Report on the “Road to Melbourne” meeting in New York – May 30-31st 2013: Young Children Born into HIV-affected Families -
Meeting #1 (New York): Early intervention - evidence and entry points

Background:

• The Coalition for Children Affected by AIDS ("The Coalition") believes that children need to be made a higher priority in the international response to HIV and AIDS. The Coalition brings funders and technical experts together to advocate for the best policy, research, and programs for children because children are a vulnerable population that is too often overlooked. Its membership comprises approximately 20 people who each represent their organizations, with the exception of three who sit as academic advisors. It is supported by one part-time director.

• Following three previous initiatives – the Road to Toronto, the Road to Vienna, and the Road to Washington, The Coalition is leading, with the cooperation and support of other UNICEF, UNAIDS and organizations, the Road to Melbourne.

• On May 30-31 2013, 49 people gathered in New York for the first in a series of three meetings organized. Called The Road to Melbourne: Young Children Born into HIV-affected Families, UNICEF and UNAIDS were collaborators in this first meeting, with UNICEF being its host. See Appendix 2 for a list of meeting speakers and participants.

• The goal of the meeting series is to build evidence and understanding amongst policy makers and programmers from different disciplines on approaches to the early identification of children born into HIV-affected families through PMTCT services and other key entry points such as ECD programming to ensure the linked provision of integrated services and support to children at risk and their families to promote optimal development. The objective is to influence funder and policy-maker priorities, and country-level practice.

• The series will:
  1. Explore the latest evidence around child development in the early years and the impacts of HIV on young children
  2. Explore other entry points to identify children born into HIV affected families who are not within the PMTCT cascade.
  3. Prioritize early interventions to prevent negative outcomes for children born into HIV affected families;
  4. Promote a more integrated and linked up approach between PMTCT services and early childhood protection, care and support services The 3 meetings will consider key questions about
a) The state of the evidence;
b) The interventions that hold promise; and
c) The policies that can change/influence the response for children born into HIV affected families.

• The outputs of the meeting series are expected to be:
  1. Evidence to influence funder and policy-maker priorities, and country-level practices, including:
     a. Peer-reviewed journal;
     b. Other academic articles stimulated throughout the process; and
     c. Successful practices as reported in the report of the second meeting on country-level programmatic evidence.
  2. A position statement adopted at Coalition-Teresa Group pre-IAC symposium in July 2014; and
  3. An advocacy plan

• The goals of this first meeting were to understand the high-level evidence, and to clarify concepts and issues. It was to better understand the gaps, and entry points. The second meeting, being held December 5-6 2013 in Cape Town, South Africa, will be a detailed review of what is being learned on the ground – presentations of promising programs and program models. The final meeting, which will be much smaller, will focus on recommendations and future action.

• As one outcome of the meetings, The Coalition is supporting a special issue of the journal AIDS, also to be launched at AIDS 2014 in Melbourne. Papers published in the special issue will be drawn from those presented in the meeting series itself as well as from an open call made in early 2013.

Presentations and Discussions

• Ms. Kate Iorpenda, Chair of The Coalition and Senior Advisor, HIV, Children and Impact Mitigation for the International HIV/AIDS Alliance, opened the meeting by giving the background of the Coalition and setting the context for this series. Dr. Christian Salazar, Director, Programme Division, UNICEF also made welcoming remarks, noting that for UNICEF, the “Road to Melbourne” is also a road to the post-MDG (2015) discussion.

• After introductory comments, meeting participants heard presentations from nine panels:
  o Panel 1 was titled "Why focus on young children born into HIV affected families?".
  o Panel 2 was titled: "PMTCT as a critical entry point for early interventions for children"
  o Panel 3 was titled: "The science of early child development: Application to HIV affected populations"
  o Panel 4 was titled: "Challenges and advances in paediatric testing and treatment"
  o Panel 5 was titled: "Comprehensive care and support models for CABA"
  o Panel 6 was titled: "Translating research into global policy"
  o Panel 7 was titled: "Integrated support to families for optimal development"
  o Panel 8 was titled: "Too expensive to do, too expensive not to?"
  o Panel 9 was titled: "Investing in Children – Funders’ perspectives"
  o The meeting ended with a synthesis discussion and discussion of next steps, with closing remarks by Mr. Craig McClure, Chief, HIV/AIDS, UNICEF
• All meeting presentations are posted on http://www.ccaba.org/road-to-melbourne-series-presentations-from-new-york/

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

• Appendix 2 is participant contact information.

• Appendix 3 provides speaker biographies.

• Appendix 4 is the complete meeting program.

• Appendix 5 is the Road to Melbourne meeting series concept note.

**Next Steps in the Road to Melbourne meeting process**

1. The Coalition will plan for Meeting #2 in Cape Town, on December 5-6 2013. We'll engage with partners to develop a presentation list.
2. All meeting participants will advertise the call for proposals for the special issue of AIDS, whose deadline is 20th December 2013.
### Appendix 1 - Presentation Summaries (with apologies to presenters - any errors or improper emphasis are the report author's alone)

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<td><strong>Introductory Remarks</strong></td>
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<td><strong>Ms. Kate Iorpena</strong>&lt;br&gt;Chair: The Coalition for Children Affected by AIDS &amp; International HIV/AIDS Alliance</td>
<td>• Introduced the Coalition, and gave an overview of how the &quot;Road to&quot; series is about bringing together the best research and practice on a focused issue. This follows on our &quot;Road to Washington&quot; on community action to end pediatric AIDS.</td>
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| **Dr. Christian Salazar**<br>UNICEF | • Warmly welcomed participants on behalf of UNICEF.  
• For UNICEF, the "Road to" is also a road to "post-2015". Tomorrow is the launch of the high-level report on that topic. And, in 2 years, UNICEF is presenting its first new strategic plan in a decade. It’s important for us to learn and to see where the different strands of technical information can feed one another.  
• We need to push the different sectors as they deliver the results but also push the collaboration. This will be in our next strategic plan. It’s extremely challenging, but strengthening inter-sectoral interventions in the early years is crucial.  
• We want to increase our resource allocation in ECD, social protection and social inclusion in the next few years but we need to present the evidence to convince donors.  
• Whatever quick bullet points on evidence that we can get would be helpful due to upcoming meetings in which those might be useful. |
| **Panel 1: Why focus on young children born into HIV affected families?** | |
| **Ms. Marine Davtyan**<br>UNAIDS<br>(Session moderator) | • UNAIDS is very pleased to join UNICEF & the Coalition in organizing this meeting.  
• We believe that addressing the specific needs of children is key in the response to the epidemic. Key to that are three things:  
  o keeping children HIV free - the Global Plan is a key priority;  
  o providing treatment to children who are HIV positive - the rate is 28% for children as opposed to 54%. We will be increasing the push to uptake of pediatric treatment by launching a new initiative later in the year;  
  o facing the multitude of issues faced by children born into HIV-affected families, whether they are HIV+ or not. Social protection is our key priority in this area. |
| **Dr. Pia Rebello Britto**<br>UNICEF, Early Child Development Unit | • The conversation is moving from child mortality to looking at the next generation is facing. We have made tremendous strides in child mortality but a 3rd of the world’s children are not achieving their potential.  
• Our strategies have to look at the nuances of different vulnerabilities -- which includes both HIV+ and HIV- children. We do this by strengthening mothers, but the challenge of OVCs offers a different challenge again.  
• Why early childhood? We look at prenatal to 8 years - looking at social, emotional, cognitive, language, but it’s a dance between the child and the context.  
• The intervention literature shows that the least cost to bring a delay pathway in line with the normative pathway is in the early years.  
• The years before school age are a huge gap in terms of intervention and these years are key.  
• ECD offers an entry point to offer an entry point to reach families through interventions that are evidence based, and can break the cycle of poverty. |
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| Ms. Gretchen Bachman  
Office of HIV/AIDS, Global Health, USAID  
Presentation title: "Focusing on the Youngest Children in HIV Affected Families" - Evidence on children born into HIV-affected families and PEPFAR/USAID programmatic approaches | - One PEPFAR/USAID project (in partnership with HSRC) is looking at the data of how HIV is affecting children in different areas -- this isn't finished yet.  
- From 2009, a review by Deedee Yates of our biggest programs looked at how well-represented our children under 5's were in our programs. It was 8% under 5, and 3% under 2. And, they determined that the statistical proportion should be 11% - HOWEVER, given the critical importance of these years, there's an argument to make that this should be even higher than 11%.  
- The Global Plan to Eliminate Mother to Child Transmission really raised the profile of young children at PEPFAR.  
- The key question is: How do we make this all work together so that we look at this as all mothers and children in the epidemic moving together in a continuum of services.  
- A study of testing in pre-schools showed 18% tested positive. And, while stigma makes it hard to go into pre-schools to test the kids, it's even more critical to catch these kids.  
- There's a huge gap in our response between the PMTCT interventions, which stop seeing kids at 18 months, and OVC that picks them up at 3.  
- We mapped an integrated care pathway from pregnancy through early childhood. What do we need to invest in to bridge the gap between 1) clinic-based care, 2) HIV and MNCH health care, 3) Community & Home based care, and 4) socio-economic support:  
  - invest in referral networks,  
  - case managers,  
  - multi-service community outlets such as ECD and social centers where appropriate.  
- We launched new guidance to get people connected. It said:  
  - start with the family;  
  - expand priority areas to include social protection;  
- In December, we came out with the Action Plan on Children in Adversity, and objective 1 is to build strong beginnings - go beyond survival to "thrive"  
- We have a new evaluation toolkit. Some of the questions now include early stimulation in the household, are they getting the HIV services they need, nutrition indicators etc.  
- We have a number of initiatives looking at gaps between PMTCT/PEDS and OVC in selected countries  
- We're also looking at an integration of parenting skills-development programs/ interventions into existing programs. |

| Discussion - key points | Lucie Cluver: How can we help the interventions?  
John Stover: how can we strengthen the funding for these connections? (Dominic Kemps: You have to include in the guidelines, as we do, the requirement that they integrate programs. We're seeing great results.)  
Jane Chege: is there evidence that integration between programs improves child outcomes?  
Claude Mellins: What is the role of mental health in all of this? |

Gretchen Bachman:  
- There's no easy answer. We've tried many things - cell phone reminders, small fund transfers to the referring organization and the mother going to a clinic (for transportation). Even in the best-case scenario, things fall through all the time.  
- However, there is solid evidence that cash transfers lead to better outcomes, and some evidence that community programs lead to better outcomes.  

Pia Britto  
- In ECD, integrated models work at very small levels but when we try to scale them up, we lose that power - because new variables come into the equation.  
- Where it does work in ECD, it's where we don't introduce many modalities, but rather integrate modalities with a different outcome. |
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<td>Ms. Monique Jackson</td>
<td>• When parenting occurs in groups, there's a greater sense of support, and a greater ability by mothers and fathers to talk about high-levels of stress.</td>
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| Pediatric AIDS Treatment Africa (Session moderator) | • PATA has coverage in 24 countries in Africa and hundreds of clinics.  
• While we're in a time of optimism, there are still 330,000 children infected every year and most children who need treatment are not receiving it. One of our key activities is that we hold forums in the clinic teams coming together to several times a year to learn. |
| Ms. Teresiah Otieno                                  | • We believe as communities of women living with HIV we hold the key to solving this problem.  
• The National Empowerment Network of People living with HIV is informed by the GIPA principles. The eMTCT agenda in Kenya was launched in 2012, but there was low awareness at the community level.  
• NEPHAK's interventions engaged women living with HIV at the community level in focused discussions, and to raise awareness and demand for PMTCT.  
• We find there's a lack of support for community caregivers. Women are expected to volunteer, for instance.  
• We need to increase community demand, sustain HIV services within the devolved government structure, incorporate qualitative research results done by women living with HIV into PMTCT programming, and ensure the meaningful participation of WLHIV, harness the capacities of communities to support PMTCT; male involvement; standardized package of health care packages.  
• Our role in supporting children affected by AIDS has not been well enough supported.  
• Supporting mothers to disclose their HIV+ children's status will help us to help their children. |
| Mr. Craig McClure UNICEF                             | • The shifts in UNICEF's programming going forward and what it means at the country level.  
• Over the past year, UNICEF has done a thorough review of its programming in prep of its new 2014-17 strategic plan. HIV is one of 7 core outcome areas, and this was important even as we change the way we do business.  
• Our vision is that all children are protected from HIV infection and live free of AIDS.  
• You'll be familiar with the 4 "P's" and these remain core approaches but this approach has become too siloed.  
• We will now look at the first two decades of life.  
• In the first decade - focus on infants, young children and mothers  
• In the second decade - focus on adolescent girls and adolescent key populations  
• To operationalize the integrated approach, it won't be easy.  
• 2012 data will be published at the end of next month but the progress continues to be impressive. In most of the priority countries remain focused we will be able to achieve the elimination of vertical transmission.  
• However, the number of exposed but uninfected children will remain large, and there are issues with those kids. We need better alignment with the child survival initiatives.  
• We need to simplify - move from PMTCT to a treatment approach for all pregnant mothers - the one-pill approach is key.  
• But integrating PMTCT with treatment programs at the local level will create more challenges. |

