Senses Lost and Found

Inspiring stories

# FOREWORD

Have you ever wondered what happens to the donations you make to various causes? Have you ever wanted to meet those unknown people whose lives are touched by you and know how they are doing?

This book is an effort on Sense India's part to give you a glimpse into those stories which you are etching by your helping hands. These lives portrayed in limited words are those lamps that you are lighting by your gifts. Those unsung heroes who have done nothing heroic in their eyes but have conquered what many think is beyond them. Through these 21 stories of hope we offer you a salute and token of appreciation for your goodwill that you have extended through the years, not only by your donations but also by your whispered prayers.

From mainstream education to vocational trainings to livelihoods, our deafblind children & adults are now seizing opportunities by the throttle, ready to take on life on their own. They are gearing up little by little to show that deafblindness is not a limiting factor, rather it is a new pathway to explore a challenging way to do the same old things.

But the scenario was different when Sense India started its work 18 years ago. These deafblind children were lost without sight or sound, often wrongly termed as mentally retarded due to lack of knowledge and understanding about handling deafblindness. There was no means for them to relate their feelings or break their barriers. Most of them have known desolation and grief at its highest and some have been victorious, others have not.

Sense India has been handholding these young adults through its capacity building and training, monitoring and evaluation of 57 partners to track progress, and you have helped by pitching in with funds to fill the needed gap. You have helped us to become the eyes, ears and the voices of deafblind people for advocating for their rights, recognitions and lobbying with the Government. All these efforts have today joined forces to make these individuals contributing members of the society. In their own ways they live fully functional lives, becoming a source of inspiration and joy to their loved ones.

In this book, you will hear not only from parents, educators but also from deafblind individuals themselves. It's a heartfelt account of their struggles and victories, feelings and thoughts about their journey with the uniqueness of being deafblind.

We certainly hope that you will enjoy reading and courting this book in your homes. We also wish to hear back from you.

With your support in the future we hope to tell you many more such stories of hope. Believe me; your donations are more meaningful and valuable than what you can only imagine.

With sincere thanks and thoughts,

Akhil Paul

Director, Sense India

# ACKNOWLEDGEMENT

This book has been a wonderful collaborative effort. We are especially grateful to all deafblind children and adults whose stories we have featured in this book. They are our heroes and true inspiration. We value all those deafblind individuals, parents, family members and educators who provided the opportunity for us to comprehend and understand them and their unique world. With them we also thank all our partners in 22 states of India who graciously provided stories and photographs for this book.

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# SENSE INDIA IS REACHING OUT TO MORE THAN 71,500 DEAFBLIND PEOPLE

# IN 22 STATES OF INDIA

* Sri Ganganagar
* Patiala
* Dehradun
* New Delhi
* Jaipur
* Basti
* Bhuj
* Idar
* Ahmedabad
* Ranchi
* Patna
* Hazaribagh
* Shillong
* Agartala
* Jamnagar
* Dhoraji
* Sayla
* Dahod
* Bhopal Indore
* Dhule
* Navsari
* Nagpur
* Raipur
* Kolkata
* Mumbai
* Nashik
* Srirampur
* Banpur
* Solapur
* Hyderabad
* Kakinada
* Goa
* Bangalore
* Chennai Puducherry
* Tiruchirappalli
* Kottayam
* Madurai
* Trivandrum
* Kanyakumari

# AMAZING DAUGHTER

As narrated by her mother, Sukhbatti Nagavanshi

"A daughter is a miracle that never ceases to be miraculous" I live as an example because not a day passes by that my daughter fails to amaze me.

My name is Ms. Sukhbatti Nagavanshi, the proud mother of Geetanjali Nagavanshi. My daughter is deafblind. When she was born, it was like a dream come true for my husband and me. A few days later we realized that our little angel refused to open her eyes.

We searched anxiously to find ways to restore her sight and ran from pillar to post. But the next harsh reality dawned on us a year and half later. We found out that she could not hear as well.

My world and all my dreams crumbled around me. While children her age ran around the house, my two-year-old simply lay on the ground- immobile and rebellious. My maternal instincts sensed her turmoil but I knew of no means to reach out to her. Days passed and I lived with a burden on my heart for my silent little girl.

This is why when Vinodji an educator from Sense India came to us and counselled us on brighter possibilities. It felt like he was God sent. He told us about deafblindness and others who also suffer from the same. He also showed us that there was hope.

Suddenly, we felt that we were not alone in this turmoil. He educated us on the therapy and training that could help normalise Geetanjali's life. Geetanjali awaited his biweekly visits eagerly.

He taught her to identify objects and express her basic needs. It became easier for her to hold the glass and let people know that she was thirsty than cry incessantly. Once the communication barrier was broken down, it was easier to reach out.

He enrolled her into home based services and slowly taught her to sit up, stand and take her first baby steps. Today, she can make her way around the house by feeling the walls. She gets ready on her own and chooses her soap and oil by the scent. She is slowly learning to participate in other activities as well.

This training has helped Geetanjali connect with our world. She and I are closer than ever. Our natural instincts have found an expression. When I see her insisting her doting grandfather to take her for a walk by the finger or play with her favourite cousin, my heart fills with hope of a better tomorrow.

I know it is still a long way to go, but my daughter is making progress. She is taking slow but sure steps to freedom.

Sneha is intelligent and has excellent grasping power. I have full faith that given the right support and training, she is going to be the next Helen Keller.

# A JOURNEY OF LOVE, ACCEPTANCE AND TRIUMPHS

As narrated by her educator Ms Jessey Joseph

Five-year-old Sneha was orphaned at the age of one. Sneha's mother couldn't handle her little daughter who was deafblind along with her violent, alcoholic husband. So she left Sneha with the missionary Sisters of Providence Home and never looked back.

Sisters of Providence Home loved little Sneha and took care of her. However, they didn't know how to deal with a child who was both deaf and blind. Coming from an estranged family and devoid of parental love and care, Sneha developed behavioural problems like hitting her head against the wall and scratching herself and others.

It increased as her world was confined to the walls of the home. Concerned, the nuns contacted Sense India's partner organisation Kottayam Social Service Society, (KSSS}, after being referred through a doctor and things began to look positive.

Two and a half years ago, I started my journey with Sneha when she joined the deafblind unit supported by Sense India, a journey of love, acceptance and triumphs. Initially when I started working with her, she used to give me a hard time by not sitting at one place and getting aggressive as she never recognised me.

Slowly as I got to know her, I realized that she has a fondness for fragrance so I used it as my symbol. I used to put tons of talcum powder on my body until she recognized me by the fragrance. Today not only does she recognize me but we share a great relationship.

Sneha has learnt to control her behavioural issues and started exploring her home and the world outside. After receiving auditory is now aware about her surroundings and recognizes different plants and other things through touch and smell.

