

**LIFE STARTS AT SIXTEEN !  
—DOWN'S SYNDROME**

**Mrs. Rekha Ramachandran**  
*President,*  
Down's Syndrome Association of Tamil Nadu



Publisher :  
**Dr. Inderjit Kaur**  
*President,*  
All India Pingalwara Charitable Society (Regd.),  
Tehsilpura, G. T. Road, Amritsar.

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—DOWN'S SYNDROME**

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## Preface

Mrs. Rekha Ramachandran has done an incredible job of sharing her daughter, Babli's story. Through this book, she takes us on a journey of a mother dealing with her daughter's Down syndrome diagnosis and treatment.

Babli is a person with Down syndrome. Down syndrome is a set of physical and mental traits caused by a gene problem that happens before birth. Children who have Down syndrome tend to have certain features, such as a flat face and a short neck. They also have some degree of intellectual disability. This varies from person to person. But in most cases it is mild to moderate. Down syndrome is a lifelong condition. But with care and support, children who have Down syndrome can grow up to have healthy, happy, productive lives.

Rearing a child with Down syndrome is not a bed of roses. One cannot underestimate the impact of an extra chromosome on the developing brain and body of a child. Through the persistent, dedicated efforts of Mrs. Rekha Ramachandran, Babli walks, talks, sings, dances and behaves like any other person. She has grown up into a confident, friendly and energetic person.

Research and studies have clearly shown that parents of Special Need kids often go through high level of stress and emotional turmoil. A wholesome development of a Special Needs child requires maximal participation of both parents in all areas. Competence, ambition and success are achieved by the togetherness of biological caregivers to deal with their situation happily. Their physical abilities,

social and cognitive skills will blossom under the umbrella of love, care and compassion.

Mrs. Rekha Ramachandran inspires other parents into accepting their special children and reassures them that their hard work will bring wonderful rewards.

I have a son with autism. After reading this book, it reaffirms my belief that a mother is the best guide and teacher for her child. This book will be beneficial not only to parents of intellectually challenged children but also to caregivers and professionals.

Down syndrome is not a dead-end diagnosis. It is the beginning of a journey into faith, hope, love and recovery.

I thank Dr. Inderjit Kaur for giving me the opportunity to pen down the preface of this book. It is an honour for which I will feel always and endlessly grateful.

Pingalwara is known for the important work they do to help families and individuals confront, cope with, and overcome challenges. Their care and commitment in publishing such informative books, guide and enlighten society from time to time.

We, at Pingalwara are continually inspired by the dedication and generosity of our donors who answer the call to give again and again. We will always remain indebted to them for their enthusiastic support and belief in our mission.

*Renu Suri*

**LIFE STARTS AT SIXTEEN  
-DOWN SYNDROME**

**A FOREWORD**

By *SHRI C. SUBRAMANIAM*



Philosopher  
Statesman  
Philanthropist  
Former Governor  
(Maharashtra)  
Former Union Cabinet Minister  
Bharat Ratna Recipient

Mrs. Rekha Ramachandran just happens to live in India and more specifically, in Chennai. She and her husband, Mr. N. Ramachandran are blessed with two children and therein lies the blessing!

*Their second child Babli , is a person with Down,s Syndrome. I shall explain...Down syndrome is a naturally occurring chromosomal arrangement that has always been a part of the human condition, being universally present across racial, gender or socio-economic lines, and affects approximately one in 800 births worldwide, causing intellectual and physical disability and associated medical issues.*

Down's Syndrome is present in around 0.1% of births and this seemingly reassuring statistic worldwide actually means that every twenty minutes, a baby with Down's Syndrome is born .....

Until Mrs. Rekha Ramachandran made desperate efforts to learn more about the condition, *there was no*

*information or books available in India.* There were no doctors around who could even advise on anything bordering on therapy and rehabilitation. Children born with Down Syndrome would be written off and the best of attention would be limited to a sheltered existence until death . Such children were not expected to live past their teens.

The saddest part of the whole situation is that if such children are given therapy with in a year after birth, remarkable recovery is possible. The children progress to such an extent that he or she becomes self-reliant in life's basic requirements and can even be employed in simple occupations!

But since there was no known treatment, children with Down Syndrome languished and obviously sank in to the quagmire from which there was no hope of recovery...

It is in this perspective that Rekha Ramachandran's immense contribution to India has to be weighed.

When her daughter, Babli was diagnosed as a child with Down Syndrome, Rekha was shattered. Her entreaties for help from the medical fraternity did not yield anything. Fortunately, she did not give up.

Drawing comfort and solace from her husband's solid support, Rekha made extensive enquiries and came to know that the Down Syndrome Research centres in Birmingham, U.K. and Rhode Island U.S.A. had a lot to offer. The rest is history.

Single-handedly, Rekha set about acquiring the knowledge to treat her own child. She was able to achieve so much that, today their seventeen year old daughter is a living testimony to her herculean efforts; Babli sings,

dances, speaks, fends for herself in hygiene, emotes, plays the keyboard, and has even won a gold medal in swimming at the Special Olympics at Hyderabad!

Most importantly Rekha Ramachandran has set up a centre in Chennai called Down's Syndrome association of Tamil Nadu where children with Down's Syndrome are offered a holistic developmental programme and integrated into normal schools wherever possible.

Today, parents of Down's Syndrome children need not despair like Rekha Ramachandran did, seventeen years ago, for they can get their all the information at the centre. Rekha exhorts that Down's Syndrome children need to receive early intervention as early as possible for the best results, and incidentally, all this is offered ,free for the under privileged.

Mere words cannot describe this intrepid lady. She has created an oasis in the desert of ignorance. For the benefit of mankind, she runs the rehabilitation centre, so that parents of Down's Syndrome children do not face the difficulties she had to face. Moreover, *she has recorded her experiences and intricate knowledge* in this book the only one of its kind in India.

This book is not only a framework of do's and don'ts but is virtually a divine beacon for the shattered parent. It reveals first hand details of Rekha's struggle against Down's Syndrome at every stage of her daughter's life.

Rekha uses simple, hard hitting words to highlight what she felt as she kept learning about the treatment for Down's Syndrome. This book is a blessing for parents and they are in debt to Rekha Ramachandran for the immense relief and succor brought about by it.

It is commonly believed that very determined people achieve *incredible* results through their untiring work, luck and maybe divine intervention. A few years ago, Rekha managed to bring the renowned American, Jack Warner and his entire team to Chennai for ten days.

Dr. Warner has developed a cocktail of vitamins he calls HAP CAPS. Down's children, when administered this nutritional metabolic therapy along with thyroid and ophthalmological support, can hope for complete cure. Even the *Mongoloid features* come back of normalcy! Apparently, Dr. Warner's therapy, under validation in the U.S.A., works best on children under two years of age.

Rekha Ramachandran is convinced that Down's Syndrome might be ***largely overcome by oral doses of vitamins!***

More strength to her, Mathru Mandir, and now, in Dr. Jack Warner's pioneering efforts.

Rekha Ramachandran was invested with the *Woman of the year Award for 1998 from the International Women's Association. Simultaneously her daughter received the Girl child of the year Award for 1998.*

It was indeed a poignant moment to see Babli, who has undergone 122 procedures under general anesthesia, walk up to the stage to receive her award. After all, thanks to Rekha Ramachandran , the whole world is her stage today.

Parents look up to Rekha Ramachandran as she works tirelessly in her crusade against Down's Syndrome. This book is the harbinger of hope to thousands of parents that life does not have to end at sixteen for their children.

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## CHAPTER ONE A Mother's Memories

I present this book with the prayer that my child, Babli, will be of help to different people handling infants and adolescents with Down's Syndrome. I hope the following pages will help both anxious parents and professionals to gain something of value, and also help anyone interested in the care of intellectually challenged children.

### **Reflection on the past 25 years**

Many times I have wondered what life would have had in store for me if it had not been for the birth of this amazing person, (my daughter Babli) who has taught me to be what I am today... a happy positive person.

