



THE ROLE OF PSS IN THE CARE OF CHILDREN WITH DISABILITY IN HIV AFFECTED HOUSEHOLDS

Children and HIV: Start Early, Start Now!
July 19, 2014
Lynette Mudekunye & Brighton Gwezera



WHAT IS DISABILITY

- **Physical /cognitive / functioning differences**






- **Societal /environmental and personal factors**



- **Activity or participation limitations**

DISABILITY AND HIV

- Strong correlation HIV  functioning differences, especially in East and Southern Africa
- Is it HIV  Disability?
- Or Disability  HIV?

PHYSICAL / COGNITIVE FACTORS

- **Clear evidence of**
 - **Cognitive and physical delays in children exposed to and infected with HIV**
 - **blindness, neuromuscular disorders, paralysis, HIV-dementia, or mental health issues such as depression in people living with HIV**

- **Also evidence of**
 - **increased risk to HIV for people living with disability**

PERSONAL/SOCIETAL / ENVIRONMENTAL FACTORS

- **Stigma – internal and external (self, family and broader society)**
 - Different ability and HIV both often considered a curse, result of witchcraft
 - Labelling
- **Discrimination**
- **Inadequate services**
 - For HIV and
 - rehabilitation of / provision for various forms of difference
 - Poor psychosocial support for people living with HIV and their families
- **Environmentally unfriendly – ramps, sign language, braille**

PSYCHOSOCIAL IMPLICATIONS

■ **Extrinsic activity and participation limitations**



■ **Intrinsic factors**



■ **Isolation –**

- Of person living with HIV and disability
- Of their caregivers / families
- Often become targets of abuse



■ **Depression / poor psychosocial wellbeing**

EARLY IDENTIFICATION

- Early identification of different function is crucial
- Extra psychosocial support – love, stimulation, social inclusion that is targeted to respond to the child’s unique needs – provided consistently from an early age –



- Environments that reduce the impediments to participation



- Children can significantly overcome the activity and participation limitations to reach their potential

COMMUNITY BASED REHABILITATION

- **Techniques – simple and more complex – to enable function**
- **In health, education, livelihoods, social and empowerment spheres**
- **Assistive devices to support – mobility, vision, hearing, cognition and communication**
- **Community sensitization**
- **Involvement of people living with disability and their families**

CBR



CAREGIVER RESILIENCE

- Is a factor of both intrinsic and extrinsic factors
- The ability to face challenges and grow from them rather than be defeated by them
- The determination to succeed when it seems impossible
- Caregivers that are poor, ill, stressed, excluded may not be resilient and may therefore struggle to give PSS.
- Building caregiver resilience through deliberate social inclusion and support is essential

ADVOCACY

- **Early identification of differences in functioning should be a part of all programmes for children and families affected by HIV**
- **Promote social inclusion for children and their caregivers**
- **Community sensitization to overcome social (e.g. stigma) and environmental impediments to participation**
- **Include psychosocial support for caregivers and children as a crucial part of the programme**

THANK YOU

LYNETTE.MUDEKUNYE@REPSSI.ORG

BRIGHTON.GWEZERA@REPSSI.ORG

WWW.REPSSI.ORG

WITH ACKNOWLEDGEMENT TO J HANASS – HANCOCK
HEARD, UKZN FOR INITIAL LITERATURE REVIEW