She is no more carried around as she has started walking and can move around the centre and climb the stairs to her room. She loves to cuddle and play in the water and sit on the swings outside. And I feel proud that after being part of the deafblind programme for the past two-and-a-half years, she has started to use and understand signs to communicate and has learnt so much.

"The difference in Sneha after joining the programme is beyond our expectation especially now that she is able to communicate her needs, now Sneha can also move to her room by herself and the way her Special educator has handled her behavioural problems are praiseworthy and we really appreciate KSSS team and are thankful to Sense India for providing us with these services" says Sr. Meritta

Sneha is intelligent and has such good grasping power that I have full faith that given the right support and training, she is going to be the next Helen Keller. Indeed she will one day!

We are proud of Sneha's achievements.

Vidyasagar's bright mind has found wings. Today he knows his alphabets in Hindi and English, numbers and simple calculations.

# WINDS OF CHANGE

As told by Vidyasagar's sister

When the only news you are used to getting is bad news, many times we give up on hope. Same was the case with my family. When my younger brother Vidyasagar was born deafblind my entire family was engulfed in despair. He had low vision in his right eye but no vision in his left eye. At the age of 6 doctors identified that he had a hearing impairment also.

My family was so disturbed by Vidyasagar's disability that we kept him confined in the house and never allowed him to go out. We were really having a tough time not knowing how to deal with this unique disability. And slowly our hopes were diminishing.

But one day Vidyasagar himself became our inspiration. He sat in a corner with a book of pictures holding it close to his nose, his face contorted as he concentrated.

This six year old's zeal to discover life led the adults in our family including me to question our own despair. He shook me out of my reverie and I took Vidyasagar under my wing and started teaching him along with the other children I tutored.

The task became easier for both us when a special educator from Ashadeep, Sense India's partner organization taught us better ways to communicate and helped us to learn and use sign language and real objects to start our journey of discovery. A vigilant Vidyasagar was also groomed to focus on all his residual hearing.

Since then we have never looked back. Vidyasagar's bright mind has found wings. Today he knows his alphabets in Hindi and English, numbers and simple calculations. He can write and read big print. He likes to go to school and enjoys drawing.

With his confidence restored he has found the courage to step out of the house on his own. He buys grocery for the house and can even buy himself a bus ticket through sign language. But what fascinates him most is the key board of a computer and all the wonderful things the screen displays on the cue of his command.

One day he wants to grow up to be a computer operator. After all science and knowledge is only an aid for the progress of bright minds and Vidyasagar, true to his name is ready to dive into the sea of knowledge and find his own pearls of wisdom and understanding.

He has been my pupil and is my younger brother but I have learnt the biggest lesson from him that inadequacy is only a state of mind.

Today Udayambika is discovering a new world full of possibilities! She enthusiastically participates in all the group activities and is responding

optimistically to the training

# UDAYAMBIKA IS DISCOVERING A NEW WORLD!

And now her mother is confident about her future

When Udayambika was born, it was like a dream come true for her parents. But when they realised that their little daughter could neither seen or hear, their world came crashing down. They visited various temples and faith healers in hope but without the right intervention it only delayed her development clinically as well as functionally.

Udayambika only allowed her mother to come near her but being daily wage labourers, her parents could hardly spend time with her. Left alone in a corner of the hut with no one to communicate, Udayambika developed multiple behaviour problems like self-biting, hitting herself among many others.

Udayambika had a ray of hope when Sense India started its work in Kakinada with our partner organisation Uma Manovikas Kendram. She was identified by Hari Babu, a trained special educator, through door to door survey. At present, Udayambika is receiving individualized training and developing skills necessary to carry out her day-to-day tasks on her own.

But few years back when Haribabu started working with her at the age of 7, it was not so simple, as Udayambika was malnourished and would hardly sit for a minute. She didn't like to wear clothes and her communication and social skills were very bad.

She would cry all the time and Haribabu had to find ways to connect to her by making loud noises which made her happy. She was provided with daily supplement of nutritious food like malt, rice and other proteins to improve her health.

When she gained enough physical strength, Haribabu shifted her to centre based services so as to work on her social skills and help her to adapt to different environments.

Today Udayambika is discovering a new world full of possibilities! She enthusiastically participates in all the group activities and is responding optimistically to the training.

Her mother cannot contain her joy as she says, “My daughter is showing a lot of improvement. She communicates with me and is healthy now. I am now confident about her future. After seeing Udaya’s improvement my in-laws have also accepted us more into the family."

Life may have dealt a cruel blow to Tinku, but he is determined to defeat all his disabilities.

# TINKU'S DREAMS

Young Tinku is like any other youth- vivacious and full of dreams.

Dreams to expand his small confectionary shop of toffees, chocolates and biscuits which he started with the support of Sense India's Income generation activity. Nothing like a beautiful dream and strong determination when life is not how you thought it would be.

Yes, Tinku's mother never thought that her excitement and happiness of having a child would turn into shock. Baby Tinku was down with pneumonia and was later identified as having developmental delay because of Down's syndrome.

This blow was little too much and before his parents recovered and adjusted to it, the doctors discovered detachment of retina in both the eyes of young Tinku.

Tinku's parents were very baffled and concerned by this incurable condition and didn't have any hopes of overcoming it until he joined the deafblind unit supported by Sense India at Association for the Welfare of Handicapped, Faridabad.

Tinku had just started receiving services when in the year 2002 his right ear started oozing discharge. He had two unsuccessful ear surgeries and one eye surgery. It was difficult for his parents as he had Down's syndrome and only partial vision and hearing.

But our educators were not the ones to give up. Tinku's educator worked hard and slowly trained him. With the right educational intervention and parental support, Tinku became independent in dressing, mobility, and started cooperating in home based activities.

He enjoys music, dance and loves to spend time outside. His socialisation skills also started improving. He likes to interact with his teachers and always greets people with a hello.

Once he completed his schooling, he was involved in our income generation activity and he started receiving support and training on the concept of money and selling.

Currently he is running a small confectionary shop and has plans to expand it. Life may have dealt a cruel blow to Tinku, but he is determined to defeat all his disabilities slowly. After all, why not make lemonade when life handles your lemons?

There is still a lot to be taught but being a keen learner he will surely pick up really fast.

# TEJUS ON THE PATH OF DISCOVERY

Waiting to discover the world out there with his hands open

Silent, shy and lost in his mysterious world, one always found Tejus playing in a corner of a room alone. Not because he liked it that way but because he had no choice.

Tejus is 8-years-old and deafblind. You will often find him with a hand on his ears, listening to soft sounds or humming noises. He dislikes wearing hearing aids and loud sounds irritate him. Looking at him no one would have thought that one day he would be playing around with a group of friends or that he would move around instead of sitting in a corner.

A series of change began in Tejas’s life the day he joined the deafblind unit supported by Sense India in Bangalore. From the day he joined his educators started training him to use all his residual hearing. He was a little restless in the beginning but slowly he learnt to sit at one place for activities.

