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Aids Prevention and Care For People Affected by Aids in India a Transnational Perspective

(Summary Report of Workshop, Organized by IDPAD-ICSSR/WOTRO, India/ Netherlands)

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The dreaded HIV virus has become a reality for India in the last decade. However much, each one of us may have wished and reasoned with our ideological stance, HIV type C has now viciously penetrated our general population. In response to this challenge, Indo-Dutch programme on alternatives in development, sponsored by Indian council of social science research and WOTRO [The Netherlands] funded a three day workshop on AIDS prevention and care for people affected by AIDS in India. The workshop was organized from 27th June to 29th June 2002 at Royal Tropical Institute, Amsterdam. The workshop was aimed at sharing experiences and learning from the failures of and successes of the countries caught in the first wave of the epidemic. Fourteen participants from India had intensive and extensive dialogue with researchers, NGOs, networking executives, State Planners and representative of the stakeholders across the continents. The participants came from Sub-Saharan Africa, Uganda, Thailand and USA. A special session on Donor's perspective had representatives from UNAIDS, AIDSFONDS, OXFAM, BERNARD VAN LEER FOUNDTION and CORDID.

Twenty- nine presentations with full texts circulated to the participants, and deliberations that lasted for more than twenty working hours covered a large spectrum of HIV/AIDS issues confronting India and many other countries in South Asia and Africa. Deliberations focused on core areas of prevention and care and examined related issues of development, social protection and community rehabilitation of those affected directly or indirectly by the virus. There were detailed discussions on special needs of the people living with HIV/AIDS, gender, orphans, and ethics in research, prevention and intervention strategies for providing available treatment. The workshop acquired vital importance as it began the day special session of UN assembly, adapted declaration of commitments on HIV in its 26th special session. The participants also reviewed 103-point draft declaration made at the UNGASS. Five of the workshop participants, who joined the workshop immediately after attending the assembly session, reflected on their experiences from New York. It was possibly the first workshop of the experts on HIV/AIDS that reviewed the UNGASS and its functional relations with the civil society. The summary report presented here is not a session wise reporting of the proceedings but is an account of the major issues that emerged in various sessions of the workshop proceedings.

POLITICS OF NUMBERS

The National AIDS control Society of India contested for a long time the figures projected by various international organizations of HIV probable in India. Though there is now a general consensus that the figure could be close to four million [3.86million as per the NACO estimates], the politics of numbers in human tragedies remains the ugliest and most acrimonious aspect of epidemics, natural and man made tragedies. Probably, India is likely to have the highest number of HIV positive people in the near future. Even if, in terms of proportion to the population, they constitute only 0.6 percent, the tragedy of the victims, their families and the society cannot be undermined. Numbers are important, indeed very important. Repetitive as these statistics may appear, they are crucial to every meeting on HIV/AIDS and to every country in the world. We have often reminded ourselves that by the end of 2000, 36.1 million people worldwide were living with HIV/AIDS, of these 90percent are in developing countries. We have already lost 22 million to the insatiable appetite of the pandemic. Nearly three million adults and children become victims of the pandemonium every year. About 5.4 million adults and children are newly affected every year. As on today almost 1.3 million children are tragically dead or waiting to die. If these projections prove to be facts, we will have 100 million or-

phaned by HIV/AIDS by the end of 2010 all over the world. Fourteen million children have already lost one parent one parent. The disaster spells doom, unprecedented in the history of mankind. These projections and figures warrant little discussion on political implications of unfortunate numbers living within political boundaries of any nation state. Peter van der veer [chairman IDPAD]and Bhaskar Chatterjee[Member secretary, ICSSR] in their opening statements cautioned against falling prey to the politics of numbers. Sam Okware[Commissioner Health Services, Uganda] in his position statement said, "Numbers are important as they determine the world attention and are responsible for drawing resources. They help generating funds from international donors and put pressure on the leadership, government and stats to put their acts together". It is widely believed that denial, silence, economic compulsions and political inactivity are catalytic to the spread of the pandemic. Hence, talking about numbers tantamount to generating pressure points for action. Some voices at the workshop reasoned that politicization of numbers for low risk countries might be desirable at this stage of the epidemic, as it may generate momentum and help scale off further rise in the incidence. But there was concurrence that politics of numbers is dangerous and is likely to be counterproductive when put on a one to ten scale. Most of the workshop participants addressing concerns in India were at pain to note that despite National AIDS control society's claims and action programmes, India was threatened by one of its worst health crisis that would pose tremendous pressure on its economy and development ventures.

