

**First Asian Conference on Deafblindness  
Ahmedabad, India  
February 11 and 12, 2000**

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**DAY 01**

## **KEY NOTE SPEECH**

**Beroz Vacha**

**Director Helen Keller Institute for Deaf and Deafblind**

**Mumbai, India**

As we all are aware that a very significant change is taking place in the awareness and existence of deafblind persons. The Asian Awakening is a very appropriate title for this Conference. I congratulate the sponsors and the Organizers of this conference and wish all of us very fruitful deliberations.

For me it is a privilege & an honor to be standing here to give the key note address. When I accepted this request. So many thoughts whirled through my mind and the one thing I was very clear about it, and that is acknowledgement. It is a very momentous and a Happy Day for all of us and on behalf of everybody gathered here that I acknowledge the tremendous contribution and support of **Sense U.K., & Sense International, The Hilton Perkins International, Christoffel Blinden Mission, Institute Voor Doven, Ministry Of Social Justice & Empowerment and Rehabilitation Council Of India.** I remember way back in 1991 that I had asked my friend Kirk Horton- When do you think we can have an Asian Conference on Deafblindness!

In to-days context Disability is no longer welfare or a charity issue. It is a development issue, an economic issue and above all a basic human issue. A quality life should be the primary goal for every human being regardless of the country or circumstances they live in. Deafblind persons should be regarded and accepted as full-fledged members of Community with the same opportunities, to seek a life of quality as other citizens. The presence of a disability even a multidisability in no way diminishes the fact that they are as much human beings as anyone else.

It was this concept that gave birth to The Helen Keller Institute for Deaf and Deafblind (HKIDB) inaugurated and Established in July 1977 with 2 deafblind children & 1 deaf aphasic child with a small band of Executive Committee & 3 teachers, including myself. This was 22 years ago when no such concept of education of deafblindness existed and yet deafblind children existed. For the first time in India the existence of deafblind children was established and it was directed to address the issues of deafblindness in our country. Since then HKIDB has increasingly focused on several important issues of Deafblind multiply handicapped persons.

Let me take you just a little before we three teachers took this momentous decision. We realised & recognised the tremendous responsibility and enormity of the task to be undertaken. Although within us was the manpower development yet each one of us looked into the following issues-

Am I afraid to take up this challenge.

I am ready but diffident to take up this challenge.

I am ready, diffident but COMMITTED to take up this challenge and what supported our decision was the famous quote of Helen Keller titled- The Key.

**Some people see a closed door and turn away. Others see a closed door, try the knob, if it doesn't open--- they turn away. Still others see a closed door, try the knob, if it doesn't open,**

**they find a key, if it doesn't fit they turn away.**

A rare few see a closed door, try the knob, if it doesn't open, they find a key, if it doesn't fit -they make one and this is what we did. We decided that we could do it. We involved our husbands & friends & formed the Executive Committee. Fortunately we were lucky in this.

The early years were very crucial-

Questions were asked from many quarters, including the funders

Who & where were these deafblind children?

Was it possible to educate & train such children?

Where will the Institute be physically established? Since we had started the programme in one of our teachers home.

Where was the money coming from? And so on! So forth!

And we persevered in the face of all odds and made it.

How did we do it ?

From outside we had the unstinted support of 4 stalwarts- Late Mr. Shantilal Mehta & his son Sunil Mehta of Paragon Textile Mills and Late Mr. Vijay Merchant the then President of National Association for the Blind- India.

In 1974, Late Dr. Edward.G. Waterhouse of Perkins School for the Blind (USA) after seeing my work with 2 deafblind persons whom I was teaching on my own, invited me to Perkins for a short period of training & Orientation to deafblindness, and supported me in many ways ? encouraging me to start something for deafblind in India.

I also visited Institute voor Doven in Holland in 1974 & later trained. Ever since then both these Institutes have always opened their doors to me in several supporting ways.

From Inside, the commitment of our Executive Committee and our teachers & staff was unquestioned. We set ourselves a few RESOLVES to govern our own actions:

1). Faith in the ability of our co-workers- the agreement to be frank, open to suggestions, commitment to supporting one another. This attitude percolated right from the Top i.e. from our President to our staff, volunteers, co-workers, donors etc.

2) Parents of deafblind children were our partners- their belief to share in our new system of education, the commitment to bring their children to a new way of Communicating, was of paramount importance.

3) The need to document & publish the first sign language book in India called the **Talking Hands** a project undertaken by Nama Bhat the then

Executive Director of National Society for Equal Opportunities to the Handicapped (NASEOH). This was in keeping with our new Communication technique. Total Communication is a combined approach of Oral & manual communication for the Deaf & Deafblind. This technique had all the infrastructure of transferring to Tactile Communication, which forms a very important link in communicating with Deafblind persons. You are already observing this technique in this conference hall.

Thus our vision was clear and a great sense of purpose was established. We also evolved our own philosophy that one is incapable of being taught- and it is the fundamental birthright of every child to be educated and loved?. This has stood us the test of time and brought rewards in the form of awareness amongst parents, well-wishers & Donors that their children now have an opportunity to be trained, educated and rehabilitated within their own sphere of abilities.

From our experience I know we have endeavoured to provide wherever possible .  
Early Intervention & family support services  
Extended classroom education.  
Safety & Health care  
Vocational & Rehabilitation programme since the last 2 years.

But that is not even scratching the surface.

Slowly & steadily we gained National and International recognition. And the support services started coming to us from our Central & State Govt, and International non-government organisations from overseas.

In to-days context for progressive expansion of any program, working & collaborating is of utmost benefit.

NETWORKING is one of the most effective ways of gaining knowledge and simultaneously builds up a support system for programs needing help !

I suggest the following:

1)Through SENSE INTERNATIONAL INDIA NEWS LETTER each organisation could write about their programme, share their experiences, queries /concerns & support could also be sought !

2) HUMAN RESOURCE & MAN POWER DEVELOPMENT & RESEARCH - is a very important factor if we want to expand our services & bring about an all round quality of life. STAFF TRAINING is of paramount importance. To have a working knowledge about ones Role is a definite must! But knowledge only becomes effective if the transferred process i.e. COMMUNICATION is done in the appropriate way. Every person involved in the Life of a deafblind, must be indoctrinated into the basics of what is Deafblindness & how can it be best managed at different levels and the need to develop communication skills.

Late Shri Aditya Vikram Birla said-

We must foster and inculcate the spirit of innovation & creativity, from questioning the present methods of doing the job, from questioning the present systems, formats & reports. We must constantly upgrade and evolve better ways and methods for carrying out existing & future activities. There has to be a ceaseless quest and hunger for knowledge, perfection technological up-gradation. This has to be woven in our management fabric and ingrained in our philosophy

3) Once a year participant from different programmes can come together on a common platform. At this point it will be profitable to involve young Deafblind adults to participate as we have today involved our 2 young adults Zamir & Pradip to talk about their experiences.

Very importantly we should not regard deafblind persons as passive receivers of help & support. They are and can be just as active as anyone else given the appropriate support at the right time. As it is they have considerable technical problems to overcome, particularly with regard to Communication & Mobility.

This brings my talk to a crucial question to which all of us should apply our mind. Soon the little child we had years ago should now be ready for Vocational Training / Rehabilitation. This aspect is a separate paper, which will be presented during this conference.

But my concern is for those young very low functioning deafblind adults who will never move independently outside their protective area i.e. their home/school; who will never be able to express themselves beyond a few gestures or signs and yet they are very important part of our Community & Society . We need to give a very serious thought to this situation. How can the Parents & the staff be supported in this. I have no ready answers. At this first historic conference I do hope we can come up with some ideas! I would recommend that this issue should be considered as part of our Recommendations.

Time is running out on our children & young adults. I am convinced that solutions to challenges and problems are not an impossible task. We have to work together to provide a practical frame work that will enable people with disabilities to the right of A Life lived with hope and dignity.

I conclude my talk with a very well known quote from Helen Keller. This I experience all the time.

Until one is committed  
There is hesitancy, the chance to draw back,  
Always ineffectiveness,  
Concerning all acts of initiative (and creation)  
There is one elementary truth, the ignorance of which kills countless ideas  
and splendid plans:  
that the moment one definitely commits oneself, then Providence moves too.  
All sorts of things occur to help one, that would never otherwise have occurred.  
A whole stream of events issues from the decision, raising in one's favor all manner of unforeseen  
incidents and meetings and material assistance,  
Which no man could have dreamt

Would have come his way.

Helen Keller continues to say-I have learned a deep respect For one of Goethe ' s couplets:

Whatever you can do, or dream you can, begin it. Now,  
Forthrightness with Boldness has genius, power, and magic in it.  
So then in the final analysis.

What are our responsibilities as educators, Social Workers, Spokespersons for the deafblind. How far can we stretch? Where do we stop/ where do we continue what do we ask of our Society our Government!

At the end of the Conference when we make our Resolutions let us Resolve to have just a few but pertinent ones that carries a message to reach any Heart & Mind.

I thank you for your patient listening May God strengthen you.

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## **DAY: 01**

### **PLENARY-I LIFE EXPERIENCES**

#### **1. My life experiences as a deafblind person By Pradeep Sinha**

I was born in Calcutta. I studied in a Bengali school for deaf children since my mother tongue is Bengali. I did not however comprehend much as my teachers didn't bother to explain much to me. I had many subjects, but most of them were given for self-study.

Language was one subject I understood well, as I knew the Bengali alphabet and grammar. I also understood a little bit of maths. However, when the teacher gave me an exam, I found it difficult to write as I could manage to comprehend only a little bit.

I started losing my vision at the age of 11. And by the time I was 12 years old, I became blind. I had to stay at home as there was no deafblind school in Calcutta. For some time, I also could not travel independently as I had also lost my vision. Also communication became a problem, as I could no longer read signs or see the facial expression of people.

At that time one lady used to come to teach me language, maths and some stories. I found it very difficult to learn because she used gestures with me all the time. It was very difficult to understand the gestures without sight and I had to practice a lot for signing on my hand at home. It was a very difficult period for me, as I had to stay home most of the time, because I could not

go to school and also could not go out of the house without my sister or somebody else escorting me. Suddenly I found myself becoming dependent on other people for things I could independently do before.

Travelling in Calcutta was very difficult as we were staying in a village, where the roads were very narrow. To add to that, people found it difficult to understand me and I used to get lost many times. I found it better to travel in the city and town, where there bigger and better roads, but that was far away from our place.

As there was no deafblind school in Calcutta, my father had a hard time find the right school for me. Finally my father found the address of the institute in Bombay and took admission for me in The Helen Keller Institute.

This was a wonderful change for me as at last, I found a school that would give me the opportunity to learn many new skills. I started learning tactile sign language and started communicating again. I started learning many different subjects, which now appeared easy. I started gaining independence in my mobility. I started travelling alone and developed many new skills that would help me in finding my own way. I also started communicating with other people through writing on their palms in print, which allowed me to communicate with many people outside school also and increased the number of people I communicated with.

At present, I work in the vocational unit of the school. I make candles. I make candles of different shapes and sizes decorative as well as simple. I would independently using different moulds and colours for making different types of candles. I prefer to have the names of the colours brailled on the colour boxes for me to understand and pick the right colour. I also travel independently from my place of work to my hostel by train.

However, sometimes, I encounter problems with people. While I am walking to the station on the road or when I am walking on the station, sometimes I accidentally bump into people as it is very crowded. However, people don't understand that I don 't do it deliberately and get angry with me, asking me to stop. Sometimes people are afraid to talk to me and that causes lots of problems in travelling because if less help is available from people then we take longer to travel or reach a particular place.

Also vendors or hawkers sitting on the bridges cause a lot of problem as sometimes it is difficult to know there are hawkers sitting down and I tend to step on their things. Similarly, sometimes there are people sitting or sleeping on the footpath, which is difficult to know. Also, sometimes there is repair work going on the footpaths owing to which we have to walk on the road and that makes it difficult.

Sometimes, when I go to people for help, people start laughing at me when I start signing. Some people make fund of me and start teasing me, manipulating my hand in different ways.

When I go shopping I manage to communicate with the shopkeeper using gestures to tell him what I want. However, sometimes the shopkeeper is not as understanding and I can't shop properly. In restaurants, most of the times, I use gestures to tell the waiter, what I want to eat

like drawing a triangle on his hand to tell him 'I want a samosa' or showing him the gesture of drinking tea in the saucer to let him know that I want tea. Similarly, when I go to the stalls, I have to use gestures to tell them what I want. Most of the people respond well to gestures as not everybody knows signing.

And sometimes gestures are easier for people to understand e.g. I have to sign sweat to people to understand work. For B.E.S.T. I have to sign for the big steering wheel and they understand. Sometimes, people help out quickly and we don't have to wait for a long time. Sometimes, however we have to wait for a long time.

Though I am independent in everything, sometimes, I feel frustrated on account of being deafblind as there are certain things I cannot do. I cannot talk on the telephone with my friends. Also I can't listen to any music or watch the television in my free time. Also since not all people know signing that limits our social interactions.

I feel deafblind people are not the same as other handicapped people. They are different, because communication with deafblind people is at a much different level. Communication is not such a big issue with other disabilities as it is with deafblindness.

When I sometimes travel alone for long distances, I feel bored as there is none to talk to. Some people who understand gestures try to communicate but not much. Also, vendors sitting on the road don't understand that if I don't touch the things that are kept, I don't understand what it is. They don't allow me to choose the things I want to buy as they are irritated if I try to touch their things. I wish they were more patient so that I could shop properly. They start shouting at me and get angry with me.

There are many things that people can do to make life easier for us. People could communicate with me through writing on my palm. If they do not understand my written cards I can also write on their palms. If they don't know signing, they can also use some gesture.

Also, when I go shopping, I would like people to help me out. Any kind of help, maybe just to get around the shop or maybe help me choose something. Also in the train, I would like them to help me get down at the right station, by gesturing to me, that I have to get down.

I wish they have a bigger compartment for handicapped people in the trains as the compartment reserved for handicapped people is so small that it is difficult to fit in more than 3-4 people. There should be one big compartment like for everyone else.

Also, on the platform, on the bookstalls, there could be some braille magazines or newspapers for us to read. Many times, it happens that we go to the police for help in finding an address but the police are afraid of us. They should be at least willing to try to understand our gestures and not send us away when we try to approach them for help.

I feel that the Government should consider giving government jobs to deafblind people as well. There are jobs only for deaf and blind people. Why not for deafblind people. Government should not give all the jobs to people with good hearing.

In general people should be more willing to help deafblind people and should be at least willing to communicate with us.

People should realise that we are just like everybody else. We are here to be able to live a life as full as any sighted persons. And it's OK to be ourselves. That means we have the freedom to be as extraordinary as the sighted.

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## **DAY 01-PLENARY 1**

### **2. A Transition from a Life of Darkness to Light**

By Anindya "Bapin" Bhattacharyya  
An Adaptive Technology Instructor at the  
Helen Keller National Center  
Sands Point, New York, U.S.A.

First Deaf-Blind International Asian Conference  
Ahmedabad, India  
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Did I imagine that there was an unexpected crisis ever to occur in my life? The answer was a big NO. I was born deaf which was as normal for me as if no disability existed in me. However, it never dawned on me that I was so naive about how many crises could occur but this one, a life of darkness. But it did not stay dark, how nice a surprise it was when it became light! I suffered from the loss of the sight in both eyes but it taught me a lesson how to live through a heartbreaking experience which later became so valuable and fulfilling.

You never know when a moment will come which will change you. You won't resist but learn to greatly appreciate it. You start to understand and realize why you've come onto this or that path which is just right for you to advance yourself and which will bring with it a great degree of maturity. One example is that last month I entered a store to ask for a power surge protector to plug in my computer equipment while travelling in India. Communicating by writing back and forth was time consuming so I asked the salesperson to allow me to use a computer and he looked perplexed. I insisted that he guide me to the computer and as soon as I typed my question, he immediately "got it" and typed back his response. My deaf friend who was with me interpreted what the salesman typed. He said that he did not have the product I wanted and that I needed to go to another store. I asked him if

he would call the store to see if they had the product. He responded back by typing that he could not because the other store was his competition. I smiled and politely urged him to help me since his store did not have a phone ready with a TTY (a machine which a deaf person uses to type to another person with the same machine) and that I needed to rely on a hearing person to make a call for me. I told him that he could always stay neutral and need not state where he was calling from! You see how I broke two communication barriers.

I am sure that there are times when we all have said to ourselves, "I can't do it" to something we really wanted to do, but were fearful of trying. After trying some things for the first time, we find ourselves wondering why we ever worried about doing it in the first place. I know that many of you may be thinking, "Wow, if I were deaf-blind, how would I live without my hearing and sight?" What does it really mean...the word "handicapped?" You've heard this word and others such as "disabled" or "impaired," but do they really mean the inability to do things? Let's examine this thought!

I remember when I first became blind at age nine it was not easy. I lost a lot of friends because they were fearful about how to communicate with me. I used to go to a club every afternoon to play with boys my age. After I became blind, I went there just for socializing, but after ten minutes they would say, "Are you ready to go home?" At that time I was naive, and didn't have enough wit to come back with a quick answer. After several years, I realized that they had no interest in communicating with me. I sat there in silence. As a result, I stopped going. They never bothered to look for me.

While struggling to acquire a new life without sight, I often had a desire to commit suicide. However, at that time, I was not a believer in God, yet God kept His eyes closely on me. This is when I began to learn one of the greatest virtues...PATIENCE! God was gracious in granting me enough strength to live through these difficult days and patience was a major tool. Again, God greatly blessed me by providing me the finest education in the United States. He showed me that He did not want for me to waste my entire life, no matter if I lost my sight. He has always kept my life fulfilled. He has always found a way to lead me to the right place where He knew I would be happy.

Being from a village south of Calcutta with farmlands and eighty-five percent of the population living in poverty and

illiteracy, it is very gratifying to think that I'm here talking to you. Born deaf, I am very grateful to have been born to parents who are prestigiously educated. From my American perspective, most people of Indian culture are embarrassed to show their disabled children in public, but my parents--exceptional folks--could understand that my needs were very special. In contrast to most parents of disabled children receiving help and counsel from agencies for parents newly exposed to disability, my parents, as teachers themselves, knew how to handle my deafness without any assistance from outside specialists.

From the very first years of my childhood, my mother taught me how to speak Bengali. She used many creative ways to describe how to make the sound of a letter by moving her lips and had me feel her throat for vibrations. I could then speak and lip read. People who had heard my voice frequently could understand me.