Gradually he started doing his work independently. He can do most of his daily living skills like bathing, toileting and brushing all by himself. He is also being taught to communicate his needs and waiting with patience among others.

Tejus has also started learning sign language. He finds it a little difficult but not wanting to give up he adds one word every day to his vocabulary. He has also become very active and loves jumping on his activity ball and playing with others.

There is still a lot to be taught but being a keen learner he will surely pick up really fast. Tejus is waiting to discover the world out there with his hands open.

Nowadays Surbhi’s father cannot help but smile. His daughter has shocked him with her achievements and made him proud!

# SURBHI MAKES HER PARENTS PROUD!

Every day is a battle half won for her

Surbhi Kumari resides in Babugoan Village, Hazaribagh District and hails from a lower middle class family. She has severe hearing loss and very little vision. Her disabilities were hindering her growth and pushing her and her family into utter confusion regarding her future. Her life was miserable as she was unable to perform her daily activities like other people of her age.

Surbhi did not get proper care, love and respect from her family given the fact that this was a unique disability and they had no clue how to deal with it Especially her father was very negative in his communication and behaviour and was not confident about Surbhi's potential. Poverty was making her disability an added burden on his shoulders.

In 2009, Surbhi was enrolled in Sense India supported deafblind unit Nav Bharat Jagruti Kendra, Hazaribagh. As soon as she joined, a team of clinical psychologist, physiotherapist and special educators prepared an intervention strategy and gave counselling to family members about Surbhi's potential and informed them about her deafblindness.

Initially, the family members were not interested to be a part of intervention program. But with regular visits, some improvement was observed in Surbhi's condition and gradually her family members· attitude started changing and they began to cooperate with the team.

Surbhi was provided trainings in reading-writing, sign language, and activity for daily living and social skills, the positive effect of which was easily observed in Surbhi. Seeing this, even her family members started taking regular training from our special educators.

With clinical assessment, Surbhi started wearing hearing aid and her vision also improved. Because of this improvement she started communicating. Today with Sense India's support, Surbhi studies in a regular school. She goes to school daily and stood first in her class annual examination.

She is also keen to learn sewing and her mother is slowly trying to teach her the same. Every day is a battle half won for her. Nowadays Surbhi's father cannot help but smile. His daughter has shocked him with her achievements and made him proud!

Today we are totally wowed by the changes I see in our daughter. Day by day, she is growing out of my lap but she will never outgrow my heart.

# DADDY'S LITTLE GIRL

As narrated by Mousami's Father, Madhu Nambudiri

"A daughter may outgrow your lap but she will never outgrow your heart". This sentence stands true for me... Mousami, my little daughter was born in 1998. My heart was filled with love and joy when I held her for the first time and she held on to my finger. But our joys didn't last long as our little daughter was diagnosed with the Rubella triad - congenital glaucoma in eyes, cerebral palsy and congenital heart problems.

It was a lot to cope with at one go and we were really worried about Mousami's eyes so we brought her to Ahmedabad as medical facilities in Madhya Pradesh were not so advanced. For a year a team of doctors worked on her eyes but even after the admirable efforts put by doctors the cornea grafting was not successful.

Things started getting more complicated as Mousami started growing. She couldn't differentiate between day and night so she barely slept at night. My wife and I spend most of our time washing the sheets, blankets, pillow covers and then cleaning Mousami and ourselves as she used to spoil the beds every night

Establishing a routine seemed impossible as we couldn't communicate with her. Mousami couldn't even understand the words that every child learns first, 'Ma' and 'Pa'. It was heart breaking. At this stage we also started losing hope and thought that her chances of improving were not much.

Our performance at work was also affected as we spend all our time with Mousami. We felt socially cut off but our priority was our little angel. In 2007, one of my friend's nephews came to stay with us for few days and he observed that we pampered Mousami a lot and were not giving her the opportunity to communicate as everything was given to her without asking. First I didn't give it much thought but later with a

little bit of convincing on his part I thought why not try it And voila! It worked. It brought about little changes in her and we were very happy. Mousami also started attending a special school where she started receiving physiotherapy as 10 years of bad posture had caused a hunch on her back.

But the true changes and progress started in the year 2012 when one fine day a lady came to our house asking questions about our daughter. On enquiring she introduced herself and told us about the Sense India supported deafblind unit at Digdarshika, Bhopal.

We enrolled Mousami into the programme and slowly as the educator started working with her we started seeing some amazing changes. Mousami started following a routine, she started to stand and walk around with support Not only this, she also started to identify things and foods. Gone were the days when she spent all her time indoors, today she loves to sit on the swing and play in water and sand.

I cannot thank the teachers enough for the difference they have made in our daughter's life. The visit from Sense India team has helped us to understand deafblindness and it has made my angel's life better. Today we are totally wowed by the changes I see in our daughter. Day by day she is growing out of my lap but she will never outgrow my heart

My mother wishes to see me married and financially independent. I am halfway there and I hope that I will make her proud of me and fulfil all her dreams.

# J FOR JOHN

John shared his life story and dreams through signs, pictures and line drawings

My name is John Moses and my name sign is the letter J. I am 26-years-old and I am deafblind. I can see better with my glasses and can only hear loud sounds with the help of hearing aids. I live with my family, my father Mr R. K. Swamy works in a government canteen and my mother Ms Annamal works in a hotel as a helper.

Today I believe I am a confident person and I use gestures and signs to communicate. I love when someone entrusts me with responsibilities. But it was not always like this. Few years back I was not even able to dress, bathe or eat on my own. I didn't even have a name sign until I joined the deafblind unit supported by Sense India at National Association for the Blind, Delhi at the age of 7. My real education began when my educators started training me.

Gradually I started becoming independent in my daily living skills and I also learnt how to count My educator started teaching me to communicate with pictures, line drawing, written words and simple word signs. I started doing activities like shopping, cooking and cleaning. I love to draw, eat and try different things.

All through my training, I had my best friend Sunii with me but he had to leave the unit His departure shook my confidence. I had lost my only best friend and it disturbed me a lot It was a very bad phase for me but with the support of my educator and continuous counselling I learnt to deal with my grief and made new friends.

Along with reading and writing I also learnt time concept and pre-vocational activities like jewellery making using beads, candles, macrame and paper machine items. I also got an opportunity to appear as a citizen journalist on National TV.

I was also able to showcase my skills of macrame work at Samarth 2014, a national festival organised by Government of India for showcasing the abilities of Persons with Disabilities (PwDs). Being a member of the national network of adult deafblind- Udaan, I have been travelling to various outstation training and network meetings, sometimes with and at times without my parents. I enjoy travelling.

Recently, I started my own small business with a small coffee shop at National Association for the Blind. I am still learning to operate my tea and coffee vending machine. I also take orders and prepare simple snacks with the help of my educators. My mother wishes to see me married and financially independent I am halfway there and I hope that I will make her proud of me and fulfil all her dreams.