WHITHER STANDS INDIA

India's national AIDS control programme was launched in 1987 with a soft loan of US$84 million, which was further consolidated at a cost of RS. 222.60 [1992-1997], and technical assistance from WHO. The money was spent but little was done to control the virus effectively. The only achievement of this phase of the programme was that it managed to identify high-risk populations located in Maharashtra, Manipur and Tamilnadu. Failures of the first phase were disturbing. There was phenomenal increase from 310 cases identified in 1992 to 3.86 million infections in a short span of eight years. The National AIDS control organization[NACO] after reflecting on their failures started working on the second phase of intervention. On 19th November 1999, a special account amounting to US$ 5,00 million was maintained in the Reserve Bank of India to meet the cost of HIV management in the country. An outlay of US $ 229.8 million, a vertical structure that talked about horizontal dispersion and decentralization was proposed. Irrespective of the proposed broad outlook, India convener of the seminar felt that the National AIDS control organization has largely remained bureaucratic, inaccessible, target oriented and distanced from the grass roots. It has taken little initiative to integrate HIV management in the existing framework of the public health system. The workshop participants believed that effective management strategy for HIV has to be based on a perception of holistic management of health system. It cannot operate in isolation with a deliberate policy of exclusion rather than inclusion. India's health and social welfare management system has an extended infrastructure. There is urgent need to make optimal use of that system. The Indian convener and some other participants at the workshop were convinced that there was urgent need to reconstruct the existing structure and functioning of NACO. It would be a good idea if ICSSR, ICMR, Directorate of Social Welfare and NACO became equal partners in the management of HIV/AIDS in India under the direct control of the Prime-Minister of India. Indian Council of Social science research has a network of 34 well-established research institutes in various parts of the country. Many of these institutes also have fully funded population centers already engaged in family welfare programmes with highly competent faculties. If services of these institutions are availed for management of information, education and awareness programme, a lot of wastage experienced by NACO till date can be avoided. Indian Council of Medical research is supporting significant medical research for HIV strain vaccine development. If they also become equal partners in providing therapeutic treatment to HIV positive people, either through various centers managed by them all over the country or by providing medical expertise to organizations involved in providing medical care to people affected by HIV/ AIDS, we can have an effective care programme uniformly spread out in the coun-

try. India is likely to have a large number of children orphaned due to HIV. There is fear that a large number of these children may be HIV positive. We need to do some proactive thinking on this account. It is important that the directorates of social welfare at the state level collaborate with the local level HIV management initiatives to provide support systems to these children. Funds have to be relocated from NAACO's resources for this purpose. It may also be argued that the National AIDS control society performs the role of a Principal NGO looking after the intervention programme. It can invest its resources in managing and networking for raising funds, designing tools for intervention and evolving the right political and social environment for the success of the proposed strategies.

The existing multi-sect oral approach of NACO is ineffective. Many Indian delegates felt that to take cognizance of the existing situation India parliament should convene a special session of the parliament to discuss AIDS policy. India has now announced its AIDS policy but there was no debate or discussion on the subject. The immediacy of the issue becomes staggering as apprehensions suggest that nearly 2percent of India and China's population was infected. Nearly 15,000 new infections occurring everyday, the dimensions of the crisis awaiting us are enormous.

India is a signatory to the UNGASS declarations. Sonia Gandhi, India's official representative at the meeting asserted that; "we can not have in Asia, the high prevalence rates now seen in Africa". She also retreated India's official stand on antiretroviral treatment by saying that; " Antiretroviral can be widely used in the developing world if very substantial resources are assured through international funding over at least a decade, to start with". The argument put forth is that the cost of antiretroviral treatment would be hundred and fifty times over the per capita expenditure on health care currently provided by the government of India does little to comfort millions already infected and seeking treatment. Categorical statements expressing Indian government's inability to make such large allocation of funds for a programme of palliative treatment, arguing that " it is likely to skew the resources between the key components of the our public health initiatives", sounds counter productive and against the spirit of best established practices in public health care.

