Caregivers Meeting

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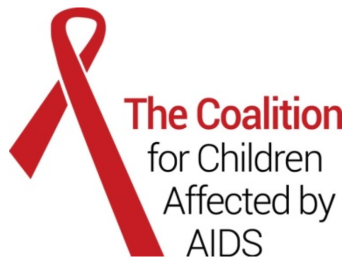
Geneva February 2016



Overview

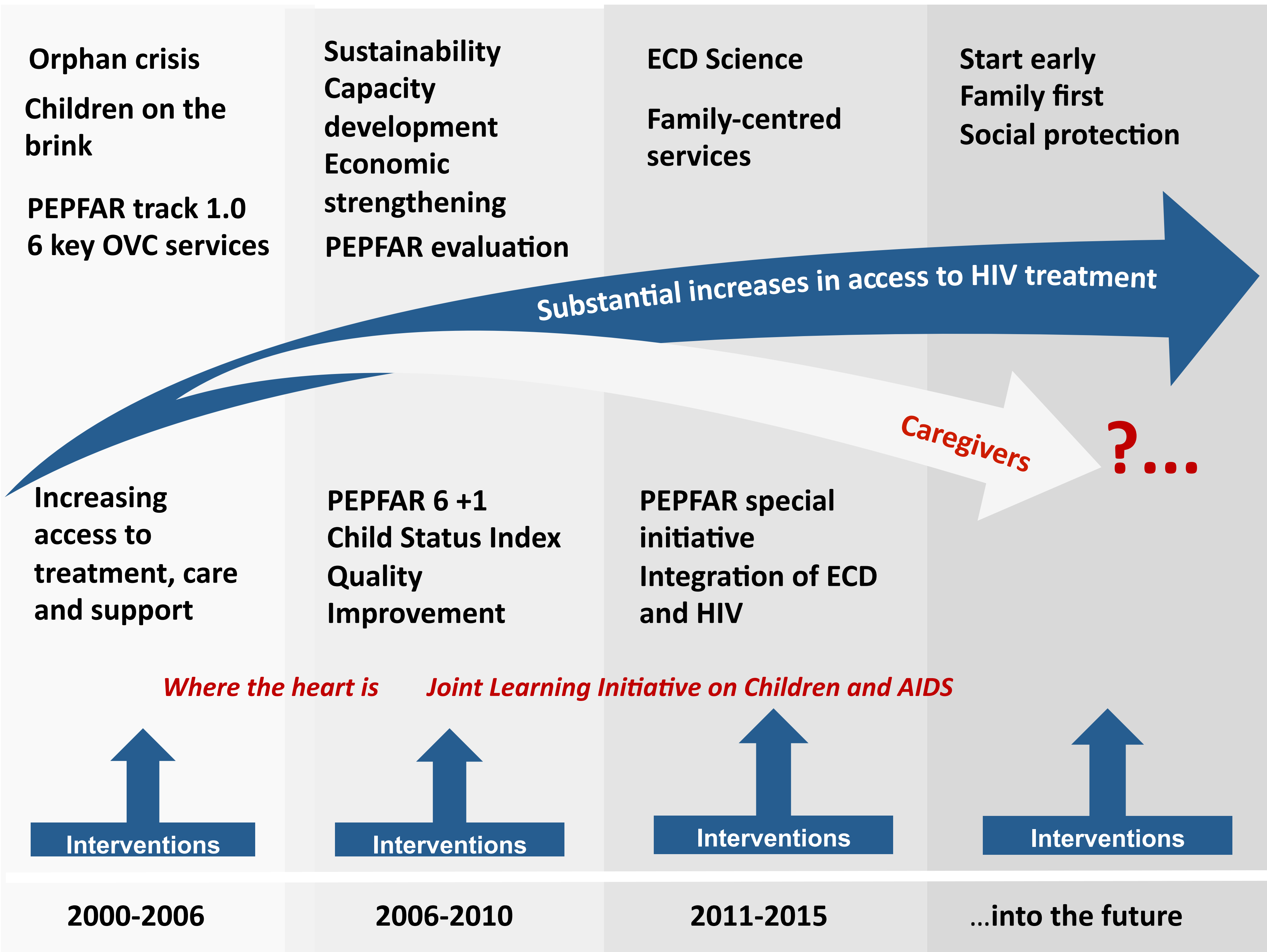
- Coalition ‘meeting series’
- The focus on caregiving
- Meeting methodology
- Developmental life course perspectives
- Setting our meeting goals