(John's mother's dreams were fulfilled in 2015. He married Kasturi, a sighted and hearing individual. Kasturi and John are now partners in life as well as in business. While John looks after operations at his coffee shop, Kasturi handles sales and customer service)

The pain and hurt in her father, Purshottam bhai's eyes are a thing of the past. Heartfelt pride and a new set of aspirations for the future have taken their place.

# HANSA-POISED TO FLY

As narrated by her educator, Deepak Bhai

Hansa was born into a family of rural-daily wage labourer in the remote village of Dhanki in Gujarat Profoundly deaf with low vision and learning disabilities, Hansa was not what the village was used to seeing in their children and was soon branded as God's curse. The family was shunned. There mere presence in the fields or homes was seen as ill luck.

Fortunately, things began to change when Sense India started its work for deafblind children in the district and I started working with Hansa. We came to know about her through our door to door survey, part of our Community Based Rehabilitation programme. When I saw Hansa for the first time, she was sitting in a corner dressed as a boy. As I looked at her, I wanted to reach out and break the barriers of isolation and communication. Thus began my struggle.

My first goal was to help her in communication and to move around independently in her house and surrounding areas. 'She will fall down, she will hurt herself, she doesn't understand' were few apprehensions her parents had. But together we overcame this challenges and Hansa started doing her work all by herself.

Hansa had learning disability so it was not easy training her. I had to come up with various methods to teach her. Her confidence grew as she started understanding and exploring the world around her. Soon a receptive Hansa began responding and displaying remarkable progress. Very soon she could count with beads and do simple arithmetic; she took over the household chores and became an asset to her mother. She began communicating in sign language and a new medium of conversation and expression opened up. I convinced the local school to admit Hansa and in a short time Hansa was spelling her name in English among other things. The unkept, reclusive Hansa transformed in to a well-groomed spunky adolescent girl. But that's not the end of it

Hansa was in her transition age - from Childhood to Adulthood. As she grew, there were other needs that needed to be addressed and being a male educator added to my difficulties. Not wanting to give up, I asked my wife and two of my female colleagues to help me by accompanying me to Hansa’s house. They joined me every time I went and helped Hansa understand her body cycle and needs. Slowly with the help of my colleagues, her mother became Hansa's support through this period of confusion and realisation.

It took a while for the reality to seep in to the mindset of the villagers, but slowly and firmly the community was swept by the winds of change. Farmers, who earlier rejected them, began employing Hansa’s parents again in the fields and in fact got impressed by Hansa’s abilities as well.

Today, Hansa has her own petty shop with the support of Sense India's Income generation activity plan. She runs the shop with the support of her mother and earns around Rs 8,000 to Rs 9,000 per month. She is contributing to the family income and is supporting her family. Recently, Hansa’s family also built their own home under the Govt of India's social welfare programme ‘Indira Awaas Yojana’.

The pain and hurt in her father, Purshottam bhai's eyes are a thing of the past Heartfelt pride and a new set of aspirations for the future have taken their place. Hansa of course is poised to fly. And I, Deepak­ bhai, as her educator feel proud to be the voice of Hansa.

# SENSE INDIA IS SUPPORTING WORK IN STATES WITH A COMBINED POPULATION OF 1.12 BILLION

* 13,119 individuals with deafblindness are receiving direct support through school and home based services run by our Partner NGOs.
* 58618+ children with deafblindness and multisensory impairments have been identified and enrolled by the government Sarva Shiksha Abhiyan (SSA) programme
* One of sense India’s important strategies is to help and encourage parents, teachers and adults with deafblindness through three of our networks:
* Prayaas-the national network for families,
* Abhi-Prerna- the national network of teachers and educators
* and Udaan- the national network of adult deafblind individuals.

There has been a steady growth in membership in the last five years.

* For us, every rupee counts! We allocate our funds so as to achieve highest value for money in growing our support to the cause of deafblindness. We practice good governance as well as transparency & accountability in communication and reporting and this has been recognised by Credibility Alliance.
* Programme & advocacy 66%
* Resource mobilisation 17%
* Management & core services 8%
* Future programme 9%

Asha is now 12-years-old and as any other young girl of her age, dreams of going to school and enjoying the little joys of life with her friends.

# ASHA IS GOING PLACES

A journey from Rudraprayag to Washington DC

Asha is from Rudraprayag, situated on top of the hills in Uttarakhand. She is the youngest in the family and was born blind due to congenital cataract. In her family, her father, brother and her sister are also blind. Life was never easy for them but in 2008 Asha started a new journey in her life as she joined Sense India's partner organisation Sharp Memorial School for the Blind in Dehradun.

She was soon examined by an ophthalmologist who recommended surgery for her eyes. After a lot of effort her family agreed for the surgery and her operation was done in Delhi. With regular treatment and medical intervention, her vision improved a lot Slowly her educator worked on her eye hand co-ordination and her pre writing skills. Within no time she learnt to read and write in print But even before her educator's hard work started paying off, Asha lost her hearing.

She had gone home for winter break and was down with fever. Once she was back the educators observed a drastic change in her behaviour. From being a happy and friendly person she turned into an unresponsive, angry and cranky child. While walking she started losing her balance. Concerned about her condition, her educators took her to an ENT specialist, where tests confirmed that she has become profound deaf due to brain fever and lack of proper treatment in the village.

Asha could only say few words which she had learnt before her hearing loss and not able to hear any new sounds, affected her learning. The biggest question was how to teach her to communicate. Sumana Samuel, her educator took a bold step and learnt the basic sign language before teaching her a new language. Today she is learning her lessons through Indian Sign Language.

Asha is a highly enthusiastic, curious, affectionate person who makes friends easily. She is very talkative, and very helpful to others. Mature beyond her age and always cheerful. Her interests are painting, reading the newspaper, playing with friends, watching TV and dressing up. Asha has won awards in painting competitions held at State and National Levels.

She is selected to participate in the World Federation of Deaf Youth Section (WFDYS) Children's camp held at Gallaudet University, Washington D.C, USA. Asha is now 12-years-old and as any other young girl of her age, dreams of going to school and enjoying the little joys of life with her friends. Sense India salutes her resilient spirit and she makes us all proud.

Bharat is a responsible son and husband and is fully involved in all family matters. I could not have asked for more" says Bharat's mother.

# A PROUD FATHER

Bharat Pardeshi's transformation from a young boy filled with fear to a proud father

"Being a father is the most important role and I want to give it my all," says Bharat as he holds his little son lovingly. He may not be able to see his son or hear his babbles but as he feels the bundle of warmth in his arms his face radiates with joy. Bharat Pardeshi's transformation from a young boy filled with fears to a joyful father filled with pride is a story worth reading.

Bharat Pardeshi was born deaf and diagnosed with Usher Syndrome which meant that he would lose sight at a later stage. Living in a joint family, he used to communicate his needs through basic signs. He attended a deaf school till 10th grade and later he joined the Sense India supported deafblind unit at National Association for the Blind in Nashik.