When I was six years old, I was sent to a school in Calcutta near my mother's family's house. As I was deaf, I had to sit in the front of the class to be able to lip read what the teacher said. Unfortunately, I faced many difficulties at this school, because the pupils took advantage and made a mockery of my deafness. They would guffaw at my misunderstandings while I struggled to lip read and comprehend what the teachers were saying. The teachers also were not aware of the situation and let it continue. At that time I was too innocent to deal with the situation, therefore, I became intolerant and behaved naughtily. The school got disgusted and expelled me after six months. I headed back to my home village.

One day, for some unexplained reason, my mother decided to examine my sight. She placed her hand on my right eye and asked if I could see from my left eye. I replied yes, and she switched to my left eye. I felt terrified to discover that I could not see a single thing from my right eye. I was afraid to tell her the truth and lied, "yes". She was clever enough to hold an object before me and requested me to identify it. I guessed wrong. Although she told me not to worry about being blind in that eye, she felt saddened. I was frozen into deep thought about what had happened. I remembered and told her that I was digging soil one day with one older boy from my neighborhood when he accidentally threw soil into my right eye. I never realized that I was blind in one eye because I still could see my other eye.

My father had me admitted to a hospital where I stayed for three months during which time doctors tried to find the cause of my blindness. All the doctors could say was that the retina had been badly destroyed. I returned home where I was accepted to a nearby elementary school. At first the school would not allow my enrollment because they thought I could not compete with other students. My father persistently persuaded the school's headmaster to let me in. I was then seven and a half years old and in the first grade.

When I was half way through the second grade, I had a fight with a boy who decided to throw ash-like dirt into my eyes. I was hurried to the hospital. The doctor could not restore my vision fully as the retina was already detached. I slowly became totally blind during a three-month period. I became horrified and did not know how to live or move around freely without any sight. I had to quit school. After the incident, my young brother was born, causing chaos for my family. It was a lot to handle at an already difficult time.

I was confined at home for four years. At that time, my blindness frustrated me because I did not understand how to express my problems, and became angry and mischievous. I often would sneak out of the house to make trouble while everyone was having a siesta. I would sometimes throw hay through my neighbors' windows. Other times I would lock their doors from outside by hooking up chains, which meant no one could come out. My father became infuriated and proclaimed that he would kill me by squeezing my neck with a tong. I told him repeatedly that I would not commit the behavior again. I failed to keep my promises due to my being so frustrated.

Although I was troubled as a child, I found a little peace in creative expression. I developed a hobby by using manual skills to make statues of Indian gods and goddesses through woodworking and ceramics. Since my mother was a talented artist, she always offered to paint these statues for me.

Finally, one specific day shook me out of my lonely existence--a dramatic turn from an old being to a new one. During the four-year period my father searched for a school for me to resume my education. Unfortunately, all the schools for the blind in India would not accept me as they had no provisions for working with deaf students. Nonetheless, his unsuccessful endeavor did not last, as not much later, my young aunt met a principal of

Behala School for the Blind in Calcutta who had attended Perkins School for the Blind in Watertown, Massachusetts as a teacher trainee years ago. She advised her that Perkins was the best possible place for me to obtain my education.

Since the government in India would not aid me either financially or otherwise, the process in making arrangements for me to enter Perkins was complicated. You all know that the salaries of the average people here do not meet the living standards of the United States, buying two round trip air tickets cost one of my parents' one full year's salary. My father wrote to Perkins to inquire about obtaining scholarships. Perkins responded immediately and generously offered me scholarships for the time I was enrolled as a student there. The principal of Behala School had acquaintances with several businessmen who were very willing to help pay for plane tickets.

The enormous step in taking a journey halfway around the globe was an awakening adventure. My life was completely changed--from a life of darkness to light--when I came to Perkins in September of 1983. My father accompanied me as well as to be my translator from English to Bengali. All I knew was the English alphabet and a few words such as "I love you," "I want to go to the bathroom," "I want to eat," and "I want to go to sleep!" Upon arrival at Perkins and entering my dorm, the first question I was asked was whether I wanted to live alone or with my father. I told my father that I wanted to live by myself to force myself to learn English. From the next day on, I rolled up my sleeves to learn English, braille, and American Sign Language at the same time. My father also learned braille and took courses to acquire new skills about how to work with deaf-blind children.

I started to see a different world by meeting other students who also were deaf-blind, which encouraged me to adjust to my deaf-blindness. I never imagined from a village with a large population living in poverty and illiteracy that there could also be people in similar situations as myself who existed on this earth. The only drawback was that I could not communicate easily with these deaf-blind students because of my limited sign language.

Originally it was arranged that my father and I be enrolled at Perkins for one year. Since Perkins saw how much progress I was making, they decided that my returning home would waste all the skills I learned. My father agreed to return to India and leave me under the guardianship of my first English teacher, Mrs. Carol

Crook.

Throughout my time at Perkins, I instinctively developed a strong interest in helping others who are in my situation. Therefore, my enthusiasm to achieve higher education continued. However, when the time came close for me to graduate with a high school diploma from Perkins, I fretted a great deal about how I was going to acquire a higher education. Obviously, the availability of services and accommodations at a college to meet my needs was still unknown to me. Yet, Perkins was a preparer for me. They helped me with the "merry-go-round" of life changes, where I need to do everything to secure services, scholarships and assistance for my success throughout my college years. I am proud to stand here holding a bachelors degree in political science from the University of Arkansas at Little Rock in the hometown of President Bill Clinton! Don't worry, I have not followed his footsteps with all the world-attention-getting scandals!

Again, after graduation from college, a "big bang" life change plagued me. I never imagined moving to New York and securing a job as an adaptive technology instructor at the Helen Keller National Center (HKNC) as my plan was to seek for a job in my field. Following many unsuccessful attempts to find work in my field, I decided to send my resume to many agencies and friends. A good friend of mine from HKNC persuaded that I had excellent computer and adaptive technology-related skills and should consider a job in technology. I was hesitant at first since I had no degree in computer technology. But I then told to myself that one can't decline an opportunity when it comes to light so I stepped forward for HKNC.

I told you earlier that I instinctively developed an interest in helping others in similar situations as myself. Now I am proud to be working at HKNC because I am helping improve the quality of life of other deaf-blind people. Not only am I amazed to see how much progress I have made since my childhood, but how my success through life has significantly impacted others to pursue their dreams for better lives.

If you asked me what day I thought was the most interesting day of my life, it was on Sunday, August 18, 1991, when I first heard a coup had taken place while I was in Russia. I immediately thought how cool it was for someone from a capitalistic world to be trapped in a world of communist activities. I, fearless and prepared, was very curious to see the outcome. My German friend

and companion, Gerald, was worried about whether we could leave Russia in two days. For me, it did not bother me at all, I put this concern in God's care. Nobody said life was easy. It was one heck of a challenge but a worthy one that I experienced through the coup and being in the real history. You never should miss a challenge or opportunity whether it is risky or jubilant.

We all have different weaknesses, and we don't need to be afraid to admit them. Some of us may be weak in certain subjects in school, or performing in plays, or sports, and so on. Sometimes we are afraid to admit to weaknesses for fear of rejection, but any weakness can become one's strength if he or she faces it, and allows God to use it in his or her life. We have to remember that there are no easy paths in life. Even people who are hearing and sighted can be disabled, not necessarily physically, but disabled in the way they deal with different situations. One example of this might be in the way hearing and sighted people become uncomfortable around disabled people, and don't even try to relate to them. We miss a lot in life when we fail to see the benefits of trying to recognize disabled people as being humans, too.

How many of you have had an old car which you lovingly kept fixing, maintaining and driving until it finally just quit running? A lot of people tend to look at deaf-blind people and say "just give up, your parts don't work anymore!" Why are cars more important than people? Just because a part of our bodies is functioning improperly does not mean we are dead. We still have our brains to help us find other ways to make adjustments. In being deaf-blind, I have lost two senses, but I still have other senses such as taste, touch, and smell. These senses are probably a bit keener in me because I depend on them more.

Being deaf-blind has both good and bad sides to it; kind of like reading the newspaper. The news always seems bad, but the advertisements are always enticing us to buy new products that claim will make life easier! For example, if I were not deaf-blind, I would probably still be in India with a very narrow mind. Due to my being deaf-blind and by God's grace, I am in the United States, and able to share good news with you of my personal experiences things that may have never happened had I not been deaf-blind. Are you hearing bad news about me because of my deaf-blindness now! All I think is that being deaf-blind does not have to be a disability or handicap. God has given me strength to overcome my disability just as He gives you strength

to overcome your weaknesses. Let me remind you of a few things: none of us should give up on anything but rather have strong faith in God and ourselves. I have a favorite philosophy that I would like to share with you: persistence, ambition, and enthusiasm--these are my THREE important principles. If you take these principles, I can more than guarantee you that you will be surprised at how much progress you can make, no matter what your difficulties or weaknesses are!

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~~~~~  
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you ask me to do something with you alike!

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**DAY:1**  
**PLENARY I**

**Life experiences**

**3. By Dr. Rajinder Singh Sethi**

Dear friends,

A person is deaf blind when he or she has a severe degree of combined visual and auditory impairment. The degree of blindness and deafness varies but the difficulties encountered by a deaf blind person are very different from those of a deaf or a blind person.

I have what in professional jargon is called acquired deaf blindness i.e. I was born blind and now I have become deaf. It has taken me nearly 40 years for my hearing to decline from mild to moderate then to severe and further to profound loss.

Before I narrate to you my life story, I would like to begin with a small poem:

**Who does not have problems in life?  
All you need is the spirit to fight.  
All great people that you can sight  
Have risen to such great heights  
Only after several sleepless nights.**

The above lines from a poem written by Smitha Shankar, wisely describe how we should cope with life's problems. I would now like to share with you some of my life experiences.

I was born in a Sikh family in 1946 and was soon diagnosed as a blind child. I lived the early years of my life in a joint family and have been fortunate enough to be showered with a lot of love by all my family members. Having my sister and young cousins around me who attended normal schools, soon helped me in picking up daily living skills, as well as I was able to grow up in a healthy manner learning to interact with others physically and socially, as other children of my age would.

The first 10 years of my life, I was unable to avail of any formal education, as there weren't present any English medium schools, suitable to my special needs.

However in 1957 I was extremely lucky to meet Mrs. Rehmata Fazelbhai, thanks to Dr. Rajendra T. Vyas. She was the first trained teacher for the blind and had studied in England. It was she who first realised that I might also have a minor hearing disability besides my blindness. With her sincere efforts and advanced training techniques, I soon picked up Braille, whereby I could read, write and do arithmetic as well. I was then put into a newly started school along with other normal children directly into the 4<sup>th</sup> standard. There was great rejoicing at home and I too felt pleased that I was attending a normal school and progressing academically.

After 3 years I got admission in St. Theresa's school, Bandra, along with 2 other blind boys. Since the school was for sighted students, we 3 blind boys naturally had to have our schoolwork transcribed in Braille. This was a very big school and initially it took me time to adjust. More so as I was going to higher standards, I found I needed to put in a lot of hard work for subjects like Maths and Science. Once I reached the 8<sup>th</sup> standard it was imperative that I get a writer for my exams. At home I took private tuition as well. Thus with the support of my family members and all around me. I was able to pass my S.S.C. Exams in 1965. This was naturally a great boost to me and I promptly enrolled in the Arts stream at St. Xavier's College where I found studies much easier.

However, it was at around this time that my hearing started deteriorating and I had to start using a hearing aid. This deterioration in hearing affected both my academic and extra curricular activities like elocution. Though I started feeling apart from the rest of the world, it was still not over as I still had some of my hearing and if I was not totally deaf and blind, I was potentially so. I also started saying to people what, pardon me. Some people would tell me that you don't want to listen to us. Some said that it is good that now you don't even hear bad

things in the world. However, in spite of my worsening hearing condition I managed to pass my BA with a 2<sup>nd</sup> Class. The joys of being a graduate were soon weighed down by my continuous loss of hearing for which there was no cure. Being unable to see right from birth, I had come to terms with my blindness, but now having to accept a new handicap, of getting progressively deaf as well, seemed all too much for me to handle and totally unfair at times. Earlier on I had hoped to become a professor of history, as I was deeply interested in the subject. However with my multiple handicap that seemed to be a fading dream. At this point of time in my life, I underwent a mental depression and was confused with how I should proceed in my life. Fortunately however this was just a temporary phase and I soon managed to gain my physical and mental strength, to successfully complete my M.A. in History. I would like to thank here my voluntary readers who have always been a source of strength and inspiration to me.

It was then that I thought I must try to gain some financial independence by selling Government securities, LIC policies etc. I also became a member of the Jaycees. My business though not successful, certainly taught me how to interact with other people and gave me an insight into the behaviour of others.

Then in 1983 I was able to procure on merit, a 5 Year University Junior Research Fellowship, which enabled me to do my Ph.D. in Education under the guidance of Prof.M.Y. Bhide. My subject was The Socio-Economic Problems of the Employed Blind in Bombay. I was awarded my Doctorate in 1990 with a lot of aplomb and praise from all. The Mayor of Mumbai personally sent me a letter of congratulations and I received a lot of publicity in both the print and electronic media. Doordarshan even made a special documentary on my achievements entitled Face in the Crowd. However in spite of all the praise and credit given to me on receiving my Ph.D., the reality I had come to terms with was that I had come to terms with was that somehow there seemed to be no jobs available for a now profoundly deaf-blind individual like myself. This was a fact I had to accept and get on with my life. At the age of 35, I had a home operating mobility instructor from NAB come and teach me to move around on my own. This gave me added freedom as I soon gained independence and confidence to move around in trains, buses and other public places on my own.

By attending deaf blind conference abroad, I started getting lot of Braille magazines, which I have made best use of. I was gleaning information for eight years for international news letter for the deaf blind and have been doing similar work for blind welfare (nab publication) for the last 12 years. I was, in fact,

consultant to the international newsletter for the deaf blind. But what gives me more satisfaction is that I have been sharing these magazines with other blind friends in Mumbai by rotation basis.

Being deaf as well as blind, I sometimes have added difficulty following instructions from people when asked for help in directions etc., as people are not aware that they have to come close to me and talk slowly and clearly into my microphone. Also people talking to me have to bear with a loud squeaking sound which is emitted from my hearing aid at times. Further recognising people from their voices is becoming increasingly difficult for me, as is everyday simple pastimes like chit-chatting on the phone with friends or simply being able to hear my Hindi film and classical music, which I am very fond of but am finding more and more difficult to appreciate these days. Most people do not consider the sense of smell as very important, but for me, the same is a very useful means for identifying people. Since I cannot hear their movements when people approach me, I use their perfume smell or body odour to identify them.

Though deaf blindness presents many unique challenges to both those who have visual and hearing impairments and to their caretakers and friends, these challenges are, by no means, insurmountable. Many persons who are deaf blind have achieved a quality of life, which is excellent. The persons who are deaf blind, who have high quality lives have several things in common. First, they have each, in their own way, come to accept the absence of sight and hearing as a life situation which gives them a unique and valuable experience of the world. This fundamental acceptance can occur regardless of the severity of the particular sensory losses or other challenges that a person has. Second, they have had educational experiences, which have helped them maximize their abilities to communicate and to function productively. Finally, these happy, involved persons lived in families, community and social groups, which have the attitude of welcoming acceptance. They have friends, relatives and co-workers who value their presence as individuals with significant contributions to make to the world around. As Helen Keller said, blindness separates a person from things but deafness separates him from people.

The thought of finding a life partner has crossed my mind sometimes but my parents would wish me to find a sighted partner. I however am of the opinion that it is the companionship that is important and personally do not mind the fact of having a blind or a sighted partner.

It sometimes saddens me that I have not totally rehabilitated myself in terms of a full-time job or business, but I have always counted my blessings and tried to make the most with what I have and with what I can do. I have been fortunate enough to attend a number of world conferences on the deaf-blind in countries like the UK, Sweden, France, Italy, the US and Bahrain along with Mrs. Beroz Vachha. Presently I am a member of the Standing Committee on the Activities of the Deaf-Blind of the World Blind Union. I am also on the Advisory Committee of SENSE International India A British Charity for the deaf-blind. I am also Executive Council member of the NAB. I also try social work in my own small way besides of course writing in a voluntary capacity for the NAB journal. I could not attend the last Helen Keller conference, in 1997. Which was held in Columbia. In the paper, which I had sent for presentation in that conference on deaf blind services in Asia, I had made certain predictions. These are slowly but surely coming true thanks to Sense International India and Hilton Perkins International Program.

In conclusion I would like to wish all my readers a very Happy New Year and hope to continue to have with you all a long-standing association through my articles and information about the blind and the deaf-blind in the next century.

I would like to end with the profound words of Dr. Bernie Siegel from his book Prescription for Living

Be thankful for your problems, for something else can always go wrong, and you don't have more. You cannot change your life, but change your attitude and you will have a better life and also get love

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## **Day 01**

### **Plenary II: RESPONDING TO THE NEEDS OF A PERSON WHO IS DEAFBLIND**

**Plenary speech given at the First Deafblind Conference Asian Awakening  
Ahmedabad February 2000**

**By Jan van Dijk (prof. dr.)  
Institute for the Deaf**

**Sint Michielsgestel and University of Nijmegen  
The Netherlands**

***Introduction***

In my long career in the field of deafblindness I have given many speeches and workshops. I have met colleagues from all over the world to discuss the needs of persons who are deafblind. I had the opportunity to carry out research both in Europe and Australia. This means that the findings of my research are based upon samples, which consist of Western oriented subjects. In the ideas I have developed over the years on deafblind education I have always emphasised the role of parents, peers and family. In my practical work as teacher, supervisor and psychological and educational assessor I have met hundreds of families and have discussed with them the upbringing of their handicapped child. In dealing with the parents I could notice the stage of denial of having a handicapped child, the stage of anger of being misled by doctors and other professionals and finally the stage of acceptance. I have observed that despite all the information I provided to the parents they sometimes secretly went to see another expert. In some cases they went on a pilgrimage in the hope that a miracle would happen. When I read Jepson's Study on The deaf experience in India (Jepsen 1991), I find some differences how parents or other family members of India deal with the problem of deafness in their family. What strikes me more are the similarities between the feelings of the people described in this study and the emotions parents and family members have in the so-called western world. What we indicate by the word acceptance is in Hindi referred to as prakritic, what is meant the natural thing, meaning that it is not abnormal to have a deaf child and that it is part of life. In another study I read to my surprise the great similarity in perceptions of teachers of India and the United States concerning the possibilities of deaf people (Parasnis, Samar & Mandke 1996). These findings have reassured me in talking about the needs of deafblind people, which ideas originate from my Western experience. I believe that basically we talk about the same things. Parents have a big need to protect their offspring. They want their child to be a happy person, who accepts wholeheartedly the responsibilities of life. Essential is that all parents have a strong desire to come in conversation with their child. I have to confess that I have reluctantly accepted the invitation for this presentation. When during the World Conference on Deafblindness in Lisbon last July a short tape was shown of an Indian mother in what we consider limited circumstances to come in conversation with her deafblind child and used part of the techniques I promoted over the years, I felt that I could do some positive work by sharing with you the most essential principals of deafblind education.

