





Report on the "Road to Melbourne" meeting in London Young Children Born into HIV-affected Families

Meeting #3 (London): Advocacy Action Planning

Wednesday February 26 2014

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I. 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 has been leading, with the cooperation and support of UNICEF, UNAIDS, RIATT-ESA & PEPFAR, the *Road to Melbourne*.
- The goal of the Road to Melbourne meeting series has been 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 has:

- 1. Explored the latest evidence around child development in the early years and the impacts of HIV on young children
- 2. Explored entry points to identify children born into HIV affected families who are not within the PMTCT cascade.
- 3. Prioritized early interventions to prevent negative outcomes for children born into HIV affected families;
- 4. Promoted a more integrated and linked up approach between PMTCT services and early childhood protection, care and support services

The series involved three meetings:

- Meeting #1 New York: 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 Early intervention evidence and entry points,* UNICEF and UNAIDS were collaborators in this first meeting, with UNICEF being its host. The goals of the 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.
- Meeting #2 Cape Town: On December 5-6 2013 in Cape Town, South Africa, 61 people gathered for the second meeting in the series, Successful and Promising Approaches to Meeting the Holistic Needs of Young Children Born Into Families Affected by HIV and AIDS— co-hosted by UNICEF and the Regional Interagency Task Team on Children and AIDS. The second meeting was a detailed review of what is being learned on the ground presentations of promising programs and program models.
- Meeting #3 London: This third meeting, called Advocacy Action Planning, was co-hosted by UNICEF &
 PEFPAR and took place in London, UK. It focused on refining key advocacy messages and planning future
 action.
- The outputs of the meeting series were intended to be:
 - 1. Evidence to influence funder and policy-maker priorities, and country-level practices, including:
 - a. Peer-reviewed journal (The Coalition is supporting a special issue of the journal *AIDS*, to be launched at AIDS 2014 in Melbourne. Papers published in the special issue are being drawn from an open call made in early 2013.
 - 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. Convergent key messaging among global partners; and
- 3. A shared advocacy plan that would include additional outputs for both The Coalition, and other meeting participants.

II. Presentations on Convergent Initiatives & 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. Mr. Craig McClure of UNICEF and Dr. Nicole Behnam & Ms. Gretchen Bachman of PEPFAR
 also welcomed the participants.
- After introductory comments, meeting participants heard presentations from 11 speakers. All meeting presentations are posted on http://www.ccaba.org/road-to-melbourne-series-presentation-from-london/.
 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 the agenda and participant contact information.

III. Discussion on Convergent Messaging

- At the 2nd "Road to Melbourne" meeting in Cape Town, December 5-6 2013, a statement was put out by the Coalition referred to in this meeting as The Cape Town Statement. It was the intention of the meeting participants to engage all speakers and participants in a discussion of whether or not the statement resonated. The aim was to bring meeting participants, as much as possible, to agreement on common messaging, with the possible goal of producing either a) key messages or b) a common statement.
- The original "Cape Town Statement" produced by the Coalition appears below.

"We know with good evidence that any child born into a family affected by HIV faces immediate and longerterm biological, environmental and psychosocial challenges. We know that if these challenges are not addressed early, they threaten a child's ability to cope and thrive.

We also know that there are proven interventions that can prevent and mitigate the damaging effects of HIV and AIDS. By integrating clinical and developmental interventions for young children born into families affected by HIV and AIDS, we can provide children at risk with a strong foundation for the rest of their lives.

Efforts to prevent mother-to-child transmission of HIV (PMTCT) present an ideal entry point for early identification of HIV infected and affected children and greater promotion of infant well-being. Early child development expertise and programmes should be integrated with other caregiver-focused and pediatric HIV initiatives to improve a multitude of outcomes for children and families."

 Meeting participants rightly questioned the usefulness of producing one document to achieve multi-level advocacy goals and to reach a multitude of advocacy targets. Nonetheless, they provided general feedback on content and on tone.

Suggestions in terms of tone/ language:

- 1. We must translate and communicate the evidence so that mothers can be in a position to be advocates to create a demand for early integrated services.
- 2. But... we must engage the community, over and above engaging parents, -- this means community health workers, community leaders, caregivers.
- 3. Style comment: simplify the language less academic language.
- 4. It's pretty inclusive, but it isn't particularly streamlined.
- 5. Needs some catchy phrases/language.

- 6. At the moment the language sounds optional and that we're trying to convince people make more as a statement of facts
- 7. Flip it around what do people need to hear?
- 8. The statement needs to be more specific.
- 9. Talk less about entry points and more about linkages entry points are confusing to the outsider.

Suggested content improvements:

- 1. PMTCT is the wrong entry point to rally around; it's the Health Sector, broadly speaking (meaning not just doctors) that we should highlight, if we highlight one entry point (this discussion started with suggesting MNCH and ended more broadly). Our audience is the medical community, which is very protreatment but isn't much compelled for the ECD/ developmental part.
- 2. If we talk about the global agenda (not just the HIV agenda), we'll be able to speak to a community beyond HIV. We need to focus on the goal of supporting children by focussing on the early part of their life.
- 3. But don't lose the multi-sectoral emphasis.
- 4. For the HIV community, we're updating the eMTCT agenda to bring in this early childhood agenda.
- 5. Poverty as an underlying factor in the health of young children our response must address it.
- 6. Early integrated interventions prevent health risks over a lifetime
- 7. There's a long-term economic return made by countries on early childhood development investment. Also, when you invest in the community, the community becomes resilient.
- 8. Make it explicit that child survival is intricately linked to maternal health
- 9. Involvement/ support of men is important to enable mothers to access to services
- 10. Children of key populations in the widest possible definitions must be highlighted.
- 11. Community-based interventions around ECD and HIV reduce stigma
- 12. The linkages between ECD, literacy and universal health needs to be brought out more.
- 13. We need a list of bullet points that are explicit about how the evidence links ECD with HIV risk.

