

Communication Workshop

for People Who Stammer (PWS) 07-17 Jan 2010



"The way I understand, my life is as a battle against silence...

Speech, even stuttered speech, affirms my existence."

(Marty Jezer, 1998)

Acknowledgement

We thank SMTA for arranging the logistics; We are very grateful to Anugrah Team and Herbertpur Christian Hospital for practical help in setting up practice sessions with their staff and in OPD. Last, we wish to thank each and every participant for the courage it takes to share their thoughts, feelings and experiences about stammering.

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Objective

TISA wishes to present self help as a valuable option for people who stammer and don't have access to speech therapy or can't afford one or who have tried much and lost interest in mainstream speech therapy. The course was based on CALMS approach to stammering management, eastern Meditative and breathing techniques and concepts of Self-motivation. We specially focused on sharing and practicing four techniques: Bouncing, prolongation, pausing and voluntary stuttering.



Giving and receiving feedback with maturity and fun

Participants

Participants were asked to send their bio-data along with the languages they are comfortable with. As most of the people who applied were adults, we planned this workshop exclusively for adults. A total of ten PWS participated in the workshop, including the two facilitators. Some participants were able to attend part of the ten day workshop due to other commitments. Here is a brief introduction.

Amaanuddin is a class 11 student. **Vineet** has cleared class 12 and is preparing for entrance tests for Engineering colleges. Both Vineet and Amaan are friends and are from Dakpatthar close by. **Sandeep K** and **Sandeep B**, both in early twenties and friends, are working in an Automobile manufacturing unit in Sahaspur, nearby. **Neeraj**, 26 yrs, is a young Telecom engineer from Meerut. **Kishore Bisht**, 22 yrs, is a Mechanical Engineer from Delhi. **Raja Bhattacharjee**, 35 yrs, is a professional photographer from Chennai. **Raja Poladi**, 41 yrs, is a senior manager in an IT firm

from Hyderabad. **Jai Prakash**, 25 yrs, is an IT programmer from Pune. **Satyendra**, 52 yrs, is a freelance Community health consultant based in Herbertpur, near Dehradun. **Sumit**, 14 yrs, is a class 8 student from Dehradun who participated on the last three days.



We roped in SMTA staff too ..

Methodology

The method was participatory, experiential and full of open ended discussions. The participants gave impromptu and prepared presentations individually and as a part of group presentations. A lot of exercises were video recorded for the participants to see and analyze, what it is that they do when they stammer. A lot of speech goals were practiced in real life situations, by going to market and using our techniques. Some outdoor activities, like one day trek and half a day boating trip were organized for fun as well as for gathering spontaneous feedback from participants. It was also a chance for us to know each other better as colleagues in a broad support network.

The two resource persons, some time played the role of facilitators and at others, became the participants. We felt that every PWS brings valid resources in terms of life experiences, questions, perception, emotions and thoughts. As such, she or he is an expert on their own stammering experience. So, most of the discussion was participatory and exploratory. For example one participant was asked to share all the "internal phenomena" presumably linked to stammering. His observations became the basis for an open discussion as to what could truly be universal, common and objective in our shared experiences as PWS.

Frequent recapitulation was used to help participants talk, think and internalize new concepts. Block correction techniques were frequently practiced. Wall writings were used to remind participants of important messages. Energizers, which often involved spontaneous talking, were used creatively. Participants posted a summary

on the blog at the end of the day. Morning meditation was a time to share and practice what we knew about relaxation and breathing techniques.

Workshop content

The work shop's main focus was on communication rather than on fluency. Also, the participants were given a chance to explore their stuttering and, feelings and emotions attached to it (play with it), and gradually move from the feeling of helplessness to a sense of being in **control**. Here is a brief description of the theme and content of the workshop.

First 2-3 days were spent in discussing what stammering is- in general and also in our own particular cases since we all stammer in a different way; we did this by sharing and discussing videos and case studies, using mirrors to observe self, mutual videography, and through "**Stuttering Iceberg**" exercise.(ref 1, ref 2)



World is a stage..

From 3rd day onwards we introduced various techniques. Bouncing, as an exception was introduced early on day one. Prolongation, pausing and voluntary stuttering were introduced, discussed and practiced in group and gradually with strangers, under increasingly difficult circumstances (more info). 'Acceptance' too was discussed as the underlying spiritual value. One can and should practice climbing the pinnacles of various techniques, metaphorically speaking- but whenever we fall, and occasionally we ALL were going to do that- we fall in the ocean of Acceptance below without getting hurt (picture below).