***Sharing the world with a deafblind person***

It might surprise you that until recently I became really aware what it means to be bereft from hearing and sight. This despite the fact that I have observed assessed and tested hundreds of deafblind children and adults all over the world. This shock in my professional career was caused by involving deafblind persons in my work. As you might know there are many many people with deafblindness who have acquired a high level of functioning. Sometimes they are persons

with Usher Syndrome, this means they are born deaf or hard of hearing and in their 30 or 40 they lose sometimes their sight completely. Very often, as our research indicates (Vermeulen and Van Dijk 1994), these Usher-people are emotionally and intellectually superior in comparison with their deaf peers. These persons are able to describe for you how they experience the world and the people around them. They tell you that even persons with the best intention violate again and again with the basic rules of how to deal with a person with deafblindness. Sometimes they are pushed instead of being guided. In the middle of a conversation the hearing and sighted persons leaves the room without announcing his departure. Very often without any announcement an object is presented in the hands of the deafblind individual. A cup of tea is presented without informing where it is placed. When you accept the deafblind individual as a person who is equal to you, has the same right to be informed about what is going on as you have, then this deafblind person will disclose his feelings and will tell you how you have maltreated him or her. He will inform you that touching an object is completely different from seeing or hearing an object. He will tell you that when the object is unfamiliar it sometimes raises anxiety because of the harm such an object may cause. They will explain you especially that IT TAKES TIME to explore and to familiarise yourself with the environment. In my courses I request the deafblind persons I am co-operating with to tell my students what the basic requirements are in dealing with a deafblind person. The student leads the deafblind individual through a narrow pathway. Later on the deafblind person tells the student that she should not push him or her to the narrow side of the road, but instead walk just a little bit ahead, so that the deafblind person just can touch the arm of the student. An untrained person makes all the possible basic mistakes. He is even not able to offer a chair to the deafblind individual.

The second very important learning experience I got was when I blindfolded myself and covered my ears with a headphone. With the headphone my hearing decreased to the 70dB sound pressure level. Being hard of hearing I was able to follow a conversation when this was aimed directly at me. The moment however that some noise occurred part of the conversation was missed. When this happened just two or three times you give up, because it is too much a strain to be longer involved in such a conversation. When you ask me what is the biggest problem of being deafblind, and I am sure all people with deafblindness will agree that is THE STRESS THEY ENCOUNTER IN THEIR DEALINGS WITH THE WORLD OF THE HEARING AND THE SIGHTED.

### *About Stress*

Every person encounters stress almost every day. It can be considered as a positive mechanism to be alert about what is going on in your environment. Some people accomplish the most when they have to work under stressful circumstances, e.g. meeting the deadline for a presentation. The metabolic processes make it possible to reach a high level of performances. Very often stress can be a very negative factor in our lives. Recently it has been demonstrated in a Dutch study on premature children, that there is a strong correlation between negative stress and the birth weight of the newborn. It had been found that when pregnant mothers are under a great pressure to continue during the pregnancy the normal duties of running a family and have the feeling that this is 'just too much' it effects the growth of the embryo (Paarlberg 1999). In direct relationship to the deafblind the findings of Romanian orphans might be very interesting. As you might know Romania has suffered considerably under dictatorship. During that period children

according to the regime of too big families were taken away and sent to orphanages. They were treated very badly and lacked mothering in particular. After these disadvantaged children were 'rescued' a therapeutic educational program was offered. It appeared that they were confronted with learning tasks many of them became very stressed. When the neuro-biologist, which was following the children measured a specific hormone called cortisol it was found that the level of this hormone was very unfavourable in dealing with stress. When a specific educational program was offered during one year, during which cortisol levels were measured regularly, it was found that learning and emotional stability improved accordingly. I am sure that you all want to know what the characteristics were of this special program, which did such wonderful things to the maturing brain of these young children. When I became aware of the content of this intervention (Meaney, Carlson, Smith and De Kloet 1998), I became rather happy. In general lines it did follow the approaches of deafblind education which I have promoted over the years. Without being aware of the enormous consequences of negative stress I advocated intervention strategies to prevent that a deafblind child is at the mercy of his environment. I mean by this that when a human being, but this also counts for other organisms, is unable to communicate even in its most basic ways with the environment, it leads to frustration, anxiety, withdrawal and self abuse. Recently this could be demonstrated in a sample of deafblind children who exhibited a range of inappropriate forms of behaviour, e.g. head banging, screaming, finger biting, throwing objects and overt aggression. In lowering the demands the environment did put on the child (e.g. not pushing the speed of a meal, teaching the educators to become aware of any signal of distress on the part of the child) it could be observed that the inappropriate behaviour decreased significantly (Janssen, Riksen-Walraven and Van Dijk, in press). The key word of this approach is appropriate responsiveness. It appears that being sensitive to the needs of a child, recognising these and relieving them encourages a balanced regulation between the adult and the child. When this child is deaf (Lederberg 1993) or deafblind (Van Dijk 1991) touch plays an essential role in the mutual process of regulation. If there is a rather consistent way of this kind of involvement of the principal caregiver and the child, the idea develops in the child mind that when he is feeling unable to cope with the situation, that particular person is physically or mentally present to rescue him. This gives a feeling of rest, security and courage to discover the world. This very fundamental relationship is called attachment. It is the bases upon which subsequent adaptive behaviour; social relationship and learning are built. There are some research findings which indicate that the development of attachment in deafblind children rather often fails. In a retrospective study Broesterhuizen comes up with a figure of 73% insecure attached deafblind children. In the normal population this is about 30%. It is argued by many researchers that one of the main reasons that the regulation between deafblind child and educator fails is because of the difficulty to recognise signals the deafblind child sends out (Chen and Heny 1995, Rowland and Sweigert 1997, Janssen et al in press, Nafstad and Rodbroe 1999). In order to alleviate these difficulties I have introduced in deafblind education the idea of co-active movement. My argument for this is that when educator and child act together, hand over hand, or move together in close physical contact, both partners in conversation sense the mutual emotions, such as pleasure or anxiety, interest or withdrawal, appetite or aversion. Hopefully that in moving-acting-together the chances for responding sensitively are improved (Miles and Riggio 1999). I have introduced this approach in the early start of deafblind education in the Netherlands (1960), but it appears to be a valuable approach because it had been adopted by many colleagues all over the world. It can be argued that the favourable situation of co-active movement is

experienced both by the child and the educator as a stress-decreasing situation.

### ***Routines***

It is a common experience of all educators that irregularity in management of children causes a great deal of problems. In a chaotic situation every child feels uneasy and therefore unhappy, which often is expressed by inappropriate behaviour, such as non-compliance. In an educational situation in which the child knows what is expected from him, it is much more likely that the child will adapt to the requirements and requests from his educator. A child and even an adult with sensory deprivation is much more likely to experience his living condition as being chaotic. I have described this in the introduction of this paper. I consider that the enormous irregularity in the world of a sensory deprived person may be one of the reasons for emotional and intellectual delay in these persons. Modern findings of the neuro scientists have thought us that the brain will develop to its full extent when the learning circumstances are characterised by regularity and repetition. When the (young) child is bombarded by every time changing stimuli, the development of neurological pathways in the brain will be at risk. On the contrary, when the child because of the regularity of the routines expects what is going to happen, this will enhance the brain development. In advising parents and teachers I always emphasised the importance of the organisation of home and school. When I look back and think about deafblind children who developed their fullest potential I always remember the situation in which we encountered Gerda for the first time. When the social worker and I encountered this 3 year old little girl she was sitting on grandmas lap. Both were ironing the handkerchiefs co-actively. Despite the important visitors the job was not interrupted. After finishing it Gerda was put on the sink with her feet in the washing water. Grandma washed the cups and co-actively 4 cups were put on the table. Gerda became curious by the two extra cups. She seized that there was something-strange happening. She became excited and right at that moment grandma introduced us by leading the little girl to the curling hair of the social worker and the moustache of mine. In this example the most fundamental aspects of deafblind education are demonstrated.

following daily routines, in which co-active activities play an essential part making small changes in these routines, so that the child becomes curious and establishing associations when the subject is alerted (aroused).

There are indications that in order to develop cognitive skills, creating novelty is fundamental. See also Meir Ben-Hur On Feuerstein 's Instrumental Enrichment 1994.

Creating situations of novelty has a very prominent place in the successful teaching of deafblind children in Russia. In the early writings of Meshcheryakov this scientist emphasises the formation of mental images in the deafblind child (we would call it now scripts) by using the miss-match. As grandma did in putting two extra cups on the table, which did not match Gerdas expectation. In using this intervention technique one should be very careful in changing the child's expectancies. We have experienced that a too long period of uncertainty may lead to anxiety, withdrawal or even self-abuse. The curiosity of the child should be relieved before a too high level of arousal develops. It is a fine line challenging the child to explore and the reinforcement of his curiosity by letting the child discover the solution. Only sensitive and creative educators are capable of doing this.

## ***Operant learning***

In connection with what is said about the orientation of the child towards the change of his environment, another important aspect of learning should be discussed. What deafblind education concerns the principal of operant learning has already been demonstrated without knowing this word, by the teacher who was the first to be involved in the formal teaching of a deafblind child, Samuel Gridly Howe of Perkins. In trying to teach his student Laura Bridgman the idea that objects have names Samuel used exercises which goal it was to associate objects with written names. He repeated this boring exercises day after day by putting a cup in his students hand and than letting her feel the embossed word cup. This approach failed completely. Instead Laura showed signs of distress being not permitted to have her accompanied by her favourite doll. Howe put the girls playmate behind doors, but Laura kept looking for it. When the girl found the door locked and tried to make it clear to her teacher to have the key, it was a most productive learning experience to feel the word and being immediately rewarded by giving the key to open the door. In analysing this situation one can observe that the initiative comes from the child (and not the teacher) and that these actions are immediately rewarded. This kind of process establishes a strong association in the child's mind. Not only in deafblind education operant procedures are more effective rather than associative methods such as matching objects to words or signs which can be so often observed in special education, especially deaf education (so-called matching exercises). Taking initiative and being rewarded is not only the foundation of learning; it creates also the very important feeling of competency in the child. As stated above this feeling is associated with a secure emotional tie with the principal caregiver, who is also rewarding the child's attempts to communicate. Teaching by operant procedures may lead to the feeling in the child to be able to influence his environment. This makes it understandable why teaching aids such as calendars are of such great value in deafblind education.

## ***Calendars***

Sometimes the question is being asked what I consider as the most important intervention technique in deafblind education, regardless whether it concerns young pre-lingual children or deafblind subjects who already have come to the notion that a language exists in which they can express themselves. I have one standard answer: CALENDARS. Right now a book is in press, written by Robbie Blaha from Texas School for the Blind and Visually impaired in the United States. Mrs. Blaha and her team have requested me to write a foreword to their magnificent publication, because with all its modesty I am considered (together with the colleague Mrs. Jurgens, who started with me deafblind education in the Netherlands) the godfather of the calendar system. Perhaps it is interesting to quote a part of the foreword to this publication.

*I remember exactly the time when the idea of the use of calendars was born. It must have been 40 years ago now, that I was as a young teacher trying hard to get a deafblind to respond. Father Van Uden, renown in that time for his conversational method for deaf children, observed my attempts and made the remark: Try to start a dialog with the child. I answered: How can I do this, when my child is hardly aware of his past and his future, there is nothing we share and can talk about. Shortly afterwards we had a family reunion and I noticed that the most lively conversations happened when old photo-albums came on the table. It made the past so present*

*and ideas were discussed about how the future would be different. I went out to a shop where they had neckties on a rack, which could be spinned around. I got one and fixed cardboard on the iron bar, one for every day of the week. Items, which were of interest for my student, were fixed to the board. I remember as the day of yesterday my excitement when after a few weeks my student turned one of the boards on which a piece of curtain was fixed. I understood immediately, that she wanted to go and stand near the window where she could feel the breeze! Being so happy that her expression was understood Joyce learned in the same week her first sign for opening the window. And father Van Uden sends us a cake!*

The calendar system is build up together with the child. I have seen wonderful creative examples of this system. Sometimes it consists of boxes in a row. They call it then calendar or memory boxes. Events which have taken place in the past are represented by a small object the child has experienced during these events. When going to visit a nearby living family member it can be a part of the latch in which the child was interested in entering the home or the paper cup from which the child drunk her tea. When the event recurs the child is referred to the box and hopefully will initiate a question, e.g. 'drink again' This is exactly how a meaningful conversation with the deafblind child starts: by creating circumstances the conditions for a meaningful conversation are laid. It goes without saying that symbols of events or activities the child has experienced can be attached to the wall or pasted in a scrapbook. In Russian deafblind education, which emphasises the deafblind person as a social human being these books are made available to other students. In this way they are successful in arousing curiosity of the doings of their peers. I have seen wonderful experiences how older more advanced students, who have had access to the calendars or diaries of the younger children, ask questions about the activities. In this way written dialogue starts between the children. A wonderful foundation to develop reading skills in this population.

### ***Final word***

#### ***Behavioural problems***

Gradually research findings support my idea that many of the challenging behaviours, which can often be observed in deafblind children are caused by inadequate adaptation to the child's possibilities and needs. For a long time we have explained such behaviours by referring to medical conditions, such as brain damage, delayed neurological growth, hyperactivity, or labels of this kind. No one who knows this population will deny that these conditions exist. I would like to raise the question why some of the children and adults who are definitely brain injured, who show soft or hard neurological signs, still are able to adapt themselves to more complex situations? From the recent research finding on stress we know now that these individuals have had a long positive learning experience of routines and rehearsal. The situation in which they grew up was characterised by a pattern of arousal and relaxation including periods of sleep. It is well documented now that positive behaviours, such as experienced in conditional learning, lay the foundation for coping with difficult problems. We can observe that in all people, but particularly in deafblind individuals, will succumb to stress when the underlying systems are malfunctioning. It appears that the daily life of an individual deafblind should be carefully organised in such a way that periods of intensive learning are followed by periods of relaxation, in which, and this can not be emphasised enough, routines have a prominent place.

In this paper I have advocated more total holistic approach to the education of deafblind children with strong emphasise on the role of environment and ecology. By environment we mean the physical environment. We now all how important good adaptation of space, light and sound is for an individual who is deafblind. The term ecology includes the hearing and seeing persons who share their life with a deafblind individual. The attitude, the willingness to creep under the skill of a deafblind person, the willingness to open oneself for his needs, is the foundation upon which a true relationship between a deafblind individual and the people who care for him can grow and flourish. In order to accomplish this one needs only a limited number of physical teaching aids. What is needed is a good insight in the special favourable living conditions in which people with deafblindness can feel comfortable. When we are able to create this, it is again proven that the SPIRITUAL WORLD HAS VICTORY OF THE MATERIALISTIC WORLD!

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**Day: 01**

**CONCURRENT I:**

## **SESSION I: EXISTING SCENARIO IN ASIA**

### **1. Special Reference to Indonesia By Mr. Sigid Widodo, Indonesia**

The Central Statistics Bureau of Indonesia stated that the total population of Indonesia is about 210 million. The Ministry of Education and Culture estimated that about 2.5% of these inhabitants would be handicapped. As per this estimation the total number of people with disabilities in Indonesia would be approximately 5.25 million. Out of which it is estimated that around 525 thousand are in the category of school going age. It is heartening to know that only 8.94% (46,945 people) of this category could obtain school services. There is no data available in the country which can hint at the total number of people with multi handicaps, but there are four schools serving some 150 multi handicaps this number represents 0.5% of total handicapped inhabitants.

Based on these facts, there are still many people with single handicaps who are out-of-reach of educational services evermore multi-handicaps. All the four schools catering to multi-handicap are located in big cities such as Jakarta, Yogya, Bandung, and Malang. One need not say that these are insufficient to cope with the massive need in Indonesia.

Another reason, why multi-handicap services are so less developed, is the unpleasant attitude of Indonesians due to misunderstanding, and misinterpreting multi-handicaps. The multi-handicap population is not getting any care or services because of the refusal of single-handicap services in including them in their existing programmes. Thus, many multi-handicaps as many as people with single handicaps, in fact remain at home- uneducated, unattended and uncared for.

With that kind of understanding on situation of people with disabilities, it would be unwise and impractical to think that people who are deafblind get better services. The growth rate of deafblind people being served by the four institutions mentioned above indicates that its time to think seriously on how to strengthen deafblind services in Indonesia. The quality of services available to deafblind people in Indonesia may be well below those of overseas ones, but the fact that there are some services, gives a good chance to us for encouraging development.

For this reason, I would like to present in my paper, some elaboration on what are our strengths, weaknesses, chances and threats over the deafblind services in Indonesia. I am also encouraged to suggest a strategy- a realistic one, on developing deafblind services in Indonesia. We are definitely sure of a future in which, we all will be able to provide good quality, outstanding deafblind services.

**DAY: 1**  
**CONCURRENT I:**

**SESSION: I**

**Existing Scenario In Asia**

**2. Special Reference to Malaysia**  
**By Ms. Punitha Kovindarajoo, Malaysia**

**Deafblind Programme:**

I feel it is a privilege for me to be here to share my experiences on deafblind programme in St. Nicholas Home, Penang. Since this is the only programme in Malaysia I will specifically deal with it in my talk. Our deafblind students are very lucky because this programme is in the island of Penang where the entire infrastructure is easily available.

St. Nicholas Home started its deafblind programme in 1996 as a home based programme. In 1997 I was asked to take over as the co-ordinator to start the programme. As I knew nothing at first it was a real challenge. We are thankful to Hilton/Perkins who have been with us right from the start and guided us all along the way by providing training and most of all financial support.

After refurbishment of the old primary school for the blind, St . Nicholas opened a residential centre for the deafblind in 1997. We started the programme with six children. The age group is from seven years old to twelve years.

**Education:**

Teachers conduct classes in small groups in bigger classrooms, under close supervision. The programme includes one -to-one teaching as well as group activities. Individual education plan is prepared for each child according to their development and needs. The children are taught self-help skills such as drinking, feeding, personal hygiene, dressing and toilet training. They are also taught basic writing, reading and counting skills as well as sign language and braille. The children also learn through play activities to develop their concentration and discipline. Areas of focus are gross motor, fine motor skills, cognitive skills, social and communication skills.

**Recreation:**

Children are taken out for visits to recreation and educational places like snake temple. Botanical garden, butterfly farm, bird park , zoo and waterfalls.