Decisions

- No decisions were made at the "Road to Melbourne" meeting in London. However, The Coalition held its own business meeting the following day and discussed the input of meeting participants.
- The Coalition decided it will produce a selection of media content— and that the suggestions would be incorporated, as appropriate, in their design:
 - A 1-page advocacy brief branded by the Coalition, which would be disseminated to all meeting participants, who would then be free to borrow from it for their own advocacy efforts. This brief would primarily target decision-makers in the health sector, broadly speaking including
 - Policy-makers;
 - Senior civil servants; &
 - Health Care professionals
 - A 4-page brochure meant for implementers to be distributed to all meeting participants.
 - Twitter and Facebook content in time for AIDS 2014 and beyond to be distributed to all meeting participants.
- All meeting participants are encouraged to make use of the messaging once produced.

IV. Advocacy Action Plan Emerging from Meeting #3

- In the final session of the day, meeting participants were encouraged to make commitments to common, organizational, or individual advocacy based on convergent messaging—as well as to suggest to The Coalition what advocacy products or tasks they felt might be broadly useful.
- The following day, The Coalition met during its annual business meeting and took decisions about its own advocacy as a group, and those tasks that Coalition members might take on.

• All advocacy tasks are summarized in the chart below. Meeting participants are encouraged to add to this list, and send The Coalition its commitments.

Category	Who	Task	
MDG Advocacy	All R2M London meeting participants	Contribute to the Sustainable Development Solution Network process – see link sent by John.	
Promotion of AIDS Special Issue	John Miller on behalf of The Coalition	 Check budget, then talk to Linda Richter to see if we should up the number of articles in the special issue from 10 to 13; Ask partners to use their booths at IAS to distribute printed journal copies & memory cards; Write a press release about the journal; Rather than print more than 750 copies of the special issue, work with AIDS to get permission to photocopy their cover – then bring photocopies of the cover & print cheap business cards with link to Open Access journal. Distribute them at our partners' booths; Get university press offices of special issue paper authors to publicize the issue. Note: Need to begin this in early June for July launch and need a press release to send them. 	
	Lorraine Sherr	 Investigate if we can publish additional papers not accepted to AIDS Special Issue in Vulnerable Children & Youth Studies; Give the winner of the IAS-Coalition prize a copy of the journal and mention it in plenary session. 	
	Louise Zimanyi	 Help John with some reaching out, as part of the roadmap at the conference – seeing if they can integrate the journal into their events. Help John connect with Takalani Sesame – to disseminate the journal. 	
General promotion of early integrated interventions messaging	All R2M London meeting participants	Sign Dame Tessa Jowell's petition. 'Put early childhood development at the heart of the new post-2015 development framework to give all children the best start in life'	
	UNICEF	 Incorporation of the theme of early years integration into the messaging of the Global Partners' Forum, taking place on July 20th 2014 in Melbourne, Australia. 	
	John Miller on behalf of The Coalition	 Produce a designed 1-page brief for use in advocacy efforts – Coalition branded, which includes a call to action – with input from Lisa Bohmer and Chris Desmond; Produce a short (4-sided) designed brochure targeting implementers, with input from Doortje 't Hart, Stuart Kean, and Kate Iorpenda; Write some advanced social media content for use on Twitter and Facebook; Send ANECCA either memory sticks – or a link to a website Contact Shaffiq Eassaje to discuss include the emerging messaging in his plenary at AIDS 2014; Update the Coalition website with links to early childhood resources on Consultative Group and UNICEF resources on early childhood and HIV; Promotion of messaging at <i>Children and HIV: Start Early, Start Now!</i> Symposium on July 19-20th in Melbourne. 	
	Doortje 't Hart	 Write an article in the STOP AIDS NOW! newsletter; Tweet about the messaging in the 1-pagers; Disseminate the designed brochure to implementers 	

Category	Who	Task
	Noreen Huni	 Use REPSSI's network of partners in 13 countries, which also works with government ministries, to advocate for early integration; Use RIATT's network, and the momentum building for child protection system strengthening, to bring in early child development messaging and issues.
	Kate lorpenda	 Link up NEPHAK and Teresia Otieno with KANCO in Kenya, who are a key partner of the Alliance – as KANCO are thinking of linking ECD into their programs.
	Dominic Kemps	ViiV will use their networks to get the word out to community groups and can disseminate the 2 nd meeting's report.
	Denis Tindyebwa	 Disseminate messaging to ANECCA members, who will be looking out to help disseminate this message as much as possible (ANECCA has focal people in 22 countries who are either pediatricians teaching on national technical working groups, including PMTCT, MNCH and so on); Monitor what each of the ANECCA focal people is doing in their countries.

