

First TISA meeting

13th April 2008, YMCA International, Mumbai.

Introduction

Many of us IPWS have been interacting on Internet and over phone but we felt that if TISA is to ever become a reality, we will need to meet in person. We can know and trust each other enough only in a face to face meeting- a necessary step towards more enduring relationships and formation of a national level association. ISA had done its job through an outreach effort earlier and now it was our turn to pick up the ball and run! This brief report documents process, [minutes](#) of the meeting and [decisions](#) taken.

Preparation

IPWS and other web based groups were used to advertise the event and to generate interest among people. The Yahoo group – IPWS, played a significant role, since most of us were already enrolled at it. First we had considered 30th March (a Sunday) as the date, and Delhi as the venue for the meet; But as the participants began showing some interest, it appeared that Mumbai will be a more convenient place for majority of the participants. March end being a busy time for most of us, the date was shifted to 13th April. Next big question was the venue in Mumbai; Dr Akash sorted this out by getting rooms booked in YMCA in central Mumbai.

Agenda

Two IPWS¹ had evolved an agenda over emails. It consisted essentially of these questions:

1. Is a national level association of IPWS needed?
2. If yes, what all could it do for us?
3. How can we contribute in this effort?
4. Website for this association? How to go about it?
5. How ready are we for regional / international conference?
6. How can we go about fund raising?

Participants

1. Viren Gandhi from Mumbai
2. Ajit Potdar from Mumbai.
3. Venu Pillai from Mumbai
4. Dinesh Chauhan from Mumbai
5. B K Singh from Maihar (MP)
6. Akash Acharya from Surat
7. Hetal Vin from Surat.
8. Birju Unadkat from Daman.
9. Satyendra (Sachin) from Dehradun

Process

The two IPWS coordinating the meeting, arrived in Mumbai on the prior evening,



Illustration 1: Meeting in progress

¹ Dr Satyendra Srivastava and Dr Akash Acharya

12th April. Barring two participants², all expected ones arrived next morning. Since we were nine only, we met in the room itself. Akash facilitated the discussion – at times translating, paraphrasing and summarizing. Sachin took brief notes.

It was an informal but warm welcome and introductions, starting from the youngest member, Birju. Introductions ended with Satyendra (Sachin), who gave a brief back ground to International scenario, ISA outreach initiative and the need for this meeting. We talked about our struggles, issues, attempts at therapy, relationships, work etc. Two areas emerged as important themes for us: work and relationships. For young participants, and for some older participants, work was an important area: you may not be able to get the job you feel you deserve because “communication” is perceived to be a non-negotiable skill by many employers for any job. Even after you get a job, promotions may not come easily to people who stutter, for same reasons.

As BK³ said, other disabilities are recognized and reasonable accommodation is made for them, but that is not the case with stammering. Relationships are often constrained by perceived worth of a person in terms of her / his 'functionality'. As A pointed out, PWS must first accept other people with disabilities- this would help them accept themselves as well. The first question is: Can we or do we accept ourselves whole heartedly as people who stammer?

Lack of correct information and its under-utilization was another big topic: B

brought out the fact that good stammering therapy was available for free at the Ali Yavar Jung institute right in Mumbai, a fact not known to many. He felt that PWS should never shy away from therapy; In fact we should go out of our way to seek it. It does help even if it does not offer miraculous cure. Other PWS had other experiences to share. Not every therapist is good at the job. Some may be too costly. Some may not take the pains for a satisfactory “transfer” to the outside real world. So, there was need to share information about good therapists, their availability etc.

A felt that women's visibility in stutter chat groups was much lower than even the well documented gender-differential as prevalent in stammering (4 males to 1 female). He felt that this was because of the devalued position of women in our society: Stammering puts you at a disadvantage, but for a girl who stammers, finding a spouse or a job may be an even harder battle. He cited a case study, where one such girl who had some speech therapy earlier, had to become very secretive about it after her marriage. She was frightened that if her In-laws learned about it, her marriage might fall apart.

V shared some interesting insights: since a little drink used to help his confidence, when it

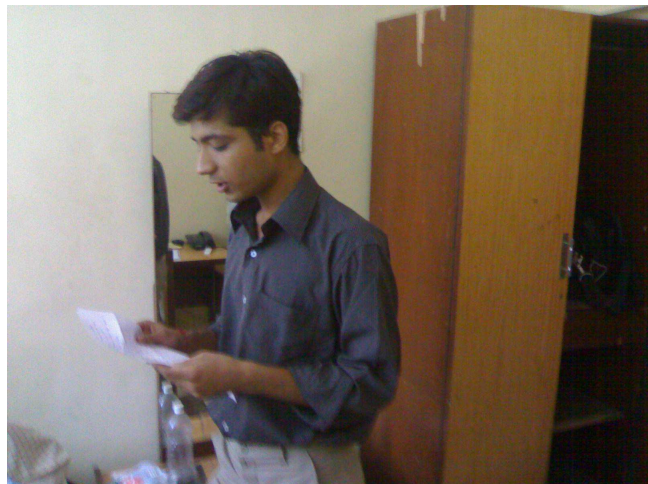


Illustration 2: Birju sharing a poem..