Coalition for Children Affected by AIDS

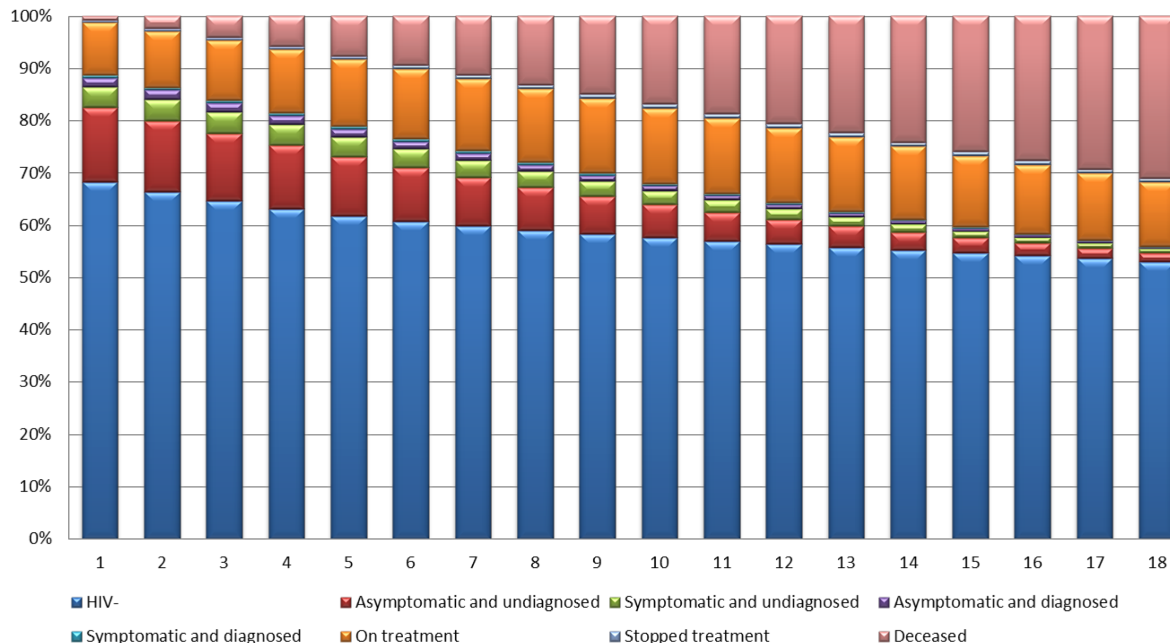
- The Coalition believes that children need to be made a higher priority in the international response to HIV and AIDS.
- We bring funders and technical experts together to advocate for the best policy, research, and programs for children, who are too often overlooked in the response to the epidemic.
- As arguably the most vulnerable population, unable to advocate on their own behalf, children have not received enough attention, research, and resources.

Coalition *"road to series"* meetings

- Road to Toronto - 2005-06: Defining the importance of, and an optimal package of psychosocial support for children
- Road to Mexico – 2007-08 Joint Learning Initiative (2009) on Children and AIDS, Social protection, cash transfers
- Road to Vienna - 2009-10: Family-based care
- Road to Washington 2011-12: Community action to end vertical transmission
- Road to Melbourne 2013-14: Early integrated interventions for children born into HIV-affected families.