Even as a child I remember reaching out to the less fortunate kids in my neighbourhood and, try to please them by giving them my pencils or my sweets.

My father constantly dinned it into my head that he wished me to be a medical doctor and do free service.

When I completed my Doctorate and got the label of a doctor, I felt I had come one step closer to his dream. When Babli entered our world I never realized that one day I would be able to serve the people by helping them to free themselves from the enormous guilt of having brought a child with challenges into the world. It seemed difficult to understand this feeling that was projected by most parents, of rejection!!!

When Babli was presented to me with all her challenges I do not remember a day that I felt weighed down or afraid of raising this child. A child is a child and every child will work to their fullest potential if they are

given the opportunity.... However one must also understand their limitations and guide them to overcome them.

During my counseling sessions, whenever I reach out to the parents I often wonder, "Is it so difficult to accept this child?" Sometimes I believe that not having the internet and the numerous sites was an advantage as I took one day at a time and allowed my child to develop at her own pace. At other times I realise that but for my website not many parents would have sought me out.

Most times I feel the parents are feeling sorry for themselves and their questions are always the same, "Why me?" Feelings of guilt, shame, rejection, and many feel they have sinned and this is a punishment. To me, if this is His way of punishing then I do not mind this punishment again and again. The pleasure I have had in raising Babli can never be equated to raising the so called "normal" kids.

I find the same questions racing through the minds of every parent and with the 4300 parents that I have reached out to and spent time with I have learnt a little more, and they have been my teachers and have actually given me a solution to all my problems. With every parent I have envisaged different level of pain, tolerance, levels of acceptance, and with some it seems like the best gift from God. I have cried with the parents, laughed with them, appreciated every single achievement of their child, been with them during medical complications, and guided them through schools and into professional careers.

What a life .....yes 25 years of working and living with people with Down Syndrome has made me what I am ... As a good friend once said "A smile is a light in the window which tells all, that there is a caring, sharing person inside"....

What made me feel really proud was when my son presented me with a smiling face stone sculpture for always smiling!! Thank you son for being there....

Down Syndrome children vary enormously in their potential. I have been repeating this in my programmes for babies with Down Syndrome. The reader should not compare his or her child's progress with that of Babli. The physical and mental stress on Babli's progress during the first two years of her life reflects also the difficulties I had in coming to terms with her handicap. Every parent should view his or her child as an individual born to offer something unique to the world. Perhaps the following passage from Morris West's "The Clowns of God" expresses best my feelings: "You need a sign. What better one could I give than to make this little one whole and new? I could do it, but I will not. I am the Lord and not a conjurer. I gave this mite a gift I denied to all of you-eternal innocence. To you she look imperfect-but to me she is flawless, like the bud that dies unopened or the fledgling that falls from the nest to be devoured by the ants. She will never pervert or destroy the work of my father's hands. She is necessary to you." She will evoke the kindness that will keep you human. Her infirmity will prompt you to gratitude for your own good fortune. More! She will remind you every day that I am who I am, that my ways are not yours, and that the smallest dust mote whirled in darkest space does not fall out of my hand. I have chosen you. You have not chosen me. This little one is my sign to you. Treasure!"

"A bundle of joy" was the description of Babli in

the Indian Express —Yes, my daughter has always been a source of happiness to our family. My world revolves round her. She is the best thing that could have ever happened to any loving, caring parent. I never think of Babli as a ‘retarded’ child. I have always disliked that description of any child—imagine calling God’s creation ‘retarded’. God made them for us to realize how small and petty we are in comparison to these SPECIAL ONES.

Sometimes, looking back on the past, seventeen years, I feel I have acted out a very effective role—of a mother. Most people have asked me what I felt, how I reacted or how acute my depression was, as I dealt with one shock after the other. I only know that but for my family and friends I might not have survived even a night. The days were easier to get by. My feelings can be expressed in just one word—NUMB. I went through the first two years in a daze—it was like viewing everyone, including my daughter, from a distance. Sure, there was a problem but I tackled it minute by minute, never thinking what the next would hold.

I never thought even for a moment, that my daughter would be what I term SPECIAL—she looked like a little Chinese doll—beautiful and angelic when she lay by my side a few hours after birth. I was a proud mother and my husband was beaming. My son then four years old, came in and called her a ‘tomato’. Mine was an ideal family. Babli looked so healthy and strong that in those first few days, I thought she would grow up to be a beautiful girl. A mother’s ambitions for her child are a different story altogether. My dreams were to shatter very shortly.

As I think back, I remember doctors streaming in one after the other. All my relatives kept talking in hushed whispers. I was blissfully unaware that the centre of attraction was my little one. It so happened that in the room opposite to mine there was a child who, they kept saying had ‘cerebral palsy’. It meant nothing to me. They described the child as ‘handicapped’. If at that time someone had told me that my daughter was a Down’s Syndrome, I might have shared my pain with the mother of that child. But all I could do was to thank God for my lovely child. At that point I suppose, the Lord above was pitying me for being so naïve and so totally ignorant of what the future held for me.

Babli and I stayed in hospital for two weeks so that I could recover my strength and be able to handle both my children. A week after I arrived home, we were getting adjusted to the place when my pediatrician wished to meet me. In the privacy of my room, he sat by the window and said in a very soft tone, “Rekha, I think Babli is blind.” I shall never forget the expression on his face, the way he tried to reach out to me with just a hint of pain. Babli, according to the medical world, was born with bilateral cataracts. It again was a description which had no meaning to me. My daughter could not see! Could my doctors be wrong? How could my daughter be blind? I was certain she was following me. She did respond to light! She had recognized me. She had smiled at me. She had such bright dove – like eyes. They were a deep grey. Was it this colour which made them so positive about the cataract? So many questions, and only sympathetic looks from friends. I sat in my room for about three hours just holding the baby,

trying to view the world *through her eyes* and finding a heavy feeling but unable to express it. I remained in that state till my son came screaming into the room asking for a pencil sharpener. I came bouncing back to reality and decided to brave the situation.

A few days later, we went to the ophthalmologist. One look at my daughter and he decided on surgery. She needed to be operated upon immediately. The cataract was very dense. After that everything moved so fast. I was in a daze through most of this. It is impossible to recollect how I felt. Both the surgeries in the sixth and seventh weeks of her life were done in a very neat and quick manner—Babli went through a series of check-ups. She was given anaesthesia week after week. They were unable to check her eyes without general anaesthesia, and every time she was given general anaesthesia, she lost a day.

I can still see this little doll all prepared for her surgery—with a little green cap and an apron, and her feet wrapped in white cotton socks. She reminded me of the little green elf from Enid Blyton's stories. So innocent and shut off from this world, she would be wheeled into the theater on a stretcher and brought out with a huge bottle of I.V. suspended from a stand.

This process went on for four months. At the end of the fifth month we were asked to take Babli to Bombay to fit her with soft plastic lenses. We rushed her to Bombay and the strain seemed too much for her. She developed an infection and was laid up with high temperature. Four days after the fever broke; she was again given general anaesthesia so that it would be possible for her to be fitted with contact lenses.

The day was bright and clear, and both my husband and I waited by the large windows at the end of a long corridor. Babli was brought out on a stretcher and seemed to be in deep slumber. She finally opened her eyes and gave a big smile. To me it seemed the gates to heaven had been opened. My daughter could see me. She no longer had to feel me. That was the only time I remember having tears in my eyes. She looked and looked as if she was aware of a whole new world of colours and shapes. The little one had suffered so much in so short a time. But what did the future have in store for her?

The next two months were filled with tension. I had a daily routine of fitting in her lenses in the morning and removing them at night. Both seemed rather painful to the child. I, however, do recall that my daughter never so much as twitched her body when I tried to fit in the lenses. Maybe she knew they gave her the power to see. The lenses had to be constantly sterilized and one had to check whether they were in her eyes or if she had rubbed them off. Babli lost more than fourteen pairs of lenses. She either flicked them off or chewed on them. We were always on all fours searching for the small pieces of plastic which would have shrivelled up by the time we traced them.