**Panel 2: "PMTCT as a critical entry point for early interventions for children"**
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| **Prof Catherine Peckham**                  | • Interventions are most effective when they're based and owned at the community level and often with people living with HIV.  
• We need to learn how to better link biomedical and social interventions to achieve common outcomes - and work together to forge stronger relationships between research and program. |
| Institute of Child Health, Harvard           | **Presentation title:** Biomedical perspective on PMTCT and pediatrics - opportunities                                                                                                                                 |
| **Discussion - key points**                  | • **Kate Iorpenda:** How do get the PMTCT community to go beyond 18 months and the OVC community to start earlier.  
• **Craig McClure:** Already progress has been made in the PMTCT world - e.g. there are virtually no stand-alone PMTCT services anymore. Many more steps need to be taken, particularly in looking beyond the post-natal period to beyond 5 years. As things get easier in terms of the pills and tests, this will help things. We hope one or two early infant diagnosis tests will come forward in 2014.  
• **Teresiah Otieno:** The Community Engagement Working Group on PMTCT has come up with some promising interventions to take things beyond 18 months. For us what is important is to have better qualitative data to track women's experiences in services.  
• **Dominic Kemps:** It's important we disseminate the results of these large numbers of programs.  
• **We're looking at 3 layers in the ViiV Positive Action Programme. 1) We're looking at case studies, 2) we're also rolling up the data and looking at it through the lens of the "four prongs" - we'll make it available publicly, and 3) we'll be standardizing the reporting coming out of our programming, and a summary sheet for each program will be published on a social media platform.  
• **Craig McClure:** on the issue of dissemination: The Coalition did a great job of putting out a journal on their last series and that was a great resource. But in terms of translating this into scaled-up programs, I’m not sure we'll ever get there. The point is that national programs need to budget for local community-driven support services, and that PLWHIV need to be central to those programs.  
• **Nigel Rollins:** The initiative is coming from the HIV side. Everyone wants to integrate as long as it serves OUR outcome without a clear commitment to bi-directional benefits. |
| **Panel 3: "The science of early child development: Application to HIV affected populations"** | **Professor Linda Richter**  
Member, The Coalition for Children Affected by AIDS & Human Sciences Research Council,  
• We're in the midst of a kind of scientific revolution in ECD. Margaret Chan’s editorial supports these initiatives. The African Union is saying that early losses in learning contribute to 6-10% loss in GDP  
• We’ve been able to take stock in an integrative way of what’s happening in this field both in basic and applied science. It’s been contributed to by the cohort studies.  
• We know now we can’t divide the biological from the social. Now it’s about how we bring this knowledge to understanding with HIV in families and children. |
| Speaker | South Africa  
| (session moderator) |  
| **Professor Lorraine Sherr**  
| Member, The Coalition for Children Affected by AIDS & University College London |  
| Presentation title: *Cognitive development, HIV and Children* |  
|  | • What do we know:  
|  | o Over 60% of adults with HIV some cognitive effects.  
|  | o Before cART treatment, almost all developed some brain pathology;  
|  | • HIV Associated Neurological Disorder: 3 kinds: Asymptomatic neurocognitive impairment, HIV-associated mild neurocognitive disorder and HIV-Associated dementia (HAD),  
|  | • What about children though.  
|  | • Cognitive effects: Most studies show a negative cognitive effect on children in HIV+ children. In an updated meta-study, 50/66 studies showed a significant detrimental effect of HIV, 11/66 showed mixed effects, but we are getting more sophisticated, and so we’re seeing in those studies that there are impacts in some areas and not others.  
|  | • In HIV-affected children? Many people used HIV-affected children as their control group, and some used totally unaffected as their control group. Looking at the affected children - their mortality is higher than the completely uninfected. With cognitive development, the control do better than the affected kids.  
|  | • In terms of programming interventions - 4 studies show that we can mitigate the effects.  
|  | • In the UCL-Stellenbosch (Sherr-Tomlinson) Child-Community Care Cohort Study - preliminary results show some effects, but we found no difference on mental health. The one difference was accounted for by parental death.  
|  | • Developmental delay: 45% showed some developmental delay, in contrast to 70% for HIV+ children.  
|  | • Cognitive effects of HIV need to be monitored and provided for - and children exposed to HIV may also have a need.  
| **Professor Stephen Lye**  
| Fraser Mustard Institute for Human Development |  
| Presentation title: *Tracing Health to Its Roots, Linking Early Childhood Development to Healthy Adulthood* |  
|  | • Provide a biological context for the effects of early life on development to adulthood  
|  | • The first 2000 days establishes lifelong trajectories towards health or disease, learning capability and social function.  
|  | • The future burden of not investing?  
|  | o *Non-communicable* disease burden is increasing dramatically.  
|  | o Failing to maximize our children’s learning capabilities  
|  | • The genetic blueprint can be influenced by the environment in a number of ways:  
|  | o slight genetic difference increasing or decreasing our risk of diseases — and our environment can either enhance or reduce that risk, but it can also impact whether or blueprint is fully functioning - it does this through epi-genetic modifications.  
|  | • Maternal stress, socio-economic status, pre-pregnancy/ maternal health, placental insufficiency, hormones and drugs, environmental toxins, nutrition.  
|  | • Reduction in food levels in the mother had effects in 15 areas of the child’s health over his/her life.  
|  | • In the Western Australian Pregnancy Cohort - 1989 -2011, stressful events of the mother during pregnancy were found to have higher risk of mental health disorders in the kids at age 14.  
|  | • We’re also learning that there are windows during pregnancy where certain organs are being developed where the risks are greater and the effects shown appear at different times in a child’s life.  
|  | • Epigenetics (the study of when different genes are "expressed" without the sequence being altered) - shows that during adversity, certain genes don’t ‘open up’ - i.e. are not switched on. Furthermore, the effects are multi-generational.  
|  | • Negative impacts of stressful effects can be mitigated by interventions during early children - such as breast-feeding.  
| **Dr. Lucie Cluver**  
| Oxford University |  
| Presentation title:  
|  | • One of the biggest mistake in HIV prevention in the past 30 years is wanting to find single solutions;  
|  | • Showing risks for AIDS-affected children. Two 4-year longitudinal studies - following 8000 children, 2600 caregivers.  

### Risks within family settings for affected children (focus on younger children)

- Effects of HIV-affected children: 2-to-3 times levels of psychological disorders, higher levels of transactional sex, transmission of opportunistic infections, child abuse.
- But there are different pathways - it’s not all the same effects.
- Toxic stress models (looking at the effects where there is an adding up of different stress factors) looking at adverse longitudinal effects on mental health - sharp rise as additional adverse experiences are added up.
- There are particular factors: family AIDS, abuse and hunger together, for instance, has a huge impact on transactional sex for adolescent girls.
- If we add in the effect of living in an AIDS-affected family on stressors we already know exist, the effects are compounded.
- Looking at what stress factors produce which results, and in conjunction with which other stress factors, and which results those in turn produce, gives us opportunities to design interventions to interrupt those negative factors.
- What we see is that 89% of the factors producing negative outcomes in children are modifiable (the only two that weren’t were AIDS orphanhood, and having an HIV+ parent) -- this is hopeful!

### Discussion - key points

#### Questions:
- What would be the 3 things you’d spend money on?  
  - **Nigel Rollins**: We shouldn’t make the mistake of seeing individual risk factors lead us to interventions that are focused on individuals. What are the policy interventions you’d make if you were a government minister?  
  - **Claude Mellins**: We look to models/ interventions that are too short (3-5 sessions) - and our research doesn’t track longer-term interventions well either.  
  - **Catherine Peckham**: Parenting work by Clyde Hertman in Canada - showed that this really worked, and was taken up by policy makers

#### Responses:
- **Lorraine Sherr**: When you look at the studies that exist, very few control the treatment. Many are in areas where they aren’t on treatment. We know that in adult studies some compounds pass the blood-brain pathways, but they’re not looking at this in children. There’s an opportunity.  
- **Stephen Lye**: Where I’d put my money: The focus for pregnancy shouldn’t be on the pregnancy itself but on young girls that will be the mothers of the next generation. Schools are a good access point. We need to empower young girls.  
- **Lucie Cluver**: The worry about only focus only on younger children is that some children only get affected. 3 places where I’d put my money: Cash transfers, ART adherence and parenting. I’d look at an approach rather than a solution. Re: parenting programs: most of the parenting programs that are shown to work cost money -- and are priced at what is above what developing countries can afford.  
- **Lorraine Sherr**: I don’t accept a limit on the amount of money. In terms of policy recommendations - we need to look beyond cash transfers. We need more evidence on the enablers, but the environment in which the child grows up is so important.