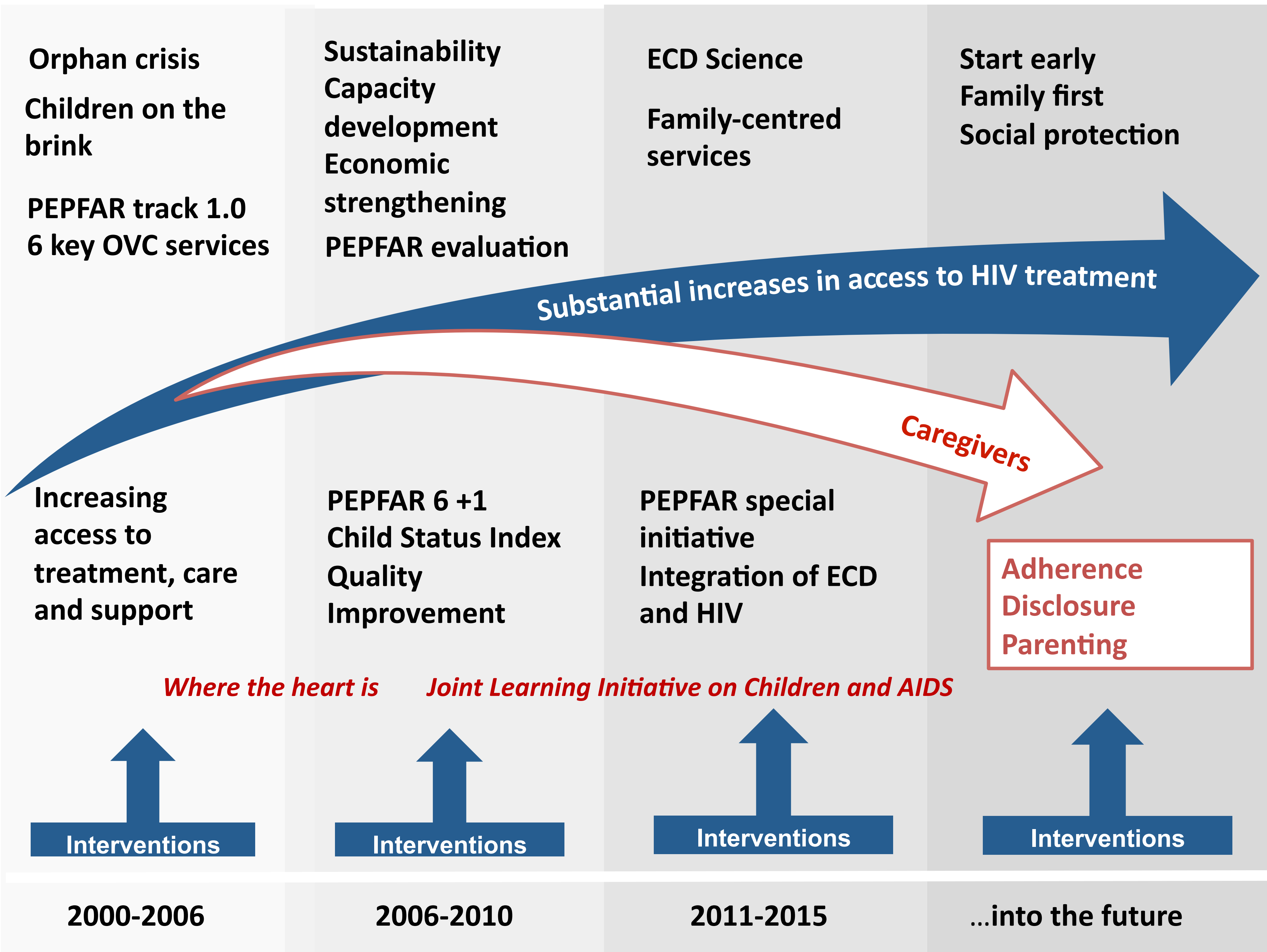

Orphan crisis
Children on the brink
PEPFAR track 1.0
6 key OVC services
Sustainability
Capacity development
Economic strengthening
PEPFAR evaluation
ECD Science
Family-centred services
Start early
Family first
Social protection
Substantial increases in access to HIV treatment
Caregivers
?...
Increasing access to treatment, care and support
PEPFAR 6 +1
Child Status Index
Quality Improvement
PEPFAR special initiative
Integration of ECD and HIV
Where the heart is
Joint Learning Initiative on Children and AIDS
Interventions
Interventions
Interventions
Interventions
2000-2006
2006-2010
2011-2015
...into the future

