“Breaking the chain of transmission” promoting health seeking behavior for Elimination of Mother to Child Transmission of HIV

Applying Social norm perspective to MTCT programming

To understand the influence of social norms and collective behaviors that influence behavior of women who access services for HIV prevention and treatment in a health care facility in the state of Andhra Pradesh, India

Background:
In India HIV programming has been well defined and robust, moving on to integrated programming with multiple sectors and leveraging on well set national programmes and schemes. National roll out of more efficacious multi drug regimen (option B) was initiated in India in September 2012 in two states of the country namely Andhra Pradesh and Karnataka this is aimed at breaking the chain of HIV transmission and keeping next generation AIDS free, it becomes imperative to reach the unreached to bridge the gap in the existing programme to reach the elimination of mother to child transmission keeping new infection below 5%. Presently the level of transmission is 8-12% (state report). As per the recent national reports 5.2 lakh people are living with HIV in Andhra Pradesh (AP) with a prevalence of 1.06%. Important to note that, half of the new HIV infections are among the young people aged between 15-24 years. Of these 39% are women and 4.4% are children. Parent to child transmission is one of the major routes of new infections. AP contributes to 20% of the national infection. The prevalence rate of HIV among pregnant women in AP is estimated to be 0.77% in 2011 (fact sheet National AIDS control society).

Lessons from present intervention & Problem analysis:
Prevention of parent to child transmission of HIV programme has been well grounded and in September 2012 the programme has adopted more efficacious multidrug regimen. This call for repeated visit to hospital for follow up and collecting medication and multiple post natal visit from 6th week to 18th month of the child. Table showing gaps in coverage and there is drop out at every stage of treatment and low coverage of children about 13% for 18 month testing. critical to reach the unreached and bridge the gap in the existing programme; adolescents, women, tribal population, marginalized groups need focused attention by having greater understanding of barriers to accessing services and facilities

Quantitative: Estimated annual pregnancies of 16 lakhs it is estimated that there will be around 12,000 infected pregnant women. Past 2 years about 3500-3600 pregnant woman were tested positive among about 11 lakhs tested for HIV infection. The gap of 9000 positive mothers can be attributed to gap in coverage of all pregnant women. There is also a trend shown in overall reduction in HIV prevalence among antenatal women.

Qualitative: Based on recent review the data analysis it was found that it is crucial to improve quality of integrated PPTCT services in the state by addressing socio-cultural issues and stigma and discrimination in order to achieve the goals set out in the plan. Most women fear stigma by service providers and community at all levels.

The programme system in the state is well developed with adequate trained human resource, coverage through integrated testing and counseling centre up to CHC, PHC (refer abbreviation) with Decentralized management and monitoring structure. This show the need for greater understanding of behavior what may cause infection or break the chain of transmission, the rights based, gender sensitive, age appropriate strategy which stems from understanding the socio cultural dynamics, norms and social factors beyond the norm that may be driving the various aspects of the epidemic.
- Quality of health care, providers behavior, Poverty, gender inequality, power dynamics and age significantly contribute to greater vulnerabilities of girls and women and their health seeking behavior
- In the concentrated epidemic stigma and discrimination increase the complexities; there are norms that are barriers in acquiring factual information, expression, protection and thus increasing risk of HIV. Cultural factors and prevailing taboo, personal and behavior being very personal issue, there is a lack of data on influencing behaviors
- Vulnerability of women: strong cultural values, norms contribute to increasing vulnerability of women and reduce their empowerment. Comparatively women lack access to knowledge, skills to negotiate, and economic empowerment in a society
- Unknown HIV status of partner. High incidence of men not disclosing their status of HIV infection during marriage or consensual sex

Vulnerability to HIV is coupled with early marriage, inadequate access to reproductive health requirements including protection for HIV, migration, trafficking, abuse, violence, other supply and structural facts

WHY:
- Social norm perspective has not been taken in to consideration while MTCT programme planning, assessment of interventions in Andhra Pradesh.
- The reference group in the case is invisible or blurred as behaviors are based on someone else’s experience, who is a strong tie and or from their own experience form past