### Panel 4: “Challenges and advances in paediatric testing and treatment”

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| Dr. Anouk Amzel Office of HIV/AIDS, Global Health, USAID (session moderator) | I) summary of the morning  
  A) Integration of community and clinical interventions to best support families affected by HIV, specifically addressing the gap between the two  
  B) We need to focus on younger children given the great and complex effect of environment and disease on their growth and development  
  C) We need to focus on both infected and affected infants and children  
  II) Pediatric treatment |
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| Dr. Shaffiq Essajee  
Clinton Foundation,  
HIV/AIDS Initiative | • Infant diagnosis is important for PMTCT, but essential for identification of infected infants for ART.  
• Challenge: over 75% of exposed infants never even receive an EID test - even though it’s scaled up from 80K in 2007 to 1.2m in 2011.  
• Solution - build maternal HIV testing and exposed infant EID testing into the entire care continuum - taking it out of the PMTCT box.  
• For the 24 % of kids who are getting a diagnostic test, we’re still not managing to follow them through the continuum of care - high loss points.  
• In Kenya, we’ve set up a partnership to set up a an automated system to manage the tracking of samples from clinics doing EID -- using SMS printers. Results are posted in real time into an online database.  
• In Uganda, they established an EID care point to make sure there was a dedicated person tracking (with tools, technology, medication) who receives all the info from all parts of services in the hospital. It’s the focal point to report to the ministry on which exposed infant received ART and which didn’t.  
• Results of the pilot suggest significant improvement in a number of areas – The percentage of exposed infants initiated on CTX increased to 99% receiving treatment.  
• Point of care testing has been a significant solution - and performs as well as conventional DNC Polymerized Chain Reaction (PCR) testing.  
• Challenge: Infants that get a test are getting it late. Average age of first test was 3-6 months, but the peak of infant mortality is before that time - probably because the success of PMTCT programs means that the kids still getting infected are probably being infected in utero and those have an early mortality rate.  
• We’re moving from a 6-week PCR to a Birth PCR, and a 10 week 2nd PCR. South Africa is considering this. WHO is planning to convene a group to allow/courcage countries to do this.  
• Money is a problem - much of the progress and scale up has happened because of UNITAID’s commodity and programmatic funding - but what happens next now that that program has ended? |
| Dr. Stephen Arpadi  
Mailman School of  
Public Health,  
Columbia University | • I could have called this talk 'getting back to basics'  
• There are few opportunities for HIV testing for children. Apart from PMTCT and EID programs, the opportunities are spotty at best. Many kids are invisible to the health care system. Not covered are children of PMTCT dropout, children of mothers not in PMTCT, and adolescents infected later.  
• Neglected portals of entry: children of parents in PMTCT and HIV services, children in hospital wards, clinics  
• Opportunities include: In health services; TB services, sexual and reproductive health/ family planning services and expanded programs for immunization. Even more neglected are opportunities in the community sector: OVC services, schools, churches, home based services.  
• There’s little testing of older children of mothers in PMTCT  
• We need to expand Provider-initiated Testing and Counselling (PITC) to children of adults in HIV treatment (only 18% of children of adults in an ART program in Malawi, only 27% in a Nigerian study).  
• Extending universal PITC in paediatric health services is a great way to expand access.  
• Examples were given of programs using PITC in schools, and one using a household survey as a way to identify children for testing.  
• What does it take to scale up universal PITC in these various settings:  
  o clear and well-known policies regarding consent for testing in children  
  o effective procurement and supply chain for test kits  
  o human resources for counselling an follow-up support  
  o in healthcare settings, reorganization of space and patient flow to support routine testing may be necessary  
  o information management - "seamless" lab/medical record system to facilitate movement of
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| **Dr. Tin Tin Sint**  
UNICEF  
Presentation title: *Nutrition as entry point for identifying HIV exposed children* | - Patters of uninfected children suggest that exposure to maternal HIV does not affect growth  
- Severely ill children had poorer growth at all ages.  
- Nutritional status of the child can be an indicator of illness in children  
- A project looked at bi-directional integration of Infant and Young Child Feeding program and PMTCT interventions including EID. Discussed results from a programmatic intervention in Sofala province in Mozambique, where there was HIV screening of children by nurses at routine child growth monitoring and vaccination services. It looked at several physical indicators including low weight for age, and malnutrition, as well as some other circumstantial indicators (non-birth hospital, other HIV+ sibling). If the child met any one of the indicators, they were given a rapid HIV test. About 11% were given a test, and 8.3% tested positive.  
- Using growth monitoring to do simple screening for HIV has an opportunity to capture a significant number of children.  
- We’ve been asked if we can reduce those criteria to even more specific criteria. |
| **Discussion - key points** | - **Anouk Amziel:** Thanks to panelists for helping us understand the need to find the children, find them early, the ways to find them, and the ways to keep them in care.  
Questions  
- **Rachel Yates:** One thing that comes out is that it's not just systems failures is that it's also poverty that is a huge factor in loss-to-follow-up. Has CHAI done any work to identify the “why” of the loss to follow-up?  
- **Chewe Luo:** How would we link this together in a national program?  
- **Lorraine Sherr:** it’s a political as well as a practical question of why so many kids aren't being tested. If they were, is there treatment for them?  
- **Lucie Cluver:** Are there any programs that aim to follow children once tested, positive or negative, into OVC programs. Also, regarding testing in churches: what are the negatives or positives of that?  
Responses  
- **Shaffiq Essaje:** there is good evidence that people will come to programs if food is offered. We need to decentralize pediatric testing and treatment and get this into primary care facilities.  
- **Stephen Arpadi:** I'm not aware that we've exceeded capacity. In many PEPFAR-supported programs, they haven’t yet met targets. Regarding church programs, I can’t comment on its wider use.  
- **Tin Tin Sint:** We've been reminded that even if we aren't doing well in finding children in need in the HIV world, we're in the same rates as other.  
- **Anouk Amziel:** The higher the numbers on treatment - the easier it is to keep them because of the procurement issues. Regarding the churches - one experience I know of was very successful. |
| **Panel 5: "Comprehensive care and support models for CABA"** | - We come to a subject that is the heart of The Coalition for Children Affected by AIDS's work - comprehensive care.  
- If we do comprehensive care and support well, they can be over a number of age ranges.  
- A key question is: "to what extent are care and support models designed for early intervention and able to meet the needs of children of all ages?  
- This question can be considered from two perspectives:  
  o First, it is about the extent to which care and support models for children affected by HIV have explicitly included ECD interventions. Both 'Taking Evidence to Impact' and the PEPFAR 'OVC Guidance' highlight the importance of ECD components being included in care and support. |
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| Dr. Mark Tomlinson      | Support programmes, especially in areas of high HIV prevalence. As a result they recommend linking ECD centres to health, PPTCT and nutrition programmes. However, there is little evidence that most care and support programmes have included ECD components. As Gretchen pointed out: the 2011 AIDSTAR-One review of USG-supported OVC programmes found that “only limited resources had been devoted to the youngest children, including ECD initiatives”. Interestingly, Lorraine Sherr has found that preliminary findings from the Cohort Study indicate that ECD interventions have been amongst the most common across the programmes studied.  
  o Second, and probably more importantly, as care and support models have evolved, they have generally become more comprehensive - looking to have impacts that support children and families both earlier and on a wider range of issues as well as in ways that complement prevention and treatment. The more comprehensive care and support programmes have been characterized by several features:  
    • They have emphasized the importance of the social-ecological conceptual framework - recognizing that children are situated in systems of relationships within families and communities that influence their well-being  
    • Comprehensive models empower children as agents of change within these systems and encourage them to be active participants, building their resilience  
    • They are holistic models that aim to meet children’s developmental, cognitive and emotional needs and as result must be multi-sectoral involving: education, health, social welfare, child and legal protection  
    • They are family-centred - addressing the needs of the whole family - adults and children - recognizing the importance of keeping parents and carers alive, hence linking OVC platforms with counselling, testing, treatment and PPTCT programmes, enabling families to function  
    • They build the capacity of communities to assist care and support and strengthen referrals between informal and formal systems of care and protection.  
    • These components can all be found in the two main care and support frameworks: 'Taking Evidence to Impact' and the PEPFAR 'OVC Guidance'  
    • The question is: to what extent are most care and support programmes fully comprehensive and to what extent are they conceived and structured to be able to link with child survival, MNCH and PPTCT programmes? |
| Stellenbosch University  | Presentation about Philani - they have a comprehensive set of interventions in the Western Cape, South Africa. Cluster randomized controlled trial. 450-500 households in relatively well-functioning health system.  
  • We’re having an effect on child cognitive development  
  • At baseline, results were:  
    o 29% HIV+  
    o 25% Alcohol using  
    o 17% Low birth weight  
    o 30% Depressed mood  
  • Saw improvements in feeding at 6 months, and in maternal antenatal depression and infant health at 18 months |
| Dr. Theresa Betancourt  | We've just done a study comparing infected, affected, and non-affected. The infected and affected weren't significantly different but were much higher than the non-affected children;  
  • We've been arguing for the SAFE model: Safety, Access to health care and basic physiological needs, family/ connection other, and Education/ economic security;  
  • We moved to family-based prevention;  
  • We see the importance of the social ecology model 1) community & societal, 2) family and 3) individual; |
| Harvard School of Public Health | Presentation title: *Interventions for HIV positive mothers and child development outcomes*  
• We've just done a study comparing infected, affected, and non-affected. The infected and affected weren't significantly different but were much higher than the non-affected children;  
• We've been arguing for the SAFE model: Safety, Access to health care and basic physiological needs, family/ connection other, and Education/ economic security;  
• We moved to family-based prevention;  
• We see the importance of the social ecology model 1) community & societal, 2) family and 3) individual; |
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| **Prevention of Mental Health Problems in Children Affected by HIV/AIDS: An Example from Rwanda** | • The intervention: Bill Beardslee's interventions were originally used for depression and has been scaled up in a wide range of setting but not in Africa, and not to HIV. It looks at 4 family-related risk factors and links them up with a corresponding core component of the intervention (e.g. misinformation and fear of HIV --> psychosocial education about HIV/AIDS and trauma), and together we see an improved parent-child relationship and diminished risk of mental health problems in children;  
• Involves a pre-session, then six weekly home-based interventions, then a family meeting review and a follow-up meeting.  
• Results: 90% participant satisfaction and 100% from interveners. 50% brought up the genocide as a significant narrative in their family without prompting. 28% of caregivers had not disclosed HIV status to their children. Trends in child-reported measures are in the right direction in reduction in depression and irritability -- though the study is not sufficiently powered.  
• 'Facilitators of change included 1) Strong connection to the interventionist, 2) Repeat processing/integration of psycho-education, 3) Encouraging stronger family-child connections, 4) Connection to formal/informal support. Challenges: 1) persistent material needs, 2) families in crisis, 3) importance of having a functioning health system, 4) prevention takes time, and 5) Funding at each phase of the research. |

| **Dr. Morten Skovdal**  
London School of Economics Institute of Social Psychology, University of Bergen & Save the Children | • There’s a potential danger of using the ECD discourse to blame parents and pathologize children - for things that are not really in their control.  
• ECD discourse is located into developmental psychology. Piaget does acknowledge the social as a factor, but he focuses less on this and more on the child.  
• ECD discourse focused, in the 20th century, on teaching working class families 'rational parental behaviour'. Today there’s a preoccupation with absent father, gay families, parents robbing their children of their future. There's a preference for parent-child interaction as practice by nuclear heteronormative and privileged families. Dr. Skovdal pointed to some US-based literature pointing fingers at HIV+ mothers.  
• In summary, ECD is not value-free.  

Instead we see local, socio-ecological responses:  
• We need to shift things to things that prevent/ enable caregivers to facilitate child development.  
• We need to activate parent-enablers  
• Child development should be thought of on a continuum, with the 'rings of enablement' at the 'good' end of the continuum. We need to better understand that.  
• There are a couple of studies suggesting that there may be a 'come-back' effect -- poorly understood -- in HIV-infected children when compared with HIV-negative children, evening out the effects over time.  
• If we look at children's and community's coping strategies, we might learn a few things about what to do!  
• The implications of this critique for "The Essential Package" on ECD: We may need more focus on frameworks 1 & 3 - the building blocks of good childhood development, and less of a focus on Framework 2 - the prescription of essential inputs, activities, environments -- which is less culturally-driven. |

| **Discussion - key points** | • **Lisa Bohmer:** Could Theresa speak about a strength-based approach to education? Could Mark comment on what it would look like if we  
• **Teresia Otieno:** To Mark: The community health workers - they were given a stipend - what does this really mean? Is it really commensurate with the level of work they were doing?  
• **Lucie Cluver:** There's a tension between should we be emphasizing the problems or the positives. If we see studies showing 2-3 levels of abuse in parents with HIV should we be publishing this? It could lead to interventions  
• **Morten Skovdal:** taking a strength-based approach doesn’t preclude highlighting the difficulties. We |
### Speaker | Selected key messages
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**Theresa Betancourt**: When it comes to statistics, we have to tell the truth, but our responses have to be strength-based.
**Mark Tomlinson**: We can't glorify cultural practices. Good and bad things emerge from cultural practices.
**Nigel Rollins**: I wonder if the same conditions that set up vulnerability to abuse the same vulnerability to HIV --- and shouldn't we be looking at vulnerabilities in the community?
**Linda Richter**: The Coalition has been a champion of strength-based approaches. We rallied around families to support them. The same with communities. 2nd point: Mary-Jane Rotheram-Borus has challenged us - we create a program externally and then many can't be scaled. But interventions develop organically in communities - something develops in the community and things take hold. MJ Rotheram-Borus has said we should really be testing organically-emerging programs.
**John Miller**: Mentioned that the Coalition has confronted the tension between stigmatizing key population parenting and the needs of their children by coming out strongly as both supporting parents, while prioritizing the needs of their children.
**Rachel Yates**: It takes all levels - community, family and state-based responses. Saying we should only focus on things that emerge from the community can lead to a neo-liberal privatization of care philosophy.

### Panel 6: "Translating research into global policy"

| **Dr. Nicole Behnam**<br>Office of the U.S. Global AIDS Coordinator (OGAC), US State Department (Session moderator) | • When we were setting out to do our new guidance, we did an intensive technical / research review - it was such an intensive process. We were trying remind ourselves that these global level policies are based on research - and we're grateful to the researchers, many of whom are in this room, for giving us this work, but we are also indebted to the practitioners on the ground.
• Everything we learn, we should apply to this work. |
| **Dr. Nigel Rollins**<br>World Health Organization Presentation title: Care for early child development | • Our development in our family has been in reading more than anything else
• There's a greater understanding of the context in which vulnerable children are growing up, and the risks that are connected to the mother's health -- and possible death.
• We cannot just talk about transmission and HIV-free survival. We want to talk about lack of transmission, survival and development.
• There is a call for global action for ECD.
• In maternal and child health there are concurrent crises - that demand cooperation. Funders are demaning more return on investment. There's a fear over the ability to sustain vertical programmes.
• The Lancet did a 2007 series with a couple of references to HIV being a biological risk to child development. The later series referenced a few robust strategies for interventions. The examples came from limited settings.
• We need clarity and agreement on the benefits, supported by an evidence base.
• You need to ready to move with the time is right, even if the evidence isn't already there.
• WHO follows a process to develop guidelines and you consider not just the evidence - you also consider the benefits and downsides, impacts on families etc. -- and every guidance has a shelf life.
• WHO has initiatives in ECD, for instance: 1) from a January 2013 meeting, 4 objectives emerged (see slide 23), and 2) there is a WHO roadmap on ECD (slide 24),
• Knowledge gaps are:
  o Build evidence around the implementation science for integrated ECD services at scale.
  o Knowledge about ECD of high risk children
  o Health system readiness needs to be evaluated prior to introduction of new interventions
  o Learn lessons from other sectors and success stories within health on feature of success for
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<td>Mr. Brian Lutz</td>
<td>The Post-2015 processes and results to-date</td>
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<td>UNDP</td>
<td>• The MDGs didn’t respond to all the things in the declarations - but there were 8 goals.</td>
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<td>Presentation title:</td>
<td>• Why do we care in the first place? People say they galvanized people around a common agenda - there was a rise of financing since then? This could be one of the reasons.</td>
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<td>How early years</td>
<td>• There’s a high level report, MDG consultations, Rio +20 consultations, and many other processes happening concurrently. I’m going to focus on the &quot;Post-2015 Framework Process&quot; mandated by the 2010 MDG summit. The 2nd process is the Sustainable Development Goals process - coordinated by member states, and mandated by RIO+20 Outcome Doc. There isn’t a clear mechanism connecting the two.</td>
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<td>investments are</td>
<td>• For the &quot;Post 2015 Framework&quot;, there’s the UN Task Team on Post-2015, chaired by UN-DESA, UNDP.</td>
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<td>coming up in the post-</td>
<td>• There’s the High-level Paonnel on Post 2015 Development Agenda, there’s the UNDG consultations, and there’s something called the Sustainable Development Solutions Network (lots of academic and technical advice here), and there something called the Global Compact.</td>
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<td>MDG responses</td>
<td>• For the &quot;Sustainable Development Goals process, there’s an open working group on SDGs.</td>
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<td>• Timelines: The secretary-general’s process, the &quot;Post-2015 Framework&quot; process, we’re just at the point that the High-level panel is being submitted to the SG.</td>
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<td>• The UN Systems Task Team is setting out goals and a framework, that include human rights (which weren’t in the original NDGs).</td>
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<td>• What are the consultations saying: 1) we can’t chuck the goals - there are things left undone. 2) let’s look to the future, including human rights, inequalities, sustainability, quality, young people.</td>
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<td>• <strong>Yesterday, the High-level Panel Report came out:</strong> The focus of the report is on 1) Environment, and 2) Poverty. There’s a new target on pre-primary education, under 5 mortality, ending child marriage. References to children in this report is stronger than AIDS. Health care is mentioned 5 times in the narrative, and then Appendix 2 has a Health goal. No mention of AIDS in the narrative but it's mentioned as a target. What is being proposed is a single health goal.</td>
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<td>Implications</td>
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<td>• Themes: inequity, human rights, vulnerability, unfinished business of MDGs, Universal health coverage</td>
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<td>• Other narratives: growth, employment, End of AIDS, healthy life expectancy, environmental sustainability and governance.</td>
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<td>• What do we do?: There are some basic choices being made fairly early, but there are multiple intersecting entry points. We need to find champions.</td>
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<td>Discussion - key</td>
<td>• <strong>Mark Tomlinson:</strong> I liked Nigel Rollins' image of supporting the mother to protect the child.</td>
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<td>points</td>
<td>• <strong>Pia Britto:</strong> the one area we know came out in the MDG report was on pre-primary education. What are the ways to advocate with the member states?</td>
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<td>• <strong>Brian Lutz:</strong> I see a wave of momentum happening around ECD, but I don't see it highlighted in this report. Where children come into the report is around their 5 pillars - making sure children have a fair chance in report. BUT - this is just one report. The Open Working Group (member states) is the juggernaut working its way through the system. We have to find champions in those member states.</td>
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<td>• <strong>Marine Davtyan:</strong> It looks like the high-level panel tried to merge and find attention between those who found the MDGs didn’t include the environment and sustainability, and those who felt that the &quot;poverty&quot; and &quot;sustainable development&quot;.</td>
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<td><strong>Linda Richter:</strong></td>
<td>We can marginalize ourselves by how we talk about pre-primary. We marginalize by talking about 'play' - talk about early learning - by then we talk our way into primary education. The Coalition should scrutinize our language in order to get into these conversations.</td>
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<td><strong>Brian Lutz:</strong></td>
<td>There’s an opportunity to talk about early childhood as a way to get at the goal of eradicating poverty by 2030.</td>
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**Panel 7: "Integrated support to families for optimal development"**

| Dr. Ann DiGirolamo | The global ECD community really is recognizing a focus on the whole child - the interaction between the physical, cognitive, languages, social and the emotional. |
|--------------------| We’ve also been meeting globally regarding integration - for instance with integration. We need to look at what this means on the ground. One-stop shopping? Different providers that are coordinators? Or one outcome driving the innovation? |
|--------------------| Let’s bring us back to: 1) how can we reach the most vulnerable children and families? how can we keep them in the system, and how can we provide them with the continuum of care from early childhood through to adolescents. |

