STOPAIDS.

UNITING UK VOICES ON THE GLOBAL RESPONSE

CHILDREN AFFECTED BY AIDS WORKING GROUP 10TH ANNIVERSARY SEMINAR

Highlights, challenges, recommendations

STOPAIDS.

STOPAIDS is the network of UK agencies working since 1986 to promote an effective global response to HIV and AIDS. With 80 members behind us, we raise a united voice to rally and maintain the UK's leadership in the global response to HIV. Together, and with people living with HIV at the centre of our efforts, we fight for a global response that respects, protects and fulfils human rights. We give decision-makers the proof – and sometimes the push – they need to make the right, smart choices to help improve the lives of the millions of people around the world needing treatment, prevention, care or support.

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ACKNOWLEDGEMENTS

STOPAIDS is grateful to the London School of Hygiene and Tropical Medicine for hosting the seminar, and to the Children's Investment Fund Foundation for financial support for the event.

Special thanks to Stuart Kean (World Vision International) and Kate Iorpenda (International HIV/AIDS Alliance), for their tireless work as co-chairs of the CABA Working Group.

The report was written by Linnea Renton.

CONTENTS

ACRONYMS

AIDS	acquired immune deficiency syndrome
ART	antiretroviral therapy or treatment
ARV	antiretroviral
CABA	Children Affected by HIV and AIDS
HIV	human immunodeficiency virus
IATT	Inter-Agency Task Team
ICWEA	International Community of Women Living with HIV in East Africa
LSHTM	London School of Hygiene and Tropical Medicine
MNCH	maternal, newborn and child health
NGO	non-governmental organisation
PEPFAR	[U.S.] President's Emergency Plan for AIDS Relief
PPTCT	prevention of parent-to-child transmission
SRH	sexual and reproductive health
WHO	World Health Organization

EXECUTIVE SUMMARY

A one-day seminar was held on 3rd April 2014 to mark 10 years of work by the STOPAIDS Children Affected by HIV and AIDS (CABA) working group. Despite encouraging global progress in promoting and protecting the rights of children and young people living with or affected by HIV, worrying gaps remain. Participants and presenters from across the international development, HIV and global health sectors identified the below recommendations for priority action.

RECOMMENDATIONS FOR PRIORITY ACTION

Participation

- Promote and support genuine participation and voice in decision-making and advocacy by young people and children, especially those living with HIV (as actors not beneficiaries) and by Southern civil society

Testing, treatment and care

- Support the development and roll-out of point-of-care paediatric diagnostics
- Better align maternal, newborn and child health (MNCH) and HIV services in order to increase paediatric HIV coverage by strengthening HIV-sensitivity of child health services, especially immunisation, nutrition and sick-child clinics as entry points for HIV testing and treatment
- Eliminate the treatment gap for children and support the development of affordable, palatable paediatric formulations in fixed-dose combinations
- Address real and perceived barriers, especially stigma, in relation to disclosure, access to care and treatment, retention in care and adherence

Child protection

- Create pathways to meaningful integration with other sectors and services including child protection
- Strengthen child protection mechanisms for those with multiple vulnerability e.g. HIV, disability, neglect
- Advocate for cash plus care: cash transfers are important, but much more effective when combined with social care interventions in the form of psychosocial support and preventive child protection, such as parenting support or alcohol and drug treatment programmes
- Push for a whole family emphasis, including those exposed to and affected by HIV as well as those living with HIV
- Provide greater support for early childhood development programmes especially in high HIV prevalence contexts, given that for children affected by HIV, the years from birth to six present particularly serious challenges for protection and risk mitigation

Evidence

- Produce more and better research on children and adolescents including randomised controlled trials with tight indicators and good age- and gender-disaggregated data to guide actions, and covering more than just Africa
- Build a better understanding of the long-term impact on children of being positive and/or growing up on treatment including disability and mental health

Accountability

- Call for better mechanisms of accountability by governments for their responses to children and young people affected by HIV
- Advocate for earmarked funding for children/adolescent issues.

