

# Providing comprehensive care for children living with HIV: lessons learned from a low prevalence country

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# Context

- HIV prevalence less than 1% in the general population in Senegal
- Low visibility of the impact of HIV on children
- HIV infected children under-diagnosed
- Access to ARV's for adults and children, PMTCT and VCT, in most of health facilities
- Guédiawaye-Pikine, a transitional zone between urban and rural areas (1M hbts)
- NGO Synergie Pour l'Enfance's background

# Children's Comprehensive Care Initiative program(3 CI) (1)

- Initiated in 2004
- Objectives
  - To provide integrated medical, psychological and social care for 100 children in one location
  - To contribute to a better understanding of how to care and treat HIV infected children holistically in resources limited settings
- Human and materiel resources
  - Core staff
  - Large network of resource-persons
  - Formal partnership with relevant institutions in the care and support of OVC and HIV infected children
  - Centre de Santé de Guédiawaye (public heath facility) and Pediatric Unit CHN Le Dantec for a continuum of prevention and care
  - Support from Secure The Future (BMSF) and USAID/FHI-Senegal

# Children's Comprehensive Care Initiative program (2)

- Package of services
  - Free medical follow up (HIV testing, outpatients visits, routine laboratory tests, chest X-ray, CD4 count, CTM and ARVs)
  - Depending on the assessment of socioeconomic status of the family at enrollment
    - Periodic provision of food kits to families
    - Educational support (public schools)
    - Money to cover travel cost for appointments
  - Psychological support
    - Home visits
    - Focus groups discussion for parents/guardians
    - Support group for adolescents
    - Artistic activities for younger children (painting)

# Children's Comprehensive Care Initiative program (3)

- Framework organization
  - Capacity-building and consensus workshops for stakeholders
  - Formal referral system
    - Between community/social workers and medical care providers
    - From primary care to national reference hospital level
  - Provision of the most competed package services possible at each contact of the family child with the system
  - Approbation by the National Ethical Committee on Health Research

# Monitoring and Evaluations

- Monitoring committee
- Synergie's annual activities report
- Evaluations
  - external mid term evaluation(BASP 96, 2005)
  - external final evaluation(BASP 96, 2008)
  - evaluation of the continuum of care in the context of HIV in Guédiawaye (Diakhaté and all, 2007)

# **MAJOR FINDINGS AND THEIR IMPLICATIONS**

# Disclosure, a family affair

- Reluctance of parents or legal guardians to disclosure child status remains strong despite counseling
- Convening with parents or legal guardians about what the child needs to know to participate in his own care and to alleviate its fears and anxiety is acceptable and effective : *informing the child and not announcing a status*

# Adherence as part of a comprehensive family care

- Adherence to treatments needs more than only counseling
- Support to adherence is to be integrated in a framework of comprehensive care: treatment adherence is only developed in a structured framework orientated towards the objective of comprehensive management of the child, extended to his family

# Integrating services to reduce stigma

- Stigmatization seems quite intrinsically linked to the provision of care
- Integration of HIV-related services into the routine and existing healthcare provision reduces the risks of stigmatization. However, without proper strengthening of the health system, this integration compromises the quality of care and limits the number of beneficiaries

# Critical roles of families and CBOs

- The current organization of the health system is not tailored to meet the needs of a child living with a chronic disease which is associated to social vulnerability
- Meeting the needs of children living with HIV demands a broader approach of child health, based on a multisectorial partnership whereby CBOs must also be strengthened to play their unique role

# Are governments failing us?

- The mitigation of OVC's social vulnerability is part of poverty reduction strategies
- It is the prerogative of public authorities to ensure access of OVCs to current child survival programs, and to expand and sustain this in the long term. *Child survival and his mental health are the core of any MDG!*

# Conclusion

- Family
  - To restore
  - To protect
  - To promote
- Towards family centered-care
  - Opportunities
  - Challenges

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