Till date, systematic assessment of barriers to programming with a social norms perspective has not been done in AP. Programme reporting, reports on ostracizing of women, family, children, and anecdotal evidences support the conclusions at personal level and larger community follow strong moral norm that make them behave in certain way with HIV infected. A script is followed. These cultural, moral, social norms around sex and sexuality, factual beliefs and factors beyond norms lead to a schema around HIV. This makes a HIV infected pregnant women and health care professional behave in a way which is harmful to individuals, their children and society at large. Therefore it is important to use a social norms perspective to better understand the current beliefs, practices and behaviour that are barriers to life saving service

“Social norms, like many other social phenomena, are the unplanned, unexpected result of individuals' interactions. It has been argued¹ that social norms ought to be understood as a kind of grammar of social interactions” in the scenario of HIV prevention it is important in order to understand the interdependent factors; what are the norms influencing safe behaviour for HIV ? What are the other types of injunction, such as moral codes, customs, traditions and structures? Has this been propagated, conditional or unconditional? To have answers to above questions is important to achieve the goal of elimination of new HIV

There are multiple interdepended factors which lead to a complex scenario for understanding issues around HIV and creating a programme environment require understanding layers that has created the barriers. Norm, as opposed to a custom, has causal influence on behavior therefore, for shifting a norm, it is important to create empirical expectation. There are factual belief in both cases of provider and seeker. The factual belief of provider is that it is not safe to treat HIV infected women; it is convenient to refer the woman to other facility .Women who seeks health hold the factual belief that they will be discriminated and punished due to their HIV status. Discrimination is part of a Schema and to script making others behave in certain way. As the schema is embedded with customs, culture and made further complex with moral values, normative beliefs

Schema are shared social beliefs that apply to individual or situations on basis of their Scripts and schema makes it harder for people to change especially in sensitive issue like HIV where the multiple layers like culture, localized beliefs, individual beliefs and larger scripts and schema developed over a period of time due to how HIV was projected as dreadful disease and emphasis given on certain behaviour to acquire infection in early years of (early 90s) HIV programming and communication campaigns. Trying to change behaviors of one person after other will be difficult as other people’s judgmental behavior seem to be key contributing barrier. As HIV scenario is very ambiguous with multiple

¹ C Bicchieri The grammar of society 2006 and class notes Upenn-UNICEF summer course 2013
factors unlike many other norms, eliminating social sanction, introducing incentive will not make the expected change or shift in collective behavior.

Trust and enabling environment is the important factor as it is to the best interest of the individual, family and society (mother –baby pair) to enroll early for treatment and continue treatment for the survival of women and their infants and for the quality of life of the family and society.

Shifting norm require creation of environment and working with both provider an client. Strengthening interactions with them based on the social norms and moral norms may increase provider’s commitment and support promotion of right based approach to care and treatment. Developing a strong network of core group and promoting health seeking behavior will promote the health seeking behavior. Creating common knowledge in the community about importance of community support to PLHA through discussion and dialogue promoting knowledge and collective action will change factual belief and attitudes Key players taken to develop example of intervention are the women who should be seeking health care and the provider who should treat her with dignity

Context setting based on theoretical tools, Concepts and Framework

Programmatic: knowing social Norm perspective an opportunity to strengthen MTCT in India

1. All women who are pregnant should be tested for HIV infection
2. All infected women should take treatment for preventing Mother to child transmission and improving quality of mothers life and to keep her alive
3. Infected women should take Ante retroviral (ARV) prophylactic treatment for temporary period up to stopping of breast feeding or as per CD4 count take lifelong therapy
4. Every child born to HIV infected mother should be tested for HIV as early as 6 weeks and adhere to treatment protocol. Child should be tested at regular interval and finally at 18 months for final diagnosis. Continued, prolonged uninterrupted (adherence) medication for mother and baby is the key to success of the PPTCT programme.