### **Physiotherapy:**

Daily physiotherapy is done by our staff for the children who need such training. A physiotherapist from General Hospital evaluates the children's progress regularly and recommends the kind of exercise suitable for each child. This activity is vital to maintain good health and improve physical movements.

### **Swimming:**

Twice a week swimming lessons are conducted. Swimming helps to develop certain muscles better in water by allowing free movements that cannot be achieved on land.

### **Orientation & Mobility:**

Orientation and Mobility is the foundation for independence travelling. Children in deafblind programme have been orientated around the school compound. Some of them are able to walk around freely without help now. Now they are taught how to use public transport to go to the nearby post office, bank, supermarket and hotels.

Even though the unit has only been in operation for a short time the number has increased to eight in 1999. Benefiting from almost one-to-one staffing, the students have all made dramatic progress, as a result of hard work and dedicated staff. The staff team have managed to combine compassion and understanding to produce the best possible overall programme for our students. But we are always looking for new ideas and methods to improve the programme.

With the progress achieved we separate the students who have progressed fast to a transitional class so that their needs are more effectively addressed. Towards this we identified four students ranging from the ages of twelve to fifteen. This class aims to prepare the students for adult life emotionally, socially and physically and to develop independent living skills. The promotion of group interaction, self-confidence and a sense of responsibility are also our objectives.

All the students attending the Transitional Class have activities to match their individual interest and needs. Most of the activities we carry out are in St. Nicholas compound before they are taken out.

### **Mini Market:**

We have opened a small mini market from a small portion of the big classroom. In this mini market we sell all kinds of tit-bits, sweets, chocolates, groundnuts, potato chips, soap and so on. The objectives of this mini market are:

Introducing the concept of money to the students. Buying, selling, realisation of the value of the money and also counting skills.

Sorting and packing sweets, chocolates and things from big bundles to small packets.

To interact with more people and have closer relationship with other staff and the members of their family.

To build confidence and independence.

### Laundry:

Twice a week the students are taken to the St. Nicholas laundry to learn to wash, dry and iron the clothes. Each of them takes turns to help each other in their duties. They are learning to use the latest model washing machine. The teamwork is extremely efficient, considering this are only four of them. Once they are able to do on their own without any assistance, they will be taken to a laundry shop or a hotel to see if they can work in community.

### Coffee Corner:

Cooking class has created a good avenue of interaction for the deafblind students. They have learned to cook a lot of local dishes . End of every month students from the transitional class prepare local dishes for tea time. They sell the food to the staff at a special rate. This has received good support from the staff. Now they are able to know more staff and also able to communicate with them.

### Kitchen:

Every Wednesday and Friday the students help in the school kitchen for about two hours. They are learning to cut and wash all kinds of vegetables. They are also taught to use different kinds of utensils. This will help them in the near future to work in a restaurant or hotel as a kitchen helper.

### Hydroponics Gardening:

This is a simple method of growing plants without soil. This may enable them to grow plants and vegetables as a hobby or even during their vacation. This hydroponics gardening has been introduced a month ago. We hope this may be commercialised one day.

### Leisure Time:

Outside the training hours, we organise leisure activities such as visits to the public library, theatre and from time to time visits to various places of interest and dinner in restaurants, hotels and stalls. They are also taught traditional games as indoor activities in their cottage.

We are planning a lot of activities to upgrade and update the facilities of our deafblind programme. We need to expose the students and upgrade their skills from time to time. There are many more challenges ahead of us and one of them is to continue to create greater awareness among the community for the deafblind students.

Finally, I would like to thank the organisers and Hilton/Perkins for giving me this opportunity to share my experiences and the rehabilitation of deafblind students in Malaysia.

**Day:1**  
**Concurrent : I**  
**Session: II**

**Impact of deafblindness on Development**

**By- Dr.Jayanthi Narayan**

**ABSTRACT**

**1. DEVELOPMENT IN CHILDREN WITH DEAFBLINDNESS  
PARENTAL PERCEPTION AND ITS IMPLICATIONS**

It is well known that children with sensory impairment have a general delay in the overall development. India is a country with very strong family support systems built in the culture. Perceptions of the family members regarding the development of their child with deafblindness, the practices they have for training the child, the involvement of various family members and the implications of available family resources for optimum training of the child are to be carefully studied.

Deafblindness being a low incidence condition, exclusive service facilities to be made available all over the country does not sound economically viable. As an alternative, utilizing the family resources and training the family members to assist the child with deafblindness achieve his optimum potential seems viable. This paper focuses on 5 families who have children with deafblindness, the way they have perceived the child's conditions and therefore, the practices, with or without support services available for them from the professionals. The implications are discussed.

**DAY: 1**  
**CONCURRENT: I**  
**SESSION: II**

**2. Impact Of Deafblindness on The Development Of The Child**  
**By Yolanda S. Quijano, ED.D., Indonesia**

Deaf-blindness is a concomitant hearing and visual impairments, the combination of which can create unique communication, developmental, social, emotional, physical and learning needs (Huebner et al, 1995).

The profiles of deaf-blind children range from those who are totally deaf and totally blind; totally deaf with useful vision or totally blind with useful hearing; those with useful hearing or vision; and those with additional disabilities. These impairments have far reaching effects on the child's general development. They have impact on communication, movement, learning, and social and emotional development.

Vision and hearing are the most important senses in obtaining information. Children who are deaf-blind cannot receive complete information and may develop distorted concepts of their environment and the world. They cannot easily interact with people and objects in their surroundings. Their inability to easily perceive stimulation diminish their motivation to communicate and move frequently so they are not able to strongly develop the skills in communication and movement. Observations and imitations of actions and language will not occur naturally and these limit learning and dramatically delay concept building, reading and writing skills and other related academic skills.

The dual impairments can have a profound influence on the emotional and social development of deaf-blind children. For the very young kids, they interfere with the interactive dialogue between the parents and their children and disrupt the basic development of trust and security which are the foundations of personal relationships. These impairments often prevent access to simplest cues for self-protection so the deaf blind children may not always feel safe. This condition will lead them to withdraw from the environment and it is likely that they feel isolated. As a result, children who are deaf blind may not participate fully in social activities. There is a tendency that they fall into the pattern of learned helplessness for it is easier for them to let others intervene, resolve problems and make decisions for them.

**DAY: 1**  
**CONCURRENT: I**  
**SESSION III**

**1. The Usher syndromes, a major cause of deafblindness in children, young people and adults of working age.**

**By: Mary Guest, Principal Research Officer - Usher syndrome, Sense**

This paper outlines our current understanding of the Usher syndromes. Defines and characterises the three main types and suggests some ways in which professionals might identify children and adults who have the symptoms of these syndromes.

Keywords: Acquired deafblindness, Usher syndrome, retinitis pigmentosa, retina, retinal dystrophy, scotoma, rod, cone, recessive inheritance.

The phrase 'acquired deafblindness', needs some clarification; currently it is used to imply that the deafblindness has developed since birth and was not always present at birth. However, the child could have been either deaf or blind at birth or partially hearing or partially sighted. This is so in the case of Usher 1 or Usher 2 where significant hearing loss is present at birth. Nevertheless, the child with a single sensory loss can and is able to gain much about their distant

world by relying heavily on the remaining good sense. What happens when the remaining sense of hearing or sight becomes impaired? This question and particularly the identification of the deaf child who starts to lose sight in late childhood and beyond will be the main thrust of my paper today.

Before we look in detail at the Usher syndromes as a major cause of acquired deafblindness, it is important to understand that deafblindness can be acquired at any age. Some will be fully hearing and sighted and lose both these senses through accident or rare virus infection. Some may have rather poor sight or hearing throughout adulthood and then suddenly or gradually lose the other sense on which they have relied all their lives. The most common form of acquired deafblindness arises in people over the age of 75 who start to lose hearing and sight together at a time in their lives when learning new skills is not easy.

What separates the one born with congenital deafblindness from the one who acquires deafblindness is age of onset. The opportunity to establish and exercise the auditory and/or the visual neural pathways when the brain is plastic enables the child to develop some order and control over their world, to see patterns and to predict when things for example, food, bathtime, hometime, will happen. The dilemma for those who become deafblind later is how they can learn to live without the daily auditory and/or visual input on which they have become so dependent.

## **DAY I CONCURRENT I SESSION III**

### **Identification & Definition of Deafblindness**

#### **2. Early Identification Of Deafblindness By Dr. Vijayalakshmi**

#### **Introduction :**

Early identification and management of a deafblind is both challenging and rewarding. Although the unique ocular and aural presentations of this population require the professionals to employ the full arsenal of diagnostic and management skills, the extra time and energy applied in these cases is easily balanced by the potential benefit to the development of a deafblind. A thorough knowledge about the characteristics of deafblind is a pre requisite to identify those with dual sensory impairment.

A deafblind, due to the dual sensory impairment of hearing and vision is multiply disabled to achieve an optimum cognitive, social, emotional and intellectual level and hence producing a lag

in communication, gathering information and mobility skills.

The exact process of identification at an early stage is to be done in a systematic way. The knowledge about the high risk factor which causes deafness and blindness. In India the high risk factors include TORCH infection, consanguinity, metabolic disorders, exposure to harmful radiations, malnutrition, infection of new born like umbilical sepsis, meningites, intracranial lesions, jaundice.

### **Low Agar Score**

Drugs administered to the mother, or the new born pre maturity, low birth weight, complicate birth toxemia of pregnancy, maternal diabetes mellitus and other syndromes, sudden retinal detachments and injuries.

One we are aware of the high risk factors, we have to get a default history which includes medical, family developmental history. Leading, questions have to be put forth to find out the level of hearing and visual acuity.

A questionnaire, which helps to identify deafblindness, could be send to special schools, regular schools and other institutions involved in rehabilitation work.

Next causes a thorough examination which is made easy if a prepared format is used to detect the degree of hearing impairment, visual acuity and to assess behavior which are distinct to detect a deafblind.

A few accurate tests that could be carried out by a special educator, or a parent or any other are to be taught to these category of people, both in the Rural and Urban areas to identify early deafblindness.

Interpretation of important results in assessment of vision and hearing without continuous assistance from medical personnel is an essential knowledge to throw light to the development of a deafblind.

## **DAY: 1 CONCURRENT: I SESSION: IV**

### **Developing partnerships with families**

#### **1. Daughter with a Difference**

**By Mr. B.P. Ayvar & Mr. Anil Kutdarkar**

Human disability means derailment in the development as a whole. Congenital disability multiple in nature to a girl child born to middle class educated parents who are moderately religious yet progressive in outlook. Whose first offspring is absolutely normal and the family hereditary history from both sides speak of no such mishaps?..

How to reconcile this was a million-dollar concern or worry. As the child was born as an addition, after having a male child, we were not much bothered about the sex except that the child should be of normal health. Immediately after birth when the doctor announced that the child is blind, both of us were naturally upset and my better half immediately composed herself. She told that we will deal with the situation expecting that the other faculties will be intact, but that was not the case so when we observed that the new arrival was insensitive to the deafening sounds of Deepavali crackers and the sound of her crying was a bit out of tune, our worst fears of the child being congenitally deaf dumb and blind proved a reality. Our instant worries were how to communicate with the child and how best to sustain her retardation from further deterioration knowing fully well that there is no medical cure by any system except to pray for the medical research to progress fast in those directions. Another anxiety doubtless was how to combat the suspicion and wild imaginations of our immediate family and friend circle, apart from the society as a whole. Typical as it is everybody who mattered advised courage and conviction and prayer, as a matter of solace but the hard fact of the future of the child remained an inconclusive mystery. Even a suggestion of remitting the child in an orphanage or for that matter mercy killing did not find fault to our subconscious state of mind since in a way the child is doubtless a liability to the immediate kith and kin and society at large.

Now there is no choice but to face the music as such approaches and thoughts were directed towards medical cure/repair of at least one faculty of human sensitivity and coaching. Although our daughters are suffering from multiple problems, nevertheless they are mentally very alert. But mental growth was not commensurate with age growth due to multiple disabilities. While tonics and vitamins were given as a matter of routine, we decided to consult eye specialists to find out whether eye sight is a possibility by cornea transplant. The cornea transplant was done with 50% hope when the child was barely 30 months old but the experiment failed and the operated eye became totally opaque. During the process we came to know that the child is having heart problems too. We decided to stop the experiment on eyes and turned to her hearing problems and here also luck or fate was not on our side. Having exhausted all medical avenues, our focus now was on training / education as the child approached her third year of living. We knew of schools giving education/training separately to deaf/dumb or blind, but wondering whether we can ever have such services for deaf and deafblind. We scanned through the whole India and when we stumbled upon the Helen Keller Institute at Mumbai, the only institute of this kind imparting coaching to the hapless multiple disabled children, it was something of treasure to us, yet groping in the dark about the success of training.

The child was admitted to the school which itself was at its infant age. Now the travails of travel to and from school, due to public apathy and insensitiveness even among the female travelling public, the 10/15 km daily journey, by the over crowded local trains during peak hours for our wives, was nightmarish in the true sense of the term.. The child's irrational behavior and

throwing tantrums at the railway platforms or inside the train invited only the wrath and ridicule of the public instead of sympathy and compassion. The child hitherto known within the vicinity of our residences became the star attraction of the travelling public for nasty comments and curses if not for sympathy leave alone support. Here we the husbands realised the full potential of the women's confidence, composure, patience and perseverance. The multi-faceted roles of our spouses, as a mother taking care of the growing needs of other children; as house wives attending to the needs of their working husbands and as mother, teacher and counselor to the disabled child with the help of the school, were beyond words of imagination and appreciation.

Our idea was to treat the disabled child as normal, taking her for outings, eating houses, weddings, places of worship etc. but here again the public turned their attention on the child instead of on prayers and the wedding ceremonies. While their curiosity is understandable, they fail to appreciate the feelings of the parents of the child with disabling conditions. In the school the teaching was by means of sign language which was hitherto unknown to us. The schools insistence of the mother being present while training is on, is another innovation which enabled the mother to repeat the training at home as well and involve other members of the family so that the entire family is on the same wavelength when dealing with the differently abled child. Another innovative idea- the periodical home visits of the teachers which give them an insight of the home environments of the child while cementing the parent-teacher relationship is very vital for the proper development of the child. When we found that the school cares for children who are discarded by their parents due to the problems, which are much more serious than ours, a feeling of despair floating in our minds so violently so far, was a bit subdued. This also helped in raising our confidence level after seeing those less privileged children discarded by parents. The sign language has done wonders and it made it possible for these children to write alphabets and numbers, participate in athletic events such as lemon and spoon race and dramatic events, drawing colors on the whole etc. It is an amazing experience to see these kids gainfully occupied for 8 hours a day, no doubt due to the sheer dedication and perseverance on the part of the teachers more appropriately called counselors.

When our daughter attained puberty, further complications arose and there was a marked change in her behavioral pattern and very often she used to throw tantrums which were followed by violence without any provocation on herself and on others at any time and anywhere. This caused us immeasurable mental agony. In such a situation the school authorities have been of immense help and gave strength and solace to us. As advised by them and doctors, to stop the child harming herself and others, besides undergoing inexplicable sufferings during her periods, she was operated upon to stop the menstrual cycle. The school teachers have been of immense and invaluable assistance during this trying time and no words of gratitude could quite explain my feelings to them. We thank god for sending us these wonderful people who have helped us on every step of the way.

Now our daughters are under vocational training with others at the school's hostel making artificial jewelry, paper envelopes etc., in different colors and sizes and these are periodically sold and the income distributed among the students who make them. They are in the hostel for 5 days a week and this has instilled in them self dependence, self confidence and above all self discipline, very difficult to impose on them due to their possessiveness and feeling of insecurity. In a way, for them the hostel is a Home away from Home. They have learnt how to be away

from the protected environments of their kith and kin. There is a ray hope in the lives of the parents, who are in the evening of their lives of the, that their wards are not a hopeless lot as thought out to be when they were born.

The initial 'what will be the end result attitude' has been converted into a 'something positive is possible' for the handicapped also. Hopes are not lost despite public apathy and inertia till such time as public spirited and socially conscious individuals and institutions exist.

**DAY: 1**  
**CONCURRENT: I**  
**SESSION: IV**

**2. Developing Partnership with Families**  
**By Milagros B. Wayno, Philippines**

**I. INTRODUCTION**

Families and professionals are the two main and inseparable partners in carrying out the goals for the disabled family member. For the success of a drawn plan, it is very important for both families and professionals to work hand-in-hand both in planning and in the implementation of the whole program:

**II. WHY IS THERE A NEED FOR A PARTNERSHIP?**

Our normal way of doing things when something is broken is to call a professional to fix it. There is no need for a partnership. The professional fixes what is broken and gets paid for his services.

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This is not possible with a disabled child. There is a need for the professional and the family to combine their efforts in a partnership for the benefit of the disabled family member. Neither the family nor the professional can adequately meet the needs of the disabled child by themselves.

The disabled child needs long-term, full time love and care. They also need experienced, professional advice relating to their specific disability. Neither partner can provide all of these ingredients. The professional can provide their expertise and experience on a temporary basis while the family can provide the long-term love and care. Only by working together can the needs of the child best be met.

### **III. HOW TO INITIATE AN EFFECTIVE PARTNERSHIP:**

To initiate an effective partnership, both partners must be willing to work together. This is not always the case. Sometimes the family might reject the help that the professional is offering because they think that some aspects of their lives are simply no one else's business. In one of my field visits, I experienced being treated as if I were a criminal or a thief coming into a house of one family and they closed the door so that I could not enter. They told me that I had no business asking them about their child

Because of this problem, it is very important that professionals first build rapport with the family. Families should feel the real concern, love and patience of the professionals in all their dealings. They should see the professionals treating the disabled family member with affection, tenderness and respect. The desire to help provide what is best for the child should be evident in the professional's approach. One of the greatest needs of families early on is someone who would just be there to listen to them when they verbalize their fears and pain and doubts. Just providing a listening ear or a shoulder to cry on may be the most important first step in building a partnership with the family.

The family also needs to be assured that we are qualified to help in areas that they feel unqualified in. At the same time, the family also needs to see that we only want to support them and not dictate what they should do. We need to listen to what the family's concerns are and what they would like to happen. Only then will they be comfortable with having a professional come into their lives.

On the other hand, some families would like the professionals to do everything for them and take all responsibility for their disabled child. I was shocked one late afternoon when a neighbor of one of my clients walked in to our rehabilitation center and told me that the boy's mom wanted to give him to me because she just cannot take care of him anymore. She wanted me to adopt the child or find someone else who would. Later she gave the child to her neighbor and simply disappeared. In another case, one of our Special Education teachers was literally begging us to visit one of her multiply handicapped pupils whom she has been waiting to be in school for almost a year. She was not coming to school for the simple reason that her parents were not willing to make the effort to bring her to the school. The parents wanted the teacher to be the one to arrange for the transportation of their child to and from the school and to pay for any transportation expenses.