V. Follow-up

- The Coalition committed to the following tasks as a follow-up to this meeting:
 - 1) Production of this report
 - 2) Posting of all presentations (with permission of authors) in PDF form on its website
 - 3) Ongoing liaison with meeting members re: advocacy items
 - 4) Production of advocacy products as mentioned in Section IV and dissemination to all meeting participants

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

Speaker	Selected key messages
Introductory Remarks	
Ms. Kate Iorpenda Chair: The Coalition for Children Affected by AIDS & International HIV/AIDS Alliance	 Kate welcomed the meeting participants and explained the purpose of both the Coalition and the Road to Melbourne series She mentioned that in Melbourne, The Teresa Group and the Coalition will be jointly hosting the Start Early, Start Now! Symposium. Mentioned the special issue of AIDS that we will be publishing.
Mr. Craig McClure UNICEF	 Craig welcomed the group and talked about how happy he was that the Coalition is focusing on early integration – it fits within UNICEF's life cycle approach, preparing children for adolescence, and for adulthood. He introduced UNICEF's team – Patricia Lim Ah Ken, Tom Fenn & Pia Britto
Dr. Nicole Behnam, PEPFAR – Office of the Global AIDS Coordinator, US Department of State	Nicole Behnam welcomed meeting participants on behalf of herself & Gretchen Bachman, PEFPAR – USAID. She mentioned how pleased she was that PEPFAR was now funding ECD-linked projects in 4 countries (Gretchen to outline later), and to be participating in this process.
Setting the Scene: What is to" meeting series	the Coalition for Children Affected by AIDS and what do we try to accomplish with our "Road
Ms. Kate Iorpenda Chair: The Coalition for Children Affected by AIDS & International HIV/AIDS Alliance	 Kate set the scene for meeting participants by explaining what The Coalition is and does – that we believe that children are underrepresented in the global response to HIV and that we bring together the best experts in an attempt to be 'thought leaders' around a strategic focus – and commented on how many thought leaders there are in the room. This meeting series tries to rally a global community around a leading idea – drawing in other people in different, connected sectors.
Professor Linda Richter Member, The Coalition for Children Affected by AIDS & Human Sciences Research Council, South Africa Presentation topic: Overview of Meeting #1 & 2	 Linda Richter gave more context to the "Road to" meeting series – and their predecessors. The Coalition began with a focus on psychosocial support (Road to Toronto), then focused on poverty and social protection (synergy with Joint Learning Initiative on Children & HIV), then moved to family centered services (Road to Vienna) – forming alliances with key population groups, to community action to end pediatric aids (Road to Washington), forming alliance with people living with HIV GNP and ICW. Since 2012, we've focused on children born into HIV affected families. There have been a number of products along each 'road', including a special issue of a peer-reviewed journal; this time it will be in AIDS; This is about prevention and treatment- reaching children before they are infected, before they experience abuse, before they lose families. The OVC response is moving in that direction to be more proactive than responsive PMTCT is a key entry point- taking advantage of it avoids duplicate processes- OVC programmes don't have to hunt for orphans when PMTCT programs can identify them. We can reach children earlier than we are doing currently: Family services offer opportunity for family testing, home based care, referrals. We're encouraging the integration of services. We need to go beyond survival and sustain integrated services for children from 0-5. She presented highlights from the first two meetings. Highlights from the first meeting in New York included: 80% of children in some countries lack ART There are a number of neglected portals of entry. PEPFAR analysis showed that programmes are reaching 3% of the 11% effected

Speaker	Selected key messages
Ms. Lisa Bohmer Member, The Coalition for Children Affected by AIDS & The Conrad N. Hilton Foundation	children under 2 Pia Britto shared the early rapid development- key period in life First 1000 days as period of marked susceptibly to environmental factors that have effects on development. Nigel Rollins talked about tools for strengthening care giver skills Highlights from the 2 nd meeting in Cape Town included: Promising practices presented by 16 community organisations who are implementers of integrated interventions focusing on early years, including some of the Hilton grantees. It gave us an understanding of what it means to try to work at scale Interesting interventions linking early childhood development to health, nutrition, livelihood strategies The meeting highlighted existing gaps in relationships between government and community in integrating a focus on youngest children – but both sides grew to understand one another There was a better understanding of the multiple entry points to integrated interventions; The need for workforce development and career pathways came out; The challenges/ gaps in working with children from key populations came out strongly; A troubling gap in programming for children 0-3 emerged; The Coalition developed the "Cape Town Statement" to close the meeting. It's been a fantastic learning opportunity to work with the Coalition on this agenda Hilton has focussed on early childhood development within the sphere of poverty alleviation health and nutrition We have a 5 focus countries in Africa, tackling ages 0-5, the period of rapid development We believe in the integration of ECD – there needs to build people's capacity around the
Presentation topic: Synergistic messages emerging from the review of Hilton-funded projects	 science of ECD. We've built a partnership with the Aga Khan University There are multi- directional benefits Building understanding in HIV and build case of the value of attention to stimulation, parenting, immunisation etc. and within ECD to address specific challenges for families affected by HIV We see even within 0-5 there is more focus on pre-school we see less attention on 0-3 Some tools look at this Care for Child Development Key needs are emerging: 1) the need for training and mentoring that includes ongoing support; 2) that we need an investment case to build momentum, creating demand, and community ownership; 3) that we need to know more about how we do this at scale The Road through Melbourne is really beyond AIDS 2014. We need to take risk & innovate. Families and children are already integrated; it is we who are all over the place!
Mr. John Miller The Coalition for Children Affected by AIDS Topic: Our goals for today	 John brought meeting participants back to the specific goals of the meeting, and reviewed common language: 1) by early we mean 0-6 (some might say 0-5, others 0-8) – but it's young children. 0 includes pre-natal & connections with the health of mothers. Integrated means that we are linking 2 or more services usually delivered separately Affected children- important not to miss children falling through cracks who are born negative in the efforts to end vertical transmission Series outputs- today's focus is to develop key messages/ position statement / plan There's a recognition that we all have own organisations and own advocacy priorities. We have synergy but do we agree on a message? Can we develop common & synergistic advocacy tasks? We've asked people to comment on the Coalition's Cape Town statement: Does it resonate? How can it support the work you are doing?

