

**Para Social Work II:**

*Practice Skills to Intervene with  
Vulnerable Children and Families in  
Special Circumstances*

**Day 2**

HIV/AIDS Update

*Recap and  
Overview of the Day*

**Objectives**

1. Increase the skills required to support children and families dealing with the process of HIV disclosure
2. Increase the skills related to HIV advocacy for people living with HIV, their families, and their communities
3. Update knowledge of HIV prevention and medical treatment
  - Medication Treatment: children, youth, and adult
  - Preventing Mother to Child Transmission (PMTCT)
  - Preventing Transmission to Others (Secondary Prevention)
  - Long-term Treatment Effects
4. Update knowledge of how HIV affects infected and affected children

**Objectives (continued)**

5. Develop HIV risk reduction problem-solving skills to use with adolescents and young adults
  - Reducing sexual risk and violence
  - Reducing risk related to substance abuse and other addictions
6. Develop skills related to problem-solving for children and youth in areas of mental health, education, and income development
7. Increase knowledge of HIV home-based care issues for children, youth, and families
8. Develop knowledge of end-of-life issues for HIV infected and affected children and families

**Day 2 Contents:  
Review of HIV for Para Social Workers**

- **Issues of HIV Disclosure**
  - Disclosure Scale
  - Disclosure to Children
  - Disclosure to Others
    - Sexual Partners
    - Family
  - Community Disclosure
- **Issues of HIV Advocacy**
  - Personal Advocacy
  - Advocacy in the Family
  - Advocacy in the Community

**Day 2 Contents (continued)**

- **Review of HIV Treatment Issues**
  - PMTCT, pediatric, adolescent, adult HIV care
- **Caring for HIV Positive Children**
- **Risk Reduction for Older Children**
  - Sexual Risk Reduction
  - Drug Use Risk Reduction for Older Children
- **HIV Problem-solving with Children and their Families**
- **Issues of Home-based Care for Children and Families**
- **End of Life Issues**

*Disclosure:  
Telling Others About One's HIV Status*

**Helping People Living With HIV  
Decide about Disclosure**

- Whom to tell?
- When is it best to tell?
- What to tell?
- Where to tell?
- How to tell?

Brief Discussion of these questions

### Mini Group Discussion: HIV Disclosure

*Talk to your neighbor for 5 minutes about this then report in large group discussion*

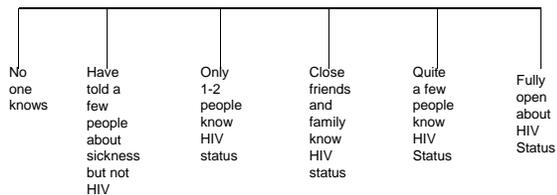
**What is your own experience with:**

- People with HIV telling others?
- Learning about someone's HIV status?

### The HIV Disclosure Scale

- People vary in terms of who they tell and what they tell
- We can think of this along a line from telling no one to being completely open about HIV status

### The HIV Disclosure Scale



### The HIV Disclosure Scale

- Group Exercise: Have people stand up and role play each stage
- Discuss how they feel and get input from the group

### **Managing Secrets**

- Reluctance to tell others the truth (or whole truth) about HIV status
- Dealing with fear of rejection, which affects how the person feels about himself (personal well being, self esteem)

### **The HIV Disclosure Scale**

- Any of these are fine as long as it is his/her choice
- Para Social Workers need to help the person living with HIV determine where on the scale they fit and why
- If they fall on the secretive end, help the person living with HIV determine if the secret is painful to him/herself , to others, or to both
  - Children
  - Partners
  - Parents and alternative care givers
  - Friends and other supporters (i.e. potential kinship caregivers)

***What are situations where it is important to tell HIV status?***

Brainstorm

### **Discussion: Disclosure of HIV Status**

- What are issues about who to tell or not? What about the related issues of “when” and “how”?
- What are the issues involved with long-term care and planning for HIV issues
  - Family support for treatment
  - Advanced planning for the care of children and disposition of property
  - Disclosure to prevent further risk
- What are ways a Para Social Worker can help people living with HIV to make these decisions?

### In What Situations Is It Important to Disclose HIV Status?

- Sexual partners
- Health care providers
- People providing care to people living with HIV/AIDS
- People providing care to the children of infected families
- Other family members and close confidantes (priests, community leaders, etc.)