In the meantime, Babli had developed another problem in her right eye. It was swollen and another visit to our ophthalmologist proved that she had glaucoma. The pressure in the eye was building up and we had to send her in for another surgery. This time an iridectomy. I wanted to scream and hurl abuses at God. Why was he picking on the same child each time he felt like lashing out? Could he not pick on someone older? However, I realized there was no point cursing the Almighty. I had a duty by my child.



Babli underwent another surgery at seven months and fortunately she cooperated so well that she was soon able to use that eye. We went down to Bombay once again and the doctor declared her fit. I had already started exercises for her to focus her eyes on objects.

Everything seemed smooth and settled when the earth shook again and took away all the courage I had built over the past few months. It was soon after the last surgery that my pediatrician walked into our lives once again, the bearer of more bad news. It was conveyed to me by my husband who came up to me and said, “The baby will never be normal”. I smiled and said; just because her cataracts were operated it did not make her any different. He pursed his lips and repeated the sentence again. I stared at him wondering why he was being so nasty, when I saw the entire family entering the room. So this was to be a family affair, and that meant something serious.

Babli was what they termed a Down’s Syndrome— i.e. a child having one extra chromosome in every cell (she had 47 instead of normal 46 chromosomes.) This extra genetic material was causing all the disorder in the human system. It upsets both the physical and mental make-up of the person. This child would be very slow and would never be in a position to live independently.

I had never heard of the syndrome and had never realized the implication of having such a baby. My husband was shattered. He could not believe that he had fathered an imperfect child.



I was unable to console him. Men, I feel, are the weaker of

the sexes and I am sure most wives would agree.

In any case since this was my battle, I sat down by myself and got my priorities straight. First of all, I decided to write to all the major institutions in the world and ask for information on the subject.

The Down’s Syndrome Centre in Birmingham seemed to be well equipped with all the basic and advanced literature. I got all the information through friends living abroad. I constantly read programmes by Rex Brinkworth and he became my mentor and guide.

I attended all the meetings in Madras on Mental Retardation. I met a number of professionals and also parents who had suffered just as I had. I shared my pain with them and just listening to their experiences made me regain my strength to fight for all of us.

India, I found out at this stage, did not have a single school, institution, or a home for Down’s Syndrome children. They were grouping them with the mentally, physically handicapped or the spastic children. It came as a rude shock when I realized that there was no place I could really go to for help for programmes. I stayed awake night after night worrying about the problem and thinking how best I could rectify the situation.

Babli was a year old when she learnt to sit. By now she was able to put two blocks, one on the other, was grasping a peg, and responding to her name. I had a special teacher, Kamini, come in for two hours a day to help me train Babli. We propped her up against pillows and talked to her. She was a keen listener and loved to look at pictures. Every picture we had was matched with an object which she would feel. Every time she recognized the picture in the book by pointing to the object, we would reward her and everyone was made to clap and say, “Good girl,

Babli ”. A reward for Babli would normally be a bag of sweets. The use of an incentive in the case of these children to show appreciation produces remarkable results.

At fourteen months , Babli stood for a few minutes without support and she got such an applause that it definitely encouraged her, and she would try it four to five times every day. For support she used the back of her baby chair (cane) and would push it all around the house. She hardly used the baby walker because that only made her move backwards. We tried to get her to climb stairs, but were too scared or too lazy to attempt this exercise.

Speech therapy was practised on our own from the materials we had. We would show her a ball and repeat the word a number of times till she recognized the object. It was then described as a ‘big ball’. Colour sequences fell with this phrase and soon it was ‘A big red ball’ This was worked on daily until she could identify four common colours. She was able to separate the objects and place them according to their colours. She had a bin full of blue, red, yellow and green toys. Shapes followed with the sizes. The one game she really enjoyed was putting in and taking out objects—“give”, take, throw, catch were all started with the big red ball. I hardly remember ever seeing Babli without the ball—like most girls are seen with their dolls.

At eighteen months, Babli started walking on her own. She was very confident and never cried even when she missed a step and fell down. It was at this time that her left eye started giving her trouble and grew to twice its normal size. Another examination proved that she had glaucoma in the left eye and it had to be operated upon. I was very hesitant because I felt that even if she missed a day, it would hinder her progress on a mental and physical

level. I tried to keep the doctors at bay and continued with her therapies.

Both the teacher and I found that Babli had been blessed with an extra sharp sense of hearing. So we decided to work on it. Also tactile sense seemed vitally important. We would tell her short stories—describe everything around her and get her to touch and feel the place, the object, herself, she was made to touch soft and hard surfaces. She started identifying the different parts of her body. Nursery rhymes were on all day long on her tape recorder. She could not say a single word. But she looked as though she understood all that was said. She would try and mouth sounds like *Amma, Tata, Anna, Akka, papa, Mama, Tanni*. We never gave up trying.

Finding a speech therapist was virtually impossible. I visited a number of centers hoping to find someone who would meet my requirements and build a rapport with Babli. It was only when Babli was two years and nine months old that I found the right person. Sudha was a speech therapist at the General Hospital and she decided to help me. I am really fortunate because Sudha became my guide and friend. With her knowledge and my persuasive nature, we achieved a fairly high level of speech and today, Babli can hold a conversation with most people and can be fairly well understood. I do owe this to Sudha without whom Babli might never have achieved such a command over the English language.

It was during my search for a speech therapist that I made a decision. I would definitely make it easier for other parents. One lost too much time searching for help. The first six years are the most vital in a child’s learning and development. It is very important that parents be guided and counseled along the right lines. Today, Mathru

Mandir', a day care centre for Down's has taken on the responsibility to guide and help parents by offering them all the therapies under one roof.

Babli never gave us any trouble when she was being toilet trained. From the time she was seven months and could sit with support, we had a toilet chair. Every two hours she was made to sit on the 'Potty'. She soon started pointing to it every time she needed to use it. Even today she gets up in her sleep to tell me she needs to use the toilet.

The only problem with Babli was that she suffered from acute constipation. Even when she was a baby, we had to give her large doses of liquid paraffin to make it easy for her to move her bowels. Even today she needs to have a laxative.

Perpetual colds and coughs are a part of the syndrome. Babli had a cold right through seven years of her life. When she was about twenty-two months, she developed a chest cold and it led to pneumonia. As it was mild and in its early stages we were able to save Babli, but that one month she suffered from a continuous cough. This made her very weak and she was unable to work with us. Even today, I become worried whenever she develops a severe cold or cough.

When she was two years and seven months, I introduced Babli to a Nursery School. I felt she needed a normal, healthy environment.

The school was close to our home, had fewer children and most important of all was that I was given permission to observe the child. Babli found the first three months a little difficult. She was constantly bullied by the older children who would push her around and take her glasses off. She soon realized that she had to defend

herself and never found it difficult to deal with the other children. She is now able to progress very well in all group sessions, especially conversation, dance, art and music. She finds it difficult during the reading and writing classes. Babli now goes for art therapy which has proved very useful for her writing skills.

Babli conducts herself very well in company. Her social behavior and manners are impeccable. She always greets everyone with a smile and a spontaneous 'Hello'. She answers most of our questions and is generally very prompt in obeying commands, except when she is otherwise preoccupied. She is a very obedient child and hardly ever throws a tantrum.

Babli is a video addict. Her language and her comprehension have improved only because of the TV and the tape recorder. She loves viewing herself on the TV and also listening to her own songs. Her favorite tapes are her 'Birthday movies' as she calls them and the Nursery Rhymes; her favorite star is Sivaji Ganesan. I always felt she had this fondness for the star because he normally sings all his songs to his sister and she has such love for her brother that she imagines him to be the one on the screen.

She is very conscious of her clothes and the food she eats, she loves wearing a "Pavadai", i.e., a full skirt in silk because it has an association with God and Pujas. She just has to wear a lot of jewellery, including clip-on earrings and anklets. And she has an expensive taste—she must match her clothes with her shoes, clips and even her bag. Flowers are a must. She collects her flowers from the maid first thing every morning.