The longer term perspective



Waiting for difficulties before acting is inefficient and often fails. Waiting for children to become orphans and experience hard times "is a little bit short-sight".

- Even with high treatment, many children will still experience mother ill health and death, it is just likely to be delayed a bit.
- Keeping parents alive and healthy until their children reach 18 is tough, we need prevention as much as mitigation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Child Status Index
Quality Improvement
PEPFAR special initiative
Integration of ECD and HIV
Adherence
Disclosure
Parenting
Where the heart is
Joint Learning Initiative on Children and AIDS
Interventions
Interventions
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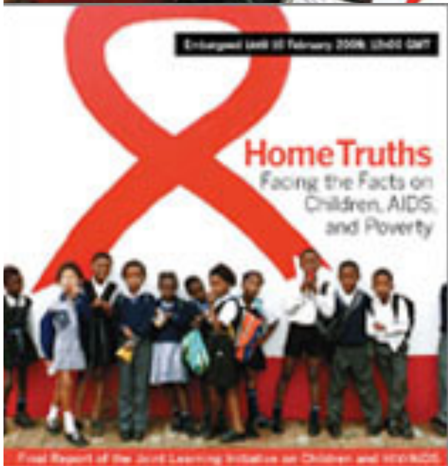
...into the future

Call to action

- Prioritise everyday systems of care families, schools and communities
- Invest long-term in integrated services to promote psychosocial wellbeing
- Realise the right of all children to access these integrated services
- Demand that more governments take the lead in guaranteeing this right
- Earmark resources for applied research to expand the evidence base



Joint Learning Initiative

- Families at the heart of the AIDS response to children
  - Keep parents alive with treatment
  - Keep children in families with support
  - Keep families in communities by reducing stigma
  - Build family caring capacity (e.g. address caregiver mental health and support parenting)

Caregivers meeting rationale

- Historically positioned within where the heart is call to action, lets look at how far we have come and what we have not done…
- Lets examine what has changed with access to treatment, where are the opportunities…
- Concerns around the increased “things to do” lists for caregivers, with support in mostly institutionalised or from outside of the home
- More focused, sustained, thoughtful attention on the needs of caregivers in the new post ART era