Families need to know that we can provide professional help but nothing can take their place and the role they play for the success of the disabled family member's program. It is important for them to realize that God has a special task for them and they are expected to perform this task. They need to realize that by working together in partnership we can find solutions for the problems and difficulties they face.

### **IV. DEFINING THE ROLES OF EACH PARTNER:**

For the partnership to be effective, the roles of each partner need to be clearly defined.

The family will be the primary implementor of the program. Because of that, they should have a

direct involvement in planning and evaluating the program for the disabled child. They should be involved in discussing with the professional what works and what doesn't work with their child. They can also help suggest alternative programs based on their observations. The family is ultimately responsible for making things happen, especially in the home setting.

Families are the first, the best, most consistent, enduring and forever back-up system as long as they live, ranging from teaching, listening and just being there when crisis comes. This was demonstrated by the father of a 12-year old low vision and multiply handicapped client. He is being advised by his officemates to put his violent daughter, who continuously hits him, into an orphanage. But he is willing to endure this for the sake of his daughter while we work together on her behavior management program. Families need to provide this kind of long-term, committed care.

It is the professional's job to assist the family in caring for their disabled child. Professionals have wide experience and knowledge and should provide the family with answers to questions about the specific handicap of their child and how to best handle it. The family members have certain hopes and goals in mind for their child but if these are unrealistic they need help in setting realistic ones. We can also provide them with appropriate materials or teaching guides.

Families are sometimes afraid because they lack the ability to provide proper care for their disabled family member. When I gave a mother of one of my clients her first assignment to work on for her multiple handicapped child, she responded with eyes wide open and said, What in the world are you talking about? Will this ever work with my child? It has been nine years that she has been kept in this crib. You are talking about the impossible! But after a few months she saw the difference and begun to be more eager to do more for her child. Now her daughter's program is one of our most successful home programs and her daughter is a functional girl despite her severe case. As professionals, our role is to give these families the abilities they need and then give them the assurance and confidence that they can properly care for their child.

The professional should facilitate linking-up with other families and, if possible, encourage families to organize support groups where they can provide encouragement to each other. Families are often overwhelmed with so many things after knowing that they have a disabled family member. A wealthy mother of a blind 4 month-old baby spent almost half of the entire time during my first visit crying. She said she just needed to cry. I saw the need to assure her that it's okay to cry. The next day I asked her if it is okay for some parents to call her up on the phone and share their experiences. She agreed to this idea and has since developed helpful relationships with many of the parents in the support group.

Besides providing contacts with other parents, we should also help to make professional referrals for the medical, educational, and rehabilitation needs of the disabled family member. This should all be done in consultation with the family and with respect to their wishes for the child.

## **V. CONCLUSION:**

The success of the program for the disabled family member depends largely on the joint effort of both the professionals and the families. Professionals should remember that they are a facilitator

and a supporter of the family during the whole process. Families should keep in mind that they are the forever back-up system and that they need to assume the responsibility for implementing the program for the disabled child. By working together in partnership, we can provide the best possible future for the disabled child.

**DAY:1**  
**CONCURRENT-II**  
**SESSION-I**  
**COMMUNICATION OF DEAFBLIND**

**1. EARLY COMMUNICATION SKILLS**  
**SHEELA SINHA**

Communication process that occurs so naturally and easily for most people can be especially difficult for people with deafblindness. Learners with multi-sensory impairment, as we all know, will always need some intervention for acquiring communication skills. Now the question is how early this intervention could start.

Experience tells us that a lot can be done at a very early age. The capacity to communicate is an inherent one and given a proper environment can start developing into 'a full-fledged interactive exchange during infancy itself. The degree to which it would happen and the ways in which it can be done would vary from one deafblind baby to another. However, the fact remains that with a suitable intervention program, we can help them all to have some form of communication much before a formal language system develops. We just need to have faith in every child's power to communicate, no matter how extensive his problem may be. A totally deafblind child who has hemiplegia too, still has one side of the body to communicate with. Another child with deafblindness and severe motor problems involving all the four limbs still has a beautiful smile in his repertoire. Therefore, we have to keep looking for what he can do rather than what he is unable to do, and use that as the initiating point of our communicative exchange.

Some of the *communicative behaviours* in the early stages could be:

*Vocalisation* - e.g. laughing in response to a preferred body game.

*Assuming positions* - e.g. climbing into the adult's lap. And sitting in a certain way to initiate a rocking game.

*Changes in muscle tone* - e.g. Lying still in response to a sound.

*Facial expression* - e.g. Grimacing in response to a disliked food item.

*Touching or manipulating another person* - e.g. Taking an adult's hand to an object, or Pulling

his clothing for attention.

*Orientation and movement* - e.g. Pointing towards an object to show interest, moving towards dining area to indicate hunger, turning away from a person to indicate refusal.

*Using objects for interaction* - e.g. bringing shoes to express desire to go out.

*Using natural gestures* - Different children may use a different gesture for the same object, e.g. for a ball, one may use throwing gesture. While another may prefer bouncing.

*Showing aggressive behaviour*- Biting, pinching, throwing objects, hitting self, etc. are also powerful ways of expressing pain, displeasure, frustration or protest.

There are numerous other subtle behaviours, which could serve communicative functions for a young deafblind child. The interpretations may be different for different children. While looking away may mean disinterest for one child, it may actually indicate interest in case of a child with central vision loss, who can see best when his head is turned.

We will now look at a few *strategies*, which are helpful in the development of communicative interactions during these early stages.

### **BONDING AND BUILDING UP OF TRUST**

In the absence of basic sensory input, a deafblind child is deprived of the comforting presence of the mother's voice or a smiling face; Special care has to be taken, therefore, to make him/her feel secure enough to start interacting with others or at least let others interact with him/her. In other words, we can say we have to *reach before we teach*.

This being the first and foremost prerequisite for the development of any kind of communication is given utmost importance in our early intervention section. In recent years, we have been getting very young children - some just a few months old - and have had a chance to start building up a relationship really early. Bonding, which develops so naturally in normal children, could be developed in deafblind children by:

**a. Maintaining a close physical contact** with the child in a way that the child finds safe and comfortable. This becomes specially important in the case of very young children who have not yet developed body awareness and do not feel secure enough to use their body to explore their environment alone. Moreover, totally blind children or children with very little vision too may initially need a lot of body contact. Being close to people who understand their need and respond to them positively gives them the security to reach out. We can encourage the child to feel our face as we smile and speak. In short,

physical contact leads to mutual understanding of each other's body language.

In case of children who are resistant to close contact, however, we need to move ahead very slowly and gently. We start by just being nearby, reaching across from time to time to see how much touching, patting, stroking, etc. they are ready to take.

**b. Going through pleasurable activities together** - One of the earliest ways of communicating with a deafblind baby is to indulge in all sorts of simple games and actions with him. Anything

that the child seems to enjoy. A look might lead to a peek-a-boo game or a movement to a full-fledged rocking sequence. Finger games, tickle games, making funny sounds, patting and clapping together. blowing on the baby's stomach. singing cheek to cheek, making faces, cooing, playing movement games, rocking, bouncing together, and so on - the list is long, and we use them all. We find them to have a great potential not only to evoke responses from otherwise withdrawn, disinterested or resistant deafblind children, but also to motivate them to initiate interactions.

We, however, have to be careful here. What is good for one child may not be good for the other. Moreover, bombarding the child with too much of stimulation also may not be a good idea. We need to observe - identify preferred ones, and then follow them in a systematic manner.

We also have to be very cautious about our *own body language*. The way we touch a child or move our body along with his, convey a lot about our own emotions. intentions, moods. etc. Quite often, our own movements or touch miscommunicate our intentions.

An over enthusiastic hug or a rocking game accompanied by loud singing and fast movements may be perceived by the child as threatening or over-imposing. A protective strong hold may convey disapproval, and so on. Such incidences hamper the growth of smooth, interactive exchanges between the child and the people around.

**c. Maintaining eye contact** - All the above mentioned activities also help in establishing eye contact between the teacher/caregiver and the child. Eye contact, apart from facilitating the development of bonding is in itself a communicative exchange. It may be difficult to engage the child's attention in the beginning. specially if he has already developed some blindness or is one of the hyperactive ones who find it difficult to sit in one place. We have to think of games, sounds. and visual stimuli which are more interesting than whatever the child may be engaged in. Once the child establishes eye contact even for a second. he must be rewarded by a smile. an exaggerated finger movements, a funny face, so on. This would not only help in sustaining his attention, but can also lead to an enjoyable interactive session.

In case of totally blind children, their hands should be taken to be their eyes. If their hands are ready to touch us or to be touched by us. it should be taken as the probable beginning of a relationship.

One thing we must remember here is that we have to initially move through *his preferred mode of communication*. A child may have good hearing, but he may still prefer to function mainly through the little sight in one eye he may be having. Thus, while we will never stop stimulating his residual hearing, we will initially centre our play activities mainly around visual stimuli, till he trusts us fully to venture into other areas as well.

## **DEVELOPING ANTICIPATION**

Young deafblind children can also be helped to anticipate what comes next. This makes their days more predictable for them and gives them the security they need. More than that, this is a

big step in the area of communication. This shows that the child has started receiving and interpreting the sensory cues from his environment. Anticipation can be developed in various ways:

*By using body cues* - a gentle tap on the lip means food is coming. stroking the feet means shoes have to be put on, blowing on the stomach means time for body games.

*By maintaining consistency in daily routine*, which mainly consists of feeding, dressing, toileting, playing, going out, etc.

*Consistency in objects and areas used for various activities.*

The time of the day, the location in the room, objects used, all these are situational clues, which tell the child what comes next. Once the child starts making associations e.g. a certain sight or smell means meal-time, or getting wrapped in a certain towel means bath-time, he starts using them himself too, for expressing his desires.

### **IMITATION AND TURN TAKING**

Turn taking has also been found to be extremely useful in initiating young deafblind children into communicative interaction. Turn taking involves responding to the child's behaviour, and then waiting for the child's response. It can be done in various ways

- a. By imitating a *vocalisation pattern*
- b. By imitating a *movement pattern* like tapping, clapping, shaking, etc.
- c. During *learning and play activities* like stacking blocks. dropping marbles in a box. or jumping on a trampoline.
- d. During *movement games*.
- e. Even *while eating* - specially while eating finger foods - *washing hands*, etc. we can have some fun by taking turns.

In turn taking, if we go on *adding a bit* more to whatever the child does, then the interaction proceeds a step further. For example, an exaggerated expression or a sound may accompany the falling of stacked blocks.

### **MAINTAINING A RESPONSIVE ENVIRONMENT**

It is important to observe a deafblind child's body language closely. A slight movement somewhere, a little fidgeting, turning of head to one side, or a certain sound. may mean something. Maybe he is wet, or maybe he wants to be picked up. In play situations, the child may start giving a signal for '*want more*' or '*had enough*'. It may be just a faint smile, or lying very still when he wants a tickling game to be restarted. If we fail to respond to these little movements/sounds/facial expressions, etc. they may lose the power to communicate. The child finds that they do not lead to the desired result, and probably would get back to the easier way of getting our attention, i.e. by crying. If, on the other hand, we respond consistently to these attempts to convey something, the child would be motivated to use more and more such *behavioural signals*.

A video taping of the infant's behaviour in a natural setting over a period of time if possible, may help in identifying such behaviours. talking to the mothers also may be helpful. Mothers are normally able to interpret these behaviours. In case of deafblind children however, specially if the child has a physical disability too, they are so subtle and so different from those of a normal child, that they are likely to be misinterpreted. Moreover, there should be consistency in the interpretations and reactions of all the caregivers. It will therefore be useful if the teacher could help the family in identifying and interpreting such communicative behaviours, and then reacting to them in a consistent manner.

In the end, we must remember a word of caution. If everything is fine - all needs anticipated and fulfilled, all desired objects made available, all pleasant activities started on time before the child could ask for it - then there will be no need for the child to communicate.

So we must **create a need for communication**. A few tips in this direction are:

We must provide the motivation to communicate by using the child's favourite activities.

We can create a need for requests by keeping his favourite object out of reach  
or keeping the jar of his favourite snacks tightly closed.

We can interrupt his/her favourite activity like bouncing or tickling in the middle, and then wait for his reaction before restarting.

We can introduce some novel factor every now and then without disturbing the framework of his structured routine. e.g. A piece of shiny paper which makes a crinkling sound, or a colourful plastic ring which can be rolled on the floor or placed around the neck. The child is likely to attend to it immediately. and then a play session can be built around it.

Above all, in everything that we do along with a young deafblind child, we need to **wait, watch and then react**. They may take some time in acting upon any stimulation they receive. **Waiting** thus becomes an absolute necessity here, (specially in case of children who are more withdrawn and have not yet started taking interest in the environment, or those who have some motor problem.

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DAY: 1  
CONCURRENT: II  
SESSION: I

## Communication of deafblind

### 2. What are tangible symbols?

By Sampada Shevde

*Symbols represent or stand for other things, such as people, objects, places, activities, and concepts. Unlike gestures, symbols allow a person to refer to entities that are spatially distant (e.g., in another room) or temporally distant (e.g., occurring in the past or future).*

*Referents are what the symbols stand for or represent:*

*Abstract symbols are those that make up languages, such as speech, manual sign language, and printed language. Abstract symbols have an arbitrary relationship to referents; there is no obvious relationship between the symbol and the physical properties of the referent. They generally do not look like, sound like, or feel like the referent that they stand for.*

*Concrete symbols do bear an obvious physical relationship to their referents. The symbolic gestures that children sometimes use are one type of concrete symbol.*

*Tangible symbols are a subset of concrete symbols. They may be either three-dimensional (objects) or two-dimensional (pictures). They have the following properties:*

- 1) They are iconic. They bear a clear perceptual relationship to a referent and thus make lower demands on cognitive abilities than do abstract symbols.*
- 2) Because they are permanent, they make lower demands on the user's memory than do speech and signs. Since tangible symbols need only be recognised out of a permanent display of symbols, they require only recognition memory, a lower level of cognitive skill than recall memory.*
- 3) They are manipulate able. They may be picked up and handed to someone, or placed next to a referent.*
- 4) They may be selected or indicated through a simple motor response such as touching or pointing, placing low demands on the user's fine motor abilities.*
- 5) Three-dimensional symbols are tactually discriminable, so that an individual without sight may distinguish between them.*

For some, tangible symbols may help bridge the gap between gestural communication and formal language systems. For others, tangible symbols may represent the ultimate level of communicative competence.

Tangible symbols however, do have some disadvantages. They are often bulky and not very portable. They are also very unconventional; since few people use them, it is sometimes difficult for others to understand that they constitute a real communication system.

## **Who needs Tangible Symbols?**

Three major indicators suggest that a learner may use tangible symbols for expressive communication:

1. The learner must have enough intentional fine or gross motor behaviour to indicate or select a symbol e.g. picking up a symbol, pointing, eye pointing, or touching.
2. The learner must have some intentional communication (pointing, extending objects, tugging or hand guiding) to control the behaviour of another person. An individual with no means of pre-symbolic communication is not ready for symbolic communication, e.g. if an individual will not extend an actual cup to request more to drink, it should not be expected that the person will extend a symbol for a cup to make the request.
3. The individual should not have the cognitive ability to communicate using abstract symbols. A person who can use a higher level of communication with reasonable efficiency should not be asked to use a lower level.

## **For Receptive Communication:**

The use of symbols may be started prior to the emergence of intentional expressive communication skills. The symbols must be used in association with specific activities or materials so that when the individual is ready to use them expressively, the symbol to referent correspondence has already been established.

### **Constructing Tangible Symbol Systems:**

The components of a tangible symbol system are:

#### **Referents**

A referent is what a symbol stands for or represents.

Thus determining the vocabulary for a learner to use involves determining the referents for which tangible symbols are to be created. In the beginning it is important to select symbols which are highly motivating and functional. They should be used regularly and frequently enough so that the learner will attach meaning to them as rapidly as possible.

Many individuals acquire symbols for less preferred activities or items more slowly than they do for more highly preferred items. The more reinforcing the referent, the greater is the likelihood that the learner will eventually initiate using the symbol, which is the ultimate goal of communication training.

There are two major contexts for finding potential referents for tangible symbols: within activities and during the transition between activities.

**Within Activities:**

Activities contain many items that are used repeatedly and or are highly motivating, e.g. during snacks or meals, potential referents are preferred foods that can be offered in small portions so that the learner requests more often for more.

Virtually any object-oriented activity has opportunities to use symbols to represent the materials used within it.

For object mediated activities that require the help of another person, the learner may use a symbol to request the specific object, and then use a gesture to ask for help with, or more of the object. E.g. the individual may use a swing symbol to request to use the swing, and then use a gesture to request another push on the swing.

**Between Activities:**

While changing activities, tangible symbols may represent the activities to which the learner is transitioning. It is best if the activities happen in separate areas as the physical location of the activity is an additional cue to help distinguish between one activity and another and helps the learner associate the symbol with the activity.

**Other Categories Of Referents:**

Some referents that don't fit either of the above categories are:

**Finished:**

The finished box where the child puts the object after the conclusion of an activity lets the individual know and also allows him/her to indicate that the person is finished with the activity or with certain materials used within the activity. It also lets you tell the learner that the activity is over or that it is time to move on to new materials.

**People:**

It is useful for the individual to be able to refer to the important people in their environment. Items of personal identification, such as jewellery or a watchband, which can identify a particular person. The item chosen has to be a distinctive feature of that person, which he/she uses regularly

**Types of Symbols:****(Levels of Representation)**

There are a number of options in terms of the type of tangible symbol to be used. The first decision is whether to use three-dimensional symbols (objects) or two-dimensional symbols (pictures) .The learner without sight has to use three-dimensional symbols, since they are tactually discriminable. Two-dimensional symbols could be used if the learner has adequate vision and is able to understand the relationship between a picture and it's referent. This can be photographs or line drawings. Often deafblind children move from objects to tracing of the object. This motor activity often helps the child remember the object associated with the activity. Some individuals may however, progress from the use of tangible symbols to abstract symbol systems, such as manual sign language

### **Three dimensional symbols:**

They are tactually discriminable objects. The relationships between symbols and referents, or levels of representation, range from very concrete (a shoelace to represent shoes) to relatively abstract (an abstract shape to represent the concept finished).

Some examples of several types of three-dimensional symbols are:

### **Identical Objects**

Sometimes an actual object used within an activity represents that activity or object. E.g. a few raisins glued to a square of cardboard might be the symbol for raisins.

### **Partial or associated objects**

Sometimes parts of objects or objects associated with activities can serve as symbols. E.g. a train ticket (an associated object) may be used to represent going by train. A handgrip from a bicycle (partial object) can represent bicycle.

