

Partnering with the Government: Achieving sustainable special education goals for children with hearing impairment: A case study from Assam

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Only the brave dare to think upon the grey –
Upon the things which cannot be explained easily,
Upon the things which often engender mistakes,
Upon the things whose cause cannot be understood
Upon the things we must accept and live with.
And therefore only the brave dare to look upon difference without flinching

Richard H Hungerford

Introduction

As a professional who has worked in the disability sector in many parts of the world, my greatest challenge has always been in constantly questioning my own levels of understanding and acceptance as in reality, the life a person who is disabled, or a mother of a child who gives birth to a child with a disability and not the perfect child she had hoped for, are truths that one cannot begin to comprehend. As I have grown older and my years of 'experience' of gaining 'knowledge and expertise' have increased, the more aware and convinced I am of how little I really do know, how quickly the professional in me jumps to conclusions and makes value judgements of good and bad practice, how easily one falls prey to feelings of superiority because one feels that we have so many answers.

This philosophy and line of thought has influenced all the work I have done, and influenced the way we approach our work in VAANI. When considering a partnership with a hearing-impaired child, a parent, an NGO, or the government, it is the belief that we need to listen, to build trust, to understand the other's point of view, before one can start any kind of a relationship and that, I can say with pride, has made most of our work successful and sustainable. It is only then truly need based.

What has this got to do with a case study of working in partnership with the government in Assam, you might well ask, and I will reply that it is a conscious attitude to respect and listen, that has made our partnership with the Assam government as successful as it has become. After working together for a number of years, the departments are so convinced about the work we have been doing together, that they are now signing an MoU with us whereby we will only give some required technical inputs, while they continue to develop the programme on their own.

Background

VAANI, Deaf Children's Foundation was established in 2005 and is the first national NGO in India focusing only on issues around childhood deafness. VAANI provides holistic services that address the social, emotional, communication, language development and educational needs of hearing-impaired children. It encourages families to learn to communicate and understand their hearing-impaired children and thus take an active part in supporting all their needs, including advocating for their rights from governments and service providers.

VAANI's genesis lies in the recommendations of the feasibility study carried out in November 2002 on issues surrounding childhood deafness. It was a national level study conducted in a totally participatory manner. The researcher met families of children with hearing impairment, with the children themselves, with professionals from the Government and non-government agencies across the country. The findings of the study and our work in the last 10 years show that the area of greatest need expressed by all who are involved in or connected with the hearing-impaired including parents, young hearing-impaired people and adults themselves, is the need to create an awareness and understanding about the whole issue of being unable to hear – what it means, how it is caused, the need for early intervention, the problems of communication, the low numbers of parents who

are empowered enough to lobby for their children, the lack of support groups, the lack of information, the lack of employment opportunities and how all this affects the lives of the hearing-impaired, leaving them without the power to direct their own lives.

In India, the statistics for childhood deafness are staggering. Congenital deafness affects 5.6-10 of every 1000 live births in the country (National Health Portal of India). This does not take into the number of children who acquire postnatal deafness due to health and hygiene reasons. Children born with hearing impairments are unable to comprehend the meaning of the world around them or to express themselves. They cannot chat with their friends and families, understand people around them or learn from their teachers. They remain totally isolated, living in silence in our noisy world.

VAANI works towards bringing language and communication into the lives of hearing-impaired children and their families, while addressing issues about their social and emotional wellbeing.



At VAANI, children with hearing difficulties are taught to communicate, and their families are trained to understand them and manage their social and emotional needs. No two children are alike. So, an Individual education plan (IEP) is drawn up with annual and quarterly goals based on that specific child's communication, social, emotional and intellectual abilities. One professional teacher of the deaf (ToD) is assigned to each child. The ToD meets with the child AND his/her parent once a week for an hour-long session. The presence of the parent as a part of the teaching process is compulsory, so that the work can be taken forward and practised at home.



On the other days of the week, the child is encouraged to go to regular school so that he/she remains a part of the mainstream and socialises with other children. The teachers at the regular school are given skill training on how to handle the hearing-impaired child in their class and get the best out of him/her.

Working in Partnership

We believe very strongly that real change and impact can only happen if we link our programmes with already existing plans and schemes that exist within the government, be this Central or State government. They have the means and the reach. Hence working in partnership with the government seems to be the logical way forward if we want sustained and far reaching changes.

