



Ms. Brinelle D'Souza

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Brinelle D'Souza is National Programme Director, Saksham, GFATM R7, HIV/AIDS counselling programme. Her institutional affiliation is to the Centre for Health and Mental Health, School of Social Work, TISS, where she is an Assistant Professor since 1999. She works in the area of HIV/AIDS with a focus on a rights based approach and counselling. Tata Institute of Social Sciences is the Principal Recipient of The Global Fund to fight AIDS, TB and Malaria, Round 7 Counselling Component. This project named Saksham, strives to build capacities of counsellors, master trainers and institutions of higher learning across the country. Saksham is now a unique partnership between 38 academic institutions that are working in close coordination with the public health system (NACO and SACS), and contributing to the National AIDS Control Programme.



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Q. Could you tell us a little about what CARAT is?

BD: The Cell for Aids Research, Action and Training- that's what CARAT is about- started its work in the field of HIV and AIDS I think in 1989. Professor Vimla Nadkarni who was there in the Head of the Department of Medical and Psychiatric Social Work had initiated the project. The Cell essentially, as I said to you earlier, was initiated to respond to the epidemic and the needs of the epidemic, basically the psycho-social aspects of HIV/AIDS. In terms of conducting research, building capacities in counselling, working with NGOs, networking... There were a whole lot of human rights issues which, you know, as the epidemic progressed came to the forefront and the Cell played an important role in relation to those human rights issues.

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Quite a few research studies were conducted. The earlier ones, the KABP studies were typically called Knowledge-Attitude-Belief-Practices, understanding institutional responses, NGO responses to HIV and AIDS and so on. And two major projects which we had done around that point of time was the continuum of care project in Sangli and in Mumbai. As I said earlier we also had a voluntary counselling and testing service, so in this way the Cell sought to respond and a lot of consultancy work also taken up by the cell. And the cell was supported by a Ford Foundation grant initially. So, a lot of training programmes, especially in relation to counselling, a lot of manual developments on HIV/AIDS counselling. The Cell for a long time played a role first as the regional centre for HIV/AIDS counselling, the western regional centre for HIV/AIDS counselling, then went on to become the epicentre for HIV/AIDS counselling in the country.



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And through that a lot of policy formulation, a lot of standardisation and you know of counselling service... essentially training and services is what the Cell has contributed to.... So right since the beginning of the epidemic, '89 onwards, and various faculty of the Institute along with project- of the Department of Medical and Psychiatric Social Work- and a lot of, I mean... and different project staff who were appointed basically carried out the activities of the Cell at that point of time. I took over the Cell in nineteen ninety... in 2001 and for a long... We had at that point of time initiated a ten week international programme on HIV/AIDS counselling and psycho-social interventions which was very, very successful. I think 25% of our participants were international participants and came from countries as diverse as, you know, Uganda, Rwanda, Australia, and countries from South Asia.

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A lot of them were mid-career professionals and then went on to lead fields and projects after they had done this ten week training, advanced training on HIV/AIDS counselling and psycho-social interventions. We also continued a lot of our training with different State AIDS control societies in counselling, training. We had a very major project with AVERT society which was a USAID-funded project on basically building capacities of counsellors working with what was called targeted interventions. These were... targeted interventions focussed on high risk and vulnerable groups such as women in prostitution and sex work, men who have sex with men, migrant labourers. So we essentially were doing capacity building and what we were able to do through these is to bring perspectives of marginalisation, stigmatisation, vulnerability from the larger Social Science domains and help people to see how those contexts of marginalisation,

stigmatisation affect people's choices and the risk therefore that people engage in because of life circumstances.

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BD (cont.): So we had brought a lot of the development focus, a rights focus to a lot of the training programs that we had conducted. We also did a very major project with UNDP on mainstreaming HIV/AIDS because there is a lot of debate over the last five years, that there's been an over emphasis of HIV as a disease; one needs to have a more health systems strengthening point of focus now instead of having disease-specific focus, there's a need to mainstream HIV. And we'd also done some of the pioneering work where we worked with the development sector organisations to show, you know with them, to see how they can mainstream HIV/AIDS in their work and therefore you know, by doing that you have a greater spread of intervention. Because if you're reaching out to not only organisations who are doing HIV work which is very specific work, but also work with development sector organisations who then are able to see the link between the epidemic and their own work, and see how they can respond in their own work to the specific needs and challenges of the communities that they are working with in relation to HIV and AIDS. So this is broadly some of the work that has been done through the Cell.

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Q: How did the transformation to Saksham take place?