The one area where I have failed and all the other parents might have scored is self-feeding skills. Babli has

absolutely no interest in food—even ice-cream. She finds it an effort to sit and eat. She dislikes chewing and swallowing. We have tried all types of food, with or without spices, sweets, mashed foods, until we realized that we had to take the help of the dietician. We fixed her a diet of proteins and vitamins, and it had to be forcefully fed. Paediatricians said that we should leave her to eat as much as she wants on her own, but we found that if we left her to her own devices, she suffered from constipation. I have also come to the conclusion that Down's children hardly ever feel hungry since they do not really exercise themselves.

Babli is not interested in any outdoor game. She dislikes the cycle or playing with a ball. Everything has to be in her room and with music.

The only outdoor activity she has shown any enthusiasm for is swimming. We did not put her in any of the pools till now as she has always suffered from colds, and the water is highly chlorinated, but of late I have started taking her regularly to the pool and she just loves water. I only hope it improves her appetite, too.

Babli has always had a strong sense of devotion to her God. Right from the time she was able to walk, she would follow my family, all of whom are very religious, to the *puja* room and spend hours just watching the activities. I used to consider this a waste of time till I realized that there was some message she was trying to convey to God. She attains peace by just watching the various pictures. A visit to the temple was a major treat, and the flames of the Aarti or the ringing of the bells to win an ecstatic squeal out of her. Even today she looks forward to a *puja*, like most children do to birthday parties.

A birthday party is also a big treat—next only to

*pujas*. She loves to dress up and go to parties where she insists on singing all by herself '*Happy Birthday to you*' clear and loud, and loves the balloons and decorations. She will insist on taking a present for the birthday child, but at the same time she will insist on a present on her way out. She knows how to demand and get her way.

A very important phase of development was the realisation that Babli has started reasoning for herself. She never answers a question if she is not certain of the answer. She would invariably repeat the question, sort it out in her mind and only then would she answer. We never forced her to do things our way. If she did not want to go to school, she would have a number of excuses as to why it was unfair to send her. She would even talk about the inclement weather!

In school she is very prompt with her replies. In the beginning we assumed it to be by rote, but soon it became evident that most of it was never even taught to her. For e.g., when the teacher asked her to name a sweet smelling white flower—prompt came the reply '*Malli pu*' (the jasmine flower). This could have been because Babli is very fond of flowers, but it could also be that she applies all what she hears.

Another instance of her thorough understanding of the situation was when I was away in Hyderabad. I called up Babli at night when she told me she was going out for dinner with her father. When I asked her what she had decided to wear, I could hear her asking him what dress he was going to give her to wear. This she never does with me. In my case, she never asks me what she must wear but only tells me what she is going to wear.

It is, therefore, important to understand these children, and realize that they are well aware of their

surroundings. It is also very important to put them in such situations to realize their reactions. Exposure to any new surrounding will evoke a different emotion from them. Babli is positively surer than other children and very sensitive to the surroundings. She will judge the person's mood and decide where she stands. She is very jealous of her brother. The thought of my petting him or his being close to me puts her into one of her moods. She loves to be fondled or 'cuddled' (as she calls it) by one and all. She has a temper, that builds up very gradually and when it reaches a point of being unbearable she starts hurling abuses.

I owe it to my younger sister Lakshmi and her two children for having helped Babli. If she is at the level she is, it is only because the other children in the family have never made her feel different. In my family, my niece Rupa and my son Rahul have actually brought her up by explaining every detail of every object, teaching her discipline and building her confidence.

The fact that Babli is fairly independent has helped us to move around more confidently. I hardly ever worry about her as she knows her routine. She only needs a little guidance when it comes to her dressing or her toilet. I have a full-time maid to help her play and keep an eye on her. This has helped me run the Down's centre.

I do agree that as a mother, I tend to get over protective at times. Having helped my daughter with methods and programmes made on our own, and having created an interest in her surroundings has taught me that with patience and perseverance, any individual can achieve the impossible. I pray that I can help as many parents as I can with my knowledge and experience. To this end, I have tried to evolve a programme for other parents having Down's Syndrome children.

## CHAPTER TWO What is Down's Syndrome?

Down's Syndrome means the child has been born with one extra chromosome, the hereditary structure in every living cell, which the mother and father have each contributed to the make-up of the child. *The extra chromosome could have come from either parent—so neither the mother nor the father carries the "blame" for this condition.*

### Parental Age

A Down Syndrome birth occurs about once in every six hundred births. About 80 per cent of Down's Syndrome children are born to women under 35, but there is a greater risk of a Down's Syndrome child being born to a woman above 35. That, however, does not mean that it is the mother who contributes the extra chromosome. Today, the father's age at the time of *conception* is also taken into consideration, as recent theories prove that he, too, could be a contributor.

### Physical-Facial Characteristics

Just as the appearance and functions of every living being are primarily determined by his genes, the physical characteristics of a child with Down's Syndrome are shaped by influences from its own genetic materials. Because of its somewhat different "*genetic makeup*" this child with Down's Syndrome has a number of bodily characteristics which make it look different from other children.



The head is smaller when compared with those of normal newborns—the back of the head is slightly flattened. The mouth is often kept open and the tongue protrudes slightly. The eyes are slanted upwards and sometimes they are set far apart. Their hands and feet tend to be small and stubby and in nearly 50 per cent of children with Down's Syndrome a single crease across the palm is observed and there is a wide space between the first and second toe.

Not every child of Down's Syndrome has all the above mentioned characteristics. Certain features may be present in one child and absent in another.

#### **Pleasant Social Nature**

The syndrome is often accompanied by a lively, social nature. They are sub-normal to us. *But such children can be taught and trained to be near normal, with patience exercised by their parents and with proper therapy and careful coaching.*

Having a Down's Syndrome child is usually a shock to most parents. There are certain unhappy facts that have to be faced. First, if the doctor's diagnosis is confirmed and you do have a Down's Syndrome child, it means that there will be some dysfunction. How severe the dysfunction will be depends on the child and its upbringing. There are quite a range of abilities.

Secondly, Down's Syndrome cannot be cured. There is no medicine nor treatment that can *eliminate* the existence of the extra chromosome. However, it has now been found that early intervention and training in fields of speech and play can help this child being, accepted by other parents and children when the child reaches the age for admission into a play group or nursery.

## **CHAPTER THREE**

### **Down, but not out! —Therapy for a Down's Child**

#### **PHYSIOTHERAPY**

Physiotherapy is an important part of a child's training. A child with Down Syndrome normally has Hypotonia (Very weak muscle tone). This can be slowly overcome or at least controlled if a lot of emphasis is placed on physiotherapy right from the beginning. Learning is a continuous process that starts at birth with the experience of sucking, touching, turning, and lifting the head, followed by looking and listening; physiotherapy consists of a programme of passive and active movements for every individual. Gait training, balancing exercises, muscle strengthening, sensory stimulation, and relaxation techniques all form part of the individual's rehabilitation programme.

#### **Early Sensory Training**

The baby is limp and unresponsive, its muscles appear completely soft and powerless. The baby rarely cries or demands anything. It is vitally important not to leave the child alone in its cot, taking it to be a "good" baby who does not appear to want anything or to move. A baby left alone to be motionless on its back in the first year has no exercise for body or mind. *The first month of life and the early years are absolutely vital to a Down's Syndrome child's development, and much can be done to improve the child's reactions and hold on life.*

#### **Tactile and Sound Stimulation**

The baby should be handled as much as possible at feeding and changing times—Whenever the baby is awake, rock and sway it in your arms to stimulate its sense of

balance. Play catchy tunes—hum and sing to the baby. A baby with Down's Syndrome easily takes to music and responds to catchy tunes. It is also necessary to talk to the baby.

### **What to talk to the baby?**

Describe the room he is in, the colours, the pictures, his parents, his brother or sisters, *the importance of his being with you.*

### **Banking on the Future**

Many parents may feel the child is not responding at all and find the effort a waste of time. *Never for once* imagine that your effort is being wasted. Wouldn't you like to explain things to your "normal" little baby? This little one is no different. In fact, he needs your time and undivided attention for a few hours every day.