INTRODUCTION

The STOPAIDS Children Affected by HIV and AIDS (CABA) thematic group was initially formed in 2004 to advocate for greater attention by policy makers, particularly in the UK Government and EU, to the needs of children vulnerable to, living with and affected by HIV. The current group brings together leading practitioners working with children and young people from across the membership, including Unicef, Save the Children, Restless Development, Plan, Mothers2Mothers, the International HIV/AIDS Alliance, World Vision and others. The group meets to share promising programming practices, publishes policy papers and briefings, and has played an essential role in advocacy work focused on the UK Government.

On 3rd April 2014 at the London School of Hygiene and Tropical Medicine (LSHTM), STOPAIDS held a day-long seminar to mark ten years of work by the CABA thematic group. The event was an opportunity to reflect on the progress and lessons of the past decade in promoting the rights of children and young people within the wider response to HIV and AIDS. It also served as a forum for presenters and participants to identify the key current challenges and priorities for both STOPAIDS members and the UK Government in strengthening their work with and for children and young people.

The seminar attracted a wide-ranging audience from civil society, academia, public health and government. A summary of the day's presentations and critical discussion follows. (See Appendix 1 for the event programme.)

Lynne Featherstone MP, the Parliamentary Under-Secretary of State for International Development, gives her presentation.
See page 7.

PRESENTATIONS AND CRITICAL DISCUSSION

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SESSION 1: PROGRESS, ACHIEVEMENTS AND CHALLENGES AHEAD

After a joint welcome by Dr Alison Grant on behalf of hosts LSHTM, and by Kate Iorpenda (International HIV/AIDS Alliance) of behalf of the CABA Working Group, Professor Lorraine Sherr of University College London outlined both the gains and the challenges of the past decade in relation to children living with and affected by HIV. The independent Joint Learning Initiative on Children and AIDS was a significant landmark in pushing children's issues up the international agenda and calling for integrated, family-centred responses. PEPFAR (the US President's Emergency Plan for AIDS Relief) was also notable in earmarking 10% of its budget for work related to children. A major advance during the period has been the growth in the percentage of pregnant HIV-positive women receiving treatment, which had reached over 60% by 2012, thereby significantly reducing the number of babies born with HIV.

> "The mental health impact of HIV on parenting results in long-lasting effects on children."

These positive aspects notwithstanding, Professor Sherr drew attention to a number of worrying trends:

- Despite the mounting evidence on effective interventions, systematic roll-out and implementation still lags behind; e.g. the institutional care model is still being funded in some parts of the world, when it has proved highly detrimental to children compared to family or family-type arrangements.
- The mental health impact of HIV on parenting, e.g. anxiety, depression (including post-natal), post-traumatic stress disorder and suicidality, results in long-lasting effects on children.
- Significant cognitive deficits, behavioural effects and developmental delays have been found, not only in infants and children living with HIV, but also in those "HIV-exposed" (i.e. negative babies born to positive mothers).
- Educational disadvantage is widespread, created by a "perfect storm" of poverty in affected families, withdrawal from school to care for relatives, HIV-related developmental delays and the impact of stigma and bullying in schools.

However, some children do cope well; the area of resilience has been understudied to date and merits further research. In weighing up the delicate balance of risk factors versus protective factors, Professor Sherr noted that adversity is cumulative, with each additional risk factor increasing a child's vulnerability. Reducing the number of adverse experiences, such as neglect, bullying and social exclusion, is critical to preventing or mitigating harmful outcomes. In this regard, although cash transfers to households have been shown to be useful, for example in reducing girls' involvement in transactional or age-disparate sex, it is a "cash plus care" model that is most effective, helping boys as well as girls to cope better with their situation.

> With 700 children newly infected every day, future work needs to be targeted at ensuring that children are born free of the virus and stay free of it, and that those living with HIV have access to the care and treatment they need."