Speaker Selected key messages **Dr. Chris Desmond** Chris talked about a project funded by PEPFAR/ USAID looking at long-term impacts for Member, The Coalition children affected by HIV - his presentation is an update of a longer term project that is for Children Affected by mid-stream. AIDS & This is an unusual project – in that in this case, we really don't have a sense of what the **Human Sciences Research** outcome will be after we go through the process. Council, South Africa Research on CABA has focused on immediate and short-term consequences – so we don't have long-term follow-up. Presentation topic: "Long-Can we take information about children in adversity and link it to children affected by term impacts for children affected by HIV and AIDS" The few follow-up studies are showing that negative experience in early childhood are -- Key messages emerging having outcomes in mid-childhood, HIV exposure in mid-childhood are having outcomes from the PEPFAR during adolescence, and HIV exposure during adolescence are having outcomes in economic forecasting adulthood. exercise There is a pile of evidence linking experience in early childhood to outcomes later in life. Can we make links between HIV impact & broader child development outcomes? Do do so, we need to understand the mechanisms. Eventually we want to know how we can model those impacts. We want to identify the points of entry that we can use to prevent the long-term consequences from occurring. For instance we know HIV has an impact on kids because of parental mental health – can we draw on the extensive mental health literature to learn more? Phase 1 papers will be: 1) Physical health outcomes (Kellerman, Gilmartin, and Dungan, 2013); 2) Psychological outcomes (Sherr, Cluver et al., 2013); and 3) Social outcomes (Desmond, Cohen, and Richter, 2013) Key insight - Phase 1 of the project: o huge growth in understanding and measurement; clear picture of multiple causes and multiple consequences; under-researched roll of stigma; o importance of resilience – we don't understand it well enough. Phase 2 – is the linking of broader child development literature to HIV – we've assembled a great group of people working in the child development field, willing to look at what this might mean for HIV. **Key insights - Phase 2:** Everything depends on the context in which they occur – you can't make big jumps too easily, but sometimes the adversity is so clear that you can (i.e. in institutional care – you'll almost always see negative outcomes). What comes out clearly across all the literature is that where there are multiple and enduring hardships and the absence of assets is that there are serious longterm negative consequences. However, most children with the support of family will be okay. A small group will not be - what does this mean. Implications: many of the conclusions are entirely obvious, but we didn't always know this (we should have). We need to address short-term harm even if it doesn't have long-term consequences. It means we need universal programs that remove risk factors (cash transfers, treatment program for parents) because we can't easily predict who these children will be. And we need targeted, intensive interventions for people we know have the most serious negative impacts (children in institutions, children experiencing abuse). Next steps: can we begin to model this? We can't really do so, but the process of trying to do so can teach us to focus on the specific interactions we're interested in, can teach us about the current data, and can hopefully inform the plans for future responses. We're trying to think about ways to model these things, and we need to simplify them (as if to make his point, Chis then proceeded to show charts demonstrated very complicated economic modelling that most participants didn't understand!) Discussion: Nicole Behnam: This is about bringing our more clinically focused colleagues along with us by providing the evidence – both about the impact/ need for care and support, but also

Speaker	Selected key messages
	 about the unique effects of HIV. Denis Tindyebwa: We think at ANECCA we've contributed a lot in terms of PMTCT and in terms of care and support of HIV+, but we realize the gaps in caring for affected children. Another opportunity is the current PMTCT approach. Now that you're treating most mothers, we have an opportunity to start the interventions in early pregnancy. We have an opportunity with the new pediatric ARV approach (treating all children earlier) – we can see kids earlier and fill that gap between treatment programs and OVC programs. I wonder how the funders will link their funding to long-term outcomes. Pia Britto: a suggestion for the forecast analysis: Because you're taking a developmental perspective, a unique contribution would be: what are times of stability and what are times of transition? We don't have this presented to us from an adversity perspective. Lorraine Sherr: can the model accommodate multiple rather than single lines? In my research, nothing happens singly. Chris: in theory yes, but can you calibrate them with available data – sometimes no. Lucie Cluver: If an outcome is bad enough, it doesn't matter if it's only a small proportion of a population – I'm not sure if we should be approaching it in a majority/minority way. Chris: it's a question of whether or not you can find those children, if they're a small proportion.
Ms. Gretchen Bachman Office of HIV/AIDS, Global Health, USAID Presentation topic: Early years OVC funding from PEPFAR	 Gretchen gave a presentation on the OVC Special Initiative When we last got together we talked about the gap between clinic-based care and community & home based care and socio-economic support – to mind that gap we have to invest in the middle – referral networks, case managers multi service community outlets such as ECSD or social networks. The OVC Special Initiative has four aims: 1) improve the health of HIV exposed, infected and infected, i.e to increase access to HIV testing and treatment in PEPFAR programs, 2) Improve the health of women living with HIV, 3) improve the developmental outcomes of young children affected by, exposed to and/or living with HIV; and 4) foster collaborative work between OVC and clinical programs to provide a coordinated approach for the long-term care of the HIV affected family. We're targeting OVC the 0-6 age range, including exposed, infected, affected and parents Doing this in 4 countries – Lesotho, Malawi, Swaziland and Zimbabwe – each has partners and at least 1 study. Launching this was very challenging – we got 3 researchers (Lorraine Sherr, Lucie Cluver, Mark Tomlinson) and 2 ECD curriculum specialists. In the four countries, there will be different kinds of sectoral linkages. The idea is to figure out how do we make these linkages, and also what keeps families coming back. Different countries are looking at a wide range of outcomes. All of these studies will be randomized control trials over a 3-year period — Gretchen made the following recommendations for our common messaging Consider including an acknowledgement of poverty as an underlying factor Highlight the contribution this approach will make to prevention of health risks over a lifetime Consider adding a reference to the economic return made by countries on earl childhood development investment.
	 Discussion: Dominic Kemps: Will there be a dissemination of the learnings? Gretchen: Yes, that would be important. Nicole Behnam: These are all the same children. We want to integrate the clinical outcomes into the community platform. Tamsen Rochat: It's fantastic that there will so many sources of evidence. I wonder about the point about this being an immediate investment into a long-term goal. Gretchen: we face challenges in the way we're funded – we often don't operate on a more than even a one year timeframe. If we build this up, we hope people will be able to continue to capitalize on it. Also, could we argue for clearer guidelines for re-enrolment of people in RCT's that are funded for only a short period of time?