India's HIV/AIDS programme is dogmatically following the policy that existing resources for prevention cannot be diverted to patient care. Evidence suggests that prevention programmes can hardly succeed, unless they are matched by equally established care practices. A positive person accommodated by the civil society and receiving adequate medical care is going to be much better resource for prevention than hundreds of posters or camps put together for the purpose of making people aware of the impending danger to their health. When we sentence unfortunate victims to certain death by not even providing for basic available medicines then we are participating in what may tantamount to homicide. Strong as this statement may appear it reflects the voice of thousand suffering under the dual burden of poverty and HIV.

It is ironical that NACO [India] spends 86% of its resources on prevention and leaves only 14% for care. TH workshop tried exploring other resources. There was a proposition that if AIDS patients can be brought under the purview of the provisions existing for disabled people then some funding which often remains unutilized can be used for providing care to the AIDS patients also. However, there were conflicting opinions on the subject. Some of the NGOs participating in the workshop agued that the existing funding for the disabled was too little and the government machinery was inapt at handling it. The disabled had to go through various bureaucratic hassles to get even their fair share out of it. Any further diversion of the same is going to deprive hundreds of their legitimate right to these provisions. It was also feared that such moves are against the struggle that the civil society has made till date to bring some kind of distributive justice in providing adequate service to the underprivileged section of the society. If any funding earmarked for HIV/AIDS care is once again channeled through government institutions then it is likely to be riddled with bureaucratic wrangles and shall be defeatist in purpose. A disabled person has to procure a disability certificate from the local 'Panchayat'. How do you expect an HIV person to reveal his status to the village panchayat under the existing atmosphere of contempt, stigma and discrimination against such people? The proposition was also strongly contested by Beatrice were a representative of the

positive people and head of NACOWLA, an organization for HIV positive women in Uganda. The argument put forth by her was that HIV positive people are not disabled till the last stage, when they are actually bed-ridden. The term 'disable' according to Beatrice was much abused. "In the Indian context, you will be overwhelmed. Too many people will be entitled to benefits and it would overwhelm the state planners and social activists by themselves. In a developing economy, where resources are restricted, competition for them is likely to create monopolies. Unfortunately, when this competition for monopoly barters for human lives and patient care, the situation becomes grim".

The system of delivery of health care in India has so far failed to evolve a relation of partnership between the public health institutions sponsored by the state and the providers of health care falling in the ambit of civil society. There is discomfort and suspicion towards each other. This has remained a stumbling block in achieving any kind of efficacy in the management of various facets of public health. Even this forum underlined the need for the state, social scientists, medical practioners and people living with HIV/AIDS to come together and work out modalities for optimizing the provisions of the prevention and care programme in the offering as at present

EMPOWERING FOR PREVENTION

The theory of HIV/AIDS management in the last two decades has undergone considerable revision. Early diagnosis of the virus in the western world, promoted the strategy of equipping people to confront the disease through information, education and communication. A literate world armed with relatively high standards of health delivery system responded well to the IEC strategy. But when the virus spread to the developing and under developed countries, IEC strategy required additional tools for prevention. Social scientists and intervention planners started emphasizing upon the need for 'behaviour change communication'. In common parlance, we were all talking about a paradigm shift from IEC to BCC. It was derived from this strategic position that the developed world was able to moderate their behavior through information an education, but the illiterate, poor populations with traditional constructs of sexuality require deliberate intervention. Sociologically speaking the paradigm shift was located in the same mould in which development was introduced in the third world countries. Voices at the workshop expressed disappointment in blind adoption of successful best practices of the first world in sub-Saharan Africa and India. There were a section of the participants that believed in moving away from IEC & BCC to empowerment models. They reasoned that unless women are empowered to take command of their bodies and make independent sexual choices, no amount of condom promotion would be of any use. In the same vein it was argued that with the female levels approximately in the range of 50%, almost half of the female population has restricted access to information on safe sex. It is imperative that local channels fro building capacities for empowerment are identified. There is need to construct rational structures around these local channels for containing the epidemic.