Social:
1. There is a strong case of pattern of behavior, informal, personal and collective behavior that is influencing the health seeking behavior of an individual/woman.
2. There are sufficient numbers of health care providers who think it is not safe to treat HIV infected women further conducting delivery or surgical procedures
3. Further multiple factors influence prevention and treatment of HIV; there are norms around sex and sexuality, gender, coupled with power dynamics leading to stigma around HIV.
4. Stigma directly influence the behavior of community, client and health care providers leading to discrimination
5. This lead to behaviors guided by default rules. Then individuals tent to confirm to certain patterns of behavior.2

Examining the script and schema around HIV
- Most women think they should not talk about sex and sexuality, reproductive health issues and HIV, AIDS. This belief prevents people/women from accessing right information leading to increased vulnerability (barrier to primary prevention).
- Women are expected not to have premarital or extramarital sex (lead to negative judgment)
- Infected women believe (from the experience she has seen around her) that she will not be accepted by either family, community and significant others. She doesn’t want to disclose HIV status as she will be ostracized.
- Non-disclosure of status limits her and her child’s access services including seeking health as their comfort levels to seek services become limited
- Women think Health care providers will behave with prejudice manner and not treat them with dignity. Therefore most women do not access treatment or do not adhering to treatment and basic lifesaving service for themselves and their children

Factual belief:
There are many factual beliefs which lead to formation of expectations and conditional 3preferences.

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2 crisitina Bicchieri The Grammar of society
- Health care providers discriminate
- Health care providers refuse to provide treatment
- HIV infected women’s family honor, community status is at stake
- HIV infected women are immoral
- Not safe to treat infected women
- They lose clientele
- All people living with HIV are not taking treatment and are still alive
- All children born to HIV infected mothers are not infected with HIV
- Death is inevitable, so why take treatment
- Adhering to treatment may incur cost and will be a burden to family
- Others who see women at HIV service facility judge them negatively

There are many extra social influences other than social norms and beliefs that influence treatment seeking behavior loosing wages economic status, distance-access to facility-availability of facility near home

Factual beliefs and expectations anchor the collective behavior and Social norms. In the above; there is an observable pattern of behavior by women and service providers.

HIV infected women are judged ‘immoral’, most of the PLHIV prefer not to disclose their HIV status due to fear of stigma. There is sanction such as isolation from family, community, denying access to basic requirements like common water source in a village etc. forcing them to leave home/ community including threat to life. 

*Women do not see other women seeking health care.* There are misconceptions, no open dialogue, shame, and honor. Most of the health care providers at all levels treat them with negative value judgment, indifferently and sometimes denying service. Moral norms have very high influence on behavior, therefore HIV infected pregnant women do not seek service or discontinue treatment, and deny treatment to their new born & children. There are multiple expectation and norm must have been created over period of time

HIV infected women expect that most others do not seek health care. (Empirical). HIV infected women think that health care providers expect them not to access services (Normative expectation) due to the factual belief that health care workers discriminate, do not treat them with dignity and accept their right to health.

**Bringing the change for breaking the chain of HIV transmission**

**Strategic intervention should lead to the following outcomes to be able to bring in the change and interventions will be state wide but UNICEF will initiate the activity in 4 Call to Action districts**

1. **Sufficient number of women believing in seeking health for the improving their health and keeping their children HIV free – breaking the chain of HIV.**
2. **Critical mass of Health care professionals form core group, become trend setters and change agents**

Introducing change to believe and change expectation to respect HIV infected mother-baby, right to life and women understands of right to survival and quality of life like any other mother and child. This will also take in to consideration how to align self-interest and priority to be able to achieve individual gains and collective result

Many of service providers behave so because other people around them do so. Though there is scientific understanding of modes of transmission, the fear of transmission while handling cases is a key barrier. It is important to take a critical mass of professionals who follow positive behavior, who are trusted, respected and high light the same. Develop core group of health care professionals to support the process of change among other practitioners and other health care providers to change the current script and schema.

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3. Glossary, class notes Upenn-UNICEF summer course 2013, C Bacchier, what matters about social norms psychology and normative constraints

4. Govt of India has identified certain districts in the country for focused convergent action with RCH+Adolescent strategy
4 levels of activity will be conducted using appropriate strategy; Pre-programme planning – result based planning—implementation – evaluation

Steps to follow:
Identify who matters and develop a core group to lead, assist and support the change - value deliberation around moral, social norms, stigma, right to health and life and practices - organized diffusion through professional bodies and network of people living with HIV-many individuals change their behavior (belief change and change occur in normative expectation) Visibility- coordinated shift occur

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Rapid assessment: will be conducted to validate existing understanding of the significant influencers, stakeholders, professional network and their standing as reference group etc

The key questions to plan an intervention are; who matters? What are the referral networks? Who can influence /their social network? How can change be brought in and sustain the same?