Principles informing the approach

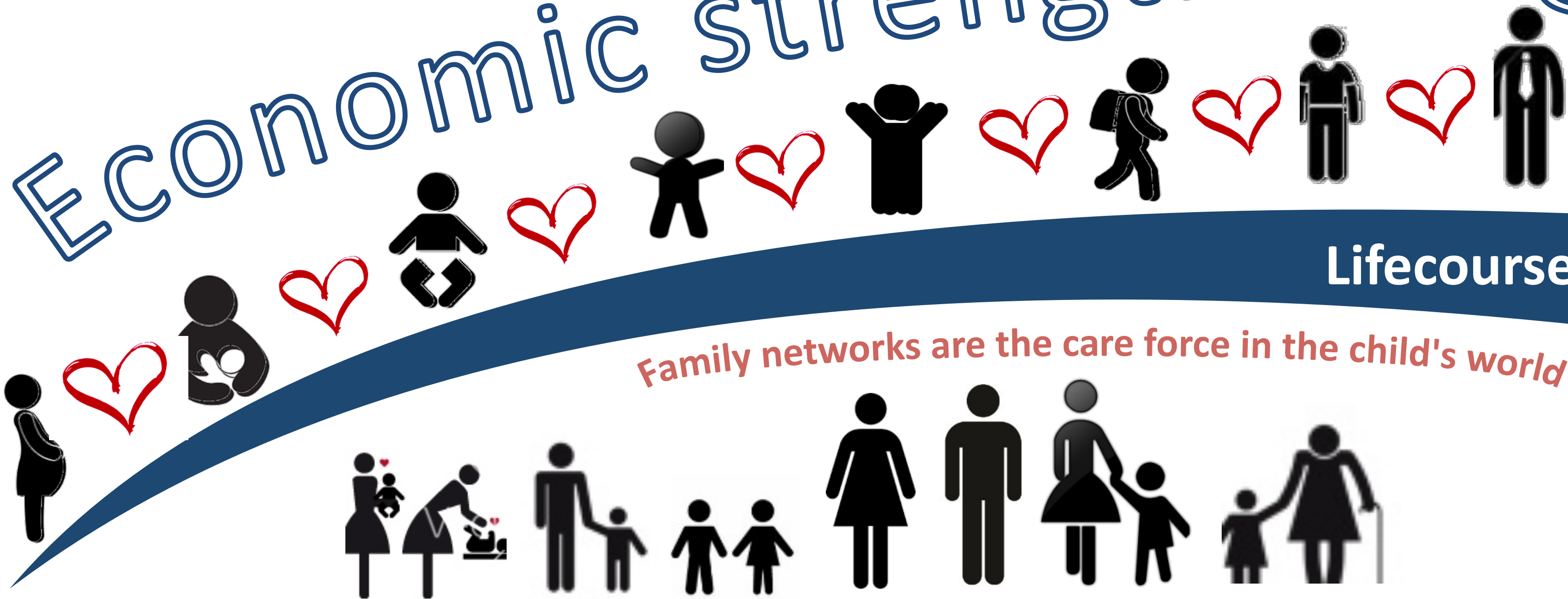
- Avoid "individual segments" and instead try to build towards a "coherent narrative"
- Not a "meet and tell" rather a "meet and talk"
- Advocate for good representation of donors, policy makers, implementers and researchers
- Encourage discussion and debate about key challenges to family-centred approaches
- Learn from both *experience* and *science*