He was very shy and kept to himself as all the other children at the unit were younger than him. He found it difficult to communicate and open up to others. His educator Ms Jyothi had to slowly make him comfortable in his surroundings. Once settled she started training him in sign language so that a medium of communication could open up between them.

Looking at his need, Ms Jyothi sent him to Mumbai for computer and Braille training. Initially he was adamant not to learn Braille as he had vision, but Jyothi was determined to teach him Braille as she knew he would lose his vision later due to Usher Syndrome. In Mumbai, as he became friends with other deafblind adults of his age, his confidence grew with newfound knowledge and friendship. He lost his sight at the age of 16 but with years of support he had learnt sign language, computer, Braille and mobility. He also learnt to use large printed books and magnifier for reading and writing as he had little vision left.

Later as he got married and started a new phase in his life, he again faced difficulties as he struggled to communicate with his wife. It was difficult for the new bride to understand sign language and things started to strain between them but with the support of his educator and proper counselling from Sense India, she started learning sign language. Soon love bloomed and the couple became inseparable. His educator often shares how during travels Bharat is often found chatting with his wife.

Currently Bharat is working as a teacher at the deafblind unit and is teaching Braille, mobility, tactile sign language, daily living skills and basic computer to children with deafblindness. He also participates in a lot of advocacy initiatives.

"It's a dream come true for me to hold my grandchild in my arms. Bharat is a responsible son and husband and is fully involved in all family matters. I could not have asked for more" says Bharat's mother.

Today Bharat is a very happy man. He has a job, a beautiful wife and an adorable son. He has overcome the challenges of being both deaf and blind and emerged a winner and a source of inspiration for others.

This family's journey has been a journey of togetherness as they walk hand in hand, learning and supporting one another.

# LIFE IS FULL OF POSSIBILITIES

It's a long way ahead for Harsh it but life is full of possibilities

Mr and Ms Poply were blessed with a baby boy whom they named Harshit. Harshit means happiness. He brought with him a world of joy and dreams that the new parents had never imagined. But as he grew older they realised that there was something wrong with their baby.

He wouldn't turn to them when they cooed his name or cry at loud noises. Trips to various doctors and medical professionals confirmed their worst fears. Their son was both deaf and blind. It was something they had never heard before and hence were pushed into confusion as to how to treat their child.

When children of Harshit's age started going to school, his parents also started knocking on the doors of one school after another but got rejected from everywhere because of Harshit's condition. His parents lost all hope and accepted that future for Harshit was a dark endless pit of despair.

But one bright day, Harshit was identified by a special educator trained by Sense India on a survey. He was immediately enrolled into home based programme supported by Sense India at our partner organisation Navchetna in Sri Ganganagar.

He started making progress very quickly. Soon with Sense India's support Navchetna helped Harshit to be enrolled into a regular school in an inclusive setup. Nowadays from Monday to Thursday he goes to school and Friday and Saturday he attends the Centre.

He is a keen learner and seeing him his parents have understood that even a deafblind person can learn to read and write and live a normal life.

This family's journey has been a journey of togetherness as they walk hand in hand, learning and supporting one another. It's a long way ahead for Harshit but life is full of possibilities.

He is a role model to many other children. Lumlang is slowly getting ready to take charge of his own future!

# OVERCOMING THE ODDS

Lumlang is slowly getting ready to take charge of his own future

Lumlang is a spirited boy born in a small village Umtasor Nongjyrmi of Ri Bhoi District in Meghalaya with a population of about 100 people. Most people in his village are marginal farmers.

Lumlang lost his vision and subsequently his hearing due to high fever when he was a year old and became completely deafblind. Even his teeth fell off due to fever. Over time one of his blinded eye developed Glaucoma, because of which it was swollen and kept watering.

Even though little Lumlang was a bright and curious child, his energies and concentration were spent on tending his eye and its watering. Deafblindness resulted in drawing more curtains between him and life and the inability to express or explain what he thought, left him more frustrated and angry.

Few years ago, when Sense India started supporting a pilot programme for deafblind people in Meghalaya, his parents were counselled to send him to the deafblind unit supported by Sense India at our partner organisation Bethany Society, Shillong.

Since then he has been under the care of educator Rosa and has been living in the hostel. She taught him basic sign language and Braille which facilitated communication with the world around him. He was taught to understand and explore the environment to help him move around freely.

At first he faced difficulties adapting to his new environment especially living in a hostel with other children. But he soon became friends with many and he enjoyed schooling. He underwent surgery on his swollen eye as a result of which swelling and watering has stopped.

Today, Lumlang is an avid communicator. He is an expert at Braille and numbers and can make his way anywhere in the neighbourhood on his own. He enjoys listening to music using his residual hearing. He likes making things out of paper- from kites to toys.

He is being trained to sell these toys that he makes. He also weaves small cane stools and chairs and even works at a printing press! His progress is amazing. His parents and educator feel that he has become quite independent and sociable. He has a very good reasoning skill and he is able to express himself well. "He has improved a lot after joining the institute. We learn many things from him when he comes home for holidays" says his mother.

He is a role model to many other children. Lumlang is slowly getting ready to take charge of his own future.

A new morning has dawned in Ramdayal's life. And the bird of faith is singing the song of dreams and possibilities.

# A NEWDAWN IN RAMDAVAL1S LIFE

The first deafblind person in the country to run a registered ration shop

"Faith is the bird that feels the light and sings when the dawn is still dark”. It is this unerring faith that enabled Ramdayal to discover his own hidden potential.

Born in a small village in Basti, Uttar Pradesh, Ramdayal was the sixth child in his family. Poverty was an unforgiving truth that the family faced each day and the glimmer of better days a distant hope. The only source of earning was the small petty shop that his father owned. When they discovered their child was blind by birth, his parents were crestfallen.

Fortunately Ramdayal's parents came to know of the school for blind in Gorakhpur about 200 km away from their village where he was provided free education. Ramdayal turned out to be a committed student and knew from the very beginning, that education was the only string of hope that could pull him out of poverty.

Yet destiny had other plans. By the time he reached 8th standard, Ramdayal began losing his hearing. Though he cleared his secondary exams through great effort, he was refused admission for further studies on the grounds of his deafblindness. Ramdayal, lost all hope and desire for life and receded into his dark, silent and lonely world.

It was about this time that Ashraf, a special educator trained by Sense India identified Ramdayal and restored his faith in life again.

Gradually, he began spending time at the centre based programme supported by Sense India at Shikshit Yuva Sewa Samiti, Basti. A quick learner, he learnt Braille and began teaching other deafblind children at the centre.

His enterprising spirit began taking a concrete shape. He went ahead and joined Udaan, the national network of adults with deafblindness and became an active participant. In fact he even took on the responsibility of vice president of the network and lent his voice to demand for rights of deafblind people.