### **Borders**

Symbols that bear a very strong resemblance to their referents (such as identical, partial or associated objects) can be difficult for the learner to distinguish from the referent. To emphasise the distinction between symbol and referent, it may be necessary to attach the symbols to some sort of border, such as cardboard backing or a square of rigid plastic. The border makes it clear that the symbol is not for functional use, but is to be used only for communication.

### **One or Two Shared Features**

The fewer perceptual features that a symbol shares with its referent, such as size, shape, colour, etc., the more abstract it is. A more abstract level of representation involves symbols that share only one or two features with their referents, depending upon the sensory abilities of the learner.

### **Artificial Symbols**

Some referents such as location, activities that do not involve particular objects or equipment without removable pieces do not lend themselves easily to representation through tangible symbols.

In such an artificial symbol would have to be created, training the symbol to referent association by permanently displaying the symbol at the activity site or on the equipment. E.g. a hollow plastic square can be used to represent the classroom door and may be attached near the handle on the door.

### **Container Symbols**

If an activity involves a large variety of materials or frequently changing materials, it may not be practical to have symbols at hand for all possible materials. E.g. It is not possible to have symbols ready for all the foods served for lunch everyday. Thus symbols could be used for the containers that are consistently used to present the food or materials. These may be pictures of the containers or actual containers. The learner could be shown what choices are there within the containers and then he could use a symbol to indicate the container for the desired item. This way a few symbols can be used to select a potentially unlimited set of items.

## **Two dimensional Symbols**

They are pictures of referents. They may be photographs, coloured line drawings, or black and white line drawings.

### **Determining which type of symbol to use:**

The symbols to be used by any learner should be:

- a) perceptible and discriminable by the learner
- b) as abstract in the level of representation as the learner can understand c) as portable as possible.
- d) highly functional
- e) motivating for the individual
- f) one that is frequently used in the individual's daily routine

### **Selecting or indicating response:**

Another important consideration is the selecting or indicating response that the learner will use. It will depend on the learner's fine motor and visual abilities as well as the learner's ability to evoke the attention of another person. It is important to remember that just as children acquire receptive language before expressive language so to children should be exposed to tangible symbols before they will use them.

The targeted indicated response will dictate such variables such as the size of the symbol, whether the symbol is permanently affixed to the array, and whether the array is portable or stationary. Also some individuals show a need or desire not only to indicate the chosen symbol, but to reject the symbols that are not chosen.

Thus it is important that the learner uses different behaviours for selecting and rejecting the symbols. Because it can be very confusing for the trainer if, e.g. the same behaviour of pushing away the symbol is used for both selecting and rejecting the symbol.

## **Size of the Symbol Array**

It is important to determine how many symbols the learner is capable of scanning and discriminating between at first. If a learner has the ability to discriminate and select from an array of five symbols, the trainer could start from an array of that size. Gradually the learner's vocabulary could be increased by adding more symbols. Many individuals start by learning to use only one symbol at a time and gradually progress to larger arrays, as outlined below:

### **1. One-symbol array**

The learner would be presented with only one symbol at a time. The learner is required to point

to, grasp or otherwise select the symbol. This teaches the required response but not necessarily the meaning of the symbol. Several different symbols could be introduced in this way, by presenting one symbol at a time.

Many individuals begin to understand the symbol-to-referent correspondence at this stage but their comprehension of symbols cannot be tested until the next stage of training.

## **2. Two-symbol array**

Once performance reaches criterion with the one-symbol array, one additional symbol could be introduced, so the individual has to discriminate between two symbols. This is the stage at which the trainer can ascertain the learner's comprehension of the one-to-one correspondence between symbol and referent.

## **3. Larger arrays**

Once the two-symbol criterion is mastered to criterion, the size of the array can be gradually increased, up to the learner's capacity to scan and discriminate between symbols.

### **Making Symbol Use A Part of Functional Routines**

Receptive and expressive communication training should be embedded into functional routines throughout the learner's day.

### **Receptive Communication**

Tangible symbols should be used throughout the day to communicate information to the students, e.g., at lunchtime, showing the symbol for milk at lunchtime to ask the learner if he wants milk, or to announce that you are going to pour more milk, or simply to comment on what the learner is drinking.

It is however important to remember that tangible symbols should not become the sole method of communication to be used with the learner. It should always be used in conjunction with other methods of communication appropriate for the learner such as speech and sign language.

### **Expressive Communication**

When discussing the expressive use of tangible symbols, it is helpful to describe the use of symbols during the transition between activities separately from the use of symbols within activities.

### **Between-Activity Sequence**

Transitioning between one activity to another offers a rich context for using tangible symbols. Upto six steps are needed to take the learner from the termination of one activity through communication about the next activity. The six steps of the between activity sequence are:

#### **1. INDICATE TERMINATION OF ACTIVITY**

e.g. Raises hand

Rings buzzer

Gives symbol for completed activity to teacher

## **2. ACCESS SYMBOL ARRAY**

e.g. walks to calendar box

Raises hand to request array

Teacher brings array to learner.

## **3. STORE SYMBOL FOR TERMINATED ACTIVITY**

e.g. Hands symbol to teacher

Puts symbol in finished box

Replaces symbol in array

## **4. SELECT SYMBOL**

e.g. Picks up symbol

Points to symbol

Touches symbol

## **5. DISPLAY SYMBOL**

e.g. Gives symbol to teacher

Shows symbol to teacher

Gazes at teacher or tap's teacher's arm while pointing to symbol

## **6. COMPREHEND SYMBOL**

e.g. goes to appropriate area for activity

Shows positive or negative emotion depending upon preference for activity

Retrieves materials needed for the activity.

The display step is critical because without it, no communication occurs. If a learner merely selects a symbol and fails to involve another person by displaying it, then the symbol is not being used to communicate.

Most individuals in the initial stages of symbol acquisition, do not use all six steps of the between activity sequence

Restricted mobility may deny a learner independent access to the array of activity symbols. In some cases the activity symbols may have to be brought to the learner. In other cases the trainer has to lead the learner to the activity area and then present the activity symbols, in effect requiring the learner to label the area.

A learner who understands the correspondence between symbol and referent may take the initiative to request an unscheduled activity; what appears to be an incorrect response may in fact be the learner's request for a change in schedule. The request could be denied if it is clearly inappropriate, however it may be granted, if the request is for bathroom or for an activity that can be feasibly completed at that time.

### **Between-Activities**

It is important to carefully track the acquisition of symbols.

Firstly it is important that the adults in all of the learner's environments at home, school, and

work use consistent cues and know exactly what responses to expect from the learner.

Secondly, evaluation of the learner's progress must be based on actual data. It is useful to analyse the learner's performance on a symbol-by-symbol basis, so you can discern differential performance for more and less preferred symbols and referents.

### **Planning the Daily Calendar**

There are many chances to communicate as the trainer sets up the activity calendar at the beginning of each day. The teacher and trainer can sort through the activity symbols together and converse about the planned activities as the symbols are placed in their compartments. The learner can be asked to label the activities using the symbols. Once the symbol has been placed in the sequence, the symbol system may be used to indicate specific materials or people associated with each activity.

Symbols for completed activities are often stored in a finished box that is kept next to the calendar system. The box lets the learner communicate about an activity that is not currently in the schedule by retrieving the correct symbol from it.

### **Within activity Sequence**

Activities offer multiple opportunities to use each symbol. The three major steps involved in using symbols within activities are:

#### **1. SELECT SYMBOL**

e.g. picks up symbol; Points to symbol

Touches symbol

#### **2. DISPLAY SYMBOL**

e.g. gives symbol to trainer

Shows symbol to trainer

Establishes eye contact with trainer while pointing to symbol

Taps the trainer and points to symbol

#### **3. COMPREHEND SYMBOL**

e.g. selects materials that correspond to symbol

Protests if you give materials that don't correspond to symbol.

Selects symbol that corresponds to materials that learner has already chosen. Here too, the display step is essential. If the individual omits it, then no communication has occurred, since the learner has not involved another person in the use of the symbol.

### **Comprehension Check**

The comprehension check may be accomplished in one of two ways:

The learner may choose a symbol from an array of symbols and then choose the corresponding item or activity. If the learner chooses a wrong referent, introduce a correction procedure or begin a new trial.

2. The learner may choose the desired item or activity from an array of actual referents and then choose the corresponding symbol from an array of symbols. If the student chooses a wrong symbol then the trainer could begin a new trial, or introduce a correction procedure.

Thus, it can be seen that any individual who is not capable of making the transition from presymbolic communication (gestures) to abstract symbolic communication (formal language) might be a candidate for tangible symbols. The techniques are appropriate for all ages, including infants in the home environment, children and youth in educational settings, and adults in rehabilitation settings.

However, it is important to remember that any technique of communication should not be used in isolation with the deafblind student. While using tangible symbols, other methods of communication such as speech and sign language should also be used along with it. The use of tangible symbols should not substitute the use of other methods of communication.

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## **DAY: 1** **CONCURRENT:II** **SESSION II**

### **1. The Government and NGO Relationship**

## **In Disability Sector**

**By: Mr. Subhash A. Datrang, Executive Director,  
National Association For The Blind, India**

### **Introduction :-**

In a Welfare State, the Government and NGOs are inextricably linked with each other. The relationship between the Government and the NGOs for building a strong foundation for the vibrant growth and development of Disability Sector is of vital significance.

According to National Sample Survey 1991, India's disabled population is 20.6 million, the concentration of which is mostly in rural areas (80%) - visual impairment 4 million, hearing impaired 3.2 million, hearing & speech impaired 4.5 million and loco-motor 8.9 million.

### **NGO - Network :-**

It is estimated that there are 8000 NGOs working in Disability Sector at present. Of these, more than 6000 NGOs are in only 9 States and Union Territories of India. Over the years they have grown in complexity and the nature of services rendered.

### **Types of NGOs :-**

NGOs are broadly of 3 types. Service Organizations and Institutions set up by social workers, disabled people or their parents/relatives. These mostly run client-centered activities and programmes. In the second type there are organizations which are advocacy agencies working as pressure groups. Disabled persons are in the forefront in these agencies, because they know best their problems. They work in tandem with social activists and media people. The third type of NGOs are International Agencies. These agencies meet their specific mission goals with the help of Indian partners by providing them funding support and expert guidance.

National Association for the Blind, India, Blind People's Association of India and All India Confederation of the Blind falls in the first category of NGOs, whereas National Federation of the Blind and Blind Graduates Forum of India are typical examples of the second type. Christoffel Blindinmission, Sight Savers International and Sense International (India) are the organizations of the third type.

### **Strengths of NGOs :-**

NGOs comprise a team of committed people who are flexible in their operation and are eminently suited to explore new ways and generate innovative ideas. They provide a wide range of services, which may be gender and/or age - specific covering one or more disabilities.

### **Weaknesses of NGOs :-**

It is sometimes argued that NGOs lack professionalism and public accountability. As a result, the service delivery programmes rendered are not necessarily cost-effective nor of very high quality. The growth and coverage of NGO programmes are also uneven which suffer from regional imbalances. These are also, by and large, urban-based. NGOs are sometimes in an unenviable situation when they are not quite able to withstand funding agencies' or political pressures.

### **Role of the Government :-**

The role of the Government is policy planning, policy formulation, human resource development, research and investigation for introduction of new and innovative strategies. No less important is the task of bridging gaps in knowledge and funding of projects, programmes and activities which the Government has a mandate to carry out. In a Welfare State the Government also has to make provision for basic services for persons with disability and continual review, direction, control and evaluation of service delivery programmes.

### **Role of NGOs :-**

The Non-Governmental Organizations in Voluntary Sector are engaged in developing new and innovative strategies for education, training, rehabilitation and mainstreaming, operating service delivery programmes, building capacities, in the empowerment of disabled groups and non-party political activism.

### **Rationale for Partnership with NGOs :-**

The benefits of collaboration with NGOs are obvious, namely, better delivery facilities for state-run services, access to grassroots as well as direct contact with beneficiaries and clients of the programme. The cost benefit ratios in collaborative projects are often very favourable. New concepts and theories envisioned by NGO Sector and which are hitherto untested can be tried out by policy planners in the Government through planned field studies and experimentation. Community Based Rehabilitation and Integrated Education are examples of such new approaches, which the Government has officially adopted, and which were NGO initiatives at one time. Voluntary organizations have rich hands-on experience of working with disabled persons and their families. This expertise can be very profitably harnessed for mutual benefit in joint projects.

### **Constraints in NGO Collaboration :-**

However, there is sometimes a danger of comparisons being made between the Government and the NGOs about their programme goals, methodologies and outcomes. When viewed in contrast, Government services are sometimes shown to be inefficient by NGOs presence and actions. The State Sector has only certain built-in capacities. Not realizing this limitation, the joint presence of the Government & NGOs in a given project at times raises unrealistic hopes among clients and the demand for Government services may increase beyond limit. Project implementation, quality of services rendered and the targets to be achieved are sometimes in jeopardy because of the lack of public accountability on the part of NGOs. This may adversely affect the credibility of the

Government.

### **Why NGOs Seek State Partnership :-**

NGOs look at Government-supported collaborative projects as a welcome opportunity for improved access to policy planning/policy formulation as well as to research facilities, expertise and new technologies. Several frontline professionals, rehabilitation, specialists and educators in NGO Sector regularly assist the Government, when they serve on expert panels, committees, and special groups set up by the Ministry of Social Justice & Empowerment, National Institutes for the Disabled, Rehabilitation Council of India as well as Planning Commission. In their position as members of these Committees they are in a position to positively influence Government policies and decisions. They help improve Government services from 'within' when they work with the Government. There is also a rare opportunity for passing on technologies and models for replication, or, 'scaling up'.

The first special employment exchange and placement service was set up in the voluntary sector by the National Association for the Blind, India, in 1957. The Government later established 17 such exchanges in different States of India. In 1960 NAB set up the first Teacher Training Centre for the Blind in Palayamkottai, Tamil Nadu in collaboration with Christian Council of India, as also the country's first Braille Press in 1958. It is now history that a number of such Training Centres and Braille Presses have been established subsequently by the Government. These are but unique instances of replication of proven models.

### **Disadvantages to NGOs :-**

NGOs fear that in a collaborative project there is a likelihood of excessive Government control. In the process, they may also assume more bureaucratic character much to the detriment of beneficiaries. There is a perceived sense of loss of autonomy among NGOs. In collaborative projects they are sometimes relegated to a mere service delivery function instead of a wider role which they are capable of playing. In this approach of outsourcing or sub-contract, there is a risk of NGOs losing all interest and motivation. Next there is often a fear that the Government would take credit for their 'achievements'.

### **A call for Introspection :-**

There is sometimes a tendency among NGOs to outsmart each other in a rather unhealthy competition. There is hardly any learning from each other. Inter-organizational communications are generally poor. NGOs are unfortunately too preoccupied with fund raising aspects of their work. As stated before, they also lack professional approach in their work. In order to bring about qualitative improvement in their services and make judicious use of monetary and material resources, NGOs' work-methods must change for the better. An NGO to be truly successful may also have to have the discipline of not looking outward for support all the time. There is, therefore, a need for a serious introspection over these issues by NGOs.

### **Suggestions :-**

These are some of the problems which the NGOs and the Government experience in their

relationship. It will be seen that some of these are largely based on mistrust and lack of understanding of each other's strengths and weaknesses. The following suggestions are offered for improving the situation :-

### **Identifying Genuine Agencies in Voluntary Sector :-**

Some Voluntary Organizations which do not have desirable credentials have mushroomed lately. Although mandatory reports and returns are stipulated for ensuring proper utilization of resources, a system needs to be evolved to distinguish the genuine from the hoax.

In this context, the recent news item in Times of India is interesting. In that, there is a move to accord ratings to NGOs on the basis of their overall performance. This is sought to be done with the help of an independent agency. This should help the Government to select the right partners for collaboration. The move should also make NGOs more accountable to public.

### **A Mutual Dialogue :-**

Periodic regional meetings with NGOs should be held to discuss solutions for difficulties in programme implementation and project funding. The biennial Workshops of NGOs held by the Ministry of Social Justice & Empowerment in the past was a step in the right direction but such meetings have not been convened since 1995.

### **Government Presence in Rural Sector :-**

As for the gap in services for the rural disabled, the Government has to think of establishing its own Institutions and Organizations for operating rural-based programmes like CBR.

### **Improved Pay Structure :-**

The NGOs are not in a position to attract people of high calibre because of unrealistically low pay-structures. The staff turnover is, therefore, unduly high. The Government has recently introduced new norms for project funding. The honorarium payable to project personnel stipulated under this scheme, will not quite solve this problem, as these provisions do not compare favourably, either with present Government salaries or labour market conditions. The authorities must, therefore, take a fresh look at this problem.

### **5. Better Conditions Relating to Grants-in-Aid :-**

The attitude among some Government functionaries tends to be that disbursing grant to NGOs is a favour. Similarly, there are often inordinate delays in the release of sanctioned grants. NGOs have, therefore, to spend enormous time and resources chasing the authorities in Delhi and the State capitals. The recent introduction of Nodal agency concept has reportedly not got off the ground yet. In metropolitan cities such agencies have not been appointed Mechanism, therefore, needs to be worked out early to correct the situation.

### **Programme Evaluation and not just Superficial Reviews and Audits :-**

Inspection of NGOs by District and Lower Level Officers who do not quite have a perception of the schemes to be processed often leads to delays and protracted correspondence. Such inspections are not very effective for raising the quality of programmes and services. Therefore, there should be programme evaluation rather than a mere financial audit and superficial reviews. The task of such evaluation is best entrusted to experts in the field, associated with leading and reputed NGOs. The Rehabilitation Council of India, appoints such evaluators/visitors for assessing the suitability of a given Training Programme for recognition. This model is ideal for the present purpose.

### **Man-power Development :-**

Lack of information of procedures for computing recurring and non-recurring expenditures and for completing mandatory returns properly often leads to avoidable delays and correspondence. Similarly, equally important are also the problems of how to write project proposals and complete funding applications. Ministry of Social, Justice and Empowerment would do well to organize regular training programmes for NGOs for this purpose.

To usher in professionalism, refresher training programmes, retraining and skill upgradation of agency personnel is very essential. Such programmes are organized by National and International NGOs, Rehabilitation Council of India, National Institute for the Disabled and Society for Service to Voluntary Agencies (SOSVA), NGO personnel would do well to take advantage of these training capsules. The extent scope and frequency of such courses will, however, have to be increased sufficiently to meet the growing demand.

### **Sensitizing Government Staff :-**

Likewise, due to frequent transfers and changes in the personnel both in the Central and State Government, the staff is not fully aware of the various programme-objectives and pattern of grants. This may cause delays in scrutiny of projects and release of grants. There should, therefore, be periodical orientation courses for sensitizing and orientation of staff of Government agencies with various schemes.