Work force – care force planning

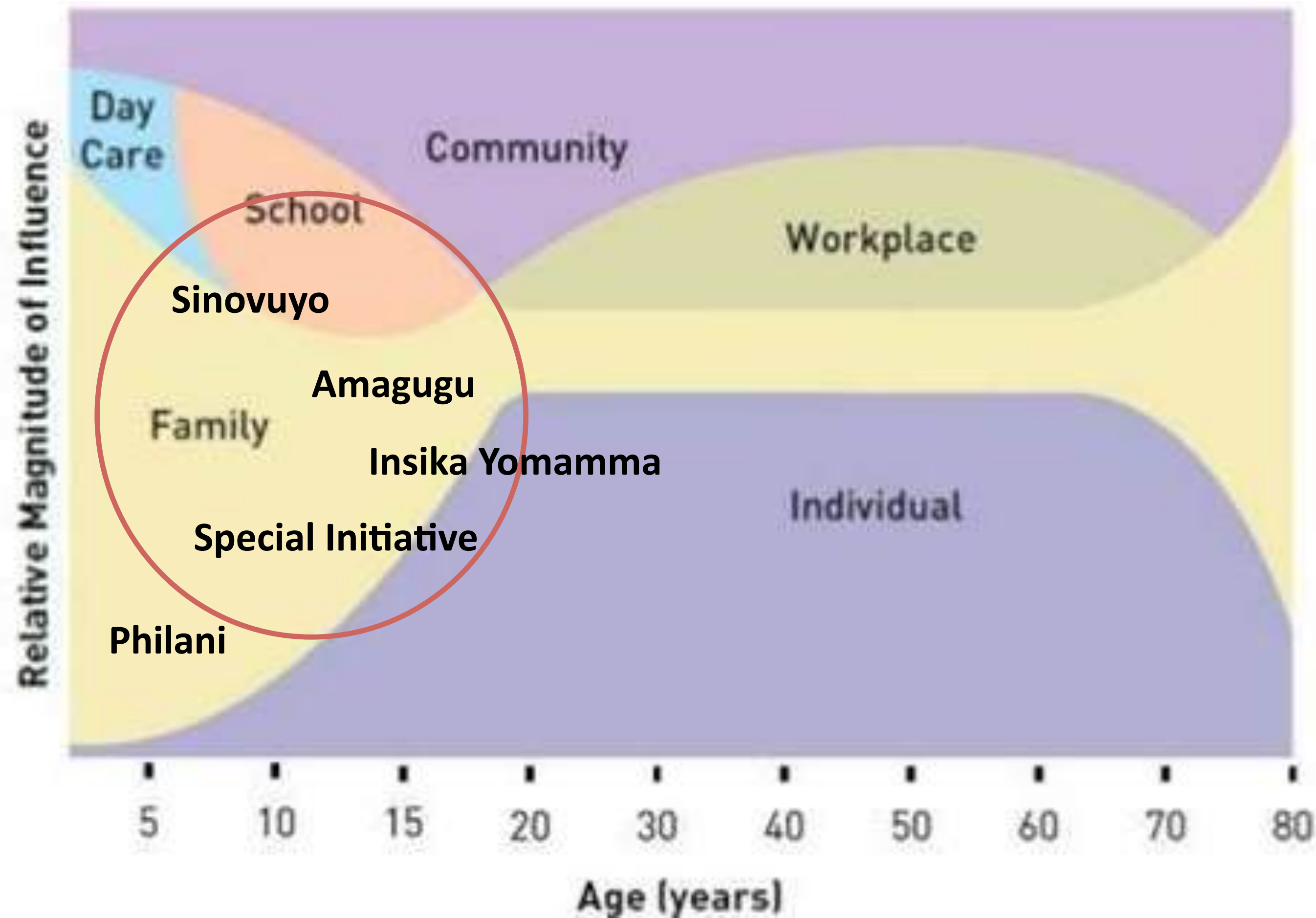
Safe delivery
PMTCT
Immunization
Infant feeding