The following specific group may emerge during assessment

- HIV infected pregnant women
- Health care professionals: doctors nurses counsellors, ANM (Auxiliary Nurse Midwife)and others working in the health facilities
- Community; family, significant others
- Communities in general

Collect anecdotal evidence (at state level and selected district to get a more acceptable views from different setting)
Understand the trust relations, networks and environment (willingness to change)

Social network analysis:

This is key to success of change in the case as the key stake holders are less visible. With the emphasis on Confidentiality, it is important to develop clarity on available networks that can carry message within society-groups, neighborhood, across the district and further to other geographical areas as individual change alone will not make the critical mass for diffusion.

Network mapping and social network analysis may indicate another women living with HIV, a friend or health worker as high degree node with the strongest tie. Professionals have strong preference from who they want to hear and learn, who mentor them, here a trusted senior colleague may be a strong tie. Community Health care workers, counsellors may form a bridge between. Or Individual who have benefited from treatment, community influences, elders and young people. Groups like professional body, NGOs, Union, PLHIV network and SHGs can be included and during the assessment

Examples of few questions to understand trust relationships and quick messaging sources to reach with right information to maximum individuals and groups of individuals

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5 C Bicchieri, R Muldoon what matters about social change, C.Bicchieri, Gerry Mackie, R.Muldoon, class notes Upenn-UNICEF summer course 2013 dynamics of norm shift, creating and abandoning norms, social network analysis
who all have the women have disclosed her HIV status (trusted member of community, family etc)

Who provides them information about what is happening in the community (gossip-stigma)

As professionals who are the people they depend for technical update?

Whom do they contact for passing on information from one office to another?

Identify core group: Catalysts of change
Identify (from above process) core group like network of people living with HIV who are already active advocates for right of infected women, have been openly disclosing their HIV status and success story. They are most likely the medical professionals who command respect and office bearers of IAP, FOGSI, IMA, (ref. abbreviation) union of front line health care workers. Build their capacity if needed and prepare them to lead the process of change. Encourage core group to spread the shared understanding

Capacity development of core groups at all levels, community, health workers, health care professionals and women/PLHIV

How change may occur:

- Based on assessment and social network analysis identify referral groups, core group. They could be Professional bodies, Union, network of positive women, women group
- Identify an influential and trusted person within core group who is trained or can be trained. Facilitate value deliberations with their support
- Understand interdepended issues, unseen behaviors and bring in a collective understanding - willingness to change
- Bring the enabling environment through correct information, knowledge, strengthening social ties
- Trigger the power with in and facilitate diffusion

Value deliberation: initiating the process of right based well grounded, participatory and change

Assumption is that there is an overall dissonance as their behavior and core values, underlying beliefs may be different (cognitive dissonance –an opportunity). Many local beliefs can often become barrier to change. Eliciting the same is key to developing trust relationship and further collective understanding

These deliberations will give opportunity to women, health worker to bring their own understanding, views, beliefs and also make the group understand the common behavior and practice with in human right based approach, existing Government orders and anecdotal evidences of prevailing positive and negative practice

Simultaneous activity will be held in all 4 districts with women, health care providers with support from PLHIV network and professional bodies for health care workers and medical professional like FOGSI, IAP and IMA

This should help understand the underlying layers of factors and dwell upon the same to initiate change

- Deliberations are conducted in homogenous group or In common group of stake holders

There are service providers who are already ‘converted ‘and positive practitioners, women who has taken treatment and having uninfected child. It is important to model on them and them. This can be leveraged for change as the critical mass who have changed and endorsed the change will be supporters of sustained change. There could be norm around mother in-law which is not observed behavior; deliberation will be guided to elicit unseen behaviors and cultural factors around stigma. As trust among professionals and people belonging to positive network are very strong and these bodies can initiate and organize diffusion as change agents (trusted figures endorsing change)

Medical professionals are morally committed to nondiscriminatory practices; legal conformity overlooks the motivational aspects and other influencing factors like fear of self-safety6. Commitment and motivation will bring in the shift in attitude and value judgment

Communication for change and BCC strategy will be developed and communication campaign will be dough tailed with existing RCH package of call to action in India and MARPU the comprehensive child survival strategy. targeted BCC and IEC will be supportive to initiate, maintain and sustain change

Diffusion
Diffusion will be initiated along with guided deliberations and simultaneously introduce the common goal to all the professionals through their own networks to have a common knowledge and take pride in their contribution.