### **Baby with Down Syndrome is Different**

Down's Syndrome do not usually have brain damage. The *brain cells* are usually *intact*. But the nerves which carry information from one nerve cell to another have very poor insulation and are not able to carry messages so readily. Therefore, a baby with Down Syndrome has a brain that is underdeveloped rather than damaged. *A great deal can be done to improve matters if the brain is subjected to intense stimulation which helps to force the brain to work more efficiently and to develop more normally.*

### **Stimulation Triangle**

Parents of the child should actively become engaged in these early learning experiences. Frequently for children with Down's Syndrome, a combination of strong visual, auditory and tactile stimulation has to be used to elicit adequate responses. Cuddling, clapping of

the hands, tapping the skin, gentle tickling or stroking as well as moving the hands and legs are some of the ways which have been used to combine tactile stimulation such as talking, singing, playing recorded music, and attaching bells to the wrists and ankles.

### **Some Points for Tactile Stimulation**

1. Place an infant on surfaces of varying textures, e.g., rough as well as smooth blankets, different kinds of floor covering or upholstered furniture. The infant's skin should be exposed to these various tactile stimuli.

2. Cover your infant's body with materials of different textures and weights—also both cool and warm garments. Since the infant's level of activity may change under different conditions, you may want to loosen his garments to allow for freer activity or use restricting garments to elicit stronger movements against resistance.

3. Touch your child in a variety of ways including stroking his skin, rubbing, tapping, gentle tickling and light squeezing.

4. Let the infant touch you. Place the baby's hands on your face, hair, clothes and on various parts of his own body. Let the baby feel different shapes and textures of toys.

5. Move the infant's arms and legs. They can be moved in simultaneous or alternate patterns. Children usually respond more actively when movements are accompanied by singing or playing rhythmic tunes.

6. When bathing an infant in tubs or sinks, do not restrict his movements. Encourage splashing and other movements while in the water.

### **PRIMARY GOAL**

Head Control—Probably the most important goal

in the initial phase of an early intervention programme, is the attainment of good head control.

Children with Down's Syndrome can lift their head while lying on their stomach almost from the time of birth. The delay in head control becomes more apparent when they are unable to maintain the raised position for a longer period of time or when they fail to turn the head from one side to another. Children with Down's Syndrome need to strengthen the muscles in their shoulders, backs, and arms. Even at this early stage of development, some variation of the push-up can be introduced to start developing strength in the muscle groups which will be needed later for creeping, place a bolster under the child's hips and stomach; the chest should not rest on the bolster. The hips should be held firmly with both hands while the child is encouraged to lift his head and upper back. Interesting and colourful toys should be placed at an appropriate level in front or slightly above the child's head. They can be moved from side to side to stimulate turning of both head and trunk.

*Rolling over* should be encouraged. It is good exercise for training body control and balance. It is also an early developmental activity, which is brought about through a child's initiative, curiosity and motivation to learn about his environment.

### **Sitting**

The child should be held firmly around the hips; he will frequently straighten his back to maintain a good balance. It may be necessary to put one's hand around the ribs of a child who still has a poor balance while sitting. Such firm support frequently controls the wobbling of the head. Gradually the child will learn to control the muscles

of the neck and upper part of the back. The child will then sit with little or no support. A "sitting chair" can be adapted for the child.

After six to eight months, it is important to teach the child to use its hands, to build up a sound basis for later speech and to prepare the child for walking.

### **Crawling and Creeping**

The following activities can be used for eliciting balance reaction.

1. Lift and then lower your child while holding him either in the upright or horizontal positions, supporting the infant with your hand around his hips. If this does not seem safe enough, place your hands around the child's chest.

2. Lie on the floor with your knees bent. Place your child against or on top of your knees and give support as needed. Rock your child forward, backward, and from side to side. Move your knees off and on to the floor.

3. While your child sits on your lap, tilt him gently forward, backward, and from side to side. Prevent excessive wobbling of the head, but do not over protect by giving too much support to head and trunk.

A child with Down Syndrome may lack sufficient muscle strength in his arms, shoulders and trunk to come to the hand-knee position, or to maintain such a position for any length of time. Therefore, the stage of crawling may be considerably prolonged.

Sometimes, the lack of motivation to crawl or creep may retard a child's progress. It is not enough to place a toy on the floor and to assume that your child will be sufficiently interested to go after it. Since a child with Down's Syndrome may not exhibit the same degree of



attention, curiosity and stamina that we find in a non-handicapped child, one must find the maximal and optimal stimuli that work best under given circumstances.

It would also be necessary to initiate the child's creeping movements by tapping lightly on the soles of its feet or by assisting the movements of his arms and legs.

### **Walking**

The child should be encouraged to explore around in a baby-walker. Let the child follow you from room to room and give him a toy to pull along.

Support the child between your knees to practice the standing position. The child by now will be increasingly mobile though it may not stand unaided until about 18 months or walk much before 20 to 22 months. Some babies take much longer.

### **Climbing a Staircase**

Help the child to crawl on the stairs. Climb a few stairs yourself and then lean down to offer the child your hand. Encourage the child to climb up to you. This will be a *difficult task*, because of the child's unusually small size, short legs, and splayed foot stance.

### **PLAYING WITH THE BABY**

Encourage the child to handle a wide variety of objects so that it practices grasping and adapting its hands to different shapes. The child should feel the texture and surfaces of objects. Teach the child how to transfer objects from one hand to the other. This takes a long time and needs a lot of patience. A coloured ring will encourage him to hold the object with both hands.

Wooden bricks can be set up for the child to knock them down. Show the child how to bang with its hands on a toy drum. Place a big ring over the child's arms, feet and

head and encourage it to take it off. Teach the child to take off its socks.

### **Using Mirrors for stimulation**

Play frequently in front of a large mirror and encourage the child to recognize you first and then himself. With the child on your knee, clap your hands and tickle. Count to five on the child's fingers and toes. Hide toys under boxes in front of the child and ask where they are. Draw the child's attention to the hidden objects and say aloud "there it is". Look at the child to do the same. Pass your arms through a large ring and grasp a toy, withdrawing it slowly through the ring to induce the child to reach through. It is a good exercise for learning to dress up.



### **Much Depends on the Parents**

It has been observed that parents who follow an early stimulation programme achieve positive results and have been able to cross the milestones at a much faster pace than others who might neglect this programme.

### **Outdoor play helps**

All children should be encouraged to play outdoors. This helps the child to overcome certain inhibitions it might have in social gatherings.

Some of the outdoor games recommended are; Hide and seek, throw-ball, cricket, cycling, swimming, running, and skipping.

### **Yoga and Breathing Exercises**

Yoga and breathing exercises help to increase the blood circulation and invigorate facial tissues, organs and the central nervous system. It is held in yoga that it is the mind that controls, governs and activates the body.

### **Co-ordination Skills—Occupational Therapy**

One's hand has frequently been called the instrument of intelligence. Children who are highly skilled in performing complex, fine motor skills activities are generally found to be intelligent, but those with lesser intellectual capacity can also be trained to become quite efficient in carrying out manual tasks.

### **Creative Skills**

Painting colouring, drawing, stitching and threading are all part of their *creative ability* and this prepares children with Down's Syndrome for the future in helping them acquire mental discipline.

### **GUIDING STEPS**

#### **Exercises :**

Children with Down Syndrome start later than the average child in swinging the thumb around the palm of the hand—the thumb-index finger grasp. The pincer grasp can be practiced by placing and holding the child's thumb and index finger around an appropriate object such as small block, a paper ball, a bead, or a coin. Gradually, he or she should be encouraged to pick up such objects

without help.