### **Speeding up Disbursement Procedures :-**

NGOs who have received grants for the last 5 years should be certified to receive similar assistance for a further 5 year period instead of every year. This will speed up the process of disbursement of funds and reduce the workload of the Government.

### **Gearing up Government Machinery to Cope with Increased Workload :**

Welfare schemes for the disabled population have grown considerably during the last decade or two. However, there is no corresponding expansion of administrative and professional staff in the Government. As a result, implementation of these projects is delayed and the funds earmarked for this sector are not fully utilized. Therefore, there is an urgent need to assign adequate professionally trained staff to complete the task in time and retrain or redeploy

them.

### **11. Decentralization of Government Programmes :-**

The Government of India had taken a welcome step by adopting a 'bottom up' approach to Rehabilitation. The Village Panchayats' involvement was ensured in this work. However, this decentralization initiative has not materialized yet, in real practice. The Government must, therefore, fulfil this mandate immediately.

### **12. Coordination :-**

Many Voluntary Organizations in NGO Sector are small in size. Their resources are generally limited, activities and operations of such agencies are, therefore, somewhat restricted. These NGOs are run by one-two employees. Hence such agencies must reorganize themselves and form federations and unit in order to be more powerful and influential. The idea is to foster better co-ordination and partnership ethos.

### **CONCLUSION :-**

In conclusion, it is important that both groups - Governmental and voluntary, should always work together towards an improvement of the services they provide for the betterment of the Disabled yet retaining an identity of purpose and mandate. It must always be borne in mind that neither sector can fully serve the Disabled without the willing help of the other. Co-operation and partnership are the keys to a good, cordial and mutually beneficial relationship.

## **DAY: 1 CONCURRENT: II SESSION: II**

### **Government and Non- Government organisations working together**

#### **2. Bangladesh Experience By A. H. M. Noman Khan**

Disability is no longer identified as a segregated issue but an integral part of mainstream development.

A notable percentage of a country's population is in some way influenced by disability. Interventions become essential to address and minimize the negative effects of disability issue

call for concentrated and collaborative efforts from all concerned sectors. Among these the roles of a Government and a country's Non-government organizations (NGOs) are of immense necessity and significant. This movement needs to be supported by the community and families of People With Disabilities (PWDs).

NGOs can be developed to possess the capacity on the skills and information on disability issues. These organizations already hold excellent program set-up and community credibility from past development program interventions. But they lack adequate resources or the capacity to address the nation in its totality. The Government has establishments from Urban to grass-root level in a country and resources. If these two actors are tagged, it could be possible to reach PWDs with rehabilitation services and development scopes. Only this collaboration could allow progress towards achieving the targets of 'Asia & Pacific Decade of Disabled Persons'. Besides, for wider implementation of development interventions require effective and appropriate policies and legislations. Government is the sole authoritative body of a nation. Only their involvement could ensure proper application of existing policies and legislations and development of new required ones. In addition Government could facilitate coordinated and comprehensive program interventions along with the NGOs- whose efforts are primarily scattered and cover limited geographical areas.

The paper focuses on the GO-NGO Cooperation and Collaboration in Bangladesh. It throws light on situation of disability issues before such movement and the current picture in Bangladesh. It highlights the need for such cooperation and suggests steps from experience how this bondage could be founded.

Though the paper is based on Bangladesh's experience, it could provide essential information to all developing nation especially the SAARC region.

## Day 01 Concurrent II Session III

### *1. Setting Up Services For Deafblind Children Gerald SwanUK*

#### ***Slide 1***

#### **Aims of the session**

Not to give you answers about setting up a service in terms of resources or organisation or local supporting infrastructures

To challenge you to look again at yourself and your colleagues and see the skills you and they have to offer - but from a different perspective. By doing this then you will begin to find the answers you need

## ***Slide 2***

**At the heart of the educational process lies the child. No advances in policy, no acquisitions of new equipment have their desired effect unless they are in harmony with the nature of the child, unless they are fundamentally acceptable to him or her**

Children and their primary schools  
The Plowden Report, HMSO 1967

## ***Slide 3***

### **Services Must Be Child Led**

All children are unique irrespective of physical or cognitive characteristics.  
Each child is entitled (as are we all) to be treated with dignity, respect and integrity.

Each child is entitled to be heard and to have his or her needs met.

Each child is on a journey; we are merely travellers who are privileged to be with the child for a period of time.

## ***Slide 4***

### **How Does This Apply to the Deafblind Child**

Three areas of developmental continuum which we might consider

visual impairment to blindness

hearing impairment to deafness

normal learning (or cognitive) ability to mental handicap

## ***Slide 5***

# Definition of Deafblindness

Deafblindness is a combination of visual and hearing impairments.

## ***Slide 6***

Functional Assessment

**or**

Getting to know somebody new

Learning to be in their shoes and to perceive the world in the way that they perceive it.

## ***Slide 7***

Functional Assessment

A possible model might consider the following areas of development

vision

hearing

cognition or learning

physical

communication

interaction

## ***Slide 8*** **As Educators**

We need to take time to observe a child

We need to begin to understand what the child is doing and learning

We need to attempt to understand how

We need to learn to take the journey with the child. If we observe the child carefully and without pre-conceived ideas

he or she will show us who they are

they will show us where to go next.

We must keep on journeying with the child. We must adapt what we do as they grow and develop.

## ***Slide 9*** **Conclusions**

Provision must be child led.

Whilst the models, definitions and knowledge we use to support us are useful, they must support the child. They cannot be used to mold the provision we make for the child in order that he or she fits the mold. If we do this, the child will not be him or herself.

Co-ordinated services give a range of perspectives from which to know the child. Each perspective supports our understanding of who the child is. One perspective is not enough.

## ***Slide 10***

# Final Points

Don't be afraid to be afraid.  
Don't be afraid not to know.

The issue is not one which is about disability;

fundamentally it is about how we learn to be with another human being  
it is about how we communicate with that person.

Gerard Swan

DbI Conference, February 2000

## DAY: 1

### CONCURRENT II SESSION: III

#### 2. Setting Up Services For Deafblind

By Sr. Agatha, Helen-Keller Indonesia, Yogyakarta

#### WHY WE STARTED WITH THE DEAFBLIND PROGRAMME?

There is no special attention given to the education of deafblind persons in Indonesia.  
(Information 1993)

There are indications in our deaf school some deaf children with sight problems. (need anticipation)

The need of public education.

#### B PREPARATION OF DEAFBLIND PROGRAMME

Handling the deafblind programme professionally need much preparation and serious study.  
After ascertaining the exact number of deafblind children in our institute, we started preparing;

Persons who shall handle this program.

Build up contacts to learn more about deafblindness.

Place and environment for the programme. (Society and Department)

#### C IMPLEMENTATION

Now we are still in the preparatory step of the deafblind programme. Among the five-deafblind children identified in our institute, we found that no one had similar potential, ability,

characteristics, needs, etc. So, we made individual programs for them depending on their potential and needs. In our deafblind programme, we have; Goal for education, Approach strategy and Maternal Reflective Method, as the basic steps of teaching.

#### **D THE SUCCESS AND FAILURE OF THE PROGRAMME**

Most of our students show progress in communication, with Indonesian Sign Language, Tactile Indonesian Sign Language (Isyandora ) and speaking Indonesian Language as much as possible. The children also show progress in self-service, Daily Living, and some other skills.

#### **The Limitations of the programme**

Limited cooperation between the team and the parents.

Very high expectations from the child by the parents.

The society does not know much about the problem of deafblindness.

#### **Solution**

To increase cooperation between the team workers and the parents.

To create awareness about deafblindness in the society.

DAY: 01

CONCURRENT II

SESSION: IV

Man Power Development

**1.Surya Bhakta Prajapati, Nepal**

Abstract

CEarth's greatest treasure lies on human personality. In all kinds of development human is the centre figure and crucial both in Government organizations and NGO's.

CIncreasing role and impact of NGOs in community development and especially in disability sector in Asia.

CManpower required by the disability sector NGOs in reference to Nepalese context and experience.

CSome practical solution for improvement of manpower development in Nepal and Asia.

C

DAY: 1

CONCURRENT II

SESSION: IV

Man Power Development

**2. Dr. D.K Menon, India**

Abstract

Manpower development is a very vital aspect in any sector. It becomes much more important in

disability sector because there is lack of trained personnel. The presenter is a senior I.A.S. and Director of Mentally Handicapped in India. He will share about various manpower development programmes being run by Government and NGOs.

**Day 02**  
**Plenary III**  
**Causes & Consequences of Deafblindness**

**Trend in the population of children with multi-sensory impairment**  
**By: David Brown, UK**

Complex and multiple disabilities have been characteristic of a significant proportion of children recognised as having multi-sensory impairment, at least as far back as the 1960s when a real body of literature began to emerge from educationalists in USA. From reading this American literature, however, and from conversations which I have had with some long servicing teachers at Perkins School for the Blind in Boston, it is apparent that the number, complexity, and severity of the disabilities encountered in the children then was on the whole much less than we are seeing today.

In 1983 Chris Best, at that time Senses Education Officer, published the results of a survey of deafblind children in the UK. This survey showed that within the previous years, the number of young children with congenital rubella syndrome appeared to be declining whilst who did not have congenital rubella syndrome but had multi-sensory defects plus additional disabilities was obviously increasing. Chris made the point that: This has resulted in many deaf-blind units changing in character and re-thinking their admission policy. If this apparent change in population is a long-term one then it has implications for the provision of placements, staffing and the development of appropriate Measures for assessment.

Professionals in North America, Western Europe and Australia can confirm that this change in population has, indeed, continued. Though no national statistics are available for the UK, figures for parts of the USA reflect these trends in a way that causes little surprise or contradiction in this country. Mike Collins reported in 1991 on students within four states in New England identified as having deafblindness, and found congenital rubella syndrome to account for only 15% of the total, and this was expected to drop to about 5% by 1995.

Marianne Riggio, surveying changing population in the whole New England region in 1992, produced similar results with a very marked reduction in the incidence of congenital rubella syndrome and a significant increase in the number of the individuals with multiple congenital anomalies.

Any discussion of the causes of these changes must be a matter of opinion. It seems obvious

to conclude, for example, that the decline in the prevalence of congenital rubella syndrome is the result of successful large-scale vaccination programmes, though we need to remember that the rubella virus has not disappeared. Consideration of the significant increase with children with multiple anomalies is more problematic and requires educated guesses.

From our experience the following seem to be likely explanations of the phenomenon:

1. A growing proportion of this group, including children born prematurely and those left with multiple disabilities following early infections, are now enabled to survive as the result of developments in medical knowledge and technology. In other words, we are now working with growing numbers of children who could not have survived much beyond birth or beyond the trauma of severe infection had they been born ten or even five years ago.
2. The willingness and ability of specialist deafblind services to accept referrals of such children has increased. Chris Best's point about the need for schools to change in character and re-think their admission policy is very relevant here, and applies also to the growing number of advisory services for children with multi-sensory impairments.
3. As a result of point 2 above and of increased teacher training courses at all sorts of level, there is heightened and growing awareness of what can be done to help children who were, perhaps, previously seen as having 'profound and multiple learning difficulties' and whose sensory impairments were not recognised or were considered 'the least of their problems'.

### **Survey of 100 children**

In 1996 I collected information about 100 children who were currently receiving services from the Sense family centre in Ealing. Much of the information came from the children's parents, and though there was medical evidence in many cases, there were also many gaps so that the information is not complete. There were 51 boys and 49 girls in the group and the age range was from four months to six and a half years.

### **Causes**

It is often very difficult to pinpoint the precise cause of child's disabilities, but parents were asked their opinion and this was often backed up by written medical information. The largest group of children (26) has no known cause for their disabilities, and 29 separate causes were mentioned for the other 74 children. Most numerically significant were prematurity (12 children), birth trauma/asphyxia (8 children), CHARGE Association (7 children), Cytomegalovirus infection (5 children), and meningitis infection (5 children). There were 9 different named syndromes including congenital rubella syndrome (2 children, Cri du Chat, Cat eye, Goldenhar, Noonan's and Pallister Killian and seven different rare identified chromosome abnormalities (7 children).

## **Anomalies**

Twenty five separate anomalies were identified within group. In addition to visual and hearing impairments these included severe hypertonia (54 children), epilepsy (45 children), severe feeding problems (43 children), heart defects (18 children), hydrocephalus (10 children), hernia (5 children), choanalatresia (4 children), and cleft palate (3 children). The child with the most identified anomalies (9) had CHARGE Association but is developing and learning at a more satisfactory rate than any other child in the study. Some of the most severely disabled children in the group have only 3 to 4 identified anomalies. Clearly the severity of each individual anomalies. Clearly the severity of each individual anomaly is a crucial factor in determining rate of development rather than the number of separate anomalies present, although severe hypertonia and epilepsy were very common features of the children who are showing extreme delay in their development. The majority of children in the study had 3 or 4 identified anomalies (58 children), 35 children had between 5 and 9 identified anomalies., whilst only 7 were reported as having vision and hearing difficulties with no other anomalies.

## **Implications of these Trends**

Within the population of children with multi-sensory impairment the increase in the incidence and severity of multiple disabilities means that every aspect of living and learning becomes more challenging, both for the children and for their families and professionals involved with them. The sheer number of different areas of professional expertise which need to be called upon presents all sorts of problems, it is not unusual to meet 18 month old children who already have almost twenty separate professionals or agencies appropriately involved with them.

More professionals means more need for co-ordination, liaison, and shaping of skills and opinions, and also more scope for confusion, waste, and mis-understanding. The fragmentation of the population into many small sub-groups defined by causal agent means that it is now much more difficult to predict development and to decide on educational approaches than was the case when working with a population consisting of mostly children with congenital rubella syndrome, whilst individualisation of assessment and educational programming has always been important for children with multi-sensory impairment it is now absolutely essential because of the huge variety of needs and learning styles presented by the present day population.

More complex and severe disabilities means a much slower time scale, both within specific activities and teaching programmes, and also in terms of speed and scale of overall development. For family and paramedical techniques including the use of suction, tube or gastrostomy feeding, the administration of enemas, injections and a wide range of medication, the use of specialised equipment for physical positioning, mobility, and feeding.

In the children themselves we see the increasing prominence of certain features which carry huge implications for those people involved with them now and in the future. The slow time

scale and very individual needs I have just mentioned are two of these features. Others include dramatic loss of skills caused by any illnesses and/or prolonged and repeated hospitalisation, and general ill-health accompanied by epileptic fits, pain, and varying doses of combined medication with undesirable side effects. Lack of mobility due to severe physical disability is another growing feature of this client group, as is the presence of severe problems resulting in prolonged tube feeding, failure to thrive, and an increasing prevalence of gastrostomy operations (15 of the children in this study have gastrostomies). Chronic constipation and persistently poor sleep patterns should never be under-estimated as factors contributing to slow development when they are associated with these other problems (which they often use). Finally, fatigue is a very significant factor in most of these children ' s lives, which has a crucial impact on their style and rate of learning.

### **Implications for Professional Services**

Based on the experiences of professionals working for various early years services and those working in certain schools/units, the following appear to be significant factors which will need to be considered in the future:

Environmental factors, particularly the suitability of premises for access, mobility, and the storage of specialised equipment necessitated by the increasing prevalence of significant physical disability.

Medical, nursing, and therapy cover at appropriate levels to cater for current needs plus the increasing likelihood of chronic ill health amongst the client group.

As mentioned above, very large numbers of different professionals are likely to be involved with this population, necessitating the establishing of precise and clear systems to achieve, maintain and maximise the effectiveness of this multi-disciplinary input.

Current agreed staffing ratios may be inadequate and may need to be re-considered.

There may be a shift in emphasis in the balance between teaching and providing care which probably need a redefining of purpose. Not only will everyone involved need to adapt to a slower time scale when working with some individuals, but previous approaches to communication work will prove inappropriate and need significant adaptation.

## Day 02

### INGO's Supporting deafblind Programmes in Asia

#### **1. Richard Hawkes, Sense International , UK**

**ABSTRACT:** Sense International is an international NGO working in the field of deafblindness and multiple disability. It was established in 1994 in response to many requests for support being received by SENSE UK from around the world. Sense UK itself is the largest

deafblind organisation in the world, established for more than 40 years and now employing more than 1500 members of staff.

Sense International does not develop its own services – we support partner organisations around the world and help those partners develop their own deafblind services. We support partners working with children, young adults and older people; and those working with both congenitally deafblind people and those who have acquired deafblindness. We provide expertise in all of these areas and, importantly, support the partners' ability to make the services sustainable. Thus training and expertise can be provided in areas as diverse as Usher Syndrome, early intervention or fundraising and financial management.

In this presentation the presenter will give examples of Sense International's work in Asia and explain how the above approaches have contributed to the vast increase in deafblind developments in India in recent years.

**DAY: 02  
PLENARY IV**

**INGOs supporting Deafblind programmes in Asia**

**2. From Transfer Of Knowledge To Exchange Of Information In The Co-operation With Deafblind Programmes In Asia**

**By Ms Drs. Lieke de Leuw, International Co-ordinator Instituut voor Doven, Holland.**

Since the beginning of this century Instituut voor Doven (IvD) in Sint-Michielsgestel, the Netherlands has trained teachers of the deaf for Developing Countries. From the late sixties teachers of the deafblind from all over the world came to School Rafaël, a school for deafblind children to follow teacher training courses in the area of deafblindness. In this paper I shall focus on the recent changes in IvD in relation to the development of the co-operation of IvD with deafblind programmes and schools for the deaf in Developing Countries, especially Asia.

In the late sixties the American Foundation for Overseas Blind in Paris, requested IvD to support beginning deafblind programmes by conducting courses for teachers of the deafblind. This request was the beginning of the first International Course in the Education of the Deafblind in

Sint-Michielsgestel in 1968. In the middle of the seventies we were also asked by number of Non Governmental Organisations working in Developing Countries to train people from Developing Countries. A three month International Course was developed to transfer our knowledge. Between 1968 and 1992 eighteen courses were conducted. During these years nearly 375 teachers from 52 countries received a diploma for the respective area. IvD established a large international network.

Regularly evaluations were carried out. In 1994 the decision was made to stop the International Courses in Sint-Michielsgestel. We realised that the transfer of knowledge to one or two people from a school team was not very effective in some cultures. Instead of we decided to build 'pilot projects' or so called 'model programmes' in several countries in Asia, Africa and Central and Eastern Europe. Members of IvD staff travel to the project-site which request assistance. This way of working gives us the opportunity to reach the administration, the whole school team and local authorities. Additionally we learn about the expertise and the way of working of our colleagues in their own context. The Western top-down model of transfer of knowledge has changed into a bottom-up model of exchange of information, an international partnership between the western world and developing countries, to improve the quality of education of deafblind and deaf children.