Speaker	Selected key messages	
Ms. Angelina Namiba Positively UK & The Community Engagement Working Group on HIV/AIDS Presentation topic: The Community Engagement Working Group's work, and its connection to early integration for children born into HIV-affected families	 I'm an HIV+ mother of an HIV- child who is 15 years old. I work for Positively UK and also am a member of GNP+ and a member of the Community Engagement Working Group of the IATT. The Community Engagement working Group of the IATT believes communities can play a vital role in reducing vertical transmission and keeping women and mothers alive. We haven't done an extensive amount on ECD and early integration, but I wanted to mention a) that we've recently done a treatment literacy guide for mothers living with HIV regarding early infant diagnosis. Examples we believe include women: 16 community based community run ECD play centres were established to provide health, nutritional an psychosocial support for OVC aged 5 years and young. The Yabonga program in the townships of South Africa The "From Pregnancy to Baby and Beyond project a mentor mother program linking up with mothers in their clinical settings – and following them up. We also have a family support worker who continues to work with the children. In short, we should: Move beyond a clinical continuum of care to a trajectory response acknowledging the needs of families living with HIV. Build on the strengths of ECD platforms to offer and monitor essential health services for children living with and affected by HIV. Link between PMTCT programs and community-based models Suggestions for common messaging: Make it explicit that child survival is intricately linked to maternal health involvement/ support of men is important to enable mothers to access to services Engaging the community more than engaging parents – it means community health workers, community leaders, caregivers We need to highlight the most important barriers to	
	Discussion: Nicole: please get us a copy of the Living and Growing curriculum.	
Dr. Elizabeth Mason Department of Maternal, Newborn, Child and Adolescent Health, World Health Organization Presentation topic: WHO's Early Childhood Initiative	 We are incorporating a new way of thinking in WHO about ECD, and we're thinking of integrating it in all areas of work. We have support from the highest level. In our global program, we're emphasizing a life-course approach and we're including an early childhood focus in this. Within each of the different communities: HIV, nutrition, child survival, we need to look at the development potential of young children. Evidence-based strategies can be integrated into different sectors, but the health sector has a particular responsibility for the first 1000 days – because that is where children are seen in those first two years. Starting at 3 is missing those first 1000 days. We also believe that we need to start, in adolescence, in preparing adolescents for parenting. How does this apply to families affected by HIV: caregivers may need support. Sensitive and (HIV) responsive caregiving is a requirement. Impact is greatest when interventions start early, and are combined. Our approach is to bring all the different departments together and look at the different interventions – to help us move this agenda forward. Our research shows that only 10-41% have materials at home for ECD based learning, but the research shows you don't necessarily need specialized materials. You can use simple things like a cup, etc. We've produced "recommendation for caring for your child's development", 	

Speaker	Selected key messages
	 "recommendation for feeding your child", We have counselling cards for community health workers – integrating activities with feeding, in preventing illness and injury, responding to illness, play and communication. We need this to be a systematic approach There's a meeting on indicators in a few weeks time. We're preparing a Lancet series, bringing in the issues around large-scale programming. We should not view this as an add-on and an extra burden. The key is the integration. By saying we should be integrating, we're seeing which of the programmatic elements can fit in. Suggestions for common messaging We need a community-based intervention – by doing so we reduce stigma
Ms. Teresiah Otieno The National Network of	Teresiah gave an overview of her own work, which has been a journey, since coming to the first meeting in New York in May.
People Living with HIV in Kenya (NEPHAK) & The International	 We work in country (Kenya) with NEPHAK, the national network of people living with HIV. We've long felt that there was a need to engage the policy-makers in the needs of PLHIV – we felt they needed champions among leaders.
Community of Women Living with HIV (ICW) Presentation topic:	 But then I came from New York. The presentations really shaped my thinking and I saw the need for promising integrated interventions – the speakers in New York were talking about my children. Sharing the multi-sectoral approach was a powerful message. When I went back to Kenya, I was nominated to the National Steering Committee on
Integrating the early years/integration agenda into the Kenyan response	 MNCH, which includes the First Lady. Integration is one of its five key strategic directions, but it was only around clinical services. There were missed opportunities. There was need to go beyond PMTCT. For instance, what about linking OVC to PMTCT interventions? If we focus on family-centred approach, it benefits all children in the family. When my children were born, they weren't reached by services.
	 Integration promotes family centered approach that benefits other children in the house hold Integration from WLHIV perspective is beneficial because pregnant women can get
	 services under one roof (one-stop shop), saves time and promotes adherence Integration of SRH services for WLHIV enables preconception counseling, boosted retention in care as there is a whole woman care in the clinic.
	 There is need to link community interventions (community strategies) and health services for holistic benefit of affected children We need to create a community awareness of the minimum package of various services –
	to enable an increased demand by the community for accountability. • What can happened next?
	 NEPHAK were invited to be involved in the country community service strategic plan – which focused on the social determinants of health. The Cash Transfer program was recently launched and NEPHAK was asked to influence it. National Steering Committee on Maternal and Child Health – I'm a member. I'm able to provide into the discussions – to advocate bringing in more stakeholders.
	Suggestions for improving our common messaging:
	 We have the evidence, but if mothers don't understand the messages, they won't be in a position to be advocates – to create a demand for these services.
	 Discussion: Pia Britto: I'd like to get a sense of how we can get guidance from Teresiah on how advocacy can inform the research agenda. Tamsen Rochat: In HIV we talk about treatment literacy. Can we translate what's happened into messaging that can be used by the community?
Dr. Douglas Webb UNDP	 Doug gave an overview of what has happened with the Post-MDG process: 1) There's the High Level political forum, 2) Open Working Group (OWG) is a critical forum – member states (60 of them) established in Jan 2013 to provide
Presentation topic: The	