*What do these groups of people have in common?*

### Helping the Person Living with HIV or a Family Member Decide about Disclosure

- **Whom to tell and how do we decide?**
- **When it is best to tell?** (is the relationship strong, does s/he feel person will be accepting, how soon after diagnosis, etc.)
- **What to tell?** (should s/he just disclose HIV status, or should s/he tell more about history, current condition, etc.)
- **Where to tell?** (privacy concerns, etc.)
- **How to tell?**

### Helping Clients Prepare to Share Their HIV Status

- It is **always** the client's decision about who, what, where, how, and why to tell
- Ensure confidentiality of this discussion
- Help client think through the advantages and disadvantages of HIV disclosure
- Role play the situation with the client, whether a parent or child; rehearse the best way to share the information, develop a strategy, and think about how to overcome possible challenges

### Why Disclose?

**What are the Client's Reasons for Telling This Person Now?**

- To address his/her own needs and concerns (relief comes with sharing the secret)
- Because it is part of the relationship
- Because they are starting HIV anti-retroviral drugs
- To avoid someone finding out from another source
- To end hiding the information, drugs, etc.
- To obtain help or support from the person as a caregiver or other resource

### **Issues That May Arise When Disclosing HIV Status of Parent or Child to a Child**

- What does the child know already?
- Does the child know his/her own HIV status?
- Who has or has not told the child?
- How does disclosure depend on the developmental stage of the child?
- Does the child know the status of other family members?
- What is the Para Social Worker's role?

### **Disclosing HIV Status to a Child**

- How does the child's development stage, as well as grief and loss, affect HIV disclosure to children?
- What are the other issues of disclosure to a child?
  - Health of the parent and care planning for the parent
  - Discussion of future planning for the child
  - Care, education, property
  - Health status of the child
- What are the special issues of school age youth?
  - Peer groups, siblings, special friends
- How do issues of disclosure to children change over time?

### **Talking to Children in an Age-Appropriate Way**

- Para Social Workers need to tailor the message to the child's emotional and knowledge level
- Even young children are likely to know what HIV is
- Knowing Mom is sick or died from an illness may be enough for young children
- Helping child to understand what HIV is and how it affects them when a parent or other family member has HIV or has died from HIV-related causes

### **What about School?**

- Is the child in a school?
- What is the school's approach or policies about HIV and who knows about HIV?
- Disclosure to directors, teachers, and other staff?
- What about disclosure to friends and peers?
- How can the Para Social Worker help?

### What about the Community?

- Is the child involved in community programs?
- What are their approaches or policies about HIV and who knows about HIV?
- Para Social Workers can help to:
  - Provide information
  - Develop a plan
  - Be a link between home and community

### Discussion

*Discuss the following questions in a large group or mini-groups with reports back to large group*

- Can you tell us about some cases you have worked with that involved the issue of who knows about HIV status?
- How can we best help children and family access community resources?

*The Role of the Para Social Worker  
as an Advocate for  
Vulnerable Children and Families*

### Helping and Linking HIV Positive Children and Adolescents

- Risk Reduction
- Testing
- Care and Support
- Taking HIV Medicines
- Planning for HIV Infected Children and Adolescents

**How HIV Affects Vulnerable Children**

- Are these children at greater risk for HIV (do they engage in high-risk behaviors)?
- Risk and risk reduction for older children, adolescents
- Affected children with family members living with HIV
  - Parents
  - Brothers, sisters, friends, boyfriends/girlfriends
- Children who have had a parent die due to HIV
- Children caring for HIV positive family members
  - Parents, grandparents, or siblings
- Health Issues of HIV Infected Children

**Children Living with HIV**

***Discuss your own experience helping HIV positive children; what are their needs?***

Brainstorm

**Addressing the Needs of HIV Positive Children**

- Disclosure and testing for young children
- Treatment issues specific to young children
- Adherence issues specific to young children
- Testing, treatment, and adherence for adolescents
- Issues of children and youth living with HIV with other problems, illness, and/or disabilities
- Long-term planning for HIV positive children and youth

**HIV Issues by Age and Gender?**

*What are the HIV issues by age and gender? Discuss these in large or small groups*

- 0-3 years old
- 4-5 years old
- 6-9 years old
- Pre-adolescence
- Adolescence

## HIV Positive Children

- **Access to Medications**
  - Finding and assuring connections to clinics and doctors
  - Helping the family to administer medication to children
- **Providing Resources to Meet Other Needs and to Support Good Medical Care and Basic Rights**
  - Food, shelter, clothing, education and other support for vulnerable children and families

## PMTCT: the Basic Facts

- HIV is transmitted from mother to baby during the process of birth (blood contact)
- MOST babies do not contract HIV in the womb
- C-section and vaginal lavage (washing) also decrease transmission
- HIV transmission during labor and birth can be decreased to almost nothing with treatment of mother and baby as early as possible
- HIV can be transmitted to infants during breastfeeding because the virus lives in breast milk and because nipples crack and bleed in the early stages of breast feeding