Lynne Featherstone MP, the Parliamentary Under-Secretary of State for International Development, praised the work of STOPAIDS and the CABA working group, noting that their collective voices had been powerful and had done much to influence responses at the international level. She emphasised that with 700 children newly infected every day, future work needs to be targeted at ensuring that children are born free of the virus and stay free of it, and that those living with HIV have access to the care and treatment they need. The UK's main focus in this area is a strong commitment to the Global Plan to eliminate new infections among children by 2015 and keep their mothers alive.

To that end, DFID has supported 67,000 women living with HIV to access treatment. However, there is a consistent lag in treatment for children, with a huge push needed to provide ART to all who are eligible. Treatment must also be seen in the context of the broader care and support needs of under-15s who are living with HIV and/or have lost one or both parents. Cash transfers are transformative in enabling families to care for their children, and better outcomes for children result when they are supported in a family environment.

In terms of DFID's support to civil society organisations, this has covered work including tackling stigma and discrimination and addressing the root causes of vulnerability, e.g. for adolescents. The minister recognised the importance of youth-friendly services and also spoke of the need to increase access to a broad family planning mix, including dual protection against HIV infection and unintended pregnancy.

> 34% of eligible children accessed ART versus 64% for adults in 2012."

Ben Simms responded on behalf of STOPAIDS, paying credit to the minister as a loyal friend to the network and to the global response to HIV. He also praised the rich expertise of the CABA working group, ably led by its co-chairs Stuart Kean and Kate Iorpenda, and emphasised the vital importance of promoting and listening to the voices of those living with HIV.

His primary criticism of the UK response related to its diminishing focus on children and young people. The original motivation for the formation of the CABA group 10 years ago was to place children's issues firmly on the HIV and development agenda. DFID's 10% earmark of funding from the HIV & AIDS budget for work relating to children was an extremely positive and welcome result of that lobbying – but sadly, the earmark has since been dropped. This is despite worrying trends such as the huge treatment gap for children (34% of eligible children accessing ART versus 64% for adults in 2012).

Ben emphasised the need to address children and young people in all their diversity – e.g. young people with disabilities, young men who have sex with men, young transgender people, young users of drugs and young people selling sex – as well as addressing underlying causes and structural drivers of the epidemic, including violence against women and girls. He concluded by reaffirming the central role of care and psychosocial support; an over-reliance on cash transfers alone will fail the children and young people most affected by the epidemic.

Setting the scene

To ground the discussions in the lived reality of those most closely affected, **Hajjarah Nagadya** of the International Community of Women Living with HIV in East Africa (ICWEA), addressed the group via telephone from Uganda. She spoke movingly of her experiences growing up with HIV and losing her mother and younger brother to AIDS; her mother died knowing her own status and that of the children but she never disclosed it to them. Hajjarah only learned that she had HIV as a young adolescent. Despite reacting very badly to ARVs, she persisted with treatment and eventually earned her bachelor's degree. She is currently caring for her father and sisters, as well as her young son who was born HIV-negative in 2012. Hajjarah remains "determined, taking my drugs and having my goal of keeping on with life".

Issues raised in discussion

- **We need more evidence on what resilience means and how it can be supported.**
- **Scaling up rapid point-of-care paediatric diagnostics could be a game-changer.**
- **Home testing to date shows a mixed picture, with a family approach still not being followed; holistic follow-up of mother-baby pairs is still not happening.**
- **Children's issues are now a lower priority on the international agenda than they were five years ago, and this has worrying implications.**

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SESSION 2: YOUNGER CHILDREN

Gareth Tudor-Williams, Imperial College, opened the session with a comprehensive summary of paediatric treatment. By 2004 there had already been considerable progress for children with HIV, from palliative and terminal care for infants to a focus on adolescent medicine, accompanied by advances from monotherapy to triple therapy.