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6 Gerry Mackie, effective rules of law requires construction of asocial norm of legal obedience
As HIV is sensitive issue this may start in small group, individual level and the ripple effect can be planned to move up to district state and story for country… amplifying may be when conducive

**Basic principles will be to Creation common knowledge, develop a Common goal and Sustain through commitment**. At the appropriate time the following may occur; Declaration of the commitment- Organized Diffusion- to others, Amplifying through media TV, radio and networks, sustain the effort through the following

**Sustaining the change:**

1. Organize periodic deliberations continue dialogue
   i. Academic presentations in conferences organized by the professional bodies and CMEs
   ii. With Government nodal officer publish articles in professional journal
   iii. sessions to addressing upcoming professionals (former office bearers and other significant influences like ex-officers)

2. Recognize positive trend setters _ client friendly Hospital, ‘model,- happy mothers with uninfected children (best practice identification)

3. Facilitate advocacy to tackle issues beyond the norms – access, supply

**4. Create an Excitement around Elimination : Track progress and announce Loudly**

4. Enhance communication activity at all levels as appropriate –conferences, media, Television, radio

National trend setter – to break the chain of transmission; as Andhra Pradesh is one of the first states in India to move to efficacious regimen in 2012 the state may move faster with the revised strategy towards elimination agenda. There may be a political environment already present by 2015 to create an excitement around the success

**Conclusion and Way forward:** Given the complex scenario social norms influencing MTCT program there is a need for further in-depth diagnosis and a road map for the above mentioned process and interventions. This case study will further lead to development of a road map for effective programming for PMTCT in the state of Andhra Pradesh and Karnataka which can be adapted as national reference. This could become best Practice for other states in India during nationwide scale up of new PPTCT regimen

Follow up action:

1. Conduct diagnostic study and understand social norms, taboos, culture stigma and discrimination that are influencing the outcomes of the existing programme
2. Develop a road map incorporating intervention based on the diagnosis, strategies mentioned in the case study to strengthen existing programming. UNICEF will assist providing technical support to the programming and monitor results

**Expected outcome:** state government and UNICEF will have capacities and a better understanding of the social norms that influence outcomes of the MTCT programme and strategies to shift norms to create an enabling environment for strategic and effective programming in the context of global priority to eliminate new infections among children born to HIV infected mothers and keeping mothers alive.

List of abbreviation included below
List of Abbreviations

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<th>Abbreviation</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency syndrome</td>
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<td>ANC</td>
<td>Ante Natal Care</td>
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<td>AP</td>
<td>Andhra Pradesh</td>
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<td>ART</td>
<td>Anti Retroviral Treatment</td>
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<td>ARV</td>
<td>Anti-Retro Viral (treatment)</td>
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<td>CHC</td>
<td>Community Health Center</td>
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<td>FOGSI</td>
<td>Federation of Obstetrics and Gynaecological Society of India</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>IAP</td>
<td>Indian Association of Paediatrics</td>
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<tr>
<td>ICTC</td>
<td>Integrated Counselling and Treatment Centre</td>
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<td>IMA</td>
<td>Indian Medical Association</td>
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<td>MDG</td>
<td>Millennium Development Goals</td>
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<td>PHC</td>
<td>Primary Health Center</td>
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<td>PNC</td>
<td>Post Natal Care</td>
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<td>PPTCT</td>
<td>Prevention of Parent to Child Transmission</td>
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<tr>
<td>PLHIV</td>
<td>People living with HIV</td>
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Bibliography


A case of option B and B+- to eliminate mother to child transmission of HIV by 2015, UNICEF document revised February 2013