<p>| Professor Linda Richter | Brought us back to a quote by John Williamson from back in 2000, that we are not reaching the scale to meet all the children. |
|--------------------------| Not even life-saving health programs are at scale. The idea that a program we come up with will be taken to scale is not realistic: we have to think differently. |
|                         | We reviewed programs in high-income countries and thought how can we apply these to lower income settings. |
|                         | The common elements are: |
|                         | o Foundational features - established for political reasons. They have a vision of a comprehensive approach |
|                         | o they are led by a lead department |
|                         | o regular reporting to government |
|                         | o high degree of transparency |
|                         | o high degree of engagement with parents |
|                         | o local variability but conform to founding principles |
|                         | o evaluated on a 4-5 year funding cycle |
|                         | o They all incorporate certain key elements; |
|                         | Should we start big and try to get better? Start with one jurisdiction that's fairly large |
|                         | In our review, it made better sense to organize the services according to the goal of parenting support (preparation for parenthood, child development, child behaviour management etc.) |
|                         | I came away with optimism: |
|                         | o Supporting parenting is integral to strengthening families, an agreed pillar of the response to children |
|                         | o There are very few studies on parental support in context of AIDS and poverty |
|                         | o but solid grounds for optimism based on positive results based on positive results and experience gained in HICs |
|                         | o Must be combined with structural enablers |
|                         | Existing programs are culture-bound, resource intensive, un-scalable - with little evidence to choose between them. |
|                         | Instead, perhaps a common elements approach. |
|                         | There’s an argument for and against the efficacy of a 'package'. The argument against is that argument is always critical, the program must always be adapted, etc. |
|                         | We should use a common logic model, a common theory, must use social support, parents must be involved (they want to be). |</p>
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| **Dr. Claude Ann Mellins**  
Columbia University & HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute and Columbia University  
Presentation title: *Ongoing follow up of HIV positive adolescents within an integrated approach – future issues and challenges* | - Pediatric HIV in much of the world will shortly be an adolescent epidemic. My comments are on research in the United States.  
- In the US, nearly there are nearly 10,000 youth/ young adults living with HIV.  
- Understanding pathways to resilience has been helpful for defining the components of intervention.  
- There’s lots that we know about the cognitive problems resulting from ART, and high-rates of non-adherence in adolescents.  
- 45-65% of the youth, despite tremendous adversity, do not present with a mental health problem—we do not know much about why. HIV+ youth are using substances much less than their HIV-peers. They’re not initiating less any earlier. Their use of unprotected sex is much lower. In terms of non-adherence, when compared to other conditions where youth take drugs, the youth with HIV are doing better.  
- We need to examine more the protective systems - health systems, parenting, etc.  
- CHAMP program: for older children and early adolescents - the goals it to promote resilience in a number of ways. Multiple families come together for 10 sessions  
- SUUBI program uses economic strengthening/ investments for $$ that can be used for education - has produced great evaluated results. |
| **Dr. Michael Samson**  
Williams College  
Presentation title: *The role of cash transfers in the early years - how does it support families and children affected by HIV* | - Works at Economic Policy Research Institute in Cape Town as well as at Williams College  
- Talk is about a new approach in many countries that is recognizing the complexity of tackling many challenges -- it focus on integrating these social protection programs into a planning framework for achieving a number of government objectives.  
- Cash transfer programs have increased in Africa from 9 to 41 countries between 2000 and 2012.  
- Social protection can have a positive impact on 1) Insufficient access to food, 2) inadequate maternal and child-care practices; and 3) poor water sanitation and health services -- which reduce disease and inadequate diet, which reduce to child malnutrition, death and disability.  
- Social protection acts to give people direct access to vital goods and services, provides greater economic power to vulnerable groups, and protect people from the vulnerability they face in their livelihoods. These have many spin-off effects. |
| **Discussion - key points** | - **Rachel Yates:** How we bring this nexus of cash and care together? We only have one example (Izibindi)  
- Can we scale up before all the evidence is together?  
- **Lucie Cluver:** Whether/ how can we combine cash transfers with things like parenting supports? The problem is these are quite different types of programs delivering these. Is there a cumulative effect of combining these programs? Do we want to combine them?  
- **Linda Richter:** There isn’t THE intervention. The success of the scaled up child-development program was that they were able to be tailor things locally while adhering to certain standards.  
- **Claude Ann Mellins:** There aren’t shortcuts - we have to focus on multiple systems.  
- **Michael Samson:** I appreciate how difficult it can be to join up interventions but I’m convinced this will be the only way to develop the cost-effective interventions we need.  
- **Dominic Kemps:** How do you identify people who make good candidates for cash transfers? |
**Selected key messages**

- **Michael Samson**: There's no good solution for the targeting problem. It's the one design problem for which we don't have a good answer. The question then becomes who do you least want to exclude?
- **Nigel Rollins**: A plea: in looking at these studies on child development, look at things like linear growth. Linear growth is most closely aligned with the opportunities to survive the non-communicable diseases.
- **Linda Richter**: We haven't effectively brought together evidence to argue that the factors affecting survival are the factors affecting child development.
- **Pia Rebello Britto**: For scaling up, we need to understand how this model fits into the existing systems. How can we support them so that they become sustainable.
- **Caroline Ryan**: How would your interventions change based on the gender of the child?
- **Claude-Ann Mellins**: We have to answer some important questions in our programming -- particularly when we're looking at talking about strengthening the protective factors of parents of adolescent girls who are being abused in their families.

**Panel 8: "Too expensive to do, too expensive not to?"**

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| Dr. Rachel Yates | • Pleased to welcome Chris and John.  
• Had to pleasure to do some costing work with John and the Futures Institute, which they'll be presenting here. |
| Dr. Chris Desmond | • The longer the period of inaction, the cost that it will take to reverse the damage will increase over time.  
• If you're prepared to allow a child to have a terrible childhood and have no schooling, it won't necessarily have an impact on the lives of elites. But if you value the goal of investing in children in and of itself, then the longer you leave it, the more it will cost.  
• Can we apply investment thinking around the investments we do? Investments in what. A single or sets of intervention? Sometimes a single investment may not be a wise investment.  
• What are the returns? Immediate benefits to children, then there are shorter or longer-term ones. Perhaps the most difficult aspect is that there's nothing neat in terms of outcomes for children - there are multiple outcomes.  
• When you narrow your focus, it changes your conclusions.  
• A single intervention will work much better in an environment where there are many other interventions in place. In settings where there isn't much, applying multiple interventions will likely produce better results as they'll work together.  
• Can we say anything about efficient interventions?  
  o Dedicating ourselves to family strengthening, and one good way to do that is cash transfers  
  o early intervention is more efficient than later intervention  
• Early intervention means shifting from a response to a prevention frame. Efficiency is gained, and suffering is avoided.  
• What constitutes early? Early intervention is at the point of contact - even if older "every ten year old was once a one year old, but no ten year old will be a one year old again"  
• PMTCT programs are a very strong entry point.  
• So why is there not enough spent or why do we think there is a risk of spending cuts? Don't people care? Don't people accept the responsibility? (yes particularly 0 to 2) Do they not understand the benefits, particularly the longer term one?  
• Deciding how to get there is easier than saying where you want to go. With our "eye on the prize" we... |
### Speaker | Selected key messages
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**Mr. John Stover**  
President, Futures Institute  
Presentation title: "Resource Needs for the Protection, Care and Support of Children Affected by AIDS" *Bringing protection, care and support for families and children into Investment thinking*
- We set out to estimate the resources required to achieve higher coverage of key actions for protection of children affected by AIDS -- this was an update of 2005 estimates.
- Since 2005, the focus has shifted from the direct material support provided by NGOs to a mix of government and NGO program.
- Who are the population in need? Over time this has gone from "AIDS orphans" to "vulnerable children" We focused on a few definitions - we focused on orphans (all orphans, not just those living with HIV). We moved to another definition: "not living with either parent, OR "lost one or both parents" OR "no educated adults in household" AND we said they should be "living in households below the poverty line" Or "living in households in the bottom two wealth quintiles in their country."
- We used data from the World Bank.
- If we used the expanded definition to "vulnerable" children as we redefined it, it moved from a count of roughly 60 million to a count 300 million children.
- Interventions:
  - Economic support (direct material support, cash transfers to families, village savings schemes, HIV insurance schemes)
  - Education support (ECD, block grants for education, scholarships for primary and secondary, training or education staff, out of school clubs)
  - Community based services (social workers community care workers, accountability
  - Administration and support (governments, NGO’s policy / legislation, M&E
  - Not yet included (pediatric palliative care, prevention of fender-based violence, alternative care (foster homes, small group homes))
- We tried to forecast which services we thought would be given by NGOs in 2020
- We tried to imagine various coverage scenarios by 2020.
- We extracted unit costs form the 110 studies of various interventions: The cost was $5B, $8B or $70B depending on if you look at a) orphans in poverty, or b) orphans in the bottom quintiles, or the more expanded definition of vulnerable children.
- We also looked at the costing in various different ways and our model is dynamic so we can change assumptions.
- Limitations of our work: Some interventions not yet included due to limited cost data; Info is missing for some services; estimates are a guide to appropriate contribution from HIV programs, not to program implementation; and current approach does not yet link unit costs, quality of services and impact.
- A likely decline in numbers of children in need offers opportunities to significantly increase coverage of key services; Increases in resources required to achieve target coverage are modest; and Shifting mix of services means a greater role for government.