The empowerment model was found to be effective in the Sonagachi experiment. It helped to organize and strengthen the voice of hundreds of commercial sex workers. Despite the regional success of the empowerment initiatives in the context of sonagachi, participants registered that the model was not successfully replicated in other areas. Though there was concurrence that the empowerment model was not only important for vulnerable groups but was also important for the general population. The constructs of empowerment also accompany the concept of social responsibility. One of the participant reasoned that the state, the civic society, the individual, all form the cohort responsible for the advocacy of safe behavioural conduct and become instruments of empowerment. All of them are equally responsible for the safe supply of blood, for ensuring sterilized needles, for necessary precautions within the hospitals, and for providing care for PLWHAS. Social responsibility becomes fundamentally and ethically essential, when dealing with the questions of stigma, discrimination and alienation of infected populations. Social responsibility impinges upon the NGOs to be accountable to the people for whom they work. We require remembering that social responsibility is not an encroachment of individual freedom. To facilitate and coordinate activities relating to empowerment and sense of social responsibility,

we have to develop networks and involve individuals and various sectors of the society in networking.

DEVELOPING NETWORKS

Multiplicity of issues and concerns involved in HIV/AIDS debate necessitates 'networking'. Multisectoral planning, methodology, orphan care or gender bias, community mobilization or anti-retroviral treatment or simply talk about prevention and care, none can be effectively addressed without establishing intra and inter networks. Representatives from Schools without walls [SAT], Asian Harm reduction network, [AHRN], Indian Network of NGOs on HIV/AIDS [INN], and coordination of research on AIDS and Mobility [CARAM] in their presentations emphasized the role networks play in advocacy, building capacity and social marketing. Networks also facilitate focused interventions in most vulnerable groups, help provide necessary wherewithal for imparting training to trainees, and utilize their organizational strength to build pressures for effective and immediate social intervention on policy planners and political leadership.

Networking in India is relatively weak as compared to well-established networks in the west and most affected countries in sub-Sahara Africa. The Indian Network [INN] is a broad configuration of grass roots NGOs doing some projects on HIV/AIDS and women empowerment. Inn's mission statement is too having holistic approach, to provide care for patients living with HIV/AIDS. What remains to be identified as to how the organizational objectives are being achieved? What are the strategies they are pursuing for the benefit of the affected people? What time frame they have in mind for achieving various short and long-term objectives? INN can learn from the experiences of organizations like 'The schools without walls' [SAT] that have worked relentlessly for the past eleven years in Southern Africa. Following the spirit of learning through method in the field, SAT successfully replaced the paternalistic notions of implementation through its strategy of facilitating intervention. Their most significant contribution is that small-scale initiatives can replicate themselves in very rapidly by local transfer of skills. SAT recommends that important coverage can be achieved by scaling out rather than scaling up. Indian networks also need to scale out. They must reach out to populations in far and remote areas.

India's AIDS epidemic is likely to acquire cataclysmic proportions in the BIMARU states. These states are poverty ridden, underdeveloped with low level of literacy, and dismal structure s of health delivery systems. These states also witness large scale out migration of male workers won move to more prosperous states seeking employment. There are number of episodes expressing serious concerns that many of these immigrants return home infected with HIV. If they do not disclose their status there is every possibility, given the gender position that they are likely to infect their wives without their knowledge and escalate spread of virus in what is relatively deemed as the safe group of monogamous housewives. Indian networks, particularly those working among the migrant workers have to draw a lot from international networks like CARAM, who have valuable experience of working among the mobile populations. TO avoid exploitation of the migrant workers, there is urgent need to draw stringent labour laws. Many countries in the world have made HIV testing mandatory for all migrant workers. Sometimes these tests are carried out without the knowledge and consent of these workers. Ivan Wolffer, who heads CARAM informed the workshop participants that those migrants, who are found to be positive are either sent back home or to a detention center. Often they are not even informed the reason for their deportation. However, in the contest of inter-state migration within India, the proposition of introducing mandatory testing is simply not desirable. Modalities have to be worked out to minimize risk. Promoting voluntary testing at work site is one such possibility. Another proposition is to provide voluntary counseling and voluntary recruitment in harm reduction networks. It is important that peer group networking is strengthened to make people feel secured and at ease with their positive status.