BD: We were doing a lot of work on HIV, as I said training, manual development for training, then to standardisation of counselling, training and practice in the country and we were also well known in the country for the quality of our work. So there was always a confidence there that a



lot of SACS had- SACS are the State Aid Control Centres, uh State Aids Control Societies- working with us because of the high quality of our work. So it was in 2007, I was in Bihar for the mainstreaming project when a letter came from NACO inviting us for a small consultation to develop a proposal for counselling training, capacity building through global fund grants. So we did almost not want to go because, you know, these are last moment invitations and I was in Bihar and then my staff said no, you just... let's just go and see what happens.

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Because the deadline for the proposal submission was May 29th and this letter came to us on April 21st and 23rd there was a meeting in NACO. So we had been there for a... and actually one of the SACS had strongly represented- because NACO had asked the SACS for, to recommend institutions who should be part of this process. So the Gujarat SACS had said that they were very happy with the quality of engagement they had with the Cell for Aids Research, Action and Training and therefore referred us to NACO, that we should be part of this consultation. And as history had it we were there, and there were a few other institutions who were invited to be part of the consultation and then Sucharita Rao who was then the Director General of the National Aids Control Organisation and subsequently was Health Secretary, Government of India, she suggested that we put together a proposal.

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And so since we had done a lot of work in this area, we had our own dreams and vision of how we would want to obtain from a lot of this. TISS had taken the initiative, and initially it was to be, we had opted to develop a proposal for the regions that we said that we would be working in, or the states we would be working in. So they were essentially, we chose to work in those states



where we would bring the mainstreaming project because it's... we said it would help consolidate our work there. So it was essentially Bihar, Chhattisgarh, Rajasthan, Gujarat; states also that nobody else wanted to work with essentially. Then we developed a project for these states and then we realised it wasn't going to work in a fragmented mode. You can't, as a country, send fragmented proposals to the Global Fund so we had... So then I called up all other institutions who were working on this, you know, for their own areas, writing proposals for their own areas, states.

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And they essentially, and I told them see we would need to come together and develop a combined proposal for the country because that's, you know, that will enable us also to have a cogent response, you know, plan a cogent response for the entire country, so. We decided to come together in Delhi and Professor Nimesh Desai was very kind enough to give us his, to make his accommodation facilities available and their meeting rooms available for us to work. And five or six, five or six of us were there in Delhi and worked on the proposal right from nine in the morning to around 12 in the night every day, because we had to do a huge proposal in a short span of time. And the rest was history, I mean TISS had played a strategic role in the development of the proposal.

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Q: In a more comprehensive way, how would you describe the work of Saksham today?

BD: Today Saksham is essentially building capacities of institutions of higher learning to respond to the training needs in relation to the epidemic, specifically in counselling training across the country. Saksham is, when we say building institutional capacity it has many

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components and dimensions to it. One is infrastructure, so we have provided institutions with infrastructure to set up, you know, offices, to set up good training facilities, to set up good accommodation facilities, so that has been one part of our work. The other part of our work is actually build capacities of these institutions to do high quality counselling training in the country.

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The other dimension would be to develop a pool of master trainers all across the country, so it's a multidisciplinary pool. Each state has a set of trainers who come from a range of backgrounds and we have been really investing with these master trainers because they're like a second line of trainers available all across the country. A major mandate in phase two of this project, which has essentially started is developing supportive supervision, or counselling supervision for... systems for counsellors. Now this counselling supervision is unparalleled in the public health domain, I think in the history of this epidemic. What India is currently doing now through the Round 7 grant is basically providing counselling supervision to counsellors, around 6000 counsellors all over the country on a quarterly basis for which we have identified, trained mentors across the country to take on this role. And it has been really humbling and a very enriching experience to see how different stakeholders have come together to make this happen.

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There is a lot of research going on in relation to counselling, in relation to training, in relation to developing tools for monitoring and mentoring, for monitoring and evaluating programme deliverables, programme outcomes. We have a very sophisticated MIS, which is Management Information System which helps us plan and strategise real time. We have a very good



transparent, accountable financial management system in place and we also have knowledge management systems which helps people who are not directly linked to programme to understand what are the resources developed through this programme. It provides opportunities to our own internal stakeholders to engage with each other. Like we have Ask an Expert blog, which supervisors can post questions that they are dealing with in the field in relation to supervision and get their queries answered, solved through this, through such systems.

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And we have a whole lot of training material which we are developing for the country. Niche areas where there... either they're niche areas where there's not much work done in those areas, they're very critical areas, say like mental health and HIV, children and HIV but there's not much of training resources coming out also with innovative training resources that can be used by partner institutions, by the SACS all over the country.

Q: Given that there's stigma attached to HIV and AIDS, what have been the challenges in the field?

There have been challenges. Since we are not working directly with clients, we are not directly dealing with stigma... issues of stigma and discrimination of clients. Yes, but indirectly we do address those issues because if you have to develop a cadre of counsellors with high quality skills to respond to the needs of people live affected with vulnerable to HIV then you have to be... stigma and discrimination are important issues to deal with.