Speaker	Selected key messages
post MDG agenda and early interventions	sustainable development goals (SDGs) to the general assembly in September 2014, and 3) intergovernmental committee – which will work out who pays for them. • The consultations are winding up, and now the Open Working Group (OWG) has to digest all of that information. In the last few days, they submitted a focus area report divided into 19 themes for consideration for the SDGs. These 19 themes are areas of focus that should become goals. • 2 of them are Health and population dynamics, and 2) promoting equality: social protection, marginalized groups. • There's a shift to multi-sectoral response to development (which supports the integration agenda). Also there'ill be a focus on: accelerating progress on the unfinished health MDGs, ensuring universal health coverage and access, social determinants of health. • HIV is being lumped in with other communicable diseases • Entry points: Poverty eradication; Education – which includes early childhood education; and Promoting equality • What's missing is nutritional support for children. • The Chairs of the OWG stress that if it doesn't appear in the focus areas – it doesn't mean it won't appear in the goals. • There's a separate "Sustainable Development Solution Network" – which is outside of the UN and this is a group of academicians who have started reviewing targets and indicators. This process might be another area of advocacy – as there seems to be a link between them and OWG members. See Doug's slides for more detail. • Opportunities to influence the process • A broad based consultation on OWG focus area report is underway till March 14, 2014. You can join the discussion at: http://www.worldwewant2015.org/node/424915 • SDSN has submitted a draft report on indicators which is open for comments till March 14, 2014. You can join the conversation at: http://unsdsn.org/news/2014/02/14/public-consultation-on-indicators-for-sustainable-development/ • Next steps: The OWG has to conclude its work on the focus areas by March 14 th – and will continue working
Ms. Louise Zimanyi Consultative Group on Early Childhood Care & Development Presentation topic: Convergent messaging from global efforts of the Consultative Group on Early Childhood Care & Development	 It used to be so hard to find evidence to support HIV and ECD programming, back in 2003 when we began discussing this – the landscape has changed for the better. While there's progress in the post-MDG process, young children aren't mentioned at all – this despite ongoing and various efforts to advocate. We've done briefs, consultations, participated in particular in the inequalities and the education consultations. What is great is that we see "early childhood education" in the Open Working Group focus areas – and that there's an opportunity to do continued advocacy. It's just that there's a lack of understanding of how it fits together. There are 5 places where early childhood is implied, but no direct reference to the research on brain development, the impact on later economic benefits In fact, the 2010 UN Sec Gen Report and resolution on implementing rights in early childhood is not even reflected – even though the member states adopted this. We advocated for 3 targets and indicators: 1) ensure healthy child development, 2) support for parents and caregivers and 3) access to quality ECD programs and services Next steps/ Opportunities: Revised technical paper based on the OWG Updated advocacy strategy Lobbying member states for champions Breakfast of champions at UN General Assembly, September 2014.

Speaker	Selected key messages
	Our homework: 1) Sign Tessa Jowel's petition. 2) Send your input to include in the background note of the High-Level Even of the General Assembly "The Contributions of Women, the Young and Civil Society to the Post 2015 Development Agenda" – due Friday!!
	 Michael Wong: Some of the work we're doing around post-MDGs: we need to have some coherence to the messaging in the OWG reports. One of our efforts is to give some coherence to the messaging that partners are putting into the subject of universal coverage. In my view it's a vital access point. We've brought together 20 OWG members and the 4 key drivers in our approach: 1) important for our approach to be people centre, equity approach 2) vital to work across sectors, 3) There are two groups left out – newborns and adolescents, and 4) how to improve local evidence for accountability. Lorraine to Doug: Is anybody doing an analysis about what about the MDGs didn't work. Doug Webb: There was a mountain of analysis going into the current discussions – the rhetoric is that the lessons have been analysed, dissected and incorporated into the new discussions. The process has been radically improved, and there's been an openness about what hasn't worked. Regarding the concept of universal: we shouldn't accept any target about universal health coverage that isn't 100% coverage. Pia Britto: We've worked very hard to get the words early childhood into the OWG and the Sustainable Development Reports – it took a lot of public speaking, a lot of one-on-one meetings, and we managed to get those words. Now our goal is not to have them drop out! So, in the advocacy we want to acknowledge that it's there.
Mr. Craig McClure UNICEF & Dr. Pia Rebello Britto UNICEF, Early Child Development Unit Presentation topic: Synergies and convergent themes in UNICEF's work in early interventions	 Craig McClure: Pia and I have been learning a lot from each other, and in particular from the Hilton work. We're in virgin territory around integration – not only in ECD, but also in the health sector, and in the areas of protection, care and support. Listening to Teresiah and Angelina, I'm reminded that people say that treatment kept me alive, but the support saved my life. That's a nice way to think about the alignment of protection care and support, with health interventions. Speaking about HIV/AIDS and where we fit in the post-2015 SDGs – many of the HIV community are coalescing around the idea of 'ending AIDS' – and what would that look like. The 2nd process – the Lancet Commission on AIDS & Health Post 2015 – the first working group tried to define it as the end of the AIDS epidemic as a public health threat – across geographic regions, key populations, ages where for every HIV infected person, there would be an infection rate of less than 1 (i.e. for every 1,000,000 HIV positive people, there would be fewer than 1,000,000 ne HIV infections). We can't talk about ending AIDS unless we talk about a vision where children are born HIV-free and remain HIV-free all the way to adulthood, and where those living with HIV have the protection, treatment, care and support to grow up to thrive in adulthood. We can't end AIDS unless we narrow the treatment gap and support the health and development interventions to achieve that goal. The 3 goals of "The Double Dividend" are 1) Narrow treatment gap; 2) to ensure all HIV-exposed children are identified, provided the services they need and linked to care; and 3) to improve child survival through better inclusion of maternal and child health. To do this we need to ensure the linkages within the MNCH interventions are connected to HIV treatment. That's translated into new country actions. UNICEF is finalizing an MOU with the Global Fund to harmonize and align the 3 disease-specific interventions with MNCH.