VAANI has been actively working in Assam since October 2007 and in the past ten years of our work, what came through as a huge gap was the need for the involvement of parents in the lives of their hearing-impaired children and also the need for identifying and early intervention with hearing-impaired infants and young children.

Early identification of children who are born unable to hear or are hard of hearing is critical to ensure that their families have the knowledge, understanding and resources they need to help their children acquire language, spoken and/or visual and achieve age-appropriate communicative, cognitive, academic, social, and emotional development. The hearing-abled child acquires the skills of communication through using speech and language which s/he hears around her/him.

This is not possible for the hearing - impaired child as the loss of hearing does not allow him/her to learn language, and who therefore has no mode of learning. There is a gap between actual communication and educational requirements of the very young hearing-impaired child and the learning opportunities available to her/him either at home or at an early pre-school programme. Hence there has been a desperate need for early intervention programmes to be set up as this will provide appropriate learning and understanding, pre-school skills and emotional bonding from the very birth of the child, ensuring a stable future growth.

We realised that to be able to integrate into already existing programmes the first step would be to create an awareness about the nature of our work amongst relevant government departments in a positive and non-threatening manner and gain their trust in working towards building a positive relationship.

The Assam Strategy

Since VAANI works to educate hearing-impaired children, we started by approaching the SSA (Department of Education) in Assam in 2007

- Slowly, with many and repeated interactions, SSA functionaries began to understand the complexities of childhood deafness. For example, in a seminar conducted by VAANI, the Director of the SSA realised for the very first time that a hearing aid without an ear mold was of no benefit to a child.
- Once officials were convinced, VAANI began training SSA volunteers and teachers and in 2010, it became the State Resource Organisation on all issues related to hearing impairment for SSA. We soon realised that via the SSA, services did not reach the 0 to 6 years age group.
- The next step then was to approach the ICDS (Integrated Child Development Service) department – Social Welfare Department. It was easier this time as we had already established a relationship with the Department of Education. In the meantime, we had conducted a State-wide study on what was happening to hearing-impaired children in Assam in particular. The breakthrough was after the seminar entitled Status of Deaf Children in Assam where the results of the study was shared and in which the Social Welfare Department had been

encouraged to participate actively and it was then, in 2011, that the decision was taken of taking the work forward with VAANI.

- In 2012 VAANI was considered a member of the State Social Audit Committee of the Department of Social Welfare, Assam.
- Subsequently, with continuous networking and finally convincing the government to approve of the decision, an MOU was signed in 2014.

‘VAANI’s work is a boost. In this project, identification of hearing-impaired children is most important and it is important that the AWWs know how to do it. All the AWWs need to be trained on identification and thus help in a more authentic data collection’ (Anil Phukan, MIS in-charge, Department of Social Welfare)
- The stigma around hearing - impairment began getting erased and more people wanted to learn to use sign language

We decided to carry out a pilot study across three districts initially. The project aimed at setting up 26 satellite centres in the blocks of the three districts, Kamrup, Nalbari and Nagaon over a three year period and strengthening a State Nodal Resource Centre in Guwahati, which would act as a one-stop-shop for all kinds of services, information, resources and expertise in addressing problems relating to childhood hearing impairment within Assam. As language is a huge issue, all our teaching learning material was made available in the vernacular.

The State nodal resource centre would act as:

- A model best practice demonstration centre extending early intervention services for the development of young (0-6 years) hearing-impaired children in developing communication, language and literacy skills and measuring its impact.
- A research centre that would carry out research into developing innovative teaching techniques and material relevant to rural communities and hard to reach communities.
- A parent -friendly centre that would provide need- based support ranging from counselling and guidance services, to skill training programmes for parents/ caregivers of young hearing-impaired children.
- Provision of educational support to older hearing-impaired children to prepare and

enable them to gain access to appropriate mainstream classes and alternative forms of education such as vocational training.

Year 1 & 2 focussed on identification of hearing-impaired children and initiating centre-based services in the Block Sadhan centres, which were in reality the *anganwadi* centres that were already in existence. We used their buildings and linked our teaching to activities that were already working. The centres began to get popular as all children coming to the Sadhan Centre benefitted as the *anganwadi* workers got training and developed skills in early identification and providing early stimulation and became efficient as teachers. Twenty six centres were equipped and became functional, with most of the *anganwadi* workers in charge of the centres assisting the VAANI team during the sessions with children's parents. With the rolling out of Year 3, work began on identifying leaders amongst parents and *anganwadi* workers who would be future resource persons in the blocks.