Illustration 3: A little step together..

² Krsihna from Vijaywada and Akhil Shetty from Mumbai; They could not attend due to urgent reasons but kept in touch.

³ As an editorial policy, we are suppressing personally identifiable information in most places in public documents.

came to talking, he became quite addicted to it. Then his search for healing led him to Alcoholic Anonymous. AA helped him tremendously even though it is run by 'ordinary' people (not clinicians or psychologists), who are genuinely interested in each other to be able to offer the necessary support. V felt that Self help groups can benefit PWS as much as (if not more than) speech therapy. His memorable message was: if you are frightened of tiger, you must enter its cage. Another participant added: *..and when you enter the cage, you find that it is an impostor in tiger skin, more frightened than you are!* The upshot was: 90% of stammering consists of fear. You must face them- sooner or later. When you face them, they melt away gradually.

A mentioned how he tried out whatever relatives suggested to manage his stammer. This showed that basic information about stuttering is not available to families even in this age of information explosion. Some of us had undergone faith healing, tongue tie surgery, hypnosis, Yoga, betel under the tongue, reciting Sanskrit verses etc. It took us sometime to realize that there was really no cure. But many self appointed therapists would offer the "complete cure" at the earliest opportunity. For example, when S phoned one such institution in Mumbai to request for a meeting place (not treatment), the first thing he was told : *You know, stammering can be cured; yes, we have been doing it for years!*⁴

V mentioned how for a long time he did not realize that professional help was available anywhere in India. He also felt that it was a futile exercise to worry about the 'original' cause. He emphasized the importance of going for 'professional' help. He also emphasized that there was no substitute for trying out everything- everything conceivable. Never holding oneself back.

H mentioned that meeting like this generated a great fellow feeling and we should meet again. This was one place where we knew we could be ourselves, be quiet or speak, stammer or not.. whatever. We understood each other intuitively, in spite of our differences in age, background, language and other experiences.

S presented a copy of a booklet- 'Twelve questions on Stammering' to every one. Around 2 pm participants went for lunch. Some of them left for urgent work. Others returned for an interaction with DNA journalist. We had a photo session with TISA banner at the end and then dispersed.



Illustration 4: Sharing a lighter moment

Decisions taken

1. We have decided to keep TISA a loose informal (but very functional) association, till a justification to formalize and register it surfaces- or when the core group decides to do so with consensus. We expect that for 1-2 years, we will maintain this character of TISA and focus more on attempting and achieving small (or big) successes collectively.
2. The core group will consist of nine IPWS present in the meeting, plus Krishna & Akhil, PLUS any other IPWS who wishes to join & give time PLUS some co-opted IPWS members for specific needs like IT pro or SLPs. For timely decision making a quorum of 7 IPWS will be considered sufficient. Consultation channel of email / IPWS yahoo group or phone would be acceptable for this purpose.
3. TISA should set following as its long term goals:
 - Providing latest, useful, unbiased accessible information to PWS through various media (electronic, traditional) and channels (website, e-groups, interpersonal communication etc) in various Indian languages. Main areas would be: therapies, therapists, support groups, latest discoveries, state policy, relationships (pen pals) etc.

⁴ Cure -yes. But it means different things to people, to therapist, to young desperate seeker. People take advantage of this ambiguity. It is often not discussed up front.

- Promoting Self Help group movement- both electronic and physical, by encouraging cross-group visits, sharing news letter, developing resource book on how to initiate and sustain SHGs etc.
- Starting a dialog with society, state and other structures of civil society on issues faced by PWS, through various channels.

Short term

- Revamp TISA website and develop it by adding translations of a primer on stammering and other articles in Indian languages, developing various resource sections, updating frequently and encouraging IPWS (and others) to interact and contribute. A web site designer would be the co-opted member of the core group and will be providing security, design and structural elements to the website. TISA core group would like to pay for the domain booking and website space- so that it can ethically be the owner and user of the website.
 - IPWS will continue to use Yahoo group IPWS, as in the past. On the other hand TISA website forum could be used for announcing events specifically connected to TISA (we may need to think more on this) .
 - TISA may consider sending a representative/s to International events but for next 2-3 years, it will be focusing on home turf: promoting SHGs, regional meetings etc.
 - Participation of women in TISA will be actively encouraged to make sure that it does not become a gender-biased or gender-blind association.
 - A mailing list of the core group will be developed and used for specific TISA related communication, not meant for public. But other open discussion can take place at Yahoo IPWS or TISA website forum.
4. TISA will be an organization with minimal hierarchy. For the sake of collection and dissemination of information, coordination of regional or national level events and for dealing with external world, Sachin and Akash will be functioning as Coordinator and Asst Coordinator for 3 years or till other IPWS with time and skill come forward.