### Discussion - key points
- **Caroline Ryan:** In order to get gov'ts to be interested in investing in these services have you don work on economic impact?
- **John Stover:** A number of studies have been done but it's not clear that these are the major factor in encouraging governments. I don't know if doing these studies is needed to convince governments.
- **Kate Iorpenda:** Were there any interventions related to health or nutrition?
- **Chris Desmond:** It’s important to try to imagine or understand why others might not agree with us, before we go about lobbying.
- **Theresa Betancourt:** How can we bring into the costing exercises the compounding effects of connecting various interventions?
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| Mr. Dominic Kemps  
ViiV Positive Action Programme  
(Session moderator) | • We’ve gone from a micro level, to the value of investments, and now we're moving to the role of funders (as if we were some homogeneous mass)  
• We have so many categories of funders - bilaterals, multilaterals, country governments, NGOs, Private Foundations, and Corporate... and within each of those, so many different perspectives.  
• We're more than just about money - we support policy-making and advocacy, we can be think tanks, do capacity building, and we can be connectors.  
• We have a lot to contribute beyond the money, but... is there something in the way we work which is also an 'inefficiency' for the sector/ response.  
• For ViiV, we’re doing work in addressing loss to follow up and early infant diagnosis. So far our data doesn’t show high levels of early infant diagnosis - so we need to look at that. |
| Dr. Shaheen Kassim-Lakha  
Conrad N. Hilton Foundation  
Presentation title: Early childhood matters | • Hilton is a private family foundation, founded by hotel magnate Conrad Hilton.  
• Hilton made a deliberate move to become a strategic grant-maker 5 years ago. We want to do strategic or catalytic philanthropy and took several years to develop the strategy.  
• We decided to focus on children from birth to five, and in Eastern & Southern Africa, and to focus on them through parents and caregivers, not in institutions.  
• We’re now needing your support to help us navigate through all the stakeholders on the way to getting to caregivers and children.  
• We’re looking at integrated services, local approaches, focus on caregivers and families, capacity building of local organizations.  
• We’ve tried to make our targets measurable and quantifiable -- but we do want to see if we can push the sector forward  
• $50M in 5 years with 5 countries and 14 international partners.  
• Working with HSRC on the monitoring, evaluation and learning.  
• We saw the Road to Melbourne as a terrific opportunity. |
| Dr. Caroline Ryan  
Office of the  
U.S. Global AIDS Coordinator (OGAC),  
US State Department  
Presentation title: The PEPFAR Blueprint, the IOM review and what they mean for children born into HIV-affected families | • PEPFAR blueprint - December 2012 - moving to an AIDS-free generation  
• Reaching the tipping point - converging factors have led us to the moment when we can and have reached a programmatic tipping point -- more people are on treatment than are getting infected.  
• What must we continue in order to control the epidemic: we have to make strategic, scientifically sound investments, work with our partners to effectively mobilize, coordinate and efficiently use resources, focus on women and girls, end stigma and discrimination, against PLHIV and key population, and set benchmarks that are regularly assessed to assure goals are being met.  
• We have 4 roadmaps in our strategy: 1) Saving lives, 2) smart investments, 3) shared responsibility, 4) driving results through science  
• The IOM comment said: "To improve the implementation and assessment of nonclinical care and support programs for adults and children, including programs for orphans and vulnerable children, the Office of the U.S. Global AIDS Coordinator should shift its guidance from specifying allowable activities to instead specifying a limited number of key outcomes. The guidance should permit country programs to select prioritized outcomes to inform the selection, design, and implementation of their activities. The guidance should also specify how to measure and monitor the key outcomes.  
• PEPFAR’s new evaluation strategy which includes:  
  o intervention-linked research;  
  o program evaluation toolkit, currently being rolled out, programs to develop and to capture age-specific core outcomes for children affected by HIV/AIDS;  
  o working with MEASURE Evaluation to develop an M&E framework for social service systems strengthening  
• An AIDS-free generation is in sight, but we have to maintain our focus and momentum. |
| Discussion - key points | • Lorraine Sherr: Did the 10% earmark help or hinder and where's it going?  
• Lucie Cluver: Great that all the funders are working with researchers. What is the most useful thing |
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| **Professor Lorraine Sherr**   | **Reflecting and synthesis:**  
| Member, The Coalition for Children Affected by AIDS & University College London  
| (Session moderator)             | o The importance of the middle way - we need to pay for it.  
|                                 | o We can't deconstruct children  
|                                 | o There have been a few hiccups along the way  
|                                 | o Remember the adolescent survivors  
|                                 | • We do see a light at the end of the tunnel!!                                                                                                                                                                         |
| **Mr. John Miller**             | • The Coalition is supporting a special issue of the journal AIDS - co-edited by Linda Richter and Lynne Mofenson.  
| The Coalition for Children Affected by AIDS  
| Subject of remarks: Overview of plans for publication and dissemination of the Coalition's special issue of AIDS – including | • Papers must conform to all submission requirements of AIDS, which are to be found on the website at http://journals.lww.com/aidsonline/Pages/informationforauthors.aspx.  
|                                 | • Papers will be subjected to the standard review procedures of the journal.  
|                                 | • The final date for submission is the 20th December 2013.  
|                                 | • Enquiries about the Special Issue: Children Born into Families Affected by HIV can be directed to Linda Richter - richter@hsrc.ac.za or Lynne Mofenson - mofensol@exchange.nih.gov  
|                                 | • The journal will be launched at the Teresa Group-Coalition for Children Affected by AIDS symposium, 18-19 July 2014 – Melbourne, Australia  
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| **Dr. Scott Kellerman**  
Management Sciences for Health  
*Subject of remarks:* AIDS special issue tie-in with other AIDS special issue on PMTCT | • There will be another special issue of AIDS – title to be determined, but the general theme will be:  
Issues related to barriers and potential successes to the eMTCT agenda.  
• Produced by the Child Survival Working Group of the IATT on PMTCT.  
• Not an open call - they’ve identified 13 topics.  
• Launching early December at ICASA in Cape Town. |
| **Ms. Kate Iorpenda**  
Chair: The Coalition for Children Affected by AIDS & International HIV/AIDS Alliance  
*Subject of remarks:* Onwards to Melbourne (Plans for two subsequent meetings, for the Teresa Group/Coalition symposium in Melbourne, for the Global Partners’ Forum, and for AIDS 2014 in Melbourne) | • My overwhelming feeling is of the quality of the presentations.  
• Thanks to the organizing committee who put together the agenda (44th version!)  
• There's a compelling case for early intervention -- the case is even stronger now.  
• We done a bit of silo busting in this room!  
• There's strength together.  
• We make sure to remember those entry points and the multiple outcomes  
• The 2nd meeting will happen just before ICASA in Cape Town and will look at the programmatic evidence.  
• The 3rd meeting will look at the policy opportunities.  
• Thanks to our partner in this meeting - UNICEF. The support has been tremendous. |
| **Mr. Craig McClure**  
UNICEF HQ  
*Closing remarks* | • The meeting was a great success  
• I want to thank John, Kate, Lorraine, Linda, Rachel and Pat and the support staff who kept things going.  
• As difficult as it is breaking down the silos in the HIV world, breaking down the silos between HIV and child survival etc. is also a massive challenge. We have to put the child together again.  
• We had a big call with women living with HIV saying you consulted with us on PMTCT but not on pediatrics! It was a reminder that for ICASA it's important to include affected populations.  
• In terms of the next meeting in the Road to Melbourne, hopefully we can bring in national program managers. |
## Appendix 2 - List of Meeting Speakers and Participants

### Panel Moderators, Opening & Summary Remarks

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### Speakers & Respondents

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<tr>
<td>Ms. Kate Iorpenda</td>
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<td>Mr. John Miller</td>
<td>Coalition Director, The Coalition for Children Affected by AIDS</td>
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<tr>
<td>Ms. Teresiah Otieno</td>
<td>The National Network of People Living with HIV in Kenya (NEPHAK) &amp; The International Community of Women Living with HIV (ICW)</td>
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<tr>
<td>Professor Catherine Peckham</td>
<td>Professor of Pediatric Epidemiology</td>
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<td>Dr. Pia Rebello Britto</td>
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<td>Professor Linda Richter</td>
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<td>Dr. Nigel Rollins</td>
<td>World Health Organization</td>
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<td>Dr. Caroline Ryan</td>
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<td>Speakers &amp; Participant List who attended the meeting</td>
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**Dr. Stephen Arpadi**

Stephen Arpadi, MD, MS is a Professor of Pediatrics and Epidemiology at Columbia University, New York, NY and has over 20 years of clinical care, research and program implementation experience in the US and sub-Saharan Africa. He is a Technical Consultant to the PEPFAR-supported activities of Columbia University’s ICAP in the areas of maternal and child health programming including the design, development, implementation, training, mentoring and evaluation of prevention of mother to child (PMTCT) HIV transmission, pediatric HIV/anti-retroviral treatment, TB, and nutritional treatment and prevention services in Kenya, Nigeria, Swaziland, and South Africa. He has served on the WHO Technical Advisory Group on HIV and Nutrition and is a member of WHO/Unicef Inter-agency Technical Task Force Child Survival Working Group. He is a co-investigator in the Asenze Study—a multinational research project evaluating the prevalence and determinants of childhood disability among preschool children living in rural South Africa (NIH); the Expanded Pediatric Surveillance Study—a 24 month observational study of children initiation ART in public health facilities in Eastern Cape South Africa (CDC); Safe Generations, a pilot study of Option B+ for PMTCT in Swaziland (USAID); and is Principal Investigator of a study of bone health in HIV-infected pre-adolescents on ART in South Africa (NIH).

**Ms. Gretchen Bachman**

Ms. Gretchen Bachman is the Team Leader and Sr. Technical Advisor for Orphans and Vulnerable Children at the Office of HIV/AIDS at the United States Agency for International Development based in Washington DC. Gretchen has worked in the field of international development since 1993 throughout Asia, Africa and the Caribbean, focusing on projects to improve the health and socio-economic well-being of women and children. She is a co-chair for the PEPFAR Orphans and Vulnerable Children Technical Working Group, a steering committee member of the Inter-Agency Task Team for Children Affected by AIDS, and both a founding member and steering committee member of the Better Care Network.

**Dr. Theresa Betancourt**

Theresa S. Betancourt, ScD, MA, is Associate Professor of Child Health and Human Rights in the Department of Global Health and Population at the Harvard School of Public Health and directs the Research Program on Children and Global Adversity (RPCGA) at the François-Xavier Bagnoud Center for Health and Human Rights in the Department of Global Health and Social Medicine. Her central research interests include the developmental and psychosocial consequences of concentrated adversity on children and families, resilience and protective processes in child and adolescent mental health and applied cross-cultural mental health research. She has extensive experience in conducting research among children and families in low resource settings particularly in the context of humanitarian emergencies. She is the Principal Investigator of a prospective longitudinal study of war-affected youth in Sierra Leone and is developing and evaluating a Family Strengthening Intervention for HIV-affected children and families in Rwanda. She has written extensively on mental health and resilience in children facing adversity including recent articles in *Child Development, The Journal of the American Academy of Child and Adolescent Psychiatry, Social Science and Medicine* and *PLOS One*.

**Dr. Pia Rebello Britto**

Pia Rebello Britto, Ph.D., Senior Advisor, Early Childhood Development, is known internationally for her work in the area of early childhood policy and programs. She has worked in over 40 low and middle income countries for developing integrated systems and policies for early childhood. In particular, she is investigating the role of governance and finance of national systems in achieving equity, access and quality. Dr. Britto has also been involved in several early intervention program evaluations in Africa and Asia. Other aspects of her international work include the conceptualization of a measurement model for quality early childhood services, and measuring and implementing the school readiness paradigm – ready children, ready families, and ready schools and understanding the best modalities to support parenting. Most recently, Dr. Britto is involved in research that is examining the relationship between early childhood and peace building. Nationally, within the United States, Dr. Britto is known for her scientific work on young children’s early literacy development, and more recently on understanding issues of identity development of Muslim and Arab children. Dr. Britto obtained her doctoral degree in developmental psychology from Teachers College, Columbia University and prior to joining UNICEF she was an Assistant Professor at Yale University. She is the recipient of several national and international grants and
awards in recognition for her work and has published numerous books, articles, chapters and reports, and has presented extensively at conferences, meetings and workshops (academic and non-academic) around the world.

**Dr. Lucie Cluver**
University Lecturer, Department of Social Policy and Intervention, Oxford University, UK and Department of Psychiatry and Mental Health, University of Cape Town, South Africa.
Lucie Cluver is a South African social worker who spent most of her time driving round townships trying to find the blue shack with the chickens. She now works closely with the South African government, the WHO, UNICEF, Save the Children and USAID to develop high quality evidence to inform programming for AIDS-affected children. Lucie is a lecturer at Oxford University and the University of Cape Town, and is lucky to have a phenomenal team of students and staff.

**Dr. Chris Desmond**
Dr. Chris Desmond holds a PhD from the London School of Economics and a Masters in economics from the University of Natal. His research has primarily focused on issues relating to HIV and children, including those related to the costs of care, the appropriate targeting of interventions, economic evaluation of policy options and policy development. Most recently Chris managed the ‘Cost of Inaction (COI)’ research project at the FXB Centre for Health and Human Rights at Harvard University. The project examined alternative approaches to evaluating the response to children affected by poverty and HIV/AIDS, focusing on identifying where opportunities for action are being missed. It argues for the consideration of not only the constitutive benefits of interventions, but also the consequential benefits which often occur over the long term. A book detailing the COI method and results was published earlier this year. Prior to moving to FXB Chris was a research specialist at the Human Sciences Research Council in South Africa. While at the HSRC Chris was a member of the Joint Learning Initiative on Children Affected by AIDS, and conducted a project examining how to evaluate how efficient alternative models of care for children are. Prior to the HSRC he was a research fellow at the Health Economics and HIV/AIDS Research Division at the University of KwaZulu-Natal. Currently based in Durban, South Africa, Chris is a Chief Research Specialist at the Human Sciences Research Council, a Research Associate at the Department of Global Health and Social Medicine at Harvard Medical School and a Senior Researcher at Witwatersrand University Medical School.

**Dr. Shaffiq Essajee**
Shaffiq Essajee is the Senior Medical Advisor to the Clinton Health Access Initiative. Until recently he served as Medical Officer for Paediatric HIV at the World Health Organization. He is a member of the pediatric infectious diseases faculty at New York University and has been caring for children with HIV for the past 15 years. In 2001 he began Kenya’s first free pediatric HIV clinic which currently serves over 3,000 HIV infected and exposed children in and around Mombasa. He is a graduate of the Oxford University Medical School, and completed his residency in pediatrics at the University of California, SF before coming to join the Pediatric Infectious Disease Division at NYU. In addition to his work as a clinician and public health advocate, Dr. Essajee is also a research scientist and has been supported the NIH Center for AIDS Research and the Doris Duke Charitable Foundation.

**Ms. Kate Iorpenda**
Kate Iorpenda is Senior Adviser: Children and Impact Mitigation at the International HIV/AIDS Alliance in Brighton UK. Kate provides technical and policy guidance and support to civil society organisations across the 38 Alliance member countries and is the focal point for children and adolescents, child protection and child rights and participation. Previously she worked as a Programme Development Adviser for HIV at VSO for 5 years and as Programme Manager in Nigeria for 3 years. She holds a MA in International Development and Health Promotion and is a trained teacher. Kate is a member of the Interagency Task Team on Children affected by HIV and in 2012 she took on the role of Chair for the Coalition for Children Affected by HIV and AIDS.

**Dr. Shaheen Kassim-Lakha**

Shaheen Kassim-Lakha oversees the planning, development, implementation, and evaluation of the Conrad N. Hilton Foundation’s international program areas, including safe water access, children affected by AIDS, blindness prevention and education, and disaster relief and recovery. In addition to managing the operations of the Hilton Foundation’s international grant program team, she leads grant programs related to global health issues and capacity building, and contributes to the Foundation’s strategic planning. Kassim-Lakha has a broad academic and professional background in health services and public health, including experience in hospital administration, developing environmental health policy for urban centers in North America, and program management in several countries in Asia and Africa. Prior to joining the Foundation, she was a senior program officer at the UniHealth Foundation for six years. Kassim-Lakha received a Master of Public Health from the University of California at Los Angeles and pursued a career in international development and environmental epidemiology. She completed the doctoral program in health services at UCLA’s School of Public Health, where her research focused on measuring results and developing an evaluation approach for healthcare philanthropy. She has served as a consultant to foundations and donor organizations on community-based initiatives, regional health systems development, program evaluation, and health policy research.