## PMTCT Guidelines Changed in January 2011

*The World Health Organization (WHO) has changed the standard guidelines for the prevention of mother-to-child transmission of HIV.*

You can learn more at:

- [www.who.int/pmtct](http://www.who.int/pmtct)
- [www.who.int/child\\_adolescent\\_health/doc](http://www.who.int/child_adolescent_health/doc)

## New WHO Guidelines

- All **pregnant women with CD4 (t-cell) less than 350** should receive anti-retroviral therapy (ART) as early as possible
- For **HIV positive pregnant women with more than 350 CD4 cells**, health provider should consider ART, but the medication (ARV) regimen may be different
- All **babies of HIV-positive mothers** should be breastfed for at least six months. Breastfed babies should receive daily ARV medicine from birth for a minimum of 4-6 weeks, or until 1 week after all exposure to breast milk has ended
- **Babies who are NOT breastfed** should receive ART until 4-6 wks of age

### WHO Infant Feeding Guidelines for HIV Positive Women

- Mothers should either breastfeed and take ARVs or avoid all breastfeeding
- Where breastfeeding is judged to be the best option, mothers should **exclusively** breastfeed for the first 6 months, then introduce appropriate additional food and continue breastfeeding for 12 months. Wean infant gradually and continue to treat for at least 1 week after last contact with breast milk. Exclusive breastfeeding for the first 6 months **unless replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS).**
- At 6 months, continue breastfeeding with additional complementary food if **AFASS** is not met. Wean within a period ranging from about 2-3 days to 2-3 weeks

### Anti-retroviral (ARV) Treatment for Breastfeeding Women

- Breastfeeding infants born to HIV positive women receiving ARVs for their own health should receive daily Nevirapine (NVP) or twice-daily AZT from birth, or as soon as feasible thereafter, until 4-6 weeks of age.
- Infants born to HIV positive women receiving ART for their own health who are receiving only replacement feeding should receive daily NVP or twice-daily AZT from birth, or as soon as feasible thereafter, until 4-6 weeks of age

### Maternal-Child Transmission: Recent Research

- Study of women and infants in Burkina Faso, Kenya, and South Africa (Kesho Boro Study)
- Triple-ARV regimen cuts HIV infections in infants by 43% and reduces risk of transmission during breastfeeding by more than half
- Infants of mothers whose virus is undetectable (less than 50 copies) with adequate ARVs at the time of child birth reduce transmission rate to 2.7% for the first year, so it is important to start ARVs early in pregnancy, ideally before pregnancy

Reference: Kesho Boro randomized controlled clinical trial in fivesites in Burkina Faso, Kenya and South Africa. 5th IAS Conference on HIV Pathogenesis, Treatment & Prevention. Cape Town, South Africa, 19-22 July 2009. Abstract LBPEC01. <http://www.ias2009.org/pag/pdf/3631.pdf>

### New Research (continued)

- Offers new hope for mothers with HIV who cannot safely feed their babies with infant formula. It will improve the chances of infants remaining healthy and free of HIV infection as breast milk provides optimal nutrition and protects against other fatal childhood diseases such as pneumonia and diarrhea
- Giving HIV-positive pregnant women and those planning pregnancy priority access to HIV testing and ARVs will help eliminate mother-to-child transmission of HIV
- Childbearing women need Para Social Work support to understand, access, and adhere to medication treatment

### **Breastfeeding & HIV Transmission**

- During the first 2 months, a bottle-fed baby is nearly 6 times more likely to die from diarrhea, respiratory, or other infections compared to a breastfed child - mostly because contaminated water is used in mixing the formula, bottles are unclean, and other reasons
- Don't switch back and forth between breast and bottle feeding
- Continue ARVs for baby during weaning and wean gradually
- For HIV positive mothers with limited access to clean water and sanitation, the new guidelines and treating both mother and child during breastfeeding eliminate the painful choice of breastfeeding and HIV exposure versus bottle feeding and unsafe food

### *What Can Para Social Workers Do to Help Women related to Pregnancy, Child Birth, and Infant Feeding?*

Brainstorm

### **Para Social Workers, HIV, and Pregnancy**

- Help mothers protect baby from HIV infection
- Encourage mothers to get treated with ARVs
- Counsel mothers to plan pregnancy, childbirth, and baby care carefully
- Support women in HIV care and support their families to encourage HIV care
- Provide information on safe baby feeding and baby care
- Work with families and communities to support HIV positive women, their babies, and their families