In this context we talked about – **cognitive distortions** (<u>ref</u>), emotional issues and need for a philosophy of life, which allows us to be at peace with ourselves. If we accept ourselves as we are at this moment, without struggle and shame, there is a chance that 'motor' techniques might work, that we might persist with the techniques and with the broader program for self-change.

In this context, we also introduced various kind of breathing (belly breathing especially), its role in conscious relaxation, positive visualization and meditation.

Valsalva mechanism and role of body language (eg. eye contact) also was shared.



Acceptance is an underlying value to life itself.

(Credit: http://www.breakingpointsystems.com/community/images/rock-climbing.jpg)

By fifth day, participants were practicing bouncing with strangers in local market, asking questions, bargaining, getting instructions and sharing the fact that they stammered- while maintaining eye contact. On sixth day we discussed moder approaches: Pagoclone and Delayed Auditory Feedback machines (DAF & FAF). Their use and limitations. In the context of "maintenance" of the gains on return, we discussed various theories of self-change, understanding of "Locus of control", and role of self help group. From seventh day onwards, participants were making formal presentations in the group, with invited guests sometime. On last day, they stood in front of a crowd in a large OPD waiting room and gave an impromptu talk, sharing about stammering (permission from Hospital authorities was taken in advance). Most of these presentations were video-graphed for subsequent review by participants.

Attitude and **values**: Participants discussed in depth the role of self-defeating, recurring thought patterns and rationalizations. Unless these were recognized and changed, change in speech will not be long lasting. Overall communication, role of listening, of genuine interest in others – as opposed to mere fluent monologue, came up as an important area of concern and change.

We concluded with a guided discussion about a personalized **plan of change**- not just about the way we communicate but the way we look at life and our place in it. We accepted that giving and accepting help could help US and therefore promoting self help initiatives in whatever capacity, was going to be very important for us in the coming years.



Many participants were watching themselves speak for the first time.

Day wise summary

To keep this document small, we are offering links to the day's reports on TISA blog: Day 1, Day 2 (one, two), Day 3, Day 4, Day 5, Day 6, Day 7, Day 8, Day 9, Day 10

Monitoring and evaluation

We continuously reviewed and monitored our daily activities by referring to our detailed plan before and at end of each session. We also took regular feedbacks from all the participants, in a recap session, before starting the day's topics. Participants were asked to write the day's report on the TISA blog. These posts also provided indirect feedback. In the sub-group activities, there was always one of the facilitators, supervising the process and the outcomes. We will be doing a long term evaluation over next 12 months.



Stammering interview with Anugrah Staff

Follow up of the workshop

- 1. We plan to continuously be in touch with all the participants through various modes like e-mail, phone and blogs. All the participants have been given author rights to TISA blog (http://t-tisa.blogspot.com).
- 2. Those participants who already have access to a SHG, will be encouraged to return and conduct sessions in their SHGs in collaboration with the Coordinators. Others are being facilitated so that they can start a SHG initiative in their town (Meerut and Hyderabad, possibly).
- 3. TISA will invite one of the participants to be the Assistant Trainer in the next Communication workshop, whenever it is organized.
- 4. As we observed during this workshop that many people can't spare 10-12 days at a stretch, including the days for traveling. Next time we would be planning a shorter workshop; We plan to have a more thoughtful selection of participants next time; also an interaction with press at the end.

Conclusion

Self help is a more empowering, affordable and enduring solution to a complex and chronic problem like stammering. For this, Self Help Group is an important strategy. Even for mainstream speech therapists, SHG could be a good option, a good place where their clients can come and practice their speech skills in a safe environmentat no cost. The bottom line is- *On my own if I achieve howsoever little, it will be mine and will never be lost*.



The Challenge begins now when we return home..

Appendix

About The Indian Stammering Association (TISA)

TISA is a self help, not-for-profit charitable trust; it's an association of Indian people who stammer (IPWS). It is active since 2007 and is registered in the office of Subregistrar, Vikasnagar, Dehradun, Uttarakhand, India on 13th Nov 2009, under Registration Act 1908. Its registration number is 6055. Its purpose is to collect and disseminate relevant, correct and unbiased information for people who stammer and their families, friends and society in general. It is promoting a self help group movement, where PWS learn to help each other and themselves in the ancient Indian spirit: "This Self is to be achieved through self effort!"