The problem of drug addiction can be effectively tackled by adopting some of the strategies mooted by Asian Harm Reduction network. AHRN has a resource mobilization strategy that works on the principle that changing behavior completely is sociologically impossible. Therefore it is imperative that we work towards a phi-

losophy of reducing harm to the individual and subsequently to the society by investing in early intervention programmers. The experiences of the network suggest that early intervention restricts the number of potential users. It also ensures increased access to health services to the existing drug users. The programme has helped reduce crime rates and help generate income incomes for drug dependent participants in the programme. The most significant contribution made by these networks is in the preparation of "Best practice documentation on Harm Reduction in Asia". The Indian networks working among drug addicts have to confront the reality of 65% drug users in the Northeast being infected. With more than five percent of the general population being infected, the situation in the north- east is really becoming alarming. Urgent and inconsistent intervention on a war footing can only make the desired difference.

FALLACIES OF TARGET INTERVENTION

The theory of HIV/AIDS management has undergone considerable revision. There is delicate difference in identifying vulnerable populations and structuring entire intervention programme by the National AIDS control organization around it. Independent commission on health in India argued that the narrow conceptualization of the 'targeted interventions is fundamentally flawed and the centrality accorded to this component in National AIDS control programme phase-11 as a core determinant of success in institutional capacity building not warranted'. The report also argued that the technical integrity of the Intervention models postulated by the World Bank on the basis of success achieved in Thailand and in the Sonagachi project in Calcutta is misdirected. The report was particularly concerned about some of the outcomes of the Sonagachi experiments and reasoned that the experiment had led to various unintended consequences. There are serious academic questions regarding 'iconization' of Sonagachi experiments. It s ability to act as a model for empowerment for women in sex work and as a cost-effective intervention to halt HIV transmission has had only limited success and has failed to register similar success when replicated in other parts of the country. Its limited reach and massive investment required in terms of cash and manpower makes it an unviable proposition in other parts of the country. The ICHI report submitted by D.Banerjee and Rami Chabra calculated that nearly '30 crores were poured into tackling a narrow sexual health agenda for a total target group of around 30,000'. These figures become significant in the light of the fact that the budgets; available with the directorate of social welfare, in various states is a small fraction of this amount. Thus the financial viability of this proposition is a near impossibility. The costs worked out by ICHI suggest that costs of treating participants in the project ranged between Rs. 700 to Rs. 3200. And if there was lower compliance level then the cost is going to be prohibitive.

Another set of arguments criticiquing the efficacy of Sonagachi experiment is based on the fact that when interventions were introduced in Sonagachi, the HIV prevalence rate among one of its most vulnerable sections was much lower than what was witnessed in Bombay. Thus the possibility of containing infection in this region among the sex workers between one to two percent may not be as significant as it is made out to be.

The third and rather controversial argument related to the social acceptability of the model and its probable impact on the traditional social structure.

Target interventions are riddled with two major paradoxes. First is the assumption that early and controlled interventions can drastically bring down the rate of HIV prevalence in both the targeted population and the general population. The argument is neither scientifically relevant nor rationally and socially acceptable. When we examine the expenditure incurred by NACO on targeted intervention and on interventions among the general population then this lacuna become quite marked. The second phase of NACO allocated 265.6 crores for targeted intervention for groups at higher risk, as compared to only 163.3 crores for preventive intervention among the general population. Disproportionate allocation becomes heightened, when only 50.5 crores of this major funding is earmarked for institutional strengthening.

It is time for NACO, and every researcher and activist concerned with the HIV/AIDS epidemic to look for indigenous alternative strategies for managing the epidemic. Community mobilization appears a very important tool in combating the

virus. Reorganization of priorities both in terms of funding and manpower utilization is required. Greater involvement of the policy planners and opinion makers in the society is deemed imperative at this stage. The existing prioritization may have been relevant in the first phase but needs immediate restructuring in the wake of the fact that the virus is threatening virtually every citizen of the country. At the level of dissemination, we have to decentralize the programme and take it to the district, village and municipality levels. If there has to be any targets, these targets need to be locally identified by the community researchers after taking cognizance of the ground reality.

National AIDS control organization in a minimal way has started the programme of decentralization. They assume that first step, in this direction was made by setting State AIDS control societies. Decentralization at the district level is yet to take off in a noticeable way. Unless the process of programme control management reaches the district, followed by effective management at the Panchayat and Municipality level, our hopes of containing the spread of the virus are rather limited. The centralized nature of HIV/AIDS planning and its obsessive focus on target interventions hardly offer any gateway for concerted mobilization efforts.