Amongst the *anganwadi* workers, prior to attending the training workshops, two percent of the participants had less than 20 percent level of knowledge. After attending the workshops, 75 percent of the participants had increased their level of knowledge on hearing impairment to above 70 percent.

Amongst the parents, 10 percent of the parents had below 20 percent level of knowledge about deafness and communication skills. After attending the workshops, 85 percent of the parents' level of knowledge on hearing impairment and communication skills increased to above 70 percent

Visits to the AWC revealed that parents had started getting involved and had shown interest in coming to the centres regularly as they believed that the teaching had improved the communication between the parent and the child. The mothers all observed that their child's comprehension power had improved as they noticed a substantial progress in the understanding and writing skills of their child, something they had not seen earlier when these children had been attending regular schools. An indirect impact of VAANI's work with the SSA was that block level Master Trainers were also being trained on sign language by VAANI trainers and were now actively disseminating skills to general school teachers.

Linkages with district and block level functionaries had to constantly be strengthened by involving them in not only the 'good' achievements, but honestly sharing the challenges as well and actively encouraging them to share ideas and thoughts. With their increased cooperation, we were slowly able to achieve the project goals.

Today the SSA and Social Welfare Department are working to identify strategies of sustaining the work in the 26 Sadhan Centres with VAANI's technical support, and taking the project forward to other districts.

Key Learnings

- Government officials needed to be educated on issues just like everybody else – politely, patiently, persistently. Government officials are traditionally wary of the 'NGO types'. There is a need to build relationships as allies and not antagonists and assist them in developing a sense of ownership with the work being done.
- Specialised training of government workers has a better response when the trainees saw it as personal skill development and enhancement and begin to see themselves as professionals who are mastering skills such as making planning schedules, writing concise reports that are not time consuming, maintaining accurate records and gathering accounting knowledge etc.
- There has to be active proof of work. The 28 Sadhan Centres that developed did so in the already existing *anganwadi* centres. VAANI equipped the centres with necessary teaching and learning material, which benefitted not only hearing-impaired children, but even the other children who came to the centres. The setting up a state resource centre was able to demonstrate good practice and was able to put government officials in touch with the actual beneficiaries.
- Working with the government often involves dealing with multiple departments/ministries who are often not used to working together. Focus has to be made on collaboration and coordination. An example of this is the Steering Committee meetings, where all levels, from the District Commissioner, the Nodal officers and the SSA teachers attended. This ensured that the plans were made together and everyone knew what they were responsible for and knew

what was expected of them.

- There has to be a conscious effort to allocate human resources for liaising with the Government. People who see the officials as their own, chosen from within their communities, who speak their language, see them as non-threatening. The fact that all our training materials and posters are in the vernacular bolstered these beliefs.
- Government workers must be compensated for additional work done or taken on by them. A small allowance to cover their transport, a small stipend or awards in recognition of work done go a long way. For example, anganwadi workers are paid only a very nominal amount of money and often just their travel consumes most of the allowance given to them.
- Possibly the greatest lesson we learnt was that working with the Government is a long term commitment and that the differences in pace and priorities need to be thought through and managed.

- The greatest challenge we faced was when officials left and we had to start afresh to educate the new officers who took over from them. However, we also saw that involving people at all levels at our meetings and awareness raising sessions proved that some degree of learning and continuity remained

Conclusion

It is important to bear in mind that government officials are no different from other people and we are all human beings, with our own personal biases, good days and bad days. Traditionally the relationship between the government and the NGO sector has been filled with suspicious mistrust. We need to break this pattern and I believe strongly that it can be done! The only way for us to ensure sustainable change is by working with the government.

Brinda is the Founder-Trustee of VAANI Deaf Children's Foundation. She is a trained special educator and seasoned development professional. She has a Master's degree in Special Education from the University of Manchester, UK. She has spent her entire working years, or more than 40 years, fiercely working for the rights and development of children with special needs. She has worked with international and bilateral agencies and NGOs, including the ADB (Vietnam and Cambodia), the IFC and the World Bank, the British Council, Cheshire International, Handicap International, Save The Children and Indian Institute of Cerebral Palsy. Her approach to work is based on a deep commitment to the right to equality for human beings. She may be contacted at bcrishna@vaani.in