His desire for self-reliance finally took shape when he became the first deafblind person in the country to acquire permission to run a ration shop under the government's Public Distribution System (PDS). Supported by his brother, he runs the shop with elan.

A new morning has dawned in Ramdayal's life. And the bird of faith is singing the song of dreams and possibilities.

She is a strong willed young woman and delivers what she promises on time. Being her educator I also feel empowered to run the vocational unit.

# STRONG- WILLED MITHU

As narrated by Smriti Makar, Educator for Mithu

Often expectant parents spend many hours discussing the name of their child. And often they lovingly disagree over it, discard a thousand suggestions and then settle for one. Sometimes it may be decided in one go.

Such was the case of Mithu. Mithu Karmakar was born in Kolkata on 7th July 1979. In English, Mithu means Parrot Somehow I get the feeling that the new parents wanted their daughter to chatter like a parrot and make the whole house lively. But who can fight destiny? Their sweet little daughter was rendered deafblind by an accident that happened when she was 3 years old. Her right eye was badly hurt.

At the age of five, she started going to school but faced lots of difficulties while reading the board. A year later, Mithu went through four surgeries to remove cataract in her right eye, but her vision did not improve. So she started going to a blind school in Kolkata.

But life is not what you expect it to be. Just when she was getting used to it she lost her hearing too. She found it difficult to communicate with her teachers which lead to the belief that she was being inattentive in her studies.

This evaluation by her teachers demoralized her! She gradually recoiled into her isolated world as she started believing that she did not possess the normal attributes of communication. Still she went ahead with her studies and graduated from the University of Calcutta which is a big achievement for a person with deafblindness.

To fulfil her dream and desire to become a teacher she enrolled herself for computer training. But as she was deafblind and didn't know Braille, the screen reading software JAWS was not suitable for her.

She couldn't complete the training and she felt shattered. It was at this stage that Mithu joined Sense India supported Vocational training unit at Society for Visually Handicapped, Kolkata. Mithu's life changed drastically after she joined the unit. She came out of her over protected world as she joined the hostel. All of a sudden her life was full of new experiences.

As she finished the training she grew more confident and joined the deafblind vocational unit as a trainee. Her parents were not very keen on it but Mithu loved coming to the unit.

Soon she started receiving a monthly stipend which covered her travel costs. She was turning into an earning member and it brought a change in her parent's attitude. They started believing that Mithu can also become a productive member of the family.

Today she plays a significant role. She is a strong willed young woman and delivers what she promises on time. Being her educator I also feel empowered to run the vocational unit.

Her enthusiasm and belief rub on everyone around her. She independently makes envelops, paper bag, decorative note pad, block print designs on handkerchiefs and table cloth, photo frame, costume Jewellery among others at the unit.

Being a member of the network of adult deafblind-Udaan, she travels a lot and shares her story during advocacy meetings. She awes the audience with her experiences. The exposure she gets through these activities has strengthened her self-confidence. It's still a long way ahead for Mithu but I know that she will become an ideal for others.

Looking back, Prabakaran’s father is happy that at the deafblind unit, his educators believed in his abilities and supported his dreams.

# COURAGE DEFINES HIM

A tale of what all a person's ·can do' attitude can achieve

33-year-old Prabakaran is a true inspiration. He was born with severe visual impairment and moderate hearing loss in the family of a poor farmer in Namakal district of Tamil Nadu.

He studied in his village panchayat school with the support of a community worker. School was a big challenge for young Prabakaran due to his dual sensory loss. From childhood Prabakaran had a very feisty spirit. He used to appear in his exams with the support of a scribe. When he was in 9th std, his classmates teased him saying that it is only because of the scribe that he was able to pass his exams.

This statement disturbed Prabakaran and he wanted to prove them wrong. He decided to write the exams himself and started learning to write. Twice he failed in his exams as his handwriting was not legible but not wanting to give up he worked hard until he passed his exams. In 2002, at pre university exams he topped in his school and proved that he has abilities in spite of having a disability.

Seeing his ·can do' attitude, Sense India partner NGO Holy Cross Service Society advised him to work and study at the same time. So he left his home. Joined a University and got a job in a canteen for a monthly income of Rs 500. He did his graduation in BA Sociology and then did his masters in Sociology. Along with this he also passed the Village Officer examination held by the State Government of Tamil Nadu. It's amazing right!

But that's not it, while doing his education Prabakaran ran a canteen on his own in a school with a sales turnover of Rs.350 to 400 per day. He bought the stocks and developed business relations with companies like Coke, Pepsi and Britannia. Once he finished his studies, along with the canteen he took up another job in a residential school for the disabled.

He was in charge of buying food materials and vegetables worth 15,000 and above for the hostel per week. He became totally independent in handling the money and became an excellent negotiator in getting goods from vendors at the best price.

He kept adding on to his abilities, he learnt to read and write Braille. While talking he uses oral language and used sign language for reception. He uses his mobile phone to calculate and is very particular about maintaining all his transactions in the account book. He tallies it all at the end of the day. He is a perfect businessman with high ethics and habits.

In May 2011, Prabakaran took up another challenge. He filled a tender at Tiruchirappalli along with many other businessmen to run a canteen in a government planetarium. And guess what, he succeeded! His canteen at the planetarium had two units, one sold snacks and refreshment drinks while the other provided food for the staff and visitors.

Sales in the canteen were high and Prabhakaran managed everything from sales to managing staff. Wanting to create awareness about the capabilities of the differently abled people, Prabakaran made a decision to only appoint differently abled people in the canteen.

Later in 2012, he joined Sense India supported project as a Supervisor. He identified many children with deafblindness and today all of them are receiving services. Looking back, Prabakaran's father is happy that at the deafblind unit, his educators believed in his abilities and supported his dreams. "I never dreamt that my son will have this much of ability and will reach this level in his life. I am proud of my son and I am sure he will take care of us in our old age" says his father with pride. Prabhakaran got married in 2015 and is looking forward to his life with his partner.

His progress motivates me to work more with him and to make him independent in all walks of life and to see him as a happy and productive individual.

# JITENDRA MUDULI- MY INSPIRATION

As narrated by his educator, Susanta Kumar Pradhan

In my life I have met many children with disabilities but no one has inspired me the way Jitendra does. He was 8 years old when I met him for the first time at the deafblind unit supported by Sense India at Nehru Seva Sangh, Banpur.

He was referred by the principal of the village school, who happened to have met his confused parents.

I say confused because hailing from a small village in Banpur, his parents couldn't understand his disability which was diagnosed at the age of 7, when an attack of jaundice claimed his eyesight rendering him totally blind with partial hearing loss.

Before Jitendra got enrolled in the deafblind programme his parents didn't know the problems of Jitendra. His development was delayed and was dependent on others to perform all his daily living activities. His family members were facing difficulties due to lack of knowledge of how to take care of him.

After a few years of working with him, he started showing a lot of progress. His confidence grew as he started understanding and exploring the world around him. Soon a receptive Jitendra began responding and displaying remarkable progress.