Illustration 5: Coverage in DNA

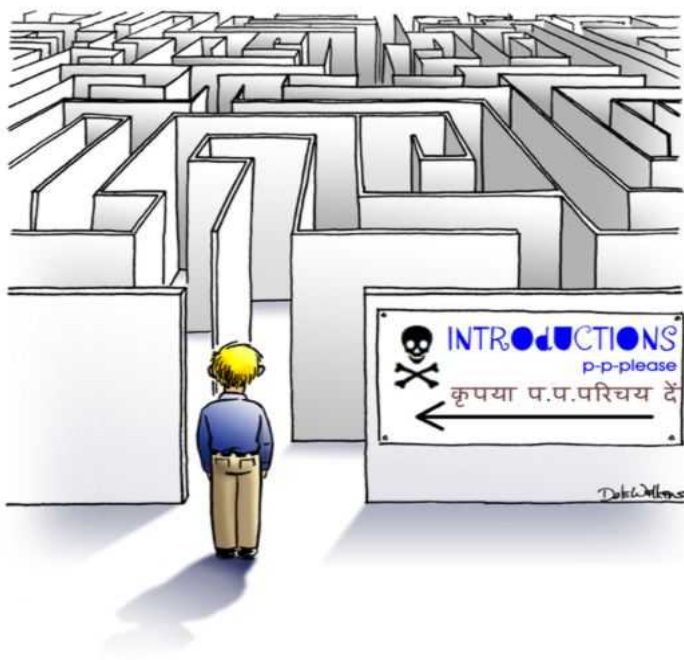


Illustration 6: Let us introduce each other- more fun!

5. Next meeting should take place either in Dehradun (at Samagra Ashram) or in Chennai in next 5-10 months.
6. IPWS from different parts of the country will try to translate/ create a brief primer or pamphlets on stammering in various Indian languages. One in Gujrati could be available in next 3-6 months. Viren and Akash will collaborate on this venture.
7. We will keep in touch through chat groups (Orkut, Yahoo etc.), emails and phone calls in the meantime.

Minutes

For the first time people who stammer (PWS) from different parts of India met on 13th April in Mumbai to form The Indian Stammering Association (TISA). Following points were discussed in the meeting.

1. It was felt that there was a need to have organized and accessible information on speech therapies (SLPs) available in the country. It was suggested that a list of therapist with available details be posted on the TISA website. PWS who have visited these therapists can share their experience with others on the website including the fee structure and cost effectiveness of the therapy.
2. Some PWS shared their stories of job discrimination and hurdles in career growth because of their speech problem. Government of India's Disability Discrimination Act was discussed and it was decided to explore the possibility to cover stammering under the act.
3. There was a concern about marriage among young PWS. It was suggested that TISA could play a role in imparting correct information about the disorder as well as can put like minded people in touch through the website.
4. Role of speech support groups was termed as critical in creating positive vibrations through sharing and caring. PWS agreed to strengthen the existing support groups as well as starting new ones in different parts of the country. Various possible activities during the support group meetings were also discussed.
5. As a part of awareness generation campaign, it was suggested to network with schools and provide reliable information on stammering to school teachers so that they can help school going PWS in their emotion management as well as educate other children not to ridicule PWS.
6. TISA website can have a section on PWS biographies or case studies so that people can read the life experience of being PWS.
7. Although less proportion of women than men (1:4) stammers, it was felt that women are more disguised for special cultural reasons. TISA would be a gender sensitive organization and will make special efforts in enrolling more women into the network.
8. It was decided that TISA will try to play some role on next International Stammering Awareness Day (ISAD) by developing some posters, T-shirts etc. More brainstorming on ISAD activities by TISA will be done on this in due course of time.
9. It was decided that on voluntary basis, PWS can reveal their contact details on TISA website so that other PWS near them can contact them.
10. It was felt unanimously that the current website needs revamping. It was required to bring life to the website by adding more sections and getting them attractively organized.
11. Being a very young organization, it was felt that TISA is still not ready for hosting the International Stammering Association (ISA) conference in India. However it was also strongly felt that the links with ISA must be preserved and strengthened by variety of ways including visits from both the sides.

TISA Core Group, Dated: 19th April 2008
Sachin (Coordinator) & Akash (Asst Coordinator)