Community Led PrEP Delivery

Getting It Right

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Community Led PrEP Delivery

• A community comes together to gain control over factors that have an impact on their lives and thereby, own the program from its design, inception, implementation and the outcomes. They are also the rightful owners of the risk and response and therefore the resources and results.

• In the context of PrEP the community leads all the above processes that includes governance, design, delivery, monitoring and therefore the results.
Introduction

• **Contrasting FSW settings:**
  • Kolkata - Brothel based
  • Mysore & Mandya - Mixed pattern (street, lodges, houses, etc.)

• **Bottom-up approach since inception**
  • WHO and BMGF discussed with Ashodaya and DMSC

• **Ashodaya and DMSC chose University of Manitoba**
  • As the support agency for the community-led research
Context

**Ashodaya - Dawn of Hope**
- for, of, by’ female, male and trans sex workers
- Initiated in 2005, governed democratically by elected board of directors
- 7000 members across 4 districts
- Proven leadership in integrated health program (HIV/STI, SRH, TB)
- Diversified to other social development programs including banking, social security, etc.
- Well recognized and acclaimed for Community-led academy, Ashodaya Academy, conducting community based research and capacity building

**Durbar - The Unstoppable**
- Organization of 60,000 SWs initiated in 1995 expanding all over West Bengal including Kolkata city
- Democratically governed
- Actively active in addressing underlying reasons of poverty, discrimination, alienation from the mainstream society as well as provide holistic healthcare to its members
- Runs 49 clinics with >500 staff (80% are sex workers)
- Runs the largest co-operative bank for SWs in Asia called Usha Co-operative, 40 educational centers, children hostels etc.
- Has remained one of the best practices for HIV intervention globally
Chronology

2012-13
WHO initiated discussion on PrEP

2013-14
• Discussion with WHO and BMGF
• Community Consultation and Preparedness
  • Expressed concern but willingness to explore and assess feasibility of PrEP

2015
• Feasibility Study
• Preparation for Demonstration project
• Approval

2016
• Demonstration Project started

2018
• Demonstration Project Finishes
Ingredients of Community-led PrEP

**Governance**
- Ashodaya Governing body (management & fiduciary controls)
- Community Advisory board for PrEP
- Advisory Committee (experts & SWs)
- Project management team- 3 SWs & 3 non-community staff

**Delivery**
- Outreach team incorporated PrEP in its daily outreach plan
- PE/CM responsible for identifying interested FSWs, bringing them to clinic, following up for 16 months, fostering community norm on PrEP & condom use
- Contextualized approaches
  - HIV+ SW promoted PrEP; SW leaders initiated PrEP first (testimonial ambassador)
- Follow-up visits to Ashodaya clinic (Static & outreach)
- Linked with ART physician at district level & accompanied referral when required
- Tailor-made dispensation plan (location, duration etc.)

**Determining the design**
- Integrated design within existing prevention program
- Design incorporated findings from FS
- Ongoing Community preparedness
- External stakeholder management
- Determining processes for mobilization, recruitment, delivery, follow-up, adherence support, drug delivery and clinic

**Monitoring and Quality Control**
- Phased out follow-up plan on the field by CM/PE
- Individualized drug dispensation plan & customized drug intake time
- Developed and used simplified tool to monitor adherence at outreach
- Self reported questionnaire during quarterly clinic visit

**Accountability**
- To the Ashodaya Governing Board
- Having accountability to the community taking PrEP; community redressal system
- Ensuring accountability to the funders, scientific community and others
## Results

<table>
<thead>
<tr>
<th>Status</th>
<th>Ashodaya</th>
<th>Durbar</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total screened</td>
<td>707</td>
<td>843</td>
<td>1550</td>
</tr>
<tr>
<td>Eligible in screening</td>
<td>652</td>
<td>717</td>
<td>1369</td>
</tr>
<tr>
<td>Not eligible in screening</td>
<td>55</td>
<td>126</td>
<td>181</td>
</tr>
<tr>
<td>Enrolled to the study</td>
<td>647</td>
<td>678</td>
<td>1325</td>
</tr>
<tr>
<td>Refused to enroll</td>
<td>5</td>
<td>39</td>
<td>44</td>
</tr>
<tr>
<td>Exited without completing 16m</td>
<td>7</td>
<td>79</td>
<td>86</td>
</tr>
<tr>
<td>Completed 16 month follow-up</td>
<td>640</td>
<td>600</td>
<td>1240</td>
</tr>
<tr>
<td># on PrEP (post study till Jul18)</td>
<td>466</td>
<td>504</td>
<td>970</td>
</tr>
</tbody>
</table>
Results (N=640)