Studies have shown that self help groups (SHGs) provide most consistent and longlasting support structure; more than any speech therapy or other technique/device. TISA co-ordinates city-wise SHGs in India; currently there are SHGs being run in Delhi, Mumbai, Chennai, Bangalore, Pune, Surat and Dehradun.

Acceptance

Acceptance in the case of a PWS, has often been mis-understood. It is the first step towards change. It does not mean accepting the problem and staying put. It also does not mean denying the problem we face or trivializing it. We reproduce here -with some minor changes, a very balanced understanding of what acceptance would mean in our case, from Tom Weidig:

- 1. I have a neuro-biological abnormality affecting my speech systems leading to a propensity to stutter.
- 2. I have to live with my abnormality for the rest of my life. (as far as we know today).
- 3. I have to work on myself if I want to improve my communication.
- 4. I have to work on myself if I want to minimize the psychological and social consequences of stuttering.
- 4. Shame, negative beliefs and most fears I held or experienced were completely unnecessary and harmful.
- 5. Stuttering had some positive effect in that I was forced to take a deeper look at myself.
- 6. Moderate to severe stuttering can be a burden to others who listen to me that I should minimize.
- 7. Some jobs that strongly focus on fluent verbal expression are not for people with moderate or severe stuttering.

Facilitators

Both facilitators are recovering stutterers.

Dr Satyendra Srivastava (Sachin) is a Community Health consultant working in voluntary sector for many years. His areas of interest are program evaluation, documentation and research in the Community health context. He lives, with Marian (and two dogs!) near Dehradun. He is fond of trekking, writing and meditation. He enjoys working with young people who are looking for something deeper and more meaningful (than fluency!) in life.

Jai Prakash (J.P.) Sunda, aged 25 years, presently on a 6 month sabbatical for community service. He is working along with Dr. Sachin in Dehradun for people who stammer. His work includes going to schools and working with kids and adults who stammer and also some IT related tasks..By profession he is a software engineer with an IT firm for the last 2 years at Pune.



A day out in the mountains...

Time Table

General structure

Lights off at 10 pm

Morning jog at 5.30 am. Group meditation by 6.45 am. Meditation ends at 8 am. Relaxation & Belly breathing will especially be taught and practiced.

Breakfast: 8 am to 9.45 am. Morning Session: 10 am to 1 pm. (Lunch: 1 to 2.30 pm) Afternoon session: 3 pm to 6 pm.

Free time: 6 pm to 10 pm (Dinner: 8-9 pm; NB: inform by 5 pm, if you are going to skip Dinner)



It is like learning a new skill..

Content

Day 1 (7th Jan):

Forenoon: Write your 'bio' focusing on speech related milestones and therapy etc.

Write your expectations from these ten days.

Sachin moderates 'expectations' with what the workshop is offering in a brief presentation. Participants will be encouraged to write down two realistic goals for themselves at the end.

Sachin and JP will discuss the ground rules (active participation in every activity is a must).

Afternoon: Screen "Unspeakable" movie and discussion

"Internet" assignments for those going to cyber cafe: like- read one personal story from ISAD archive at Kuster's home page and share next day

Day 2 (8th Jan):

Forenoon: Mirror exercise- describe your stammer (as it is now) in detail – lceberg exercise (catalog every related behavior- motor, feelings, primary, secondary); then discuss your iceberg with your partner

Sachin presents briefly- what stammering is? Most likely causes? CALMS approach (valsalva mechanism- blow out)

Afternoon: Screen "Courage to speak"- followed by recalling and sharing our experiences as children- JP will facilitate this session to isolate "common" features and will offer insights.

Bouncing Technique - explanation by sachin and then practice (in group, then in pair, then with invited strangers, then in market over next few days); "Internet" assignments

Day 3 (9th Jan):

Forenoon: (Recap Bouncing) Prolongation & pausing techniques - explanation and then practice as for bouncing above.