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So this has been tackled at two levels. There are issues about stigma and discrimination, one coming from HIV; there's also stigma and discrimination coming from one's sexual and gender

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identity which you have to help master trainers to deal with and look at their own issues, value conflicts that they have in relation to gender, sexuality, you know marginalised populations. So one is that you... and we have been doing a lot, our work with the master trainers has focussed a lot on understanding what are their own personal and political positions on these issues. Because that would definitely influence the kind of training they give in relation to a whole lot of sensitive issues concerning marginalised groups and populations. So one is at that level, then how do we prepare these trainers to address these concerns as they may be in the counsellors. So our work is at two levels. We have different mechanisms in place, we have what we have developed is the GMAT which is a global assessment of master trainers which basically assesses their.... It's a 360 degree assessment tool and has three components to it.

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One is their own self-introspection and reflection of themselves as trainers in this domain, and what are their own discomforts, comforts, struggles in relation to a whole lot of issues, you know value conflicts that they may face in relation to gender, sexuality, say sex work, same sex behaviour. So these tools... we look at these issues as they emerge, the data as they emerge and strategise around that you know, so. We notice that our master trainers were still struggling a lot with these issues which are very fundamental to the epidemic. So we have this year for example done, had very in depth trainings on gender and sexuality for our trainers which were conducted by TARSHI, Delhi. We also have another group called Samraksha which works in Karnataka which has done some very, very good nuanced work on, with marginalised groups such as women in sex work and prostitution so another set of master trainers are being trained by those organisations. So they get not only the skills, the content for, you know, and the skills for



training but they're able to then also get the perspectives, the discourses that come with working with these groups.

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Because that is very, very important, so that is one aspect. So how we use data through different kinds of monitoring and evaluation mechanisms to re-strategise to work with. The other thing is we have also come up with an E-learning course on gender and sexuality for all our trainers which is largely, it is largely a capacity building, self-reflective exercise you know, we're not going to grade them but it's an opportunity for them to look at their own political positions in relation to these issues and see where they are located. Then if they have further struggles and issues then they can definitely contact us. We've looked at, our training materials are also geared, and we have a little handbook on gender and sexuality for our master trainers. From a discrimination and stigma point of view, at the client level we are currently working on two posters. One is a poster that will go to every counsellor, but it is largely... to every counselling centre in the country under the national program. It basically will focus on what rights clients have in relation to counselling services.

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And definitely one of those things will be to receive services which are free of discrimination, which are accessible, equitable to all. So drawing from patient rights charters, and other human rights this thing, how do we create something specific to the HIV/AIDS counselling context but sort of empowers clients. And this will be in the local language, so clients will be able to read it. So we have what we call as our schedule list of languages in this programme because of the diverse programmes spread all over the country, we have eleven languages for which all of our

materials have to be produced in. So otherwise the end user, if it's the client and in any case is the counsellor may not be able to access languages, I mean access... are not fluent in English language, so.

Q: What is the strength of the counsellor, master trainers and supervisors?

BD: We are 12,000 counsellors, around 550 master trainers, 1200 counselling supervisors all over the country, 38 universities of higher learning, institutions of higher learning of which say 70% are universities, and the other institutions are medical institutions where the departments of psychiatry are involved in, or say community health.

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Our other stakeholders are the SACS, the State AIDS Control Societies, so the SACS in every state of this country and the national programme, so NACO. A whole lot of other stakeholders like UN agencies, bilateral organisations, I think what we've really been able to do and probably that's because of TISS's institutional credibility and reputation is expand this partnership and bring in as many people as possible at different points in time. So it's a real celebration in that case of, you know, that together we can make a difference, you know. And it's not.... We draw on heavily with NGOs, either from the development sector or HIV/AIDS sector because they've done some of the pioneering work in this field. So while we're a programme that largely focuses, where the universities are our primary stakeholders, or institutions of higher learning, we've drawn in everyone who has the expertise to forge a very meaningful alliance. We work closely also with positive people's groups because we recognise them as central to the epidemic and their voice is important in all that we do.

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Q: How do you think that this shift to a rights-based approach, especially with HIV and AIDS, has come about, or why has it come about?

BD: It has actually come about for various reasons. One is that those who were affected; I mean, who were the ones affected? The nature of the epidemic which essentially made people.... Okay, I'll put it differently. The rights-based discourse I think was central to the epidemic because of two essential features of HIV as a disease which probably is not so central to others is that at, you know, some years ago HIV was a fatal disease and the morality issues surrounding the epidemic. That sort of made either people victims, made people responsible; people were either blamed for their infection and who, and the one, I mean.... You also saw a whole lot of marginalised people being affected with HIV. It was the poor, the vulnerable, and the marginalised.