Very soon he could count with beads and do simple arithmetic. He is independent in his activities and mobility. He uses facial expressions and speech to convey his needs and express his views. He often visits some friends he has made at the centre.

His parents have been a great support to him. They also actively counsel other parents of children with disabilities. Jitendra is also learning his family's traditional occupation of pot making in which his parents are involved.

He is a foodie by nature and it has been a pleasure to have known such a jolly person.

His progress motivates me to work more with him and to make him independent in all walks of life and to see him as a happy and productive individual.

Gursangat has also become the talk of the town. His achievement is creating awareness in the village and even in his family.

# GURSANGAT- THE TALK OF TOWN

A neglected child goes on to transform his destiny

Birthing a child is a precious gift, an experience you will cherish your entire life. And having a baby for the first time offers an unexplainable happiness that can never be equalled by anything in the world.

Jarnail Kaur and Jagmel Singh from a remote village in Punjab were experiencing the same joy when their son, their first child was born on 20th December, 2002. Lovingly they named him Gursangat Singh, which means one who will spread goodness amongst the masses.

But their life turned upside down when at the age of two, Gursangat was identified as deaf. Filled with sorrow they thought it might be God's will and let it go. After some years they were blessed with perfect children and life was joyful again. But over the years Gursangatwas growing unattended with no development in his life as he was not receiving any kind of services or education.

Not because his parents didn't try but because at the age of 7 when he joined the local village school, his teachers declared him unfit as he could not see clearly what was being written on board. He had to leave the school and his poor parents left him to his fate.

In 2009 his life took a positive turn when Patiala School for The Deaf identified him through a survey. After lot of persuasion his parents agreed to send Gursangat on the basis of providing free residential education.

As soon as he joined, assessment and audiometric tests showed that he was a deaf child but over the months it was observed that he was also losing his vision gradually. By 2010 situation became really difficult. Gursangat’s education was suffering.

Sense India started providing educators and teachers support through workshops and trainings and soon they started working with Gursangat. New learning techniques were introduced and Gursangat’s life took a new direction.

The transformation in his life is amazing! Today Gursangat is a responsible student who shoulders responsibility and is eager to learn. He does his daily living activities confidently and has become quite independent in his life. Currently he is learning mobility skills and tactile sign language.

Gursangat has also become the talk of the town. His achievement is creating awareness in the village and even in his family. Today his parents have realised his true potential and are very proud of him.

*She is slowly but steadily regaining her self-confidence and we are sure she will fulfil her dream very soon.*

# ONE STEP AT A TIME

A teenage girl's attempt at self-discovery

"No matter where you are or where you grow up, you always go through the same awkward moments of being a teenager and growing up and trying to figure out who you are." - Aimee Teegarden

20-year-old Beverly Gonsalves is going through the same stage. Her mind is a maze of intense emotions which her educator and her family is trying to understand and help her with these dilemmas, fears and angst that go with this phase of life.

Beverly's mother passed away when she was entering this crucial stage of life. She lives with her grandmother as her father works out of India. Having low vision and severe hearing loss combined with the turbulent phase of teenage confused and demotivated her. She didn't like to interact with anyone and she was not interested in her studies.

Three-years-ago when she was referred to the deafblind unit supported by Sense India at Caritas, Goa things began to change. "First and foremost we did her medical assessment and found out that she has high diabetes" says Priyanka Sawant, her special educator.

Today with the help of Sense India supported vocational training unit many options are being worked out for Beverly's future. She is trying to find out her true calling like any other teenager, thus trying different skills like making jewellery and candles among other things.

She also started learning tailoring and computer but her interests are mainly towards jewellery making. Her dream is to start a jewellery business with help from Sense India's livelihood support programme. She is slowly but steadily regaining her self-confidence and we are sure she will fulfil her dream very soon.

Slowly Beverly started opening up and talking. Day by day she grew more confident. We then introduced her to a tutor who helped her with her studies. She passed her 10th std exams and started coming to the centre for further training.

Her achievements may look ordinary for others but for her it's been a big leap of faith and confidence.

# INDEPENDENT RUMA

A big leap of faith and confidence

Ruma Debnath is a 21-year-old young lady. Some of her educators find her headstrong and moody yet sweet and helpful. The only hitch in this young lady's life is her deafblindness. Before joining the deafblind unit supported by Sense India at Abhoy mission Tripura, she used to spend all her days loitering around.

She was independent in all her daily living activities. Ruma found it difficult to listen to low range sounds and could only communicate using gestures and signs. Only when she was angry she would utter sounds. She could also draw lines and shapes on her slates.

But the educators had big dreams for her they wanted to make her a contributing member. So first her educator worked on increasing her attention span and slowly moved on to teach her social skills and other activities one at a time. Her confidence grew as she started understanding and exploring the world around her.

Soon a receptive Ruma began responding and displaying remarkable progress. Very soon she could count with beads and do simple arithmetic; she took over the household chores and became an asset to her family. She began communicating in sign language and a new medium of conversation and expression opened up.

Today after receiving years of training Ruma is in a much better condition. She can do almost all household activities like cooking and other household chores. She grooms herself and also grooms small children in the neighbourhood. She takes part in colouring earthen lamps and packaging of candles. She has mellowed down quite a lot and is developing good social skills.

Ruma’s desire is to get married and become a good wife and mother. Her future maybe uncertain but we believe that efforts are what will make all the difference in her life

Her achievements may look ordinary for others but for her it's been a big leap of faith and confidence. Ruma exudes confidence in her thinking and hopes that the world will realise and recognise her potential one day.

# THE JOURNEY CONTINUES ...

We hope you had a great experience on your journey through the 21 stories and are truly inspired and touched by our deafblind children and adults. Yes, we absolutely believe that no one is lost and there is hope for all, if only we persist. We had a wonderful time putting together this book of hope for you.

"'Challenges are what make life interesting and overcoming them is what makes life meaningful."" Sense India is on a mission to help people with deafblindness overcome their challenges and find meaning for their life.

You can also be a part of someone’s destiny waiting to be fulfilled. All they need is a thought and a kind deed to set them on their way. We hope you will keep holding our hands to reach out to the 500,000 lives still remaining to be transformed. We anticipate your support. You are our champions and this book would not have been possible without you.

But it doesn't end here. We are still looking forward to adding many more stories of dreams, success and hope. We are awaiting to share with the world some good news about how people with deafblindness are defeating disability and rising from the ashes of limitations and prejudice.

We are excited. Are you too?

# TESTIMONIALS

## Brinda Crishna, Chair, Vaani For Deaf Children, Kolkata

I have been fortunate to know Sense India in some depth, as evaluated a number of their programmes. It is a highly professional organisation, working tirelessly for the rights of deafblind children and adults, and their families. They are pioneers in India in this field but what makes them unique is that they continue to work with the same zeal, honesty and dedication as when they started.