Click here for Gareth's presentation

http://stopaids.org.uk/wp-content/uploads/2014/04/Gareth-Paed-HIV-Rx-GTW-2014.pdf

Current treatment research priorities in relation to children differ regionally: in high income countries, the focus is on new drugs and simplification of ART, but in low and middle income countries, improved diagnosis, better access to treatment, paediatric formulations, monitoring, retention in care and adherence are the key concerns. The importance of early treatment for infants was highlighted, with data showing a fourfold difference in progression to AIDS or death in infants receiving deferred treatment versus those receiving early ART. WHO guidelines have shifted from the 2010 recommendation to treat all under-twos regardless of clinical symptoms, immune status or viral load; advice as per their 2013 update is to treat all under-fives. Adherence for adolescents remains a challenge, though developments in treatment potentially allowing occasional gaps (e.g. weekends off) could be promising in this regard.

> "Evidence compiled for the Inter-Agency Task Team on Children affected by HIV and AIDS shows that HIV can increase the risk of serious child protection violations."

Siân Long, independent consultant on children and HIV, focused on the issue of building HIV-sensitive child protection systems, noting that necessary linkages between HIV and child protection to enhance outcomes for all vulnerable children are not yet being made. Within the child protection field, there has been a shift from single-issue interventions to a systemic framework which identifies what is needed to provide a protective environment for children at all levels against abuse, violence, exploitation and neglect. Child-focused HIV responses must be situated within long-term, locally owned and sustainable approaches to child protection; likewise, strong and equitable child protection systems must include a focus on children vulnerable to, living with and affected by HIV.

Click here for Siân's presentation

http://stopaids.org.uk/wp-content/uploads/2014/04/Sian-CP-HIV-synergies-presentation-StopAIDS-030414.pptx

Evidence compiled for the Inter-Agency Task Team (IATT) on Children affected by HIV and AIDS shows that HIV can increase the risk of serious child protection violations such as physical and emotional abuse, mental health and behavioural problems, exclusion and bullying, and abandonment and institutionalisation. Conversely, childhood abuse, violence and exploitation can increase the risk of acquiring HIV, through higher rates of and/or earlier initiation into exploitative sexual behaviours, injecting drug use and transactional sex. The risks are cumulative, requiring a long-term response that includes better integration, information-sharing and mutual referral mechanisms.

Hannah Kuper of the International Centre for Evidence in Disability, reminded the audience that people with disabilities are more vulnerable to HIV, both because of the prevalence of abuse and because HIV prevention activities are not targeted to their needs. She then highlighted the existing evidence on whether HIV itself causes disability, noting recent findings that children living with HIV (whether or not on long-term treatment) experience a range of visual, hearing, speech and learning/cognitive impairments as well as developmental delays. Parents often do not recognise or report these problems, leading to a massive unmet need for rehabilitation. Despite these multiple connections, only Uganda and South Africa include disability in their national HIV plans. More research, especially on children, and better integration between the HIV and disability sectors are urgently needed.

Click here for Hannah's presentation

http://stopaids.org.uk/wp-content/uploads/2014/04/Hannah-HIV-and-disability-CABA.pdf

> "Children living with HIV experience a range of visual, hearing, speech and learning impairments, only Uganda and South Africa include disability in their national HIV plans."

Issues raised in discussion

- The overlap between HIV, child protection and disability needs to be better understood and joint responses developed, e.g. in addressing violence against children in schools.
- Water and sanitation issues are also relevant for families affected by HIV.
- Given that third-generation drugs are largely unavailable in low and middle income countries, how can we best support people – including children and adolescents – to maintain adherence and not develop resistance?
- With WHO's recommendation of treatment for under-5s, what happens to those who are 5 plus one day? This is a huge disservice to the older children.
- We need to hear the voices of children and young people living with HIV.
- Initiation on treatment is very easy to measure, but well-being downstream (e.g. 18 years later) is much harder to gauge.
- "Treatment as prevention" is getting the headlines, but we must not lose sight of upstream determinants and drivers of infection.
- The long-term implications for children of being on treatment are still poorly understood.
- Campaigning around the patent pool and generics remains a major priority for STOPAIDS.