Safe households
Play
Stimulation
ECD services

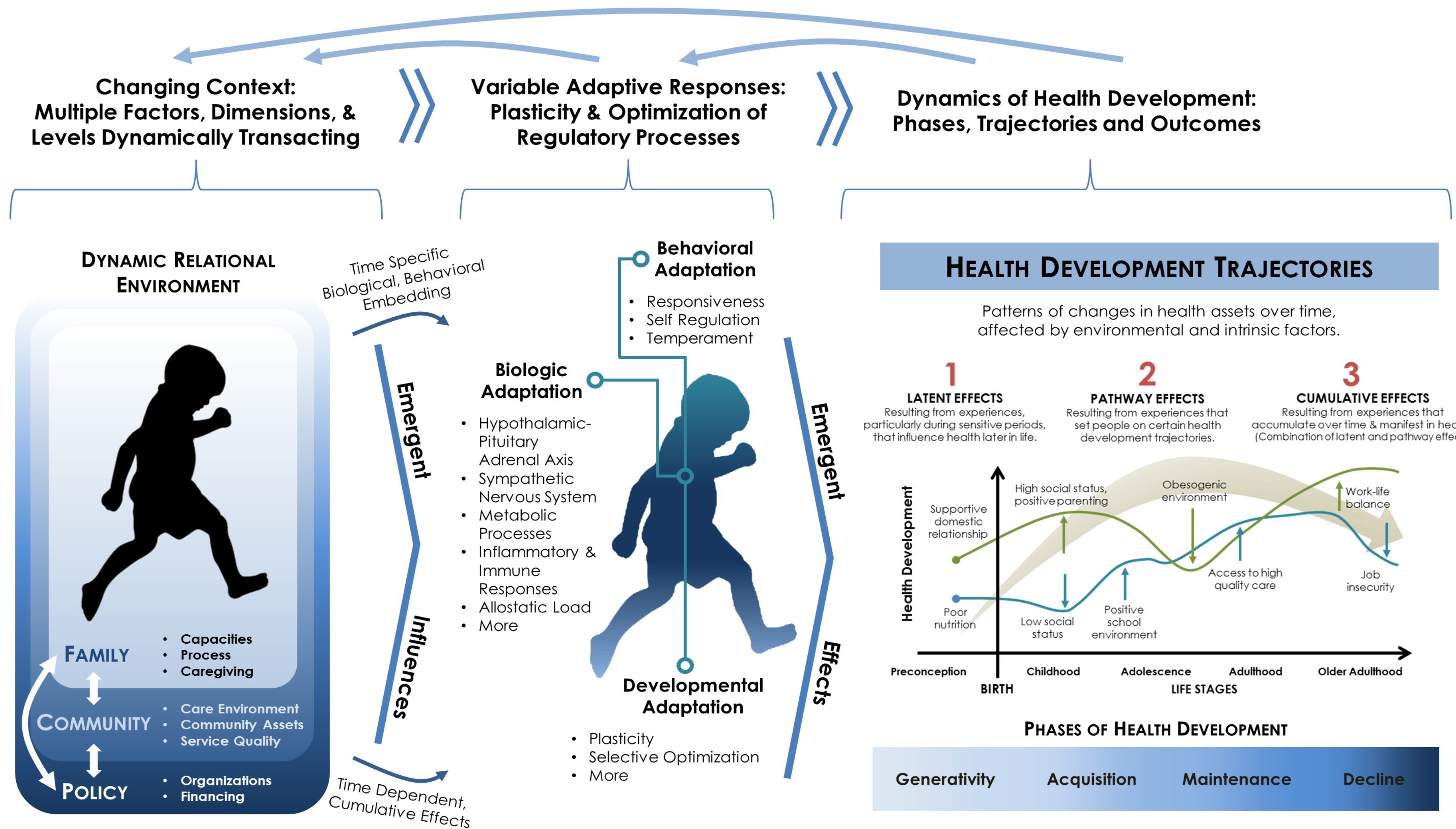
Safe environments
Learning
School services
Family strengthening



Relative places of influence



Life Course Health Development Model



Life Course Health Development Core Principles

1. Health development is an **emergent property** of living systems.	2. Health develops **continuously over the lifespan.**	3. Health development is a **complex, non-linear process** that results from person-environment interactions that are **multidimensional, multidirectional, and multilevel.**	4. Health development is highly **sensitive to the timing and social structure** of environmental exposures.	5. **Evolution enables and constrains** health development pathways and plasticity.	6. Optimal health development **promotes survival, enhances thriving and protects against disease.**	7. The **cadence of human health development results from synchronized timing** of molecular, physiological, behavioral, cultural and evolutionary processes.

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Meeting outputs

- Editorial piece and potential for individual papers
- Pulling meeting outcomes into our AIDS 2016
- Meeting report published jointly
- Roadmap or call to action on caregiving

Adapting the workforce model

1. Care force analysis – who is available care
2. Care forecasting – project needs based on a developmental framework
3. Analysis gaps – what policy do we already have and is it working
4. Develop strategies – how do we think at scale about changing things for families and children
5. Panel – pause and reflect based on experience
6. Investment – building a new narrative

Meeting aspirations

- Increase the impact of researchers, donors, policy makers and implementers as a group
- Move towards a collective effort, cohesion in advocacy efforts
- Move towards a language which better describes this “force” which is at the heart of caring for children – complex between ‘giving’ and ‘work’
- Develop clear policy, advocacy ad research goals
- Key roles of speakers, discussants, facilitators, note takers and participants