**Mr. Brian Lutz**

Brian Lutz is Policy Specialist: AIDS and MDGs in UNDP’s HIV, Health and Development Group. He works on issues of national strategic planning, co-financing of development synergies, social determinants and social protection. As a member of UNDP’s post-2015 Secretariat, he supports the UN Development Group’s global thematic consultations on health and population dynamics as well as the UN Technical Support Team to the Open Working Group on the Sustainable Development Goals. Prior to joining UNDP, Brian was an Associate at McKinsey & Company, where he worked on strategies related to U.S. health reform. He has also worked for UNFPA and the UN Millennium Project. He holds a M.Sc. in Epidemiology from the London School of Hygiene & Tropical Medicine, a M.Sc. in Environmental Change & Management from the University of Oxford and a MPA in International Health Policy & Management from New York University.

**Professor Stephen Lye**

Professor Stephen Lye Ph.D., is the Executive Director of the Fraser Mustard Institute for Human Development, University of Toronto. Dr. Lye is an expert in women’s and infant’s health and pioneered investigations into the mechanisms underlying preterm birth. His research has integrated discovery, clinical and translational studies including the commercialization of discoveries in partnership with industry. Dr. Lye has established international research consortia focused on identifying interactions between an individual’s genetic make-up and their environment during the first 2000 days of life that underlie obesity and cardio-metabolic disorders. He has published over 180 research papers on pregnancy and maternal-child health and holds a Canada Research Chair in Improved Health and Function. Dr. Lye has received numerous awards and honours, including the President’s Scientific Achievement Award from the Society for Gynecologic Investigation and the Excellence in Research Award from the Association of Professor of Obstetrics and Gynaecology. Dr. Lye has led numerous large-scale, peer-review funded, research programs at the local national and international level. He is a Professor of Obstetrics & Gynaecology, Physiology and Medicine at the University of Toronto and Associate Director of the Samuel Lunenfeld Research Institute of Mount Sinai Hospital.

**Mr. Craig McClure**

Craig McClure is Associate Director and Chief of HIV & AIDS Section in Programme Division in UNICEF. Craig has a background in political science, international relations, education and counselling. His involvement in the fight against AIDS began in 1991 when, while teaching secondary school in the UK, he joined the activist group ACT-UP Manchester. He returned to his native Canada in 1993 and worked for five years in the community-based sector with the Canadian AIDS Treatment Information Exchange (CATIE) as an educator and coordinator of treatment advocacy, information and literacy programs. After leaving CATIE, Craig co-founded the consulting firm Health Hounds, focused on organizational development and HIV policy for government, not-for-profit organizations and industry.

From 2000-2002, Craig worked for the International AIDS Vaccine Initiative (IAVI) on public policy and community-preparedness for vaccine trials. He joined the World Health Organization (WHO) in 2002 to support
partnerships for the “3 by 5” initiative. As Executive Director of the International AIDS Society (IAS) from 2004 to 2009 he oversaw the staging of six major international and scientific conferences. He previously coordinated the treatment and care team in the HIV Department at WHO. He is currently the Chief of HIV and AIDS section with the Programme Division in UNICEF.

Craig is committed to working to end the AIDS epidemic through approaches that balance investments in research with achieving and sustaining universal access to prevention, treatment and care, and promoting and protecting the rights of people living with and most affected by HIV.

**Dr. Claude Ann Mellins**
Dr. Mellins is a clinical psychologist with research and clinical expertise in psychosocial aspects of HIV disease in women, children and families living in impoverished environments in the US and Globally. Over the past 22 years Dr. Mellins has completed projects examining neurodevelopment, mental health and sexual and drug risk behavior in HIV-affected children, adolescents and adults; as well as factors influencing medical adherence, sexual and drug risk behavior and psychiatric functioning in HIV infected and HIV-affected children, adolescents, and adults. She has been the Principal Investigator or Co-investigator of a large number of foundation and federally-funded research projects based in the US and internationally, including multiple cohort studies of perinatally HIV- infected and perinatally HIV-exposed children and adolescents.

Since 2009, she has been a standing member of NIH Behavioral and Social Consequences of HIV/AIDS Study Section and has consulted on international issues related to children and risk behavior for the New York State Psychiatric Institute’s IRB. In addition to her research, she co-founded and co-directs the Special Needs Clinic (SNC) at New York Presbyterian Hospital (NYPH), one of the first and currently one of the largest mental health clinics for HIV-infected women, children, and families. She brings to this project extensive skills in cognitive and behavioral research and the interface with biomedical issues; integration of HIV prevention and mental health services, academic-clinical partnerships, studies in clinical and hospital-based settings, experience with oversight of longitudinal studies with women and children and families from impoverished communities, and assessment of pediatric cognitive and mental health function, as well as adolescent and young adult sexual risk behavior. She has worked in low-to-middle income countries on studies related to pediatric HIV highlighting the need for intensive understanding of the mental health, educational, risk behavior and health care needs of this vulnerable population. She also have expertise in rapidly translating basic determinants data into interventions to promote child wellbeing in the US and Africa.

**Mr. John Miller**

John Miller has a Masters of Arts degree in International Development Studies from the Institute of Social Studies in The Hague and held positions of progressive responsibility in refugee settlement services, with young street-involved sex workers, and in HIV/AIDS support before being appointed the executive director of a palliative care hospice in 1994. Between 1998 & 2002, John was a senior policy analyst and manager in the Ministry of Community and Social Services of the Government of Ontario, Canada. Since 2002, John has provided private consulting services to clients in policy and organizational development, and since 2005 has concurrently been the Coalition Director for the Coalition for Children Affected by AIDS. He is also the author of two critically acclaimed novels, *The Featherbed* (Dundurn, 2002) and the award-winning *A Sharp Intake of Breath* (Dundurn, 2007, winner of the Martin & Beatrice Fischer Award for Fiction for 2008). His third novel, *Shed Your Skin* is forthcoming.

**Ms. Teresiah Otieno**
Program Officer, African Gender and Media Initiative(GEM) and founder member and Coordinator of Personal Initiative for Positive Empowerment (PIPE). I have been involved in Advocacy on HIV, Elimination of MTCT, TB issues and Sexual Reproductive Health Rights of women living with HIV at the national, regional and global level.

Social Worker by Profession. Worked with Women Fighting AIDS in Kenya and the National Empowerment Network of People Living with HIV in various capacities. A member of the International Community of Women Living with HIV (ICW), Representative of ICW East African region to the ICW International Steering Committee.

**Professor Catherine Peckham**
Catherine Peckham was appointed to the UK’s first chair in Paediatric Epidemiology and established the Centre for Paediatric Epidemiology and Biostatistics at the Institute for Child Health, University College London.

A major theme of her work is infections in pregnancy and early childhood focusing on impact of maternal infections on the fetus and child, at birth, during childhood and later in life as well as the effects of treatment on outcome. Knowledge of the prevalence of specific infections, risk of mother-to-child transmission, associated risk factors and natural history of congenital and perinatal infection is essential for policy, clinical management and prevention.

She founded the multi-centre European Collaborative Study (ECS) of HIV infection in mothers and children to address specific questions about mother-to-child transmission. In the UK she introduced unlinked anonymous testing of HIV using routinely collected newborn blood spots to assess maternal HIV prevalence. She established national surveillance of HIV infection in pregnancy and childhood, which is still ongoing.

She is currently Professor of Paediatric Epidemiology at University College London, and Director of the National Infectious Diseases Antenatal Screening Programme. She chairs the Scientific Advisory Board for Positive Action for Children a charity that supports community-based projects focused on the prevention of HIV in children in countries with a high prevalence of infection.

Dr. Linda Richter
Dr Linda Richter is a Distinguished Research Fellow at the Human Sciences Research Council in South Africa. She is an Honorary Professor in Psychology and an elected Fellow of the University of KwaZulu-Natal; an Honorary Professor in the Department of Paediatrics and Child Health at the University of the Witwatersrand, and a Research Associate in the Department of Psychiatry at the University of Oxford (UK). From 2003-2006, she was a Visiting Researcher at the University of Melbourne, and from 2007-2010 a Visiting Scholar at Harvard University (USA). From 2010-2012 she was on a two-year contract from the Human Sciences Research Council to the Global Fund to Fight AIDS, Tuberculosis and Malaria in Geneva, as Senior Specialist (Health of Vulnerable Children) for half of her time. Linda has conducted both basic and policy research in the fields of child, youth and family development as applied to health, education, welfare and social development, and has published more than a 400 papers and chapters in the fields of child, adolescent and family development, infant and child assessment, protein-energy malnutrition, street and working children, and the effects of HIV/AIDS on children and families, including HIV prevention among young people.

Dr. Nigel Rollins
Dr Nigel Rollins joined the Department of Maternal, Newborn, Child and Adolescent Health at WHO in July 2008. Prior to joining WHO, Dr Rollins was Professor and head of the Centre for Maternal and Child Health at the University of KwaZulu-Natal (UKZN), Durban, South Africa, where he lived and worked for 14 years. His work focuses primarily on prevention of mother-to-child transmission of HIV through infant feeding but is also involved with implementation research to improve newborn and child survival, health systems research and severe malnutrition.

Dr. Caroline A. Ryan
Dr. Caroline A. Ryan received her BSc and MDCM from McGill University in Montreal, Canada. She did her residency in internal medicine at Yale-New Haven Hospital. She completed an infectious disease fellowship at the University of Washington and then remained on the faculty in the Infectious Disease Division of the Department of Medicine at the University of Washington. She received her Masters in Public Health from the University of Washington. In 1997, she joined the Centers for Disease Control, and served as the Associate Director for International Activities in the Division of STD Prevention and later as Chief of the Prevention Branch in the Global AIDS Program. Since October of 2004, Dr. Ryan has been on detail from CDC to the Office of the U.S. Global AIDS Coordinator where she serves as the Director of Technical Leadership for the PEPFAR program.

Dr. Michael Samson
Michael Samson is Director of Research of the Economic Policy Research Institute in Cape Town, South Africa. He has 27 years of experience working in social protection, and specialises in designing, implementing, monitoring
and evaluating social protection programmes and policies, and his project experience in these areas includes work in 32 countries in Africa, Latin America, Asia and the Pacific as well as many related publications. Michael co-ordinated and co-led the team implementing the South African government's first integrated qualitative-quantitative impact assessment of the Child Support Grant, and he has implemented both impact assessments and ex ante evaluations of social protection programmes in other countries in Asia and Africa. He was the lead author of the policy guide Designing and Implementing Social Transfer Programmes, he wrote the OECD's policy guidance on social protection, and he convenes courses in South Africa, Thailand and Kenya on this topic. Michael lectures at policy conferences and training workshops around the world. He is also on the economics faculty at the Williams College Center for Development Economics in the United States, and he has a Ph.D. in Economics from Stanford University.

**Professor Lorraine Sherr**
Lorraine Sherr is a Professor of Clinical and Health Psychology at University College London Medical School. She is head of the Health Psychology Unit. Born in South Africa, she studied Psychology at Warwick University UK, PhD from Warwick and BPS Clinical Psychology qualifications in London. Prof Sherr has worked at a National and International level on HIV, mental health, treatment adherence, switching, gender, pregnancy, families, children, parenting, discrimination and HIV infection. She has appeared as an expert witness in court cases protecting the rights of people with HIV and has addressed governments and policy makers to challenge decisions and address discrimination. Prof Lorraine Sherr is editor of three International Journals; AIDS Care (in its 23rd year of publication under her editorship), Psychology Health and Medicine and Vulnerable Children and Youth Studies. She is one of the organisers of the AIDSImpact conferences which, delve into the detailed psychosocial aspects of HIV. She acted as co-chair of the Learning Group on Families for the Joint Learning Initiative on Children and AIDS (JILICA-Harvard University). She also sits on the steering committee of the International Coalition on Children affected by AIDS (CCABA), has sat on the Strategic and Technical Advisory Committee on HIV/AIDS (2004-2007) for the World Health Organisation HIV section, and was appointed a Churchill Fellow for life for her work on HIV – women and children. She has comprehensive work in Europe and Africa, sitting on the board of REPSSI (the Regional Psychosocial Support Initiative covering sub-Saharan Africa), and the monitoring and evaluation IATT/CABA M&E Working Group (Co-ordinated by UNICEF). Prof Lorraine Sherr has provided Psychosocial evaluations for international organisations such as the World Health Organisation, UNICEF, Save the Children, Care, Bernard van Leer Foundation, World Bank, USAID and Norad. She provided a critical review of the first phase of the Pepfar programme, commenting on the evaluation, evidence and future plans. Prof Sherr sat on the British HIV Association (BHIVA), both on the Social and Behavioural Group and the Executive. She has contributed to a number of national guidelines such as Adherence, Psychological support, Reproduction, and treatment. She chaired the World Health Organisation committee providing guidelines for HIV disclosure for children. She has published over 190 articles in Peer reviewed journals, and fully written or edited chapters in over 40 books. She has a wide range of research grants and initiatives, currently coordinating an innovative cohort study to address the gap in evidence from Community Based organisations in the AIDS response; contributing to a large study on the behavioural aspects of early treatment, looking at a randomised controlled trial of Palliative care in Africa for those with HIV and AIDS and contributing to a 9 year study of the unfolding HIV epidemic in Zimbabwe.