### **Para Social Workers, HIV, and Pregnancy (continued)**

- Support the family when facing the double stressors of child birth and HIV diagnosis simultaneously; many complex family situations can erupt during this high-stress period
- Help medical staff communicate complicated clinical knowledge to the mother and family in a way that they can quickly understand; time is very important
- Advise mothers to get ARVs during breastfeeding for themselves and their infants
- Help mothers get medical care for breast problems, along with sores or thrush in an infant's mouth

**What Para Social Workers Can Do to Reduce Mother to Child Transmission**

- Help pregnant women to obtain HIV testing and receive ARVs as soon as possible to avoid transmission to their infants
- Help solve problems of funding, transportation, and access to make it possible for mothers to obtain this critical medical care
- If their status is discovered during pregnancy, treat as early as possible with the most effective therapy available

**Adhering to Medicine: A Review**

- **Issues of Adherence to ART for:**
  - Family
  - Child
  - Other caregiver issues related to adherence
- **Why is Adherence to therapy important?**
  - To prevent disease progression
  - To prevent symptomatic progression
  - To prevent secondary transmission
  - To prevent resistance

**In Context:  
Medical Care for Children**

- Family specific issues
- Community specific issues
- Bridging barriers of knowledge and education

**How Can Para Social Workers Help the Medical System Communicate with Families?**

*Cultural issues and community context:  
What are the beliefs and usual ways people do (or do not) get medical care in the community?*

- **Family circumstances**
  - Economic status
  - Disease-affected status
    - Parental disclosure
    - Child-specific disclosure

*Reducing HIV Risks for Older Children:  
Sexual Risks and Other Risks*

*What Are the Risks of HIV for  
Older Children?*

Brainstorm

**What are the Risks of HIV for Youth?**

- **Sexual behaviors**
  - Unprotected sex
  - Early sexual initiation
  - Untreated sexually transmitted Infections
  - Unplanned pregnancy
  - Sex with consent versus forced sex
  - Sex for money or drugs
  - Alcohol use leading to unprotected sex, early sex
- **Needle use and injection drugs**
- **Others?**

**Sexual Risk**

*Discuss the following question, first talk to your  
neighbor, then report to the group:*

What is your experience with children you are  
working with related to HIV, sexual feelings,  
and behaviors, etc.?

### Discussing Sexuality

- How comfortable are we discussing these issues with youth?

### Discussing Sexuality

- **How can we discuss these issues with youth?**
  - Using simple and direct language
  - Asking child if they are comfortable with this discussion
  - Using peers as resources for education and help

*How Can Para Social Workers Help to Reduce the HIV Risk of Youth?*

Brainstorm

### Sexuality Issues with Youth

**What kind of information do children get about sexuality?**

- From whom?
- At what age?
- What is included?
- How can we reduce their risks?

### **Sexuality Issues at Different Ages**

- How are these alike or different?
  - Romantic feelings
  - Sexual feelings
  - Sexual behavior
- What kind of sexual behavior might youth engage in?

### **What is the Para Social Worker's Role in Addressing...**

- Sexuality
- Substance Use
- Other Risks

### **Reducing HIV Risks for Older Children**

- What are some HIV risk reduction methods?

### **Reducing HIV Risks for Older Children**

*HIV risk reduction methods include:*

- Delaying sexual behavior
- Other social activities
- Making good decisions about sexual behavior
  - What is safe?
  - What is risky?
  - How to decide?
- Protection
  - Condoms
  - Other alternatives
- Reinforcing the message

### Sexual Information for Youth

- Sexual identity and sexuality
- Sexual abuse
- Informed consent to sex vis-à-vis forced sex
- Risky sexual behaviors
- Safer sex
- Preventing pregnancy (birth control)
- Getting help (i.e. medical treatment, education, information, counseling)

### In Class Small Group Exercise

*Working in groups of 6 people, role play a short counseling session with either the caregiver or the child. Discuss possible sexual or risk behaviors with the child OR discuss effective ways of communicating on the subject and helping the child with the caregiver :*

Neema is a 12-year-old girl who lives with her grandfather because both of her parents are dead. She is beginning to stay out of the house very late at night and once did not return home at all. Her grandfather is concerned that she has boyfriends or is having relationships with strangers.

### How Can Para Social Workers Help Reduce Sexual Risk Factors of Children

*Sex with a child, whether willing or not, is child abuse according to Tanzanian and International Law.*

- What can Para Social Workers do to help mitigate risky sexual environments that children encounter?
  - Are there different needs and techniques for young boys and young girls?
  - What does economic vulnerability have to do with early sexual risk and initiation?