CARE: The Neglected Component

Who, ever said that investing only in prevention could control an epidemic? Unfortunately, advertently or inadvertently India's national AIDS control programme has come to believe in this fallacy. If HIV infected is left to fend for themselves and wait for eventuality, their dependents are not even being provided any societal support or state help. We seem to overlook the fact that most of the infected patients are in the age group of 20to 49 and they are the providers for their families. When these bread earners fall sick, the fabric of the family collapses. The sub-Sahara Africa is already witnessing families comprising of grandparents and dependent grandchildren with the middle generation being wiped out by the epidemic. We in India are not learning any lessons from the plight of these nations. We are not preparing ourselves to face the challenge of thousands of children likely to be orphaned by the epidemic in the coming decade. Many of these children are likely to be victims of pediatric AIDS. Neither the civic society nor Directorates of Social welfare is gearing themselves for any eventuality. They are reticent in assuming that Indian kinship network and extended family system will absorb the crisis. Experiences from Gujarat and Latur earthquake have shown India's insensitivity and inability to address the issues involved in orphan care. Orphan care does not began or end at adoption or 'rehabilitation'. We overlook the fact that children who are victims of these tragedies are both physically and mentally scarred. If on the one hand specialized institutional care is required for their up bringing, they also need personal care and structural family support. The concept of 'community care' as being practiced in some African societies may be one such possibility, whose acceptability by the affected communities can be probed. Shanti George, who has worked extensively in the field in Sub-Sahara Africa on this project was of the opinion that if funds allocated for orphanages and foster homes are channelized to communities for taking care of their orphans, we can ensure community participation and better care for the affected individuals. Zimbabwe has taken initiatives to start hospices to support HIV positive children. India may also explore strategies for starting similar support services that provide institutional care.

Attached to orphan care were also questions relating to child labour laws. Beatrice were an HIV positive mother felt that there was need to review these laws. In many households children orphaned due to AIDS, have to own the responsibility of supporting younger siblings. Some of these siblings may be infected. These children need money to support them. How do we regard this necessity for child labour? In the context of poverty and child labour in poor countries, it is economic need that drives children to work.

In India it is the domestic sector where maximum exploitation of child labour takes place. It is in settings like this that child abuse leading to frequent teenage abortions and sexual infections is frequently recorded. Even within highly publicized concept of extended families, evidenced research has reported high rate of child abuse and unrecognized child labour. We in India have failed to evolve instruments that facilitate rehabilitation of these children within community settings. If there is need to reexamine adoption laws,

there is also an equal case for building strong community structures cutting across religion, caste and all other diversities and inequalities to provide security and care to children who are the building blocks of any nation.

In conclusion, the proceedings of the workshop asserted that there is urgent need to develop a framework for muti-sectoral HIV/AIDS programming at the district, Municipality, Panchayat and community level. The success stories recollected in the course of discussion from Zimbabwe, Senegal, Uganda demonstrated that when we shift focus from individual to social vulnerability, perceptive differences are recorded in people's acceptance of intervention programmes. Significant difference has also been reported in acceptability of intervention modules on moving away from 'project strategies' to 'people strategies'.

The task of developing appropriate methodologies for HIV/AIDS research and intervention was critical to combating the epidemic. The relevance of cultural approach and importance of anthropological methodology and ethnographic method of research was emphasized by various participants. It was argued that ethnographic approach empowers researchers with 'right attitudes', 'appreciation of cultural relativism', 'theoretical insights' to understand 'other cultures' and evolve 'participatory approach' to help break barriers. Focused ethnographies help develop enabling methodologies for intervention.

HIV/AIDS prevention and care for people affected by AIDS in India has to be galvanized on a war footing. Policy Planners, instruments of the state, researches, epidemiologists, health workers and social activists have to share common platforms to meet the challenge of the worst epidemic in recent history.

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Prof. Shalina Mehta of Department of Anthropology, Panjab University, India jointly convened the workshop with Dr. Inge Hutter of Groningen University, The Netherlands. Marc Verhagen, Coordinator, IDPAD, coordinated the workshop.

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