**Dr. Tin Tin Sint**
Dr. Tin Tin Sint is a medical doctor and a public health expert in HIV/AIDS. She is originally from Myanmar and has been working in the field of HIV for over 15 years. Dr. Sint previously worked with WHO in Geneva where she was responsible for the development of WHO guidelines on PMTCT. She joined UNICEF in 2011 in the capacity of nutrition specialist for HIV/AIDS, and is responsible for overall policy and technical guidance on maternal and infant nutrition for those infected and affected by HIV.

**Dr. Morten Skovdal**
Morten Skovdal is a community health psychologist advising on ways to appropriate and align health and development interventions with local realities, currently doing so for Save the Children UK. Morten is also a visiting Research Fellow at the Institute of Social Psychology at the London School of Economics and Political Science.
**Mr. John Stover**

Mr. John Stover is President of Futures Institute, an organization dedicated to policy analysis, strategic planning and resource mobilization for international health. His work has focuses on family planning, HIV/AIDS, child survival and safe motherhood programs. He leads efforts in modeling, forecasting and resource planning. He has developed computer models that are in wide use today for demographic projections, HIV/AIDS estimates and projections, family planning program analysis and resource allocation. He is also Treasurer and a member of the Board of Directors of the International AIDS Economics Network.

**Dr. Mark Tomlinson**

Professor Mark Tomlinson is based in the Department of Psychology at Stellenbosch University and received his PhD in Psychology from the University of Reading in the UK. His scholarly work has involved a diverse range of topics that have in common an interest in factors that contribute to infant and child development in contexts of high adversity, and how best to prevent compromised infant and child development in these contexts. He has completed research investigating the impact of maternal depression on infant and child development. He has also completed four large randomised controlled trials, all of which have examined the impact of interventions delivered by community health workers on maternal and child health. He has received research grants from the Wellcome Trust (UK), Nationa Institute of Alcohol Abuse and Alcoholism; National Institute of Drug Abuse (USA), Department for International Development (UK), and recently from Grand Challenges Canada.
Appendix 4 – Meeting agenda

PROGRAM

The Road to Melbourne:
Young Children Born into HIV-affected Families

Meeting #1 (New York): Early intervention - evidence and entry points

Date: May 30th 2013, 8:30 to 17:15 (Group dinner at 18:30) &
May 31st 2013, 8:45 to 16:30 (there is an additional in-camera
16:30-17:30 meeting for members of the Coalition for Children
Affected by AIDS)

Location: UNICEF, 22nd Floor, 633 3rd Avenue, New York 10017 (between
40th and 41st streets)

Meeting convened by: The Coalition for Children Affected by AIDS, UNICEF & UNAIDS

DAY 1: Thursday May 30, 2013 - 8:30 - 17:15

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<tr>
<th>TIME</th>
<th>AGENDA ITEM/ PAPER/PRESENTATION</th>
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<tr>
<td>8:30 - 8:45</td>
<td>Registration &amp; Tea</td>
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<tr>
<td>8:45 - 9:00</td>
<td>Welcome and introduction to the Road to Melbourne meeting series</td>
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<td></td>
<td>• <a href="#">Ms. Kate Torpenda</a> 7 minutes</td>
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<td>Chair: The Coalition for Children Affected by AIDS &amp; International HIV/AIDS Alliance</td>
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<td>• <a href="#">Dr. Christian Salazar</a> 7 minutes</td>
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<td>UNICEF</td>
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<td>9:00 - 10:00</td>
<td>Panel 1: Why focus on young children born into HIV affected families?</td>
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<td></td>
<td>• <a href="#">Ms. Marine Davtyan</a> 5 minutes</td>
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<td>• <a href="#">Dr. Pia Rebello Britto</a> 15 minutes</td>
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<td>UNICEF, Early Child Development Unit</td>
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<td></td>
<td>-- The changing landscape of child health, child development and HIV/AIDS</td>
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<td>• <a href="#">Ms. Gretchen Bachman</a> 15 minutes</td>
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<td>-- Evidence on children born into HIV-affected families and PEPFAR/USAID programmatic</td>
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<td>approaches</td>
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<td>Questions &amp; Discussion 20 minutes</td>
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<tr>
<td>10:00 - 11:00</td>
<td><strong>Panel 2: PMTCT as a critical entry point for early interventions for children</strong>  &lt;br&gt; Chair  &lt;br&gt; • <strong>Ms. Monique Jackson</strong>&lt;br&gt; Pediatric AIDS Treatment Africa  &lt;br&gt; <strong>Presenters</strong>  &lt;br&gt; • <strong>Ms. Teresiah Otieno</strong>&lt;br&gt; The National Network of People Living with HIV in Kenya (NEPHAK) &amp; The International Community of Women Living with HIV (ICW)  &lt;br&gt; -- Community engagement within the Global Plan for the Elimination of Vertical transmission – promising practices and new opportunities for linking to early intervention.  &lt;br&gt; • <strong>Mr. Craig McClure</strong>&lt;br&gt; UNICEF  &lt;br&gt; -- The continuing push for PMTCT its potential as a critical entry point.  &lt;br&gt; • <strong>Prof Catherine Peckham</strong>&lt;br&gt; Institute of Child Health, Harvard  &lt;br&gt; -- Biomedical perspective on PMTCT and pediatrics - opportunities  &lt;br&gt; <strong>Questions &amp; Discussion</strong>  &lt;br&gt; 20 minutes</td>
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<td>11:00 - 11:30</td>
<td><strong>Tea</strong></td>
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<td>11:30 - 13:00</td>
<td><strong>Panel 3: The science of early child development: Application to HIV affected populations</strong>  &lt;br&gt; Chair and introductory remarks  &lt;br&gt; • <strong>Professor Linda Richter</strong>&lt;br&gt; Member, The Coalition for Children Affected by AIDS &amp; Human Sciences Research Council, South Africa  &lt;br&gt; <strong>Presenters</strong>  &lt;br&gt; • <strong>Professor Lorraine Sherr</strong>&lt;br&gt; Member, The Coalition for Children Affected by AIDS &amp; University College London  &lt;br&gt; -- Cognitive development, HIV and Children  &lt;br&gt; • <strong>Professor Stephen Lye</strong>&lt;br&gt; Fraser Mustard Institute for Human Development  &lt;br&gt; -- Tracing Health to Its Roots, Linking Early Childhood Development to Healthy Adulthood  &lt;br&gt; • <strong>Dr. Lucie Cluver</strong>&lt;br&gt; Oxford University  &lt;br&gt; -- Risks within family settings for affected children (focus on younger children)  &lt;br&gt; <strong>Questions &amp; Discussion</strong>  &lt;br&gt; 20 minutes</td>
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<td>13:00 – 14:00</td>
<td><strong>Lunch</strong></td>
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<td>14:00 – 15:30</td>
<td><strong>Panel 4: Challenges and advances in paediatric testing and treatment</strong>  &lt;br&gt; Chair and introductory remarks  &lt;br&gt; • <strong>Dr. Anouk Amzel</strong>&lt;br&gt; Office of HIV/AIDS, Global Health, USAID  &lt;br&gt; <strong>Presenters</strong>  &lt;br&gt; • <strong>Dr. Shaffiq Essajee</strong>&lt;br&gt; Clinton Foundation, HIV/AIDS Initiative  &lt;br&gt; -- New science on early infant diagnostics and continued bottlenecks  &lt;br&gt; • <strong>Dr. Stephen Arpadi</strong>&lt;br&gt; Mailman School of Public Health, Columbia University  &lt;br&gt; -- Innovations in getting children into paediatric services  &lt;br&gt; • <strong>Dr. Tin Tin Sint</strong>&lt;br&gt; UNICEF  &lt;br&gt; 15 minutes</td>
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<td>15:30 – 16:00</td>
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<td>16:00 - 17:15</td>
<td><strong>Panel 5: Comprehensive care and support models for CABA</strong>&lt;br&gt;Chairs and introductory remarks</td>
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<td><strong>Dr. Stuart Kean</strong>&lt;br&gt;Member, The Coalition for Children Affected by AIDS &amp; World Vision</td>
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<td><strong>Dr. Morten Skovdal</strong>&lt;br&gt;London School of Economics Institute of Social Psychology, University of Bergen &amp; Save the Children</td>
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<td>-- When 'early childhood development' pathologises HIV-affected parents and their pre-school children: The case for a local and social ecological response</td>
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<td><strong>Dr. Mark Tomlinson</strong>&lt;br&gt;Stellenbosch University</td>
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<td>-- Interventions for HIV positive mothers and child development outcomes</td>
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<td><strong>Dr. Theresa Betancourt</strong>&lt;br&gt;Harvard School of Public Health</td>
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<td>-- Family-Based Prevention of Mental Health Problems in Children Affected by HIV/AIDS: An Example from Rwanda</td>
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<td><strong>Questions &amp; Discussion</strong></td>
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<td>17:15</td>
<td><strong>Meeting adjourns until Friday</strong></td>
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<td>18:30</td>
<td><strong>Group Dinner at Cibo Restaurant</strong> - courtesy of The Coalition for Children Affected by AIDS 767 2nd Ave at 41 St, New York - cibonyc.com</td>
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<td><strong>DAY 2: Friday May 31, 2013, 8:45 - 16:30</strong>&lt;br&gt;(<em>NOTE: for members of the Coalition for Children Affected by AIDS, there is an in-camera business meeting from 16:30 to 17:30</em>)</td>
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<td>8:45 - 9:00</td>
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<td>9:00 – 10:15</td>
<td><strong>Panel 6: Translating research into global policy</strong>&lt;br&gt;Chair and introductory remarks</td>
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<td><strong>Dr. Nicole Behnam</strong>&lt;br&gt;Office of the U.S. Global AIDS Coordinator (OGAC), US State Department</td>
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<td><strong>Dr. Nigel Rollins</strong>&lt;br&gt;World Health Organization</td>
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<td>-- Care for early child development</td>
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<td><strong>Mr. Brian Lutz</strong>&lt;br&gt;UNDP</td>
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<td>-- How early years investments are coming up in the post-MDG responses</td>
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<td>10:45 – 12:00</td>
<td><strong>Panel 7: Integrated support to families for optimal development</strong></td>
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<td><strong>Chair and Introductory remarks:</strong></td>
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<td>• <a href="#">Dr. Ann DiGirolamo</a> 5 minutes</td>
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<td>Member, The Coalition for Children Affected by AIDS &amp; Consultative Group on Early Childhood Care &amp; Development &amp; CARE USA</td>
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<td><strong>Presenters:</strong></td>
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<td></td>
<td>• <a href="#">Professor Linda Richter</a> 15 minutes</td>
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<td>Member, The Coalition for Children Affected by AIDS &amp; Human Sciences Research Council, South Africa</td>
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<tr>
<td></td>
<td>-- Parenting and review on national and state-wide programs to promote child development</td>
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<td></td>
<td>• <a href="#">Dr. Claude Ann Mellins</a> 15 minutes</td>
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<td></td>
<td>Columbia University &amp; HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute and Columbia University</td>
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<td></td>
<td>-- Ongoing follow up of HIV positive adolescents within an integrated approach – future issues and challenges</td>
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<td></td>
<td>• <a href="#">Dr. Michael Samson</a> 15 minutes</td>
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<td>Williams College</td>
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<td>-- The role of cash transfers in the early years - how does it support families and children affected by HIV</td>
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<td><strong>Questions &amp; Discussion</strong> 25 minutes</td>
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<td>12:00 – 13:00</td>
<td><strong>Lunch</strong></td>
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<td>13:00 – 14:15</td>
<td><strong>Panel 8: Too expensive to do, too expensive not to?</strong></td>
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<td><strong>Chair and introductory remarks</strong></td>
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<td></td>
<td>• <a href="#">Dr. Rachel Yates</a> 5 minutes</td>
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<td></td>
<td>Member, The Coalition for Children Affected by AIDS &amp; HIV/AIDS Programme, UNICEF HQ</td>
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<td><strong>Presentations</strong></td>
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<tr>
<td></td>
<td>• <a href="#">Mr. John Stover</a> 20 minutes</td>
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<td>President, Futures Institute</td>
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<td>-- Bringing protection, care and support for families and children into Investment thinking</td>
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<td></td>
<td>• <a href="#">Dr. Chris Desmond</a> 20 minutes</td>
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<td></td>
<td>Member, The Coalition for Children Affected by AIDS &amp; Human Sciences Research Council, South Africa</td>
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<td></td>
<td>-- Can we afford not to invest in children?</td>
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<td><strong>Questions &amp; Discussion</strong> 25 minutes</td>
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<td>14:15 – 14:45</td>
<td><strong>Tea</strong></td>
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<td>14:45 – 16:00</td>
<td><strong>Panel 9: Investing in Children – Funders’ perspectives</strong></td>
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<td><strong>Chair and introductory remarks</strong></td>
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<td></td>
<td>• <a href="#">Mr. Dominic Kemps</a> 10 minutes</td>
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<td>ViIV Positive Action Programme</td>
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<td>• <a href="#">Dr. Shaheen Kassim-Lakha</a> 15 minutes</td>
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<td>Conrad N. Hilton Foundation</td>
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<td>-- Early childhood matters</td>
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<td>• <a href="#">Dr. Caroline Ryan</a> 15 minutes</td>
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<td>Office of the U.S. Global AIDS Coordinator (OGAC), US State Department</td>
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<td></td>
<td>-- The PEPFAR Blueprint, the IOM review and what they mean for children born into HIV- affected families</td>
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<td><strong>Questions &amp; Discussion</strong> 35 minutes</td>
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<td>16:00 - 16:30</td>
<td><strong>Synthesis and Next Steps</strong></td>
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<td><strong>Chair and introductory remarks</strong></td>
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|            | • **Professor Lorraine Sherr**  
Member, The Coalition for Children Affected by AIDS & University College London  
**Brief Remarks**  
• **Mr. John Miller**  
The Coalition for Children Affected by AIDS  
& **Dr. Scott Kellerman**  
Management Sciences for Health  
-- Overview of plans for publication and dissemination of the Coalition’s special issue of AIDS – including tie-in with AIDS special issue on PMTCT  
• **Ms. Kate Iorpenda**  
Chair: The Coalition for Children Affected by AIDS & International HIV/AIDS Alliance.  
-- Onwards to Melbourne (Plans for two subsequent meetings, for the Teresa Group/Coalition symposium in Melbourne, for the Global Partners' Forum, and for AIDS 2014 in Melbourne)  
• **Mr. Craig McClure**  
UNICEF HQ  
-- Closing remarks  
**End of Meeting Summary Discussion**                                                                                                                                 |
| 16:30 – 17:30 | **In-camera meeting: The Coalition for Children Affected by AIDS (preliminary planning for meeting #2 in Cape Town)**                                                                                                                                 |
|             |                                                                                                                                                                                                                           |
APPENDIX 5 – Meeting Series Concept Note