### Substance Use: Alcohol and Other Drugs

- What drugs may the youth use?
- Do you see these in your community?

**Substance Use:  
Alcohol and Other Drugs**

- Tobacco
- Alcohol
- Marijuana / Bangi
- “Hard Drugs” (i.e. heroin and other drugs that may involve needle use)
- Other Substances (i.e. – glue, mirungi/khat, petrol sniffing, abusing anti-pain drugs, etc.)

**Substance Use:  
Alcohol and Other Drugs**

*Which of these substances lead to:*

- HIV Risk?
- Other Risks?

**How Can You Help?**

*First ask yourself:*

- Is the child using drugs?
- Are there other associated behaviors (i.e. sexual or criminal behaviors)?
- Is the child interested in stopping drug use?
- Can we help the child be safer using the drugs (harm reduction)?
- Can counseling or support help with this?

**Discussion and Case Studies**

- Questions
- Examples from the group
- Discussion

*Problem Solving with HIV Infected and Affected Families and Children*

**Problem Solving:  
HIV Related Issues for Children**

*What are some of the issues you have experienced as a Para Social Worker working with HIV infected and affected children and families?*

Brainstorm

**Issues Affecting HIV Infected and Affected Children and Families**

- Stigma
- Grief and loss related to HIV
- School issues
- Legal issues
  - Adoption and guardianship
  - Property rights
- Loss of economic stability and opportunity
- Health and Medical issues
- Behavioral problems and mental health concerns
- Relationships with caregivers and peers
- Dating issues
- Anger and disconnection from the future

Problem Solving for HIV Infected and Affected Children and Families:

**Roles of the Para Social Worker**

- Listen
- Support
- Refer to existing resources
- Link with district social welfare officer and other support providers
- Provide accurate, updated information on HIV
- Crisis problem solving

### **Role of the Para Social Worker: Problem Solver**

- Help improve communication with others, including parents, caregivers, school, etc.
- Be the link to getting better by building a relationship
- Help address issues of abuse and neglect \*\*
- Help determine if families can provide care and, if they cannot, assist in locating alternatives \*\*
- Work from the strengths perspective

*\*\* These topics will be discussed more on in the coming days.*

### **What a Para Social Worker Does NOT Do**

- Provide in depth counseling or therapy
- Provide medical or health-related services
- Deal with complex emotional problems beyond helping the client get help elsewhere
- Solve all the child's problems

### **Group Exercise**

- Form in groups of 7-8
- Each group will work on a case study that will be provided or developed by the group with the help of a facilitator
- Identify at least one counseling need of the child or family
- Identify at least one approach to help the child or family
- Role play how we might do this
- Discuss what we have learned and how we can apply this to other cases

*Home-based Care and Services for  
Children Living with or Affected by HIV*

### **What is Home-based Care?**

- Discuss what home-based care is
- What are your experiences with home-based care in your area?

### **Home-based Care and Services for Children Living with and Affected by HIV**

#### **Case Study: Anna**

*Anna is a 7-year-old child whose parents both died of HIV. She now lives with her grandmother. She has been weak and feverish and was tested for HIV and found positive. Her grandmother wants to care for her at home.*

*You, as a Para Social Worker, have been sent by the municipal government to see what are Anna's needs are and how this family can be helped. You want to be sure they are connected with needed services.*

### **Case Study: Anna (continued)**

*Get together with two other participants and discuss:*

- Based on your experience in your village or town, what specific home-based programs might be of help to Anna and her grandmother?
- Brief large group discussion

*End of Life Issues*

### **End of Life Issues**

- Disclosure
- Preparing for death – personally
- Preparing for death as a parent
- Preparing other family and friends for your final illness

### **Role of the Para Social Worker:**

**Helping Families Facing Death Prepare for the Future**

*How Can Para Social Workers Support Mothers?*

- Provide support for the mother herself
- Help her to communicate with successor caregivers for her children
- Help her to communicate with her children
  - How does the age of the children and other support factors affect this communication process?

*What kind of support would a Para Social Worker require to give this kind of support to mothers facing death?*

### **Role of the Para Social Worker:**

**Helping Families Facing Death Prepare for the Future**

*How Can Para Social Workers Support Orphaned Children?*

- Provide support for children individually, as siblings
- Help them to communicate with successor caregivers and NEW siblings
- Help them to communicate with friends, classmates
  - How does the age of the children and other support factors affect this communication process?

*What kind of support would a Para Social Worker require to give this kind of support to orphaned children?*

*Summary and Debriefing for the Day*

Final Plenary and Pashas