Children with Down's Syndrome need extra stimulation, encouragement, guidance and training in manipulatory skills. They have to be shown how to explore objects with their hands, how to roll paper into a ball and even how to hold on to something that could easily slip out of their hands. *Therefore, it is very necessary to encourage the use of their hands as early as possible.*

### **Learning to Dance and Sing :**

*Music and dance* as therapy bring forth positive feelings in a child with Down's Syndrome. It provides an outlet for physical and emotional tensions as well as considerable fun. Music helps in developing a sense of rhythm and tempo and aids coordination by encouraging the use of larger and smaller muscles in a controlled manner. Group involvement like dance and drama is important, because many future life experiences depend on whether individuals can identify group situations or not.

### **WATCH THE CHILD GROW**

The physical growth of a Down's Syndrome child is much slower, and this is determined by genetic and nutritional factors. It is a must to maintain a growth chart for each child and their diets should be constantly checked by the dietician as these children have a tendency to put on excessive weight. Parents are advised to follow a programme which is invariably a diet high on protein and vitamins. All the children are fairly independent when it comes to self-feeding skills. When a child can experience meal times as enjoyable get-togethers, he/she will gain a feeling of security.

### **Feeding the Down's Syndrome Child :**

Fortunately most children with Down's Syndrome do not have major feeding problem. The reflexes that involve sucking and swallowing are usually well developed at birth; and a stimulus to the mouth such as touch or taste will elicit a sucking motion which is usually well coordinated with swallowing.

Some infants, however, may have initial difficulties with sucking, swallowing and later with biting and chewing. There are several reasons why this occurs during the first few months of life.

1. Often there is decreased muscle strength of one or several structures of the mouth. Such muscle weakness may make it more difficult to move the food from the front to the back of the mouth or from one side to the other.

2. Some children tend to keep the mouth open which may further impede transporting food to the back of the mouth.

3. The roof of the mouth (palate) is usually narrow and shorter in length.

4. Another factor is related to the overall delay in the development of the infant with Down's Syndrome.

Since the baby's swallowing reflex is not well developed, feeding tends to be difficult. In such cases:-

1. Keep the baby in an upright position and do not lay the baby down until you are certain that it has brought up all its wind.

2. Bottle feeding can be very slow because the baby forms a seal with its lips and tongue round the teat, so that air cannot return to the bottle. To prevent this from happening, twist the teat and work it from side to side in the baby's mouth until bubble come up into the bottle.

After the first few months, begin adding cereals to the milk in small quantities to form a very thin cream that can be spoon fed. Spoon feeding can be very frustrating, as the child's swallowing still tends to be poor and the child will try to push out each mouthful. But if the food is kept thin and placed well back on the tongue, success will come in time. Soft rusks can be soaked in milk and given; gradually a cup can be used.

Solids should definitely be introduced before the end of the first year as their tongues tend to thrust food out and spit it out. *Chewing* is a new experience and will take long, if liquids alone are given. Speech, which is invariably delayed in a Down's Syndrome child is apt to be still further delayed. Tongue-control is difficult and speech, when it does come, may be ill formed and slurred.

After the child is in a sitting position, offer rusks, apples or any hard foods to help the child practice finger feeding.

Most children with Down Syndrome have difficulty in turning the spoon towards their mouth and have to be guided until they can do it with a fair amount of accuracy.

The child should not be given heavy and fattening foods, as the liver of a child with Down's syndrome is incapable of handling carbohydrates.

Cheese, fish, meat, salads, fruits are all good body-builders, but potatoes, bread, and rice should be given only in small quantities as they tend to make the child fat. This can make walking more difficult and will throw an extra strain on the child's heart.



The rate of development in a child with Down's syndrome may be slower and it may have need that requires special understanding. A Down's Syndrome child's bowels are narrow, though fairly efficient. Over feeding or constipation can lead to dangerous stoppages.

## CHAPTER FOUR Some Problems and Solutions

*Speech Development* is a very important step in any child's life. The child with Down's Syndrome, generally takes time to speak and develops speech slowly. This is because of lack of co-ordinations in the organs of speech and in the section of the brain which governs speech. This, together with problems raised by an often thick tongue and a small lower jaw, generally resists efforts to speed up matters. Yet, words and connecting them with objects, persons, actions and ideas is vital to the child's development. However, such knowledge and understanding of words and phrases does not necessarily demand active speech. Without words, connected human thought, memory and learning are difficult if not impossible.

A common mistake made by parents is to presume that because a child does not speak, it is a waste of time to speak to the child. On the contrary, it is vitally important. Children learn to speak by imitation. They cannot possibly develop speech on their own.

In early life, Down's Syndrome children are often diagnosed as deaf. Infact, real deafness is comparatively rare in children with Down's Syndrome. Where they are weak is not in their ears, which are usually adequate at picking up sounds, but in the brain areas associated with the analysis and location of sound, its source and direction. These areas are underdeveloped and inefficient. If they are to develop, they will need deliberate and planned training.

### **Gesturing—Expression of self :**

It should be noted that these children often seem reluctant to speak rather than unable to produce the sounds.

Many of them show a remarkable capacity for making themselves understood by gestures and actions rather than speech. They often succeed so well at this that they feel no urgent need to express themselves in words. Care should be taken not to encourage the child in this tendency or it may become a fixed habit from which the child is slow to break away.



### **Hearing Words Stimulates Speech**

Of course, some indulgence is necessary as it is most frustrating to a child when it faces the inability to communicate. At the same time, try to put in words what the child should have said, *Repeat* this every time the child makes the gesture involved.

### **Locating Sound—Sound Tracking**

Help the child to locate sound of a rattle, a bell, a gong, a ring, a buzz. Pick a toy that can produce a continuous sound and hold it in front of the child. Move the toy slowly round the child's face at a distance of, say 12 to 18 inches and get the child to follow the toy with its eyes.

### **Continue Stimulation**

Let the child touch, handle anything safe. Start with objects that are familiar and repeatedly name object as he/she touches or grasps them. Always compliment the child when he/she succeeds in correctly naming the objects; never scold if it names them incorrectly.

### **Identification of Self**

Start with naming the parts of the body—a few at a time. Teach him to name it by placing his hand on your nose, hair etc., and then on his own. From here make it a practice to name things such as chair, table, spoon, dish, stairs. Take the child around the house, pointing out and naming common objects.

### **Play with the Nature**

Apply the same to flowers, trees and grass; let the child touch and feel them. Moving and sound-making objects, such as cars, lorries, scooters and autos should be pointed out to the child. Teach the child the names of items of dress, as you dress or undress the child.

### **Speak slowly—one Language**

It is very important that parents speak to the child in one language. In India, the child gets exposed to a number of languages, but this can be very confusing to a baby especially when it is trying to be understood.

Comprehension forms the basis of a language. It is important that parents use the same words and speak in one language.

It is also important to remember that all children identify objects in terms of action or function, like climbing the stairs, sitting on the chair, drawing with a pencil, etc. See that your teaching is accompanied with plenty of action, and gesture. Verbs and prepositions should be introduced gradually to develop language.

A tape recorder is a very important and useful equipment to help improve speech. It acts as a feedback and a reinforcer to a child even when he/she listen; later make the child repeat and then tape it.

### **Pre-Talking to Talking - Tips to Help :**

What can you do to help your child communicate?

In the early stages of language development :

1. Say the child's name often.
2. Imitate the sounds the child makes—either vowels or vowel-combinations.
3. Encourage eye contact while communicating with your child, eye to eye level is best. *Don't* talk to your child from another room.
4. Teach your child baby games like pat-a-cake, cover his face and say 'where are you', and answer 'There you are'. Hide big objects like ball or car under a box in *front* of him and ask him where it is. Then point "there".
5. Teach the child "no"
6. Teach the child playful sounds such as tongue clicking, cough and kiss. Later teach specific tongue, lip, breathing, blowing and mouth imitations. Some tongue exercises include tongue side-to side, in/out, to chin, to nose. Mouth exercises include to pucker, smile, open/close, whistle, blow bubbles etc.
7. Play babbling games with your child: ba ba ba ba da da da.
8. Respond to the child's jabbering, jabbering is non-direct vocalization. It has the tone of speech without any meaning.
9. Try to find out what the child is saying.
10. Read simple books, one picture to a page; one word to a page. Play "point to/ touch apple."
11. Make your own books on one subject only: Cars, dogs, kitten.
12. Play touch body parts/objects.
13. Sing to the child.

