington • Can we think of some quick-timeline research that can be useful in working towards 2015 • Round 11: most of us are uninformed about how these things. If people from TGF could tell us how our networks can be useful, this will help us to be more efficient • If we are to have impact on the Global Plan, we need to know what part we should focus in on. • Final comments from participants included: ➢ Stefan Germann: The Women Deliver Conference in Thailand next year; 205 of 400 partners in the Partnership for Newborn, Maternal and Child Health are civil society. We haven't started to engage with them and we need to find a way. ➢ Linda Richter: We need to partner with IAS in mentoring for abstracts for IAS. ➢ Doortje 't Hart: We need a kind of translation of our journal for

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	people in the field. Need to budget for it? Then get it out through our networks ➢ Kate Iorpenda: We need to go to the Harm Reduction Conference and they need to come to our conferences. We should think of presenting at the Harm Reduction Conference next year.
Mr. John Miller, CCABA Slide title: *Road to Washington Meeting –Geneva4 types of presentation/discussion topics at this meeting*	• Clarified that we've seen four kinds of presentations during this two-day meeting, with more evidence presented in the first and less and less evidence as we move to number four: 1. Status quo –health service separate from community-based services, separate from social protection 2. Examples of programs / program models where there have been linkages between the health system and community-based organizations & peer support/ PLHIV groups 3. Data that proves making linkages with communities & with social protection has had an impact on women & children, PLHIV, key populations in terms of: a) reducing rates of vertical transmission; and b) reducing stigma and other barriers to health system access 4. Recommendations: a) Frameworks, b) Program support/ funding, c) Scale-up • Meeting number 2 in Addis will present more from 3 & 4.

Appendix 2 - List of Meeting Speakers and Participants

Meeting attendees - Speakers & Participants	
Panel Moderators, Opening & Summary Remarks	
1. Dr. Paul De Lay Deputy Executive Director, Programme UNAIDS	 delayp@unaids.org
2. Dr. Ade Fakoya Senior Advisor HIV & AIDS, The Global Fund	 ade.fakoya@theglobalfund.org
3. Dr. Stefan Germann Global OVC Specialist World Vision International Geneva, Switzerland	 stefan_germann@wvi.org
4. Dr. Gottfried Hirnschall Director, HIV/AIDS Department WHO	 hirnschallg@who.int
5. Ms. Kate Iorpenda Member, CCABA, & Senior Advisor: HIV Children and Impact Mitigation International HIV/AIDS Alliance	 kiorpenda@aidsalliance.org
6. Dr. Robin Jackson Special Advisor UNAIDS	 jacksonr@unaids.org
7. Dr. Karusa Kiragu Senior Prevention Advisor Programmatic Priorities and Support Division Evidence, Monitoring and Policy Department UNAIDS Geneva, Switzerland	 KiraguK@unaids.org
8. Dr. Peter Laugharn Chair, CCABA & Executive Director, Firelight Foundation Santa Cruz, USA	 peter.laugharn@firelightfoundation.org
9. Mr. Peter McDermott Managing Director Children's Investment Fund Foundation	 peter@ciff.org spowell@ciff.org
10. Mr. John Miller Projects Coordinator, CCABA Toronto, Canada **** Meeting organizer - Logistics***	 john.miller@ccaba.org
11. Dr. Lydia Mungherera Mama's Club, Uganda	 lmungherera@ymail.com

Meeting attendees - Speakers & Participants	
12.Dr. Christian Pitter Elizabeth Glaser Pediatric AIDS Foundation	cpitter@pedaids.org
13.Professor Linda Richter Member, CCABA & Executive Director, Child, Youth, Family and Social Development Programme, HSRC Durban, South Africa **** Meeting organizer - Academic Program***	lrichter@hsrc.ac.za
14.Professor Lorraine Sherr Member, CCABA Professor of Clinical and Health Psychology, University College London London, UK	l.sherr@ucl.ac.uk
Speakers / presenting papers	**Email addresses**
15.Ms. Ginna Anderson International Community of Women Living with HIV and AIDS (ICW) Center for Health and Gender Equity	ganderson@genderhealth.org
16.Ms. Gretchen Bachman PEPFAR OVC TWG co-chair, Sr. Technical Advisor, Orphans and Vulnerable Children Office of HIV/AIDS, Global Health, USAID Washington, USA	gbachman@usaid.gov
17.Dr. Mitchell Besser Founder & Medical Director Mothers to Mothers	mitch@m2m.org
18.Ms. Olive Edwards GIPA Facilitator Jamaican Network of Seropositives	olive_edwards@yahoo.com
19.Dr. Chukwumuanya Igboekwu Physicians for Social Justice, Nigeria	drmuanya@yahoo.com
20.Dr. Stanley Kiplangat Health Services & HIV Programmes Manager Christian Health Association of Kenya	skiplangat@chak.or.ke
21.Dr. Chewe Luo Senior Programme Advisor, UNICEF UNICEF Headquarters, New York	cluo@unicef.org
22.Dr. Boshishi Mohlala Imperial College London	bmohlala@doctors.org.uk
23.Ms. Gladys Mukaratirwa Program Coordinator Chiedza Community Based Orphan Welfare Zimbabwe	gmukaratirwa@yahoo.com munongwidadi@gmail.com
24.Dr. Benjamin (Ryan) Phelps US Agency for International Development	bphelps@usaid.gov
25.Dr. Nigel Rollins World Health Organization	rollinsn@who.int