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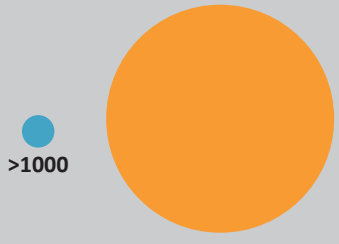
SESSION 3: OLDER CHILDREN AND ADOLESCENTS

Helen Leadbitter of the Children's Society, examined issues for young carers and their families affected by HIV, including those who are "hidden" carers because of HIV stigma and bullying. No care package should rely on a young person taking on an inappropriate caring role that may damage their health or put their education at risk. Other negative impacts may include isolation, guilt, resentment, lack of recognition, psychological burden from keeping family secrets, underachievement, lack of career choices and life opportunities, and problems with transition to adulthood. It is important to deal with the whole family, not treat them as separate individuals. Referrals and information sharing (e.g. between education, social care and health services) are vital.

Click here for Helen's presentation

http://stopaids.org.uk/wp-content/uploads/2014/04/HelenCABA.pdf

> "No care package should rely on a young person taking on an inappropriate caring role that may damage their health or put their education at risk."



Adolescents reached by harm reduction services 2012

Population size estimate 10–19 injecting drug users (Unicef)

Maria Phelan of Harm Reduction International and **Kate Iorpenda** of the International HIV/AIDS Alliance co-presented on working with adolescents who inject drugs. One major challenge is the lack of data:

- A global population size estimate for under-18s who inject drugs is unavailable, and national estimates are exceptionally rare
- The contribution of injecting among under-18s to HIV epidemics is largely unknown
- Age disaggregation in HIV surveillance is poor.

This means that some of the adolescents most at risk, including those who are street-involved, are "hidden in plain sight" and very unlikely to be reached by harm reduction services. Although there are considerable variations within and between countries, available studies show low ages of initiation of drug-injecting behaviour across regions, and in some countries significant proportions of people who inject drugs are adolescents (e.g. estimated at 20 per cent in Nepal). Risk-taking behaviour also varies by age, with adolescent injectors more likely to share needles.

Click here for Maria and Kate's presentation

http://stopaids.org.uk/wp-content/uploads/2014/04/Maria+-KateCABAWG-presentation-Hidden-in-Plain-Sight.pdf

Click here for Lucy and Stefanie's presentation

http://stopaids.org.uk/wp-content/uploads/2014/04/GRS-STOPAIDS_April-3-2014_final.pdf

Despite these factors, treatment is hampered by a lack of youth-focused services, as well as by the existence of laws, policies and attitudes that restrict or deny access to those under 18. To assist service providers to handle more effectively the legal, ethical and practical dilemmas involved in working with children and young people who use drugs, a tool (Step by Step) is currently being piloted and will be launched at the International AIDS Conference in Melbourne in July.

Lucy Mills of Grassroot Soccer (GRS) and **Stefanie Dringus** (LSHTM) spoke about the use of sport for development, in particular mobilising and educating young people about HIV and challenging gender norms through football. The curriculum developed by GRS uses football-related activities and metaphors, for example dribbling around cones to represent avoiding risks, to help adolescent girls and boys develop life skills. Pre- and post-intervention questionnaires are administered to measure changes in knowledge and attitudes. An evaluation is currently being conducted on the impact and effectiveness of sport-based HIV prevention in South African high schools, using a cluster-randomised controlled trial. Preliminary findings show the importance of coaches as meaningful adults in young people's lives.