Speaker	Selected key messages	
	Children and AIDS. We want to focus on the life-cycle approach, beginning with the pregnant mother, the infant, then the early years, then on the transition to adolescence, then adolescence, then the transition to adulthood.	
	Dia Duitta	
	 Pia Britto The work in the 3 countries funded by Hilton has stimulated a conversation – supported by excellent work of some of the people at this meeting. And that Convergence of ECD and HIV across our 3 countries look like on the ground? 	
	 In Kenya, the focus has been on children's readiness for school. On the surface, it doesn't seem like this relates to our conversation. But this sets children on a good trajectory – and Kenya is looking at what we need to do if children aren't ready. 	
	 In Tanzania, it started with an ECD, but has broadened for a child development policy. It has resulted in a discussion about entry points. In Zambia – There's been an alignment of the Ministry of Ed, Community 	
	Development and local government re: the training of ECD teachers in high burden communities.	
	 Learning: ECD in most countries sits in Ministries of Education. We're talking about shifting that. 	
	 We're not there yet in terms of our programming but we're starting to expand our thinking and that's a huge shift. Here is some food for thought: 	
	O 1) What does "convergence" look like at the level of the beneficiary? In ECD, it's that child's developmental potential. How can we enhance the convergence to the interests of the mother?	
	 2) What does it look like in terms of the setting? We know services appear in clinics, and in different settings. How do we bring them together? It's not just about locating them side-by-side. It's supports that links them together. 3) Systems-level convergence. This convergence appears to lie in building the 	
	capacity of service providers to see the connections.	
	Tom: HIV is an integral part of the ECD system, but what's really bearing fruit is HIV's experience doing multi-sectoral programming and in informing policies and guidelines.	
Synthesis and Agreement	on Key Messages & Advocacy Commitments	
General Discussion on	Tamsen Rochat	
Messaging	 What can we do in advocating for creating data platforms that enable re-enrollment strategies for RCT in Africa as a point for building evidence in Africa? Even if funding is limited to short follow up, can we advocate for creating platforms that link to existing data and allows for re-enrolment later? 	
	• In the USAID Special Initiative presented, for example there will be up to 10 RCT in African countries, all of the outcomes are relatively short term, about 12 months post intervention, and while this is the nature of the game, we should be asking ourselves what things can we get into the conversation to funders, researchers, government in terms of longer term follow up. Simple strategies can include for example asking for consent to reenroll or the trace and track.	
	 Thinking about being more explicit in language on intervention versus parental literacy, how do we communicate this so that it does bring some of the inherent capacity of the caregiver themselves to the conversation, the idea that we are acting with and not acting on. The idea of treatment literacy in HIV could be useful in child development or a way to marry HIV and child development better, and how does it translate to developmental literacy, economic literacy. 	
	Doortje 't Hart:	
	 I need the how these linkages are mademy audience are implementers. We're missing the leading role of government – we need to give them something to grab onto. 	

Speaker	Selected key messages	
	 Tamsen Rochat: In HIV, there's an aspiration to find a message that will fix it all. I'd like part of the message to be that ECD can't flop – that it works no matter what, that it can be done cheaply and universally. 	
	Craig McClure: • I've seen 6 messages emerging: • CABA can survive and thrive • Early investment is critical • Starting with pregnancy, HIV testing, treatment and basic health services are essential • These need to be complemented by early development interventions – eg. Stimulation, play, • Focus on equity – the most excluded children are critical, and so we need to access their mothers, families, households & communities. • Aligning health and development interventions in early childhood makes a difference.	
Advocacy commitments	• See body of the report	
Advocacy communents	See body of the report	
Wrap up and Closing Remai	rks	
Ms. Kate Iorpenda Chair: The Coalition for Children Affected by AIDS & International HIV/AIDS Alliance	 Thanked the group, asked people to consider other advocacy items up to, and beyond Melbourne, and not necessarily tied to the journal. We want to remember that we take people with us along our journey. Let's remember Angelina Namiba's and Teresiah Otieno's points that we must remember that this matters most to the parents and the children – and we need to remember how this impacts on them. We need to remember how to make this matter to different people. Sometimes at the end of a meeting, it seems like we don't agree but we do have lots of agreement. Furthermore, we'll probably realize that something has emerged from this meeting series that we couldn't have expected. 	

Appendix 2 – Meeting Program & Participant List







PROGRAM

The Road to Melbourne: Young Children Born into HIV-affected Families Meeting #3 (London) Advocacy Action Planning

Date: Wednesday February 26 2014

Location: Thistle Holborn, The Kingsley, Bloomsbury Way, London, UK

Meeting convened by: The Coalition for Children Affected by AIDS

Supporting funders: This meeting is made possible thanks to the financial contributors to the Coalition for

Children Affected by AIDS: The Conrad N. Hilton Foundation; Elizabeth Glaser Pediatric AIDS

Foundation, Firelight Foundation, Save the Children, STOP AIDS NOW!, World Vision

International, UNICEF, The Diana, Princess of Wales Memorial Fund (through a legacy grant), The Norwegian Agency for Development Cooperation, Sweden, & ViiV Positive Action Program.