## **DAY: 02 PLENARY IV**

### **3. INGOs Supporting Deafblind Programmes In Asia**

**By Marianne Riggio, M.Ed. and Kirk Horton,  
Hilton Perkins Program, USA**

The Hilton/Perkins Program has the mission to improve the quality of life for children who are blind with additional disabilities including those children who are deafblind. This mission is realized through four major priority areas. These are:

To develop, refine and expand educational programs and support services for children who are multihandicapped blind and deafblind;

To strengthen the regional network connecting service providers, families and those with related interests;

To expand and enhance local and regional expertise as well as materials and literature for professionals and parents.

To increase public awareness of the value of services to children and youth who are multihandicapped blind and deafblind and their families.

The Hilton/Perkins Program has been a presence in Asia since its inception in 1989. During

this period, efforts have primarily focused upon the direct assistance to programs in order to create models for services to this population throughout the region. It is our belief that through the development of model programs that services evolve. In order to help programs build their abilities and confidence in serving children who are deafblind, we have, in recent years prioritized the development of linkages between seasoned professionals within our own country to work in partnership with those individuals who are providing direct educational services to the children of Asia. These partnerships have include a great deal of on-site work within program, the selection of experienced professionals to participate in outside training opportunities, the assistance with the development of materials written within the local context, and broad training opportunities within country. As many programs have now taken hold and staff, through there own dedication and commitment we are now pleased to be able to support the efforts of Asian professionals to assist other programs within their own country and throughout the region.

**DAY:2**  
**PLENARY-V**

**Approaches To Education And Rehabilitation Of Deafblind**

**1. Home Based Service Programme - Model for working with Deaf-blind Children in India By**

**by**

**Meena Nikam, NAB (India)**  
**(National Coordinator)**

**Present Scenario:**

Deafblindness is a hidden disability which is—least, understood and most misunderstood of all the disabilities. In India, no survey exists regarding this population. But it is estimated that out of the population of 980 million, there might be around 250,000 persons with this dual sensory impairment. At present only less than 150 are getting some kind of services. This is about 0.06Pr, of the estimated Deaf blind population. That means remaining people have no facilities available for their education and rehabilitation.

It might be because education to these children is a most challenging job due to various reasons, viz. high financial cost of the programmes, the medical assistance, intense

supervision which these children require, need of highly individualised plan, high teacher children ratio, etc. There is also lack of trained professionals in this particular area.

Thus, –considering all the above problems the only way of reaching to unreached deaf blind children is to initiate and develop a service delivery model by which services of high quality will be delivered at very low cost.

### **Initiation of Home Based Model:**

National Association for the Blind, India, have initiated and developed Itinerant Type of Integrated Education for Children with Visual Impairment in different parts of the country both in urban and rural areas. Experience gained in this area during the past over 15 years proved a driving force for initiating a Home based service programme for children with multi-sensory impairments in the City of Mumbai and its adjoining areas. This approach was taken after considering some important factors, such as

*Transportation problem*

*Physical and mental health of the Children*

*Socio-economic status of the family*

*Lack of appropriate services available.*

The aim of this home based programme was to:

Reach out to children who are not getting any kind of services.

–

Work with the family as a team - Help them to accept the child and understand his/her special needs.

Help child's parents to learn essential skills to deal with this child, regardless of their financial and educational status.

Educate the child in his/her own home environment where he/she will be able to use his/her skills without having a problem of skill transfer.

Make maximum use of local resources and infrastructure.

Create awareness about existence of children with multiple disabilities, special needs and potentials of this group of children

## **2. Operational stages of home based model:**

With this aim in mind, home based programme was started in the year 1995. Operational stages of this programme involve initial visits of Coordinator and Special Educator. The programme is explained to the parents and process of building up rapport

with the child and family begins.

Simultaneously, assessment process starts by involving professionals in the community. Functional assessment is done by Special Educators involving family members to discover unique strengths and needs of the child. Based on the results they, as a team, develop the Individual Education Plans. ~~Skill-~~ training programme starts in home environment. Teacher visits each family thrice a week, demonstrates the activity to the parents.

The parents copy the activity in front of the teacher as well as do the follow-up as explained. The teacher also explains purpose of each activity and when it could be naturally carried out. Regular home visits enable the teacher to see if parents have understood why and how to impart different skills. Home visits also enable involvement of all family members which lessens the burden of the mother.

### **3. Family strengthening programme:**

Partnership with the parents at each step and involvement of parents in the programme is the essence of success and sustainability of such programmes. Therefore, in this home based model utmost care has been taken to devise some strategies to strengthen the families. The activities for family strengthening programme can be summarised as follows :

- *Periodic Parents meetings*
- *Individual and Group counselling sessions*
- ~~parents training programmes~~
- ~~Week-ends~~ away for children
- ~~Siblings Workshops~~
- ~~Week-end~~ away for families
- *Celebration of festivals, birthdays, etc.*
- *Family picnics*

Helping parents to feel more confident in order to become more competent may be difficult but above activities certainly provide opportunity to share feelings, experiences, enhance interaction and encourage effective participation of all family members. The success of any intervention programme should be measured not only by the child's ~~development but by~~ increased family comfort, decrease in emotional stress and lower incidence of behavioural problems in siblings.

### **4. Community Based Instructions :**

Services for such children should go much beyond imparting of training in the area of daily living skills, mobility and communication. The overall ~~development~~ of the child can be attained only by establishing strong community support which also ensures the sustainability of any programme.

In our home based model we cover a wider area by providing children the opportunity to mingle with the community. As a part of their educational process, children are familiarised with the facilities in surrounding environment such as shops, bank, post office, hospital, public transport, swimming pool, gyms,—ete. They are also trained to have access to these facilities and learn to use them. At the same time, persons managing these facilities are also sensitised to the unique needs of children and are advised as to how to deal with them, for imparting such training, we use the environment where child lives, which makes learning of skills by the child as well as creating public awareness a simultaneous process. Thus, it serves our ultimate objective of integrating these children in their own community.

### **5. Development of Low Cost Material :-Material:**

Home based programme enables to have an ongoing relationship with families and to understand the particular constraints which parents may have to work under. As we train the child in the environment where he/she lives and learns to perform the task, it enables us to think and make appropriate supportive teaching aids, mobility aids, seating arrangements, communication boards, etc, by using low cost material, i.e. ~~P.V.C.~~PVC pipes, wood, cardboard, etc., which is locally available. In the process of development of low cost material, parents can also contribute by providing practical tips as regard to specific need of their child and assisting in making them.

The ~~concept~~—of parents as partners is not that easy to implement. The growth and development of our programme during the last four years have clearly ~~shown~~—that with appropriate strategies, parents can be ~~effective~~—educators and can deal with their children confidently in the absence of professionals. Again, it is a cost effective and result oriented ~~model~~, which includes all aspects of education. Most of the parents expressed their happiness and said that they considered themselves lucky to have such kind of services at their doorstep. This model helped to establish healthy and meaningful bond between them and their child.

## **DAY: 02 PLENERY:V**

### **Approaches to Education and Rehabilitation of Deafblind**

#### **2. Presentation by: Vimal Thawani, India**

#### **ABSTRACT**

**Services for the deafblind in the country like India are relatively a new concept. Until now there were few services which are near to nothing for such a cast and thickly populated country like India. The rough estimates received from data of CBRA projects all over the country suggests that there could be 250,000 people with deafblindness.**

**The ultimate aim of any programme or service or any approach is to reach the target population that help them to achieve independence as for as possible and to have a better quality of life. The approach could be centre based, family based or community**

based. Each approach is complementary to one another. It mainly depends on the needs of an individual, geographical and other socio-cultural factors. In the present context, I would present before you our experience of working with people with deafblindness through the Community Based Rehabilitation (CBR) approach.

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**DAY 02-CONCURRENT III-SESSION II**  
**DBI CONFERENCE**

**PAPER 1 ON NETWORKING**

*Mrs. Aloka Guha,*  
*Director,*  
*The Spastics Society of Tamilnadu,*  
*Opp. T.T.T.I., Taramani Road,*  
*Chennai 600 113*

**INTRODUCTION:**

In the absence of a blueprint on Networking, and without an opportunity to review existing literature on the subject, this paper is presented on the basis of several years of professional experience devoted to developing linkages and forging collaborations between and within a whole spectrum of related and unrelated groups and individuals who may or may not represent Government, NGOs, Organisations and Communities.

Always, with the single and determined objective of promoting the inclusion of disability issues into other, more mainstream, more routine matters; and almost always, seeking to upgrade disability concerns within existing priorities of various departments, organisations, groups, and communities.

An active network can help to sensitize, to push, to share and sometimes just to keep on the agenda, a concern like disability which is not on anyone's priority list.

The oldest Network in the World is organised Religion? The largest and strongest network of mankind. Before the advent of modern telecommunication and modern transport, how did it survive? Indeed, How did it grow in the first place? and WHY was it felt to be necessary? What were its objectives?

**DEFINITION:**

The Oxford Dictionary defines 'Network' as:-

# H

?A Group of people who exchange information, contacts and experience for professional or social purposes.

In a recent SubRegional Seminar organised by UNCIEF in Chennai on ?Innovations in ECCD?, the subgroup on Networking evolved a consultative definition which says ?A process of building linkages and capacities, connecting individuals and groups, providing an accessible forum for exchange of information, ideas and good practices, focussing on issues with in-built mechanisms for expansion and sustainability.?

## **WHAT IT IS:**

The key words from both definitions are EXCHANGE, SHARE, CONNECT, LINKAGES, PROCESS.

This leads us to ask ?What is Networking??

Keeping in mind the current situation with respect to globalization and the market flooding by Information Technology Network may be seen as an [1] Approach and an attitude, [2] as a Tool and a Methodology, [3] as an ongoing process with in-built mechanisms for monitoring, for flexibility and for sustainability, [4] as an social technology in a very contextual ? in urban, or in rural setting, [5] as an activity that definitely promotes inclusion [which is the main goal of the Disability sector] and [6] finally, that is, in today?s world, an absolute imperative although Networking is neither new in concept or in design . What IS new, is the centrality of it, the primacy of it, the top priority it how receives, in any professional sector. It is no longer at option, or an additionality as it was a few years ago. Now, its an imperative. If you want to stay ahead, and ?with it? then you have to network.

## **The WHY of NETWORKING**

1. Promotes brotherhood
2. Builds capacities /competencies
3. Decreases duplication
4. Provides peer support, encouragement and motivation
5. Facilitates large scale transfer
6. Has cumulative or additive effect
7. Has spread effect
8. Is more cost-effective
9. Has greater, wider, overall impact [provides critical mass]
10. Fosters excellence through competition



## **STEPS IN NETWORKING**

- Acknowledge - ?I do not have ALL the answers?
- Sourcing others who do
- Be willing to share what one has
- Be willing to learn from others, unreservedly
- Take initiatives to form linkages
- Persist with follow up
- Be prepared for setbacks, sabotage, severance
- Respect individuality and democracy
- Source funding / reallocate budgets
- Be transparent, encourage openness
- Evaluate, grow, sustain

## **KEY COMPONENTS OF FAILURE**

1. Arrogant, overbearing, dictatorial condescending attitude
2. Misinformation - dissemination
3. Attempts to get mileage by creating barriers between other partners [the colonial syndrome]
4. Material and financial misuse of resources by few
5. Short-sighted approach to common goals
6. Donor-directed priorities
7. Membership disparity
8. Political interference

9.

Positive Attitude  
Clear Goals and purpose

Transparency

Financial Integrity

**KEY COMPONENTS**

Cross Disciplinary

**OF SUCCESS**

Clear channels of Communication

Equity-based ? gender, age, status

Democratic Functioning

Size of Network

Nature of Activities

## **PROBLEMS FACED 1**

## **PROBLEMS FACED 2**

### **COMMUNICATION**

## **.PROBLEMS FACED 3**

### **Lack of Understanding Goals**

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## **PROBLEMS FACED 4**

### **Time Schedules**

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## **ACTIVITIES MOST SUITED TO NETWORKING**

1. Information - dissemination
2. Development of data banks
3. Partnership Marketing
- 4.a. Transfer of Skills
- b. Staff - Development
5. Organisation Development
6. Activism - Advocacy
7. Self Help Movement

## **THE HOW OF NETWORK:**

Person to Person Contact                      ? Traditional Method  
Telephones, Fax, E-Mail, Z-Mail ? Contemporary Methods  
Written information ? fact sheets, journals, bulletins  
Floppies, Discs, Computer link-up, Mass media  
Documentation ? films, books audio cassettes  
Formal and Informal meetings, seminars, workshops etc.

Professionalism - Enables

**DISADVANTAGES /**  
**WEAKNESSES**

**KEY INDICATORS OF SUCCESS**

|                     |                                |
|---------------------|--------------------------------|
| <u>Requests for</u> | <u>Greater Awareness</u>       |
| <u>expansion ?</u>  | <u>Attitudinal Changes</u>     |
| <u>replication</u>  | <u>More Programmes</u>         |
|                     | <u>Greater professionalism</u> |
|                     | <u>Enhanced competencies</u>   |

**THE LIGHTER SIDE**

N - NEED- based felt  
expressed

E - Eveready, elastic

T - Tenacious

W - Work, worthwhile

O - Often, over & over, opportunities

R - Result-oriented, resource-happy

K - Commitment or kinesthetic

I - Forget the I otherwise, be innovative

N - Now

G - Ground realities - based, gregarious. GOOD

Network takes time to conceive, to plan, to set in MOTION, to implement and to show observable, palpable results.

It is like the developing brain of a newborn baby ? it needs to be nurtured lovingly in the early years; it needs carefully structured external stimulation, in order to multiply its neural connections and grow into an active, vibrant healthy, human being. I chose this symbol because MAN is born with a social compulsion to reach out and touch others, he aspires to learn as well as to teach, and he dreams of leaving his mark on the World in whatever way he can.

NETWORKING gives him/her that perfect outlet.

MAN is born to Network:

As Advocates, Educators and Catalysts

As Monitors and Whistle Blowers

As Mediators, Conciliators and Bridge Builders

## **CONCLUSION:**

Managing a growing organisation which is constantly striving to improve the quality of its work means that professionals have to be well placed to learn from the experiences of others. Networking is an important tool in this. Networking is important because it involves the sharing of information, knowledge and experience. This means that everyone in a network is both a source of learning for others and a learner from others? experiences.

Professionals often say that they do not have time for networking because they are too busy ?doing the real work?. My response is that seeking ways to improve the quality of what they do and contributing to the development of others are part of ?the real work?. Networking is a major management responsibility, and should not be an ?optional extra? which gets done only if time permits.

Networking does require time. But more importantly it requires humility. By becoming a member of a network, a professional is admitting: ?I do not have all the answers. I need to learn? as well as recognising ?I have something to offer to others.?

Increasingly, NGOs which do not network with other organisations may be left without budgets as funding bodies look more and more for signs that their funding will lead to a ?scaling-up? of impact. Networks are a way of influencing others as well as a source of learning for an organisation. NGO managers are recognising that networking is a skill which is a ?must know? rather than a ?should know? in their work.

## **DAY 02-CONCURRENT III-SESSION II**

### **PAPER 2 ON NETWORKING**

**by: Mamum Jawaharul Islam, Bangedesh**

**Abstract:**

The presenter will concentrate on the need and importance of Networking among organisations in general. Since deafblindness is a very recently identified category of disability, there are not many organizations working for this population. The presenter will present Bangedesh experience in Networking among organizations working for persons with disabilities.

## **DAY 02-CONCURRENT III-SESSION III**

**Orientation and Mobility for Deafblind People**

**Paper by Mr. Zamir Dhale, India**

**Abstract:**

In this paper the presenter, who is a deafblind adult, tries to explain the different types of mobility techniques used by him. He elaborates on the difficulties faced by him in various day to day life situations and he explains how he uses his mobility techniques to deal with the situation. The presenter also mentions about the good and bad experiences he had and expresses his expectations from normal people.

## **DAY 02-CONCURRENT III-SESSION IV**

**Conditions leading to Deafblindness - CHARGE Association**

**David Brown, UK**

The presenter is one of the leading experts in the world on CHARGE Association. He has given presentations in many countries about CHARGE Association and was instrumental in establishing the DbI CHARGE Network. The presenter will talk about CHARGE, how to diagnose it, how to work with children with CHARGE and the importance of working in partnership with others.

**Notes by Stan Munroe**

CHARGE first noted in 1979; acronym created in 1981. Oldest individual with CHARGE in UK is 31; in Europe 40+.

- C Coloboma of iris or retina
- H Heart defects
- A Atresia of the chonal or chonal atresia (uni or bilateral)
- R Growth retardation (after birth)
- G Genital abnormalities (males only)
- E Ear anomalies (external, middle or internal)

**Major Criteria:** Coloboma, atresia, ear anomalies and CNS abnormalities

**Minor Criteria:** genital anomalies, developmental delays, heart defects, short stature, oral and facial defects, tracheal and esophageal fistula.

**Diagnosis:**

Determined to have CHARGE if person has 4 major criteria or 3 major plus 3 minor criteria.

Further diagnostic criteria on CHARGE.

- C** Coloboma of retina (hole)  
Coloboma of iris (keyhole notch)  
Microphthalmia (small eyes)  
Anophthalmia (eyes missing)
- H** Hearts defects, including ventricle, atrium, patent ductus etc
- A** Atresia or stenosis of nasal passages. Includes cleft palate lip; abnormal form of tracheal and esophageal problem. This can lead to swallowing problems. Also can include malformation of larynx; micrognathia or small jaw.
- R** Retarded growth and development. Question whether this is related to problem with growth hormone or due to nutrition. Also refers to delayed dental eruption.
- G** Genital anomalies include: cryptorchidia, delayed puberty, renal abnormalities (born with no kidneys or one kidney); genital hydrophasia
- E** Outer Ear      absence of pinna  
narrow ear canal  
No ear canal  
Middle Ear      problems with bones - welded or blocked  
Inner Ear      High Frequency Sensorineural hearing loss  
Severe to profound hearing loss  
Mild loss  
Semi-circular canal abnormalities  
Mixed hearing loss  
Central auditory processing

**OTHER ISSUES:**

- Skeletal anomalies
- Sleep disorders
- Hypoglycemia (leading to irritability, low activity, fatigue)
- Di-George like problems (immune disorder, growth problems)
- No sense of smell

According to David Brown:

" if you don't get the environment right we can turn these children into MR children with autistic tendencies

" the medical profession tells families of these children that they are deafblind

" We don't know the cause of CHARGE. Some families believe it is environmental or chemical. Others think it is a rogue gene.