14. Teach common Nursery rhymes.

15. Repetition is most important.

16. Use speech that is appropriate to the situation. When he is having a bath, say "bath".

17. Expose the child to different sounds and identify them: Bell, telephone, dog barking.

18. Listen for single words. The child may say "ba" for "baby".

### **Play made interesting :**

A baby can tell you very clearly whether it likes, or is ready for the games that you play with them. If you begin to play, with or without toys, and the child is interested, engaged and happy to take it as an appropriate game.



If the child is not attentive or begins to fuss, that means something else. Watch for these signals. If the child is happy, keep going, if not, change the game. Keep in mind some of these ideas as you play with your special child.

**Toilet training** is a must as it is easy to train a child with Down Syndrome to be clean. If the "potty" becomes a happy game with much approval for success, the child will learn to use it.

### **Scolding Puts Fear—Block in Development**

Never scold a child at this stage for "accidents". Later you may mildly scold the child and immediately put him on the pot and show approval. Always praise success.

Discipline—teach the child to obey rules. A sharp



“No” accompanied by a restraining hand comes to be understood. Being soft on the child, when he needs to be stopped from undesirable action, can make it difficult for parents later on. Be firm on issues which you feel he must be disciplined in.

### **Group Play Helps a Lot**

From about one year, the child will benefit a great deal from the company of other children of the same age or a little older. Children with Down’s Syndrome gradually develop an extraordinary capacity for mimicry. They can copy actions and mannerisms with almost uncanny accuracy. It is important to provide them with good examples, both in yourself and in those of the company selected. For this reason it is advisable not to put children with Down’s Syndrome in the company of other children with other challenges, especially those who have severe mental handicap, as mannerisms acquired at this stage are apt to persist.

Many children with Down’s syndrome are very shy in strange company, surroundings and do not show what they really can do. Parents should try to encourage children to meet more people, more children and overcome their inhibitions.

### **Nursery School Years**

Just as early intervention programmes enhance the development of the child with Down Syndrome, the nursery school plays a very important role in its life. School becomes very important to the family because it extends the feelings of family and represents community support. Both the child and his family need the extra reinforcements that can come from school.

Public exposure is probably the best method

of introducing a child with Down’s Syndrome to his community. Let him get to know strangers through everyday contacts. Take him to the supermarket, the zoo, the park wherever you go regularly, to help your child feel comfortable in everyday situations.

What can the child with Down’s Syndrome learn in a nursery school? Just as our normal children have varying talents, a three year old child with Down’s Syndrome will also span a wide range of development. Each child can definitely profit from social interaction and gentle discipline by working on self-help ad skills, by improving gross and fine motor coordination and by learning to live with all types of behavior.

If you choose a regular nursery school, it should be small. To be effective, its teacher should have an interest in the special child and a *sound, general understanding* of child development. Some parents send their child to a regular nursery school for three days, then to the special school for two days. The main advantage of this arrangement seems to be a greater exposure to language from children who are more advanced in order to aid the child with Down’s Syndrome in language development.

Whichever school you choose for your child, it is *important* that there be frequent interaction between teachers and parent. Parent participation should be welcomed and encouraged since it helps carry over school training into the home.

### **Creating Identity**

Learning situations in school should help the child with Down’s Syndrome obtain a feeling of personal identity, self-respect and enjoyment. They should give him/her an opportunity to engage in sharing relationships

with others and prepare him/her so that he can later contribute productively to society. Schools should give a foundation for life by encouraging the development of basic academic skills, physical abilities, self-help skills and social as well as language competence.

#### **Teaching the Three R's :**

Some parents think that the school is supposed to teach only reading, writing and 'Arithmetic. While children with Down's Syndrome do need basic academic instructions, a good educational programme, however, should also prepare a child for all areas of life. Things like getting a job done when it should be done, and getting along with people, are perhaps more important than the three R's.

#### **Concepts of Space and Time**

1. All things have a size and weight—and these are impressions that register with the child.

2. Concept of space can only be learnt when they crawl under a table or stand on top of it. When they climb, run, jump, roll, skip, swing and crawl children get a feeling of height, distance and speed.

3. It is also very important that the child with Down's Syndrome learns his address and telephone number and where to turn for help if he gets lost.

4. The concept of time is often difficult for young children with Down Syndrome to comprehend. It should be introduced early. Soon they begin to understand not only the length of time, but words such as after, before, tomorrow, today, yesterday. They should also be instructed how to tell time.

5. Seasons and special days must be taught to develop a calendar-time concept. The days of the week,

months of the year—that Saturday and Sundays are holidays and are days to spend with the family.

#### **Birthday Celebration :**

Birthdays are very special days for children. Down's Syndrome children enjoy the attention they get on their birthdays as much as any other child does.

#### **Enhancing Natural Potential :**

It is most important that a child be put into a situation where he can achieve something in the education process. Each child has his own potential which must be explored, evaluated and then worked with. Achievement always gives a child a good feeling. A smile or praise makes the child try harder. Children learn best when they are happy, when they can do well, when they know what we want, and when we let them know we like what they do.

#### **Some Basic Characteristics of Down's Syndrome**

Stubbornness, impulsiveness, trusting, nature, shyness and mimicry.

Reasons for a child with Down's Syndrome being stubborn :

1. Some of it arises out of a limited understanding of what is expected of it.

2. Difficulties in communication as speech comes much later.

3. Due to the nature of the child's mental process which does not permit rapid changes from one conscious activity to another. One must gauge whether obstinacy is natural or deliberate pertaining to the situation.

#### **Impulsiveness:**

A child with Down's Syndrome can be very impulsive. This is again because his powers of reasoning



are not as well developed as his emotional powers.

Down Syndrome children trust almost everyone. This can be improved with increasing age and training.

**Shy and Inturned:**

To prevent this, the child should be taken out as much as possible to meet other people and children, to shops, to fairs, parks, the zoo so as to gain valuable stimulation and new experiences.

These children are the world's greatest mimics. It would be advisable to avoid undesirable company. Prevent him/her from being a clown. These children try to attract attention. When he/she is clever, praise the child so that he/she knows that he/she is doing the right thing but stop him/her from clowning.

In our experience we have found that complex process of thought and reasoning are the last to develop and the slowest in the child with Down's Syndrome.

The older parts of the brain, those that govern vital bodily functions and those connected with feeling and emotion are more advanced than those governing conscious thought and reasoning. Features like affection, sympathy and sensitivity to moods of others are related to basic emotions rather than reasoning.

**CHAPTER FIVE**

**Play Equipment for the Child with Down's Syndrome**

**DESIRABLE PLAY EQUIPMENT:**

**For outdoor play:**

- Swing
- Sliding object
- Rocking objects (boat, horse)
- Planks and logs of wood
- Climbing frames
- Large pipes (for crawling)
- Nets and rope ladders
- Push-pull toys
- Balls
- Tyres, hoops, rope
- Dance accessories-sticks, clubs

**For Imaginative Play :**

- Blocks (large and small size)
- Dolls
- Dolls house
- Household articles (utensils, used items, toy-size things)
- Toys-soft rubber, wooden
- Dressing up clothes—old saris, shawls, shoes, caps, belts, other items of dress.
- Mops—sticks, swords, spectacles/goggles, beards.
- Masks of animals and people
- Traditional/local toys.

**For Music and Dance:**

Drums  
Bells  
Ghungru  
Flute  
Whistle  
Rattle

**For clay work :**

Large earthen pots or plastic tubs or buckets for storage clay.  
Wooden boards for working on  
Tools: knives sticks.

**For constructional work :**

Blocks of all types  
Assembly toys  
Constructional sets  
Tools, hammer, spanner, nails Cardboard cartons  
Beads  
Building materials from waste.

