UNDER THE CURVE:

Understanding the most neglected children in the HIV & AIDS response

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Many have observed that children are neglected in the HIV response. Within this there are sub-groups of the most neglected who are very difficult to reach and may be overlooked, resulting in even greater levels of suffering. In a scenario of great need, and donor focus on results based payments, there may be a tendency to reach for the "low hanging fruit". This research explores the challenges of reaching those most marginalised and hardest to reach children.

Methodology

The research included a **systematic review of the literature** to explore neglect, understand who the most neglected groups were, generate predictors of neglect and summarise evaluated interventions to reach such groups. Traditional systematic review procedures resulted in 72 published papers available for scrutiny, of which 67 studies identified a total of ten groups who were neglected. Secondly, the research conducted a series of **key informant interviews** with 26 international experts representing wide geographical and experiential perspectives to explore the front line experience and expertise relating to neglect, possible causes, areas of future focus and suggestions for future input.

Neglected groups and predictors

The systematic review identified ten such groups:

- Orphans and vulnerable children (OVC) (including HIV-infected, HIV-affected, orphans, child heads of households, non-biological children in extended families)
- Girls
- Adult caregivers of children
- Women
- Children in specific countries/continents or of specific ethnicity
- Adolescents
- Adoptees
- Abused children
- Urban children
- Children affected by poverty.

Six major predictors of neglect were described in the studies, namely:

- Childhood abuse
- Sexual abuse
- Poverty
- Orphaning
- Mental health
- Parenting problems and challenges associated with rearing environments.

However the poor evidence base shows that we are not yet in a position to fully understand where such groups are, whether they are truly the most neglected and how best to reach them.

Key problems

The key problems related to neglect identified in the literature review were:

- Neglect of OVC, orphan disadvantage and neglect
- Psychosocial distress of orphans
- Access to and quality of education for OVC
- Abuse and neglect of girls
- Neglect of children of HIV+ mothers/parents
- Grandparents have difficulty offering quality care to young children
- Child neglect and abuse (UK/US)
- Young women early sexual relationships
- High levels of sexual risk behaviours of adolescents and poverty.

Other problems that were raised less frequently included:

- Abuse of street children
- Increase in HIV infections among children
- International adoption
- Poor health of OVC
- Neglect of child-headed households
- Medical neglect of HIV+ children
- Father absence and patrilineal neglect
- Sexual abuse of children within their own communities
- Ostracism of HIV+ children.

Additional problems emerged from the key informant interviews including:

- Problems of alcohol and drug use
- Gender considerations
- Abuse
- Bereavement
- Mental health and well-being
- Geography

- Resources
- Education
- Poverty
- State resources
- Disclosure
- Stigma and community attitudes relating to HIV & AIDS
- Cultural norms
- Legal and procedural/policy hurdles
- Political will
- Developmental delay
- Disability
- HIV overwhelming
- Family and family roles
- Age
- Problems with children who fall under the detection radar.

Reasons for neglect

Reasons for neglect/barriers raised by both the systematic review and the key informants included:

- The need for more evidence to inform OVC interventions/programmes
- The need for more programmes to support adolescents
- The lack of parental love for orphans (e.g. stepmothers not wanting the children)
- Poor access to healthcare
- Patrilineal neglect
- The lack of identification of HIV+ status in children with HIV illness
- Unavailability of basic laboratory and testing equipment in many districts
- Lack of available antiretroviral treatment to children
- Women and children being most disadvantaged with a pecking order in the receipt of medical care (children depend on mothers and mothers are the last to receive medical care)
- Problems with Universal free education (not really free because money is asked for school results and insufficient financial contributions threaten it)
- Negative attitudes/misunderstanding of teachers towards HIV+ children
- High dropout rate in schools (particularly for older children)
- Girls giving sexual favours in return for money or goods (e.g. school fees, groceries)
- The high levels of abuse of girls
- The need for empowerment of girls
- Poverty was highlighted as a major barrier for several reasons (e.g. large families, lack of access to school, not being able to afford school uniform).

Possible interventions

Thirty six studies offered suggestions for action, these clustered around:

- Supporting caregivers
- Addressing the needs of OVC
- Reducing neglect and abuse
- Supporting young women/girls
- Helping communities respond to the impact of AIDS/involving communities
- HIV & AIDS prevention
- Developing effective health services
- Promoting adherence to HIV medication
- Providing support for children through their families
- Strengthening community support for families
- Reducing family poverty
- Delivering integrated family-centred services in health, education and social welfare.