“The Road to Melbourne”
Young children born into HIV-affected families

This concept note frames the core theme that the Coalition for Children affected by AIDS will take forward on the ‘Road to Melbourne’ 2012-2014 meeting series, and at the pre-IAS Symposium in 2014. This series of meetings will build on the previous Road to Washington series that focused on community engagement for improving PMTCT outcomes and will promote a more integrated HIV response for young children and families which strengthens the synergies between PMTCT services and early childhood care, protection, and support services. The meeting series will identify priority early interventions that can prevent negative outcomes for children born into HIV affected families.

"The Road to Melbourne," will be made up of three high-level meetings to be held in New York in May, 2013, in Cape Town in December, 2013 and in London in February 2014. These meetings will respectively cover: 1) the research and policy landscape, 2) country-level programmatic evidence, and 3) policy implications of the evidence for developing an advocacy agenda. The findings and recommendations from these meetings will feed into the Coalition-Teresa Group’s symposium in Melbourne in July 2014, the 2014 Global Partner’s Forum on children and), and the XXth International AIDS Conference - AIDS 2014.

Background

Remarkable improvements have been made in the response to HIV and AIDS. The number of people on treatment has increased, leading to a slowing in HIV-related mortality. Prevention efforts have been expanded, leading to reductions in new infections. According to UNAIDS, in 2011, approximately 8 million people were accessing antiretroviral treatment, a 20% increase since 2010. Since the peak of AIDS deaths in 2005, UNAIDS estimates that the number of AIDS related deaths has declined by nearly a quarter. HIV incidence is estimated to have fallen 20% since 2001.

Improvements in prevention and treatment do not mean the war is won, nor do they mean that mitigation activities are no longer needed. Even under the most optimistic scenarios many millions of people will die as a result of AIDS in the coming decade, either because they remain unreach by treatment interventions, or because their treatment fail. There are still an estimated 1.7 million AIDS-related deaths annually, compared to 1.9 million in 2001. Moreover, millions of families and children will be affected by the social and other challenges associated with the long-term treatment of HIV as a chronic disease on such a large scale.

This concept note builds on the Coalition’s work over the last 2 years that focused on the role of communities in reducing vertical transmission. The Coalition recognizes that despite the successes of reducing new infections amongst children there will continue to be many children born HIV positive and many more born into HIV affected households. There is still significant work in bridging the gap between PMTCT services and ongoing care and support and mitigation activities for affected families. There is a need to find strategies across health and community systems to ensure PMTCT interventions retain and link families at the earliest opportunity to comprehensive services that address health, social and economic challenges faced by affected families. There is also a need to maximise additional entry points...
to identify young children and their families affected by HIV and ensure they are receiving services and support at this critical time for their optimal development.

Children infected or affected by AIDS are at a distinct disadvantage, especially with regards to education, nutrition, health, safety and development. As these children are less likely to have their basic needs met, they are more likely to be sick or malnourished, suffer psychological trauma, endure abuse, and become HIV positive. Furthermore, young children are especially vulnerable to the effects of HIV and AIDS, given the critical importance of the first five years of life in brain development and in providing the foundations for lifelong development. Not addressing the needs of these children during the early years can lead to lifelong deficiencies, not only in brain development but in other areas such as nutrition, health and wellbeing.

**Extending the impact of PMTCT**

PMTCT has been identified as one of the priority HIV interventions as set out in UNAIDS Countdown to Zero and the 2011 Investment Framework¹. UNAIDS estimates that in 2011 some 57% of the approximately 1.5 million HIV positive pregnant women living in low- and middle-income countries received antiretroviral drugs for PMTCT (a 10% increase since 2010). The most challenging aspect of further expansion of PMTCT programs will be to reach the most disadvantaged and socially excluded populations who have to date not been accessing PMTCT services. There is increasing awareness of the role community mobilization has to play to ensure PMTCT services' greater inclusion of underserved and marginalized populations. Community participation is particularly important for maintaining people through all prongs of the PMTCT cascade and beyond, linking families with ongoing support, protection, care and mitigation activities. Many mothers are lost from the care continuum during pregnancy or during the first months of their child’s life, and the rate of attrition may very well be much higher among marginalized populations. These first months and years are critical and this will be the focus of the current Road to Melbourne series.

PMTCT is an obvious and clear entry point to identifying children born into HIV-affected families as early as possible—an entry point that continues to be underutilized. PMTCT is also a strategic opportunity to promote more integrated family-based support that brings in services that can address the comprehensive set of needs (e.g., medical, stimulation and learning, nutrition, psychosocial, economic) of HIV-affected families. This presents a challenge to the current clinical model for PMTCT to extend beyond its current parameters to become part of a continuum of services and support for children born into HIV-affected families into a system of services and support for their care and protection in the early years.

Providing services to affected families identified through PMTCT also has the potential to improve access to pediatric treatment. Pediatric treatment currently lags well behind treatment for adults. UNAIDS reports that coverage of pediatric treatment stood at 28% in 2011 compared to 57% for adults. Integrating services for affected families would improve the early identification of infected children and help increase their enrollment in treatment and support programs before the age of 2.

**Other entry points for early identification**

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¹ Schwartlander et al. June 3 2011, The Lancet
There are many benefits associated with identification of HIV-affected children through PMTCT programs, including the opportunity to retain these children in the health system and link families to clinical and community care and protection services. However, there are many affected families in more marginalized and hard to reach communities who will not be reached this way. Therefore, it is critical to identify additional opportunities for reaching these children to ensure early identification of children and ensure that children’s basic needs are met, particularly during the younger years. Potential entry points may include testing and treatment programs and early childhood care and development programs that address optimal parenting practices, nutrition, stimulation and learning, immunization, education, social welfare and child protection.

PMTCT and testing and treatment interventions are clearly effective mechanisms for identifying HIV-exposed children. However by relying entirely on these approaches there is the risk of excluding children and families not presently accessing more clinical HIV services. In order for there to be universal access to HIV services there will also be a need to identify children born into HIV-affected families through other mechanisms. This requires exploring the other entry points and having a focused way of getting the most disadvantaged and socially-excluded children and families linked up to appropriate HIV services. In addition, this will ensure that young children who are most at risk will be linked to the variety of services noted above that are critical to promoting a strong start in life.

**Why Focus on the Youngest Children: Proactive vs. Reactive**

For interventions designed to protect children affected by AIDS (CABA), this means a shift towards a proactive frame (before children show distress), shifting away from the current reactive “treatment” approach of responding when children are already experiencing ill-health or social and economic distress. Many protection, care and support programs are responsive to the negative consequences of HIV in families and impacts of parents on treatment, illness and death but are not able to intervene early enough to prevent negative outcomes. The major disadvantage is that this makes children’s distress and disadvantage eligibility criteria for children to receive services. Children have to suffer to achieve the imperative for support. We need to re-frame responses so that a child’s right to receive care and support comes from being born into an epidemic whose ramifications we have not yet fully provided for or can fully anticipate. One advantage of reaching children through PMTCT services is that it allows for such early intervention if the links are made to comprehensive family support services in early childhood that can assure a child’s best chance to thrive. Furthermore, reaching children at risk through integrated early childhood development programs may also help keep mothers and children involved in HIV services, providing another strong connection that ties families into services.

Children should be targeted early to avoid or reduce suffering. Interventions for families and children affected by HIV and AIDS should seek to prevent ill-health and social and economic distress rather than react to this distress. We know that evidence-based investments early in the lives of children are cost-effective and successful, mitigating the risk factors that cause long-term harm. The shift to a proactive frame requires intervention at the earliest opportunity and ensuring we can continue to respond to children throughout their life-cycle.

**Promoting strong beginnings**
Children, who are born to mothers living with HIV, face a number of health, social and economic risks. Children may still become infected, even when provided with PMTCT services, and children who are themselves uninfected but who are living in families affected by HIV can still be negatively impacted by the epidemic, including through psychosocial and economic distress. If children are uninfected, they are likely to face a number of risks associated with their mother’s infection, a condition most likely shared by their fathers. Moreover, these children may face threats to their health and wellbeing associated with both their exposure to the virus and to ARV’s used in PMTCT programs. Identifying children through PMTCT programs allows for services to be provided to these children, including testing and treatment, child protection services, economic support and early childhood development (ECD) interventions. These services not only provide access to life saving treatment but also ensure stronger families that are better able to cope with the economic and social realities of living with HIV. Through a greater understanding of the development of a child in the early years and specific impacts that HIV has on those stages of development we can ensure that we are intervening with the right support that can make the biggest difference across the life span of each child.

Early childhood is a critical stage in the development of the child. For children born into affected families, their HIV status is not the only concern; these children might be born into poverty, face abuse and neglect or suffer malnutrition, which can all affect their long-term development and ability to thrive and grow up to become productive adults. Programs need to retain and link children and families to more comprehensive support services to address these other challenges if the full benefits of reduced infection rates are to be realized. Similarly, care and support and ECD programs rarely provide HIV medical interventions, and therefore must be complemented by prevention and treatment programs, including PMTCT programmes. Given that PMTCT and early protection, care and support programs seek to deliver services to the same population and that they work best when provided together, they should be better linked. Once affected families are identified, they can be provided with the package of PMTCT, ECD and other comprehensive care and support services, thereby avoiding the need to identify these families once for PMTCT services and then again later in children’s lives for CABA services. From the beginning they are provided with a combination of clinical, psychosocial and economic support to provide the best start in life for a child affected by HIV.

Improved efficiency

Identifying and prioritizing efficient interventions must become a central part of programming for children affected by HIV if the limited resources available are to have the most meaningful impact. Identifying children as soon as possible, early in their lives, could improve the effectiveness and efficiency of CABA programs. The development of children and adolescents is strongly influenced by early experiences. Interventions, especially in the first 1,000 days of a child’s life, can be highly beneficial in compensating for adverse conditions, and may provide children with personal and health resources to deal with later challenges. Identifying children through PMTCT programs will allow protection, care and support programmes to provide cost-effective early interventions. Similarly identifying HIV-exposed children through other community-based early childhood care and development programmes can provide life-saving access to testing and treatment and nutritional support. Given how difficult it is to later redress harm suffered in this early period, protective interventions are likely to be more effective and efficient than interventions which seek to respond to those who have already been harmed. The approach set out above aims to ensure children affected by HIV are reached as early as possible and with interventions that are built on the science of child development and HIV and its impacts in order to deliver better outcomes for children born into HIV affected families.
Considerations for the Road to Melbourne

A proactive frame encourages the development of integrated services for young children from HIV-affected families. PMTCT, pediatric treatment, early childhood care and development interventions all seek to benefit the same population. Collectively, they can prevent many of the negative consequences of HIV and AIDS for children. Using PMTCT as a primary entry point to link these families into broader protection care and support services, and also exploring other key entry points for reaching the most at risk children, the Road to Melbourne will examine how early intervention and integrated services should be structured and adapted for specific contexts and specific family circumstances.

Objectives of the meeting series

The meeting series will build evidence and understanding amongst policy makers and programmers from different disciplines on approaches to the early identification of children born into HIV-affected families through PMTCT services and other key entry points such as ECD programming to ensure the linked provision of integrated services and support to children at risk and their families to promote optimal development. The objective is to influence funder and policy-maker priorities, and country-level practice.

The series will:

5. Explore the latest evidence around child development in the early years and the impacts of HIV on young children
6. Explore other entry points to identify children born into HIV affected families who are not within the PMTCT cascade.
7. Prioritize early interventions to prevent negative outcomes for children born into HIV affected families;
8. Promote a more integrated and linked up approach between PMTCT services and early childhood protection, care and support services The 3 meetings will consider key questions about
d) The state of the evidence;
e) The interventions that hold promise; and
f) The policies that can change/influence the response for children born into HIV affected families.

Outputs

• Evidence to influence funder and policy-maker priorities, and country-level practices, including:
  o Peer-reviewed journal;
  o Other academic articles stimulated throughout the process; and
  o Best practices as reported in the report of the second meeting on country-level programmatic evidence.
• Position statement adopted at Coalition-Teresa Group pre-IAC symposium in July 2014
• Advocacy plan