Issues raised in discussion

- **Ethical challenges in research include what kinds of questions are approved to ask young women versus young men, for example about intimate partner violence and rape.**
- **Some type of follow-up or referral is necessary after asking about these destructive behaviours.**
- **As with age disaggregation, gender disaggregation of data around drug use and its impacts is lacking.**
- **The issue of payment and/or other incentives for the volunteers on whom many interventions depend remains hotly contested.**

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SESSION 4: FUTURE PRIORITIES

Victoria Forsgate of Restless Development opened the final session with a presentation on the opportunities, challenges and priorities for youth in shaping the post-2015 development agenda. Young people have been involved in the process in different ways to date, with varying levels of participation and engagement:

- Youth as target groups and beneficiaries
- Youth as collaborators and partners
- Youth as initiators and leaders

> "Are we working for young people, engaging with young people or supporting young people to take the lead?"

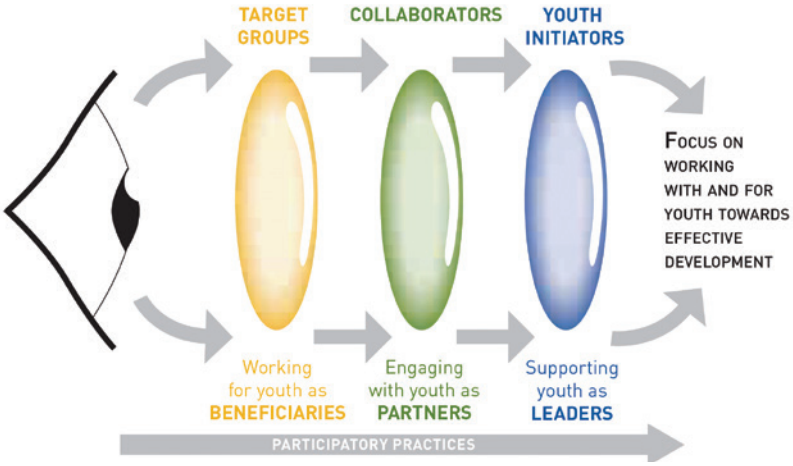
This distinction was a reminder to question our own organisations' missions and ways of operating: are we working for young people, engaging with young people or supporting young people to take the lead?

One difficulty with youth advocacy is that there is not a common youth position on issues such as governance, health (including sexual health and HIV), jobs, education, environment and equality. Moreover, the rights aspect for young people is still contentious within less progressive organisational or national contexts. Victoria emphasised that despite these challenges, a huge amount can be done to support youth involvement in national advocacy, including but by no means limited to the post-MDG process.

Click here for Victoria's presentation

http://stopaids.org.uk/wp-content/uploads/2014/04/vicYP-Post-2015_STOPAIDS_Apr14.pdf

The three-lens approach to youth participation



Adapted from: The World Bank *World development report 2007*.

> "Special attention should be given to integration with other child survival interventions such as immunisation and nutrition."

Click here for Louise's presentation

http://stopaids.org.uk/wp-content/uploads/2014/04/Louise-Holly-presentation-for-CABA-event-3April2014.pdf

> "We must create a stigma-free environment at school and provide youth-friendly centres for sexual and reproductive health information and services."

Louise Holly of Save the Children followed with a presentation on what a child-centred focus would look like. She outlined the substantial recent progress made on reducing under-five mortality, which almost halved from 12.6 million deaths in 1990 to 6.6 million in 2012. However, she noted that this still means nearly 18,000 children are dying each day, with just five countries (India, Nigeria, DRC, Pakistan and China) accounting for half of this number. Moreover, the bulk of decline is in the older end of the under-five age range, with the neonatal and infant mortality rates (deaths within the first 28 days or first year of life per 1,000 live births, respectively) declining much more slowly.

HIV remains the cause of approximately 2–3% of child deaths, but children born to women living with HIV, whether or not they themselves acquire the virus, are at increased risk of morbidity, disability and mortality, and must be identified early in order to receive appropriate treatment and follow-up care. Special attention should be given to integration with other child survival interventions such as immunisation and nutrition.