Barriers to action in tackling the "unreached"

1. **Traditional neglect – made worse by the HIV epidemic**
   - Neglect triggers, e.g. disability, abuse, mental health/mental illness
   - Children of already marginalised groups, e.g. key populations, prisoners, refugees, slum dwellers, disabled, alcohol users, etc.
2. **Places to seek out neglect - so obvious we forgot to look**
   In an effort to identify neglect, there can be omissions from overlooking the obvious, e.g. much neglect was clustered among children in the poor rural areas which may divert attention from the many neglected in urban areas.
3. **Provider limitations**
   "Low hanging fruit" - Within the HIV epidemic there has been an approach with the need to show delivery and efficacy. This may trigger disproportional draw towards children who are easiest to reach.

   Inability to look at compound challenges - preponderance of delivery mechanisms in a streamlined (or perhaps a silo) approach, e.g. medical care may be unable to incorporate psychosocial care.
4. **Data collection**
   Methodologies utilised to gather such evidence may overlook or miss the most neglected children: *Sample inclusion, failure to follow up, methodological constraints, significant effect bias, quantum of input, bias in research, impediments in the knowledge cycle.*
5. **Excluded by the very mechanisms that are meant to protect**
   Ethical approval of studies may remove children's voices from the evidence base and lack of dialogue about sexual abuse.
6. **Out of focus lenses**
   Studies to examine the effects of HIV infection may have overlooked those who were HIV exposed but uninfected. Parents may simply not have the strength and energy to provide optimal child care or they may be affected by a myriad of psychological traumas known to effect child development such as depression, anxiety, post traumatic stress or cognitive effects of HIV itself.
7. **Political will**
   Children generally do not muster political power, are rarely consulted or included and their issues are often not high on the political agenda, e.g. the late focus on prevention of infant infection which although a current priority has been delayed for 16 years when the proven interventions were established and readily available.
8. **Ignorance-driven policies – lack of evidence base**
   Many gaps in evidence (and/or where evidence was available but was often not heeded) results in ignorance-driven policies.
9. **Narrow thinking**
   Focus on some programmes may have obliterated insight into others, e.g. so much concentration on preventing vertical transmission that the programmes forgot to keep mothers (and fathers) alive.
10. **Lack of solutions**
    It is clear that we do not have definitive answers to all the neglect problems at this point in time. Having effective interventions or solutions is the next vital component.
11. **Secondary veils**
    A prime example in the HIV arena is associated with the veil created by stigma. Stigma may leave children without a diagnosis and effectively blocked from any interventions, treatment or care.
12. **Loss to services**
    Some children do access services and are then neglected if the service does not meet their needs.
13. **Economic diversions**
    Economic factors may play a role at many stages of child neglect in the HIV response, ranging from inadequate finances or financial policy at the highest level down to the claimed contention that money for children is spent on alcohol or tobacco.
14. **Cycles of disadvantage**
    Cycles of disadvantage or clusters of factors with a compound effect on neglect – e.g. in child development parenting and the quality of parenting/caring is well established as a fundamental contributory factor to child achievement.
15. **Pocketing**
    Macro level policies have specific effects on the most disadvantaged or neglected children, e.g. mass immunisation programmes so-called "pocketing approach" – often in a narrow area of provision – ensure very comprehensive coverage.

Policy Recommendations

- **Attention to traditional areas of neglect** may provide a key to identifying and isolating key groups of children where the most neglected may be concentrated
- There is need to **retain staff expertise** at a national level and build competencies at a front-line level (family and community) to ameliorate the expertise gap
- **More and better targeted funding is needed with clearer outcome requirements to address child neglect**
- **Need to address the distinct and differing needs of children of different genders and different ages**
- **Further studies and understanding of neglect are needed** to explain the factors associated with neglect, as well as recipient factors to explain why some children fare worse than others given equal exposure to certain hazardous or difficult situations
- **There is need to give greater priority to emotional health**
- Funders need to be sensitive to the **output demands on programmes** as these may make it more difficult for the most neglected children to become priority recipients of care. Simple head counts and short or one off interventions are the least likely to reach the most neglected children
- There is a need to **tackle long standing societal problems** that contribute to neglect in the HIV area, e.g. alcohol, drug use, poverty, mental health, disability and gender.

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