## Nandini Rawal, Executive Director, Blind People's Association, Ahmedabad

Sense India has spearheaded the movement of initiating professional services for deafblind people in India and reaching out to thousands of deafblind people in remote areas. They have pioneered services, created a cadre of professionals and helped several outstanding deafblind persons to be self-advocates and prove their abilities through demonstration. I have seen the lives of several young people who are deafblind transformed by the services provided by Sense India.

## Gerard Swan, Course Director, Deafblind Studies, UK

I did some voluntary work with Sense India back in 1998 and have been a keen follower of its progress since then. What struck me then and continues to strike me now is the incredible impact this organisation is making across India. Sense India's team is tremendously committed to changing the lives of deafblind people and educating the people around them. This organisation is well worth supporting. Supporters can be assured that every penny/rupee/cent will have maximised impact

Ekta Bhagwat, Client Servicing, GolNT Design Studio, Ahmedabad Sense India not only commits but delivers in every possible way, the way they work toward the betterment of deafblind people in India is commendable. I feel really proud that I ran in Standard Chartered Mumbai Marathon 2013 supporting Sense India and people with deafblindness.

## Deep Bhuta, Proprietor, M/s. Paras Motors, Santrampur

Sense India has been doing great work and is improving the quality of life and condition of identified deafblind people across the country. One of the noblest acts of humanity that one can do is to achieve their purpose of existence and I started this journey when I got in touch with the team of Sense India.

Little did I know about the intensity of work done by the team which brought almost a paradigm shift in my outlook towards life and people. I thank Sense India for introducing me to this noble work and giving me an opportunity through events, donations and many other activities to do my bit and make a difference.

## Trupti Chengalath, Communication Head, Mahiti, Bangalore

Sense India is run by a great team and addressing a very important and unique cause that requires much care and patience - working with deafblindness. I have met them and am confident that they will make the difference they seek to create with deafblindness in India and across South Asia.

 Javid Baig, Sr. Vice President- Strategy & Planning, Sodexo (USA)

My association with Sense India started more than 10 years ago when they hired the selfless leader Akhil Paul as their Director. I applaud him and his team for doing what they do every day for the well-being and education of the children that they help become part of our community.

## Anuradha Bagchi, Principal- Training Centre for Teachers of Deafblind, Helen Keller Institute for Deaf and Deafblind, Mumbai

I had the opportunity of coming in contact with Sense India fourteen years back, just few months after I joined this field. I had worked very closely with them. I have seen how they are transforming the lives of deafblind people with or without additional disabilities in all parts of the country especially working for the forgotten people in rural India. They have been highly successful in bringing this population from isolation to inclusion.

I feel so overwhelmed and touched when I visit their programs even in the remotest part and see how the children are provided services at their doorstep by young committed educators and brightening the lives of these children, improving their quality of life and making their parents smile.

Sujata Bhan, Professor- Dept of Spl. Education, SNDT University, Mumbai

Sense International India works for persons with deafblindness across the country under the great leadership of Mr. Akhil Paul. Not many people know about this disability and the implications it brings along with it in one's life. It has to be recognized as a separate disability by PWD Act which is possible only because of the efforts put by Sense International India. There is a dedicated, selfless, passionate team of workers who are doing a remarkable work in creating the awareness, developing resources, doing advocacy at local and national level for the rehabilitation of persons with deafblindness. They are making an impact both at the micro and macro level. I wish to congratulate Mr. Akhil Paul and his team for their work and wish them success in all their endeavours to make more and more positive difference in the lives of persons with deafblindness.

## Anant Shah, Jt Founder- Meghraj Croup, UK

I have been a supporter of Sense India for over 10 years. During that period, I have been amazed at the outstanding work that Akhil and his team have performed to improve the lives of the less-fortunate.

## Kaipen Shah, K. Pravinchandra & Associates, Chartered Accountants, Ahmedabad

It takes a while for all fortunate people like us to absorb and bring to consciousness the meaning of deafblindness as disability. We rarely understand how to communicate with these people, let alone think about how they cope with daily living. Sense International India precisely does that; it acts as a bridge between a deafblind person and the real world, by empowering them with not only basic motor skills but by making them self-sufficient to live a meaningful life.

By advocacy and networking, they make sure that deafblind people get equal status in the society. For this act of kindness alone, I always admire the Team Sense International India. Untiring efforts put in by everyone from Governing Council to Lowest level employee makes it a unique organisation. They are driven by passion and work with moral code of conduct and subject themselves to the highest standard of ethics.

# DEAFBLINDNESS

95% of what we learn is through our eyes and ears. Imagine what it is like to be deafblind.

Deafblindness is a unique disability that combines varying degrees of both hearing and visual impairment. It may seem that deafblindness refers to a total inability to see and hear. But, in reality, it is a condition in which there is a combination of visual and hearing impairment that cause "severe deficits in the areas of communication, orientation & mobility and accessing information". The impact of a dual sensory loss is significantly different from a single loss as the individual's ability to compensate with the remaining sense is reduced.

Many people will not be totally deaf and totally blind, but will have some remaining use of one or both senses. However, all individuals who are deafblind experience extreme challenges and are 'educationally isolated'. They require special and unique educational approaches to reach their full potential. Persons with deafblindness face neglect and discrimination owing to their inability to communicate and relate to the world. They are thus denied even the basic human rights like education, medical care, amongst other needs that are taken for granted by most of us.

There is very little awareness about deafblindness amongst the government, general public and other NGOs working in the area of disability. Due to this situation many deafblind children and adults are left without support and even considered severely mentally retarded incorrectly. What most people do not know is that deafblind children and adults can become active members of society if provided with the right care and support.

There are multiple causes for deafblindness depending on the onset of occurrence i.e., - Before birth, during birth and after birth. It may be due to Infections, some syndromes, accidents, illness or aging. Pre mature birth, low birth weight, birth injury, respiratory distress such as hyperoxia and hypoxia, jaundice, nutrition, infections such as meningitis and encephalitis are some of the common causes during birth that may lead to deafblindness.

Rubella also known as German measles causes a group of congenital defects known as congenital rubella syndrome (CRS). The disease can be easily transmitted from an affected pregnant mother to her unborn foetus and once exposed to the virus, the cells of the developing eyes, ears, brain, Central Nervous System (CNS), and heart can be damaged.

Usher syndrome is the most common condition aside from aging that affects both hearing and vision. It comes with varying degrees of severity and progression of symptoms. It is a genetic disorder characterised by hearing impairment and an eye disease called retinitis pigmentosa.

Another cause for deafblindness is a syndrome known by its abbreviation CHARGE which is, Coloboma, Heart defects, Atresia choanae, Retarded growth and development, Genital abnormality and Ear abnormality. The incidence of CHARGE is about l out of 8,000-10,000 births. Deafblindness can also be caused by Cytomegalovirus, belonging to the herpes virus group, if contracted by a pregnant mother can be transmitted to her unborn child.