Hajjarah Nagadya of ICWEA rejoined the meeting via Skype to offer a personal perspective as a woman living with HIV. She advocated for empowering mothers to be in a better position to disclose the status of their children, and also to support the children to address the challenges they face such as transitioning to adolescence and entering relationships. She also emphasised the importance of creating a stigma-free environment at school and providing youth-friendly centres for sexual and reproductive health (SRH) information and services. Further areas for priority action include tackling the attitudes of service providers; integrating HIV with other SRH services; engaging males in testing and preventing vertical transmission; and addressing issues of gender-based violence. Lastly, Hajjarah urged the audience to put mothers at the centre of planning, implementation and monitoring.

Pete McDermott from the Children's Investment Fund Foundation gave the final presentation, setting out his vision of the highest priorities for investment. He noted the increasing marginalisation of children and adolescents, especially girls, on the global agenda. To redress this, we must make the most of all available funding (both domestic and international) and spend it in the right places to get the best return. Areas for particular attention include:

- Better data, evidence, measurement and evaluation. For example, the current measure of success for paediatric ART is the number of children initiated on treatment. Where is the information about the number not accessing testing in the first place? The number lost to follow-up? The number still alive at age 5? etc.

> “How do we make HIV everyone’s business, and ensure that the HIV sector collaborates with others such as child survival, early childhood development and education etc.?”

- Institutionalised accountability. Who is making progress, where, how and at what cost, and what are the mechanisms for getting successful initiatives programmed? Where is the independent peer review of progress on issues related to children living with and affected by HIV?
- Meaningful integration and collaboration. How do we make HIV everyone’s business, and ensure that the HIV sector collaborates with others such as child survival, early childhood development, education etc.? How do we measure successful integration?
- Meeting the unique challenges of adolescents living with HIV. Currently there is “lots of noise” on this but where is the evidence-based, evidence-driven programmatic response?
- Addressing critical barriers with our funding. When we aim to increase coverage with our interventions, what does this mean? How do we break down the cascade and make sure that the barriers at each stage are addressed?
- Regaining the cutting edge of the civil society voice. We had this on treatment action, for example, but seem to have lost it. Advocacy is now “aspirational” and “soft”, not evidence-based. How can we recapture the initiative?
- Putting women and girls at the centre of the response. Where is the next major initiative to follow the Global Plan, and how can we shape it?

Issues raised in discussion

- **What are the social, cultural, faith etc. factors that are preventing the scale-up and implementation of proven interventions?**
- **One key systemic barrier is human resources, from the ministry level downwards (technical, managerial and leadership skills, distribution, retention, etc.).**
- **Are we really being honest about Southern voices and Southern ownership? What if those voices are saying something we don’t want to hear? e.g. expressing or condoning homophobia**
- **Similarly, when we talk about meaningful involvement of Southern civil society, what do we mean? Is it genuine engagement of local communities or just a gloss for the national programmes of international NGOs?**
- **The issue of inclusive language is important – e.g. vertical or parent-to-child not mother-to-child transmission; living with HIV not HIV-infected; etc. in order not to alienate or assign blame.**
- **Good governance and bringing governments to account must be at the core of our work.**
- **We need more nuance re low-income versus middle-income countries; there is a real lack of political will in concentrated epidemics and we need to stop the UK walking away when there are still groups in need.**
- **We have to stop accepting aggregated data. Disaggregation is the only way to tell who is being left behind, and we can then link that to action.**
- **Southern civil society must play a key role in gathering, interpreting and using this information.**
- **Getting children and youth back on the agenda is crucial, but we need to do this in a way that places HIV in a broader global health context (given what the post-2015 agenda is likely to look like).**
- **We will use the run-up to the 2015 general election to push for political commitment from all main parties.**
- **The theme of children and young people living with and affected by HIV is still essential.**

KEY RECOMMENDATIONS

In addition to the issues raised in the presentations and discussion sessions, there was also an opportunity for participants (either individually or in small groups) to submit written suggestions about priorities. The following recommendations are drawn from a combination of these sources.