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If governments, or if we had to control the epidemic, if we had to respond meaningfully to the epidemic there was no way we could do it without respecting the rights of people and engaging with people. And I think this is what for the first time governments did... because also there was no cure. So if you don't have a pill, then I think governments are forced to engage because they have no other options, isn't it. Today unfortunately, the very advances and the successes of the epidemic in terms of medical science have also led to a dilution of the rights-based work and a comprehensive response to the epidemic. So today because you have anti-retroviral available you're again going back to a very disease approach, a very public health disease control approach to the epidemic. Earlier you had, you didn't have many options, and you didn't have a biomedical

response, option. So you didn't have products like vaccines or drugs or, I mean there were drugs to manage opportunistic infections so you have to engage with people. You have to talk about rights, you have to talk about interventions, and you have to talk about empowerment if you want a behaviour change to happen. And I think that's been the strength of the epidemic because then it also made the entire successes around access to drugs which the HIV epidemic has actually initiated and making anti-retroviral therapy accessible, getting pharmaceuticals to lower their pricing are lessons that other activists on... who are working on access to drugs are actually drawn and learnt from.

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You know but some of us who have travelled that journey of the epidemic now feel that it is we are losing some of that. You know like we've got into a very public health, disease control, product centred, no? Like if you have polio, then you have a vaccine, if you have HIV then you have drugs, so you're not really then going on to see what are the larger vulnerabilities and other factors making people vulnerable to the epidemic.

Q: Where do you see TISS and its involvement with HIV/AIDS counselling going in the next few years?

BD: I think the Global Fund programme has actually been a tremendous opportunity to be able to influence the national programme. You know right know this programme here is supporting the national programme in very critical and fundamental ways in terms of building institutional capacity, in terms of developing standards for counselling training in the country, developing quality assurance systems, doing some... doing very critical research and also we're right now part of the National AIDS Control Program phase for strategic planning exercises.



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And there's a very close engagement and support happening. TISS will also need to... two lessons that TISS can probably learn from a programme like this is how do we leverage such funds which gives us an opportunity to make a large-scale impact like this, because it's really TISS leading 38 universities across the length and breadth of the country. And how do we support government to the use of such funds. Because also we've been able to have a fairly cordial relationship with the national programme. There was initial hesitation and resistance, but we've been able to... the relationship has really matured over the last two years. So how do we sustain such responses, because through such large scale grants and opportunities, one can really make a difference? So maybe applying for another round of the Global Fund grant in other areas in which we can respond; maybe also shift focus, I mean, enter into additional other areas for intervention. It doesn't only have to be HIV, maybe TB, maybe other diseases, other issues. So how can we establish these partnerships where we can support government?

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What I constantly tell people is this is a very interesting public-public partnership model, because it's the Ministry of Health vis-a-vis institutions who are part of the Ministry of Human Resource Development. So it has been in that sense a public-public partnership, so how do we engage in such public-public partnerships or even public-private partnerships to support a national programme or, you know, a large, a particular Ministry in various other areas that we may be working with. So it can be... the Institute is doing work in a whole range of areas, like women, families, mental health, and we need to grab these opportunities of being able to make that kind of a difference. And to source... I think TISS, you know, even many people say the



HIV/AIDS sector has the money so you can get it. It's a highly competitive world so it doesn't mean that the money comes in easily, there are too many players.

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But say in other diseases also, the kind of credibility that the Institute has and the leadership role it can play; I don't think money will be the issue, I think we need to grab and see our role as academic institutions playing. You know I always feel that the AIDS epidemic is controlled so much by multi-lateral organisations, bilateral organisations, international NGOs and you know, or external universities. You know, we need to claim those spaces now and provide support to government. Of course there's also this recognition of this, say a person. So we need to claim, reclaim those spaces. And in that, to that extent we have done this with this programme; at least some of the focus has come back to Indian institutions on at least certain areas and that needs to be strengthened. So I think the Institute needs to grab those opportunities because with this kind of opportunities then you can influence on a whole lot of issues; whether say it's homelessness where the Institute is....

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One has to have those, you know, very ambitious large scale, macro-level ambitions and.... Because it's actually what you can then influence. You know today's small projects are, have a limited impact. They're important, they're relevant, we should continue with that but you know mark two, three niche areas where we can, we can play a strategic role, leadership role and make a difference. We don't compromise, we're always asking; this is the only university system managing a grant globally. There's no other institution managing a global... But we have not compromised in the sense, you know somebody would say is this a university, is this what



universities should be doing. But if you look at the kind of influence we can have with the national programme, if you see the kind of research potential, policy potential, then I think universities need to get into large scale programmes like this.