Video analysis- showing various kinds of dis-fluencies and what it means to stammer easily, effortlessly and nicely..and role of EYE CONTACT and positive body language (videos- Julia Irani, IBN7, Rithik's and other from youtube)

Afternoon: Video exercise in pairs (record each other and then discuss, analyse); Count your dis-fluencies and calculate the percentage; "Internet" assignments

Day 4 (sunday, 10th Jan)-

Forenoon: Introduce Buddy system; then assignments will be given (with SMTA staff or in the market- to do specified numbers of bouncing, prolongation with strangers; note their eye color etc); Review in the plenary group

Afternoon- watch a movie: my left foot or rocket science or Forrest Ggump etc. and then discuss common issues in a large group- issues like notion of equality in relationship etc.

Day 5 (11th Jan):

Forenoon: Recap and Voluntary stuttering (exercise- "longest / best stutter award") and self admission; benefits of; how to go about it..Innovative ways. Why Acceptance? Philosophical and practical issues; other attitudinal issues. Market assignments to Buddies; review in the night by JP.

Afternoon: movie/ video clips and discussion

Day 6 (12th Jan):

Forenoon: self motivation- how to go about it? Role of Goal setting, planning etc.; modern approaches- DAF, Pogoclone: how useful? Is there a cure? **Afternoon**: Guru Kirpa complex- for Public speaking in a group with videography and subsequent analysis

Day 7 (13th Jan):

Forenoon: Lehman Hospital OPD- Speaking in a crowd; Stuttering interviews; Review:

Afternoon: Transfer and maintenance- issues: what will most likely happen



Boating in Assan lake- just before the presentations!

when you go back? How to deal with relapse? Role of SHG in maintenance? How to start a SHG? Brainstorm and plan (JP to share a case study about PUNE, briefly); Role of self-help in Chronic disorders; helping others- how does it help us?

Day 8 (14th Jan)

Day outing: Bhadraj trip with buddy assignments (talking on the way and giving feedback)

Day 9 (15th Jan)

Forenoon: Summarize main learning by participants as short presentations (video-graphed and reviewed); Develop personal plans for working on your speech on return; Free time for q&a and review.

Afternoon: Video clips / movie

Day 10 (16th Jan)

Visit Lehman Hospital for 'Stammering Interviews'; practice talking in a big crowded space. Short picnic. Formal presentations in the afternoon.

Day 11 (17th Jan Sunday) Dispersal

Calms Approach

Calms Approach is a holistic way of looking at stammering, understanding it and doing something about it. This is an improvement on therapies based on limited understanding of a complex phenomena- "Stammering is a breathing disorder while talking" or "Stammering is a speech disorder" or "Stammering is the result of a psychological conflict". Calms approach views stammering in five dimensions:

Cognitive- how we view and interpret events around us like someone knitting their eyebrow, while listening to us.

Affective: Our emotions intricately associated with speech and related phenomena.

Linguistic: How we construct our thoughts into words, phrases and sentences.

Motor: The actual act of making meaningful sounds- act of speaking

Social: Communication takes place in a social context. Social skills are a part of communication.

(Ref: http://www.mnsu.edu/comdis/isad8/papers/kaufman8.html)

Here is more details of what a self help course should attempt, adapted from the above reference:

Cognitive

- * Increase the participant's understanding of stuttering
- * Education about normal anatomy and physiology of speech production and mechanism
- * Inform peers, family members, etc. about stuttering and its treatment (also Social)
- * Develop consistent "language of fluency", defining terminology of the communication system, of stuttering, of perceptions so that the group is "on the same page."
 - * Identify stuttering behaviors

Affective

- * Decrease negative emotions and sensitivity to stuttering
- * Decrease feelings of fear, anxiety and/or tension related to stuttering
- * Increase ability to cope with negative responses by others, including teasing
 - * Improve areas of self-esteem and self-confidence
 - * Change negative thinking
 - * Observe, reflect, probe and validate feelings

* Increase ability to discuss stuttering with others (also Social)

Linguistic

- * Increase linguistic complexity from concrete to abstract
- * Increase length of utterance from single words to conversation, as level of smooth speech is defined
 - * Decrease word avoidance

Motor

- * Identify speech modification and/or fluency shaping techniques
- * Increase practice and use of techniques
- * Define individual strategies for each participant
- * Increase awareness of self-monitoring skills (in all domains)

Social

- * Increase social/pragmatic skills
- * Increase verbal interactions in familiar and unfamiliar situations
- * Increased number of opportunities for the participant to use new skills in realistic speaking activities



Change begins with one- you!

The end.