Participation

- Promote and support genuine participation and voice in decision-making and advocacy by young people and children, especially those living with HIV (as actors not beneficiaries) and by Southern civil society

Testing, treatment and care

- Support the development and roll-out of point-of-care paediatric diagnostics
- Better align MNCH and HIV services in order to increase paediatric HIV coverage by strengthening HIV-sensitivity of child health services, especially immunisation, nutrition and sick-child clinics as entry points for HIV testing and treatment
- Eliminate the treatment gap for children and support the development of affordable, palatable paediatric formulations in fixed-dose combinations
- Address real and perceived barriers, especially stigma, in relation to disclosure, access to care and treatment, retention in care and adherence

Child protection

- Create pathways to meaningful integration with other sectors and services including child protection
- Strengthen child protection mechanisms for those with multiple vulnerability e.g. HIV, disability, neglect
- Advocate for cash plus care: cash transfers are important, but much more effective when combined with social care interventions in the form of psychosocial support and preventive child protection, such as parenting support or alcohol and drug treatment programmes
- Push for a whole family emphasis, including those exposed to and affected by HIV as well as those living with HIV
- Provide greater support for early childhood development programmes especially in high HIV prevalence contexts, given that for children affected by HIV, the years from birth to six present particularly serious challenges for protection and risk mitigation

Evidence

- Produce more and better research on children and adolescents including randomised controlled trials with tight indicators and good age- and gender-disaggregated data to guide actions, and covering more than just Africa
- Build a better understanding of the long-term impact on children of being positive and/or growing up on treatment including disability and mental health

Accountability

- Call for better mechanisms of accountability by governments for their responses to children and young people affected by HIV
- Advocate for earmarked funding for children/adolescent issues.

APPENDIX 1: **PROGRAMME**

3 April 2014, Manson Lecture Theatre, LSHTM

Session 1: Progress, achievements and challenges ahead		
09:30	**Welcome**	Dr Alison Grant – LSHTM and Kate Iorpenda – International HIV/AIDS Alliance
09:35	**Setting the scene: Story of the last decade**	Professor Lorraine Sherr – University College London
09:50	**Setting the scene: Personal experience**	Hajjarah Nagadya – ICWEA
10:00	**How DFID is prioritising children and youth, as outlined in *Towards Zero Infections: Two Years On***	Lynne Featherstone MP – Parliamentary Under Secretary of State for International Development
10:15	**Response: Challenge for today and into the future for DFID and civil society**	Ben Simms – STOPAIDS
10:20	Q&A	
10:30	Break	
Session 2: Younger children		
10:45	**Paediatric HIV treatment: progress, challenges and opportunities**	Gareth Tudor-Williams – Imperial College
11:00	**Building protection and resilience: synergies for child protection systems and children affected by HIV and AIDS**	Siân Long – Independent consultant
11:15	**HIV and disability: unpacking the issues**	Hannah Kuper – LSHTM
11:30	Q&A	
11:45	Discussion groups	
12:30	Lunch	
Session 3: Older children and adolescents		
13:15	**Young carers affected by HIV**	Helen Leadbitter – Children's Society UK
13:30	**Working with most-at-risk adolescents**	Kate Iorpenda – HIV/AIDS Alliance and Maria Phelan – Harm Reduction International
13:45	**Educating and mobilising communities: introducing the Grassroot Soccer initiative**	Lucy Mills – Grassroot Soccer and Stefanie Dringus – LSHTM
14:00	Q&A	
14:15	Discussion groups	
15:00	Break	
Session 4: Future priorities		
15:15	**Post 2015**	Victoria Forsgate – Restless Development
15:25	**Child-centred focus in the future**	Louise Holly – Save the Children
15:35	**Where should we focus our efforts/investments? A positive woman's perspective**	Hajjarah Nagadya – ICWEA
15:45	**Where should we focus our efforts/investments? A funder's perspective**	Pete McDermott – Children's Investment Fund Foundation (CIFF)
16:00	Q&A	
16:10	Discussion groups	
16:45	Wrap up	

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