TIME	AGENDA ITEM	Notes & Timing
8:30 - 9:00	Tea/Coffee	
9:00 - 9:10	Welcome & Introductions	What is the Coalition for Children Affected by AIDS Brief welcomes by cohosts.
9:10- 10:30	Setting the scene: What is the Coalition for Children Affected by AIDS and what do we try to accomplish with our "Road to" meeting series Ms. Kate Iorpenda Chair: Coalition for Children Affected by AIDS, International HIV/AIDS Alliance Overview of Meetings #1 & 2 Dr. Linda Richter (by teleconference) Human Sciences Research Council, South Africa, & member, Coalition for Children Affected by AIDS Synergistic messages emerging from the review of Hilton-funded projects Ms. Lisa Bohmer Conrad N. Hilton Foundation & Coalition for Children Affected by AIDS Our goal for today Mr. John Miller Coalition Director, Coalition for Children Affected by AIDS	Overview of New York & Cape Town meetings Timing: 15 minutes per presentation 20 minutes for discussion
10:30 - 10:45	Tea/Coffee	
10:45 - 12:30	Presentations & discussion of how other synergistic initiatives might	Presentations on related

TIME	AGENDA ITEM	Notes & Timing
	support the key messages	initiatives will be made
	Support the Rey messages	and emerging key
	Moderator	messages will be drawn
	Mr. John Miller	out
	Coalition Director, Coalition for Children Affected by AIDS	A facilitated discussion
	Presentations	will draw out other key
	Key messages emerging from the PEPFAR economic forecasting	messages from
	exercise	participants not making
	Dr. Chris Desmond	formal presentations
	Human Sciences Research Council, South Africa, & member, Coalition	
	for Children Affected by AIDS	Timing
	Early years OVC funding from PEPFAR	10 minutes each per
	Ms. Gretchen Bachman DEDEAD (LIGHT)	presentation
	PEPFAR/ USAID	Nata
	The Community Engagement Working Group's work, and its	Note:
	connection to early integration for children born into HIV- affected families	The following people called in:
	Ms. Angelina Namiba	1: 1 0: 11
	Positively UK & The Community Engagement Working Group on HIV/	Linda Richter at 9amJoan Lombardi at
	AIDS	10:45am
	WHO's Early Childhood Initiative	o Doug Webb at 12pm
	Dr. Elizabeth Mason	S Soug West at 12pm
	Department of Maternal, Newborn, Child and Adolescent Health,	
	World Health Organization	
	Integrating the early years/ integration agenda into the Kenyan	
	response	
	Ms. Teresiah Otieno	
	NEPHAK	
	Convergent messaging from global efforts of the Consultative	
	Group on Early Childhood Care & Development	
	Ms. Louise Zimanyi	
	Consultative Group on Early Childhood Care & Development	
	The post MDG agenda and early interventions (joining at 12pm)	
	Dr. Doug Webb joining by teleconference	
13:00 - 14:00	UNDP Lunch	
14:00 – 14:00	(Continued from before lunch): Presentations & discussion of how	
14.00 14.50	other synergistic initiatives might support the key messages	
	January State Control of Control	
	Synergies and convergent themes in UNICEF's work in early	
	interventions	
	Mr. Craig McClure & Dr. Pia Rebello	
	UNICEF	
14:30 – 15:30	Synthesis and Agreement on Key Messages	
	Moderator A 1 to A 2 to	
	Mr. John Miller Coolition for Children Affected by AIDC	
15.20 15.45	Coalition for Children Affected by AIDS	
15:30 - 15:45	Tea/Coffee Opportunities for advocacy and products to support it	Doortio procented on
15:45 – 17:00	Opportunities for advocacy and products to support it	Doortje presented an analysis of the kinds of
	Moderator	advocacy products
	Ms. Kate Iorpenda	people at the Cape
	Chair, Coalition for Children Affected by AIDS & International	Town meeting wanted
	HIV/AIDS Alliance	to see
	Brief overview of analysis from Cape Town advocacy meeting	We discussed the
	• <u>Ms. Doortje 't Hart</u>	feasibility of ideas
	STOP AIDS NOW! & The Coalition for Children Affected by AIDS	presented and develop
	Report from co-editors of the AIDS special issue – and	others.
	discussion about journal dissemination	
	Dr. Linda Richter, by teleconference	Participants took on
	Human Sciences Research Council, South Africa, & members,	advocacy tasks &
	Coalition for Children Affected by AIDS	suggested tasks for the
	Discussion and decision-making / division of warmanihilities as in-	Coalition.
	Discussion and decision-making/ division of responsibilities going	

TIME	AGENDA ITEM	Notes & Timing
	forward	
17:00 - 17:15	Wrap up & Closing Remarks	
	Ms. Kate Iorpenda	
	Chair: Coalition for Children Affected by AIDS	
	International HIV/AIDS Alliance	
18:30	Group supper – Kopapa	
	32-34 Monmouth St, Covent Garden, London WC2H 9HA, United	
	Kingdom. www.kopapa.co.uk/	

Joined in person 1. Ms. Gretchen Bachman PEPFAR OVC TWG co-chair, Senior Technical Advisor, Orphans and	
1. Ms. Gretchen Bachman	
1. Ms. Gretchen Bachman	
TETTAM OVE TWO CO Chair, Schiol Technical Mavisor, Orphans and	
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17. Mr. Dominic Kemps	
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Joined by teleconference for part or all of the meeting	
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