Meeting attendees - Speakers & Participants	
26.Dr. Vernon Solomon Lecturer, University of Kwazulu-Natal	Solomon@ukzn.ac.za
Participants	
27.Ms. Terhi Aaltonen Member, CCABA, & Programme Officer, Evidence, Monitoring and Policy Department UNAIDS Geneva, Switzerland	aaltonent@unaids.org
28.Dr. Rachel Baggaley WHO	baggaleyr@who.int
29.Ms. Catherine Connor Member, CCABA, & Director of Policy Elizabeth Glaser Pediatric AIDS Foundation	cconnor@pedaids.org
30.Dr. Lynn Collins Technical Advisor, HIV/AIDS, HIV/AIDS Branch, Technical Division UNFPA	collins@unfpa.org
31.Dr. Luis Andres de Francisco Serpa Partnership for Maternal, Newborn and Child Health	defranciscoa@who.int
32.Ms. Olivia Dix CCABA Member, Head of the Palliative Care Initiative The Diana, Princess of Wales Memorial Fund	Olivia.Dix@memfund.org.uk
33.Shaffiq Essaje	
34.Dr. Robin Gorna Consultant, AIDS Strategy, Advocacy and Policy	rgorna@gmail.com
35.Ms. Doortje 't Hart Senior Advisor, "Orphans and Vulnerable Children" STOP AIDS NOW!	DtHart@stopaidsnow.nl
36.Dr. Shirin Heidari Executive Editor Journal of the International AIDS Society	shirin.heidari@iasociety.org
37.Mr. Stuart Kean Member, CCABA & Senior HIV and AIDS Policy Adviser World Vision	stuart.kean@worldvision.org.uk
38.Mr. Dominic Kemps Director, Positive Action Program Viiv Healthcare	dominic.x.kemps@viivhealthcare.com
39.Dr. Mary Ann Lansang Unit Director, Health Advisory, Knowledge Management Unit The Global Fund	maryann.lansang@theglobalfund.org
40.Dr. Greg Martin Editor-in-Chief, Globalization and Health Technical Officer (UNITAID) at WHO	drgregmartin@gmail.com

Meeting attendees - Speakers & Participants	
41.Dr. Elizabeth Mason Director of Child and Adolescent Health WHO	masone@who.int
42.Mr. Christoforos Mallouris Director of Policy GNP+	cmallouris@gnpplus.net
43.Ms. Ntombe Kyaha Matsha Senior Civil Society Officer The Global Fund	Ntombekhaya.Matsha@theglobalfund.org
44.Dr. Francoise Ndayishimiye Senior Gender Adviser Strategy, Performance and Evaluation (SPE) Cluster Health Advisory Unit The Global Fund Geneva, Switzerland	Francoise.Ndayishimiye@theglobalfund.org
45.Ms. F. Amolo Okero Technical Officer, Department of HIV/AIDS WHO	okeroa@who.int
46.Ms. Sally Smith Partnerships Adviser UNAIDS Geneva Switzerland	smiths@unaids.org

Meeting email distribution list (includes people who sent regrets):

delayp@unaids.org; ade.fakoya@theglobalfund.org; stefan_germann@wvi.org; hirnschallg@who.int; kiorpenda@aidsalliance.org; jacksonr@unaids.org; KiraguK@unaids.org; peter.laugharn@firelightfoundation.org; peter@ciff.org; spowell@ciff.org; lmungherera@ymail.com; cpitter@pedaids.org; lrichter@hsrc.ac.za; l.sherr@ucl.ac.uk; sidibem@unaids.org; saldanhavp@unaids.org; ganderson@genderhealth.org; gbachman@usaid.gov; mitch@m2m.org; olive_edwards@yahoo.com; drmuanya@yahoo.com; skiplangat@chak.or.ke; cluo@unicef.org; bmohlala@doctors.org.uk; gmukaratirwa@yahoo.com; munongwidadi@gmail.com; bphelps@usaid.gov; rollinsn@who.int; saso.imp@gmail.com; Solomon@ukzn.ac.za; aaltonent@unaids.org; fareed.abdullah@theglobalfund.org; anurita.bains@theglobalfund.org; baggaleyr@who.int; cconnor@pedaids.org; collins@unfpa.org; Olivia.Dix@memfund.org.uk ; rgorna@gmail.com; DtHart@stopaidsnow.nl; shirin.heidari@iasociety.org; stuart.kean@worldvision.org.uk; dominic.x.kemps@viivhealthcare.com; maryann.lansang@theglobalfund.org; drgregmartin@gmail.com; masone@who.int; cmallouris@gnpplus.net; Ntombekhaya.Matsha@theglobalfund.org; Francoise.Ndayishimiye@theglobalfund.org; michael.oconnor@theglobalfund.org; Mohamed.osman@ejaf.com; shaffern@who.int; smiths@unaids.org; presernc@who.int; defranciscoa@who.int; john.miller@ccaba.org, fyfet@who.int; okeroa@who.int; AdernN@nmcf.co.za; angelica.valenzuela@caaf4kids.org; adigirolamo@care.org; eva.nordfjell@foreign.ministry.se; karenvw@on.aibn.com; linnea.renton@egmonttrust.org; lzimanyi@ryerson.ca; Nyambura.Rugoiyo@bvleerf.nl; sobara@helpage.co.ke; swinterstein@unicef.org; TTweedley@elmaphilanthropies.org; vdunning@globalfundforchildren.org; gupta@globalfundforchildren.org