**Socio-demographic, reproductive**
- Age: Median 35 (18-48).
- Literate: 268 (41.42%)
- Regular partner: 559 (86.4%)
- Median monthly income: Rs.5400
- # of children: 2 (0 – 6)
- # using contraception: 617

**Sex-work characteristics**
- Age of entry: 28 (15-44)
- Avg of years in sex-work: 6 (1-30)
- Place of sex-work: Urban/Rural

**Risk perception**
- Participants were 3.72 times more likely to feel at high risk at baseline when compared to exit visit (p<0.0001)
Results

Sexual Behavior
Percentage of condom usage during last sex during last week

<table>
<thead>
<tr>
<th></th>
<th>BL</th>
<th>1M</th>
<th>3M</th>
<th>6M</th>
<th>9M</th>
<th>12M</th>
<th>15M</th>
</tr>
</thead>
<tbody>
<tr>
<td>condom</td>
<td>63.0</td>
<td>95.4</td>
<td>98.0</td>
<td>98.9</td>
<td>98.4</td>
<td>92.2</td>
<td>98.4</td>
</tr>
</tbody>
</table>

With occasional clients (%) - With repeat clients (%) - With Regular partners (%)

STI Syndrome, HIV, Pregnancy

<table>
<thead>
<tr>
<th>Visit</th>
<th>N</th>
<th>STI Syndrome n(%)</th>
<th>HIV positive n(%)</th>
<th>Pregnancy n(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1M</td>
<td>637</td>
<td>1 (0.16)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>3M</td>
<td>642</td>
<td>5 (0.78)</td>
<td>0 (0)</td>
<td>2 (0.31)</td>
</tr>
<tr>
<td>6M</td>
<td>641</td>
<td>2 (0.31)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>9M</td>
<td>641</td>
<td>0 (0)</td>
<td>0 (0)</td>
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<td>640</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

Screening: 707
- Syndromic STI: 13 (1.8%)
- HIV positive: 9 (1.27%)
Adherence

Self-reported adherence

Blood Tenofovir level (ng/mL)

- Pill taken every day during last month (%)
- Pill taken every day during last 7 days (%)

R1 = M3 & R2 = M6
PrEP in Zimbabwe

General Support

- SMS reminders
- Active follow-up through phone call & home visits
- **CM sessions**
  - Testing & linking to care
  - PrEP & adherence

Adherence Sisters Programme

- **Building Sisterhood** & supporting HTC, PrEP, ART uptake & adherence
- Women nominate their ‘Buddy/Sister’
- ART & PrEP users **together without disclosing**
- Discussion & Action on the issues discussed by the women

Insights & Results

- **500 initiated, 402 came for 1st follow-up**
- Early adopters, peer support & buddy system helped overcome barriers
- FSW on PrEP reported it as **empowering**
PrEP in South Africa

Lessons Learnt

- First 3 months crucial for 'client drop-off'. Hence active intervention
- Planned follow-up for structured messaging encourages adherence & retention
- Stigma over mistakenly identified as HIV+ discourages PrEP
- Multi-disciplinary approach to actively address side-effects

Supporting Clients:
- Incorporating PrEP in daily outreach activities

PrEP Ambassador
- PE draw on their own experience when addressing concerns
- Creative Workshops to discuss challenges and bring solutions

Track & Monitor:
- Weekly microplanning, SMS, WA, sitevisits

Performance against Annual target

2369

54%

Performance

0%

Annual Target

Enrolled on PrEP (Q1-Q3)

FY18 PrEP New Uptake

Esselen Clinic

Q1

Q2

Q3

106

110

205
Challenges

- Time taken for community consensus generation and preparedness
- Regulatory approvals & drug imports
- Working with the existing community systems and ensuring rigor, speed, quality
- Ensuring data is reviewed regularly, focus on adherence, condom use, STI, etc.
- Leads to ground swell in demand – managing the demand without dampening the spirit

Lessons Learnt

- Community led process could be time intensive but has assured results
- Integration with existing prevention program that includes outreach plan and PE responsibilities
- Ongoing community preparedness for both ART & PrEP
- Context specific delivery & individualized intake can minimize hurdles & maximise adherence
- Maintaining community cohesion
Are we ready to get it right?

- Placing the 'trust & faith' in community
- Investing in the leadership
- Enhancing their capabilities based on 'community intelligence'
- Providing fiduciary controls
- To stand by the community for them to succeed & not pass judgement
Acknowledgements

• All the Sex Workers at Ashodaya and DMSC - My Gurus
• Dr. Smarajit Jana, DMSC and STRI
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• National AIDS Research Institute
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• The Bill and Melinda Gates foundation