**For cognitive activities :**

Picture pairs  
Picture families  
Sequence cards  
Bingo board  
Jigsaws  
Puzzles  
Cards: Cards in series graded pictures  
Number Cards  
Board games  
Counters.  
Dice  
Assembly and constructional material

Mosaic shapes  
Activity books  
Slates  
Pencils

**For language work :**

Story books  
Picture books  
Picture  
Charts  
Puppets  
Picture cards

**For Art hand work:**

Paper-Newspaper, brown paper, Coloured Paper, glazed paper, paint, powder, chalk, crayons, cardboard, cloth, thread, containers.

## CHAPTER SIX

### **Life starts at 16!**

As we approach the 21st century, human expectations for the quality of life are higher than ever before. Our hopes and dreams still soar at the impending birth of a baby. Yet, when we are told our baby has Down's Syndrome and we must reshape our hopes and dreams, I believe, the original parental sorrows remain the same.

Of all the joys and sorrows of a lifetime of living, no event can be more traumatic in the life of any parent than the birth of a handicapped child. No woman ever really expects to give birth to a defective child—mental retardation is simply a statistic, something that happens to someone else.

If you have an older child with Down Syndrome you must have already formed a bond with other parents of children with special needs—parents who have shared the same joy and sorrows. If you are in special education or a related professional field, you too must be elated at the progress that has been made in mental retardation and human services. Your continued encouragements and reinforcement and your willingness to see each child as a unique and valuable human being can add immeasurable dimensions to the life of the child with special needs and to his or her family.

If you are a new parent, we share your deep sorrow. You feel, in every fiber of your being, the aching disappointment, the hurt pride, the terrible fear of the unknown. But, I can tell you from personal experience, that having known this ultimate sorrow, you will soon

learn to cope better with every phase of life. You will be happy once again and through this child, you will receive undreamed of love, joy and satisfaction.

Compared to the bleak future that formerly awaited the child with mental retardation, these last two decades have seen remarkable progress for the child with special needs. The public in general is experiencing a new awareness and compassion. New programmes and services are mandated by law to guide and support us and our children from birth to adulthood and we, as parents, must work to ensure their continuation.

If your child is young, you will soon learn that the child with Down's Syndrome does almost everything a normal child does, though more slowly. With love and understanding, these children can achieve many things unexpected of them. They will walk and run and laugh, and be able to tell you when they are hungry or thirsty. They usually will be able to read and write, will love going to school and listening to music, and will take delight in travel. They will enjoy sports, go to camps, play musical instruments and love visiting temples, besides so many other things we might wish for. They will respond well to gentle discipline. They will have a definite sense of humor, and will learn much from socialization and imitation. Their sensitivity will even console us when we are sad. Unlike our other children, they will love us unconditionally and unquestioningly with a resolve and tenacity that almost defies understanding.

What do we expect from these children? I think the most precious thing we can give them; is complete acceptance of them as they are and a desire to make them as independent as possible for the future. From

the community we ask for compassion, not pity and the change to prove themselves as fully as possible while being accorded all the rights of a human being within their capabilities. As Maxim Gorky remarked, “The greatest of delights and the biggest of joys is to know that people need you and to know yourself close to them.”

Our greatest hope is that one day, when we are no longer here, these children may live in a carefully supervised setting within the community, where they may know the joys of Friendship, the dignity of self-worth and the usefulness of work in a protected atmosphere.

As parents, we have learned that there is little more that we can wish for any of our children, but that they develop their potential to the best of their abilities. In the end, all the material accomplishments of this world will not matter much at all—what will endure is the quality of love we have given each other. For a few of us as parents, what seemed like a tragedy of our lives has become our greatest and most fulfilling opportunity. We have to thank our children for having shown us the only path—service above self.

With the birth of every child, a star is born—My star was born 17 years ago and she still shines bright. This star has been my Guru, my Guide and a blessing.

*Thank you my little one  
for showing me the way  
I was drifting along aimlessly  
till you arrived one bright sunny day  
I often wondered who you were  
You said you were my light  
You had always been there in my heart  
But now you have entered my life*

*Through you I learnt to live  
Through you I saw the rainbow  
Through you I discovered music, art and dance  
Life never held meaning till you came along  
You taught me to smile through difficult times  
I appreciate each day only because of you  
I thank God for this bundle of joy  
that I call “Bubbles”.*

Each life has a meaning and the birth of a child, any child, is meant to be a blessing—“Every dark cloud has a silver lining” —I live with that adage in my mind and I have never been disappointed.

My daughter is a special child and each day, she breathes life into me. She makes me want to live. Life is full of fun, thrills and laughter with her. I know for certain that but for her I would never have been what I am. I may never have had this opportunity of sharing with so many thousands of people, an experience that God gave me. This has resulted in my being able to be of service to people.

*Yes, that is what Babli has made me see in life—  
that service comes before self.*

I am not denying that the birth of an impaired child is a shock. It can traumatise the weak and the strong. But after the initial period of grief, one has to realize that this pain cannot last forever. We have to come to terms that we are faced with a challenge.

*This book is written on a note of optimism.* Most people believe that the handicapped are a lost cause after the age of sixteen. But, as the mother of a seventeen year old, Down’s Child I firmly believe that there is a big world waiting out there for her to make her mark. Handicapped or otherwise, life has so much to give and she has so

much to offer.

I often wonder why people ask “After 16 What?” Are we to believe that after a particular age, human beings must lose their desire to live? Surely not at 16?

First, we need to believe that our children are not sick but are healthy. They are merely different from other children and continue to learn, though slowly even after they are 16 years old or more.

As parents, we want our children to live a full life in which they will have a variety of sources of pleasure and enjoyment. I find that my daughter Babli, today, finds life more satisfying than she did between 9 and 13 years of age. At that time, she was quite dull and listless and I do not recall any moments of interest.

In the last 2 to 3 years, we find a vast change in her life pattern. She wants to make more friends, wants to listen to more music, wants to go out and have fun. She understands certain concepts that we would never have imagined her to be capable of. She wants to see different places, feels she is in love with actors and people, loves dancing and music, hates the 3R’s ( reading, writing, arithmetic!) and going to sleep.

We plan our vacation with her in mind. However, sometimes, just sometimes, my husband’s work takes us to the same place more than once. Babli would be up in arms and refuse to come despite the fact that Rahul, our son, was coming along—Reason being it was awfully boring and that she was sick of the place! She should have already planned her new movies and music.

I was very impressed by her firm decision. I like to do things my way, so why not let her lead her life?

#### **AFTER WE ARE GONE .....**

One of the major problems for parents of a child

with a disability is the worry of how their child will be looked after when they are no longer there or able to do so.



For parents with severely handicapped teenagers, the big worry is “How will he survive”, or “Who will be willing or able to do all that we are doing.” Yes, this is the big problem that parents face as their children grow older.

It is imperative that for the well-being of the youngster, he or she should develop a way of life of his or her own. We have to make a long term plan so that the child has a future that will ensure safety and care.

A number of such parents have requested that I set up a residential unit for the care of Down’s Syndrome adults. I do have a plan to adopt at least six people above the age of 35 depending upon the age or medical health of their parents or guardians. It is not right, in my opinion, to separate the child and the mother at infancy or the growing years because the initial bonding is the most important pivot on which the child’s life is balanced.

Yes, if the parents are too old or incapacitated to care for the child, then we will provide shelter to the child.

As parents, we too are painfully aware that one day, we will face the same situation.

However I believe in taking one day at a time. Human beings, when faced with a seemingly insurmountable problem say “I just wasn’t born with the strength or ability”. I believe that we should emulate Helen Keller who called up deep inner reserves of will power to overcome being blind, deaf and dumb. She won respect, fame and the love of thousands.

Do constant fears keep you from relishing tomorrow? If fear ruled us, then we would certainly be sucked into a vacuum or float around like floatsam or jetsam on the ocean of life.

I believe in people like Winston Churchill who faced utter defeat for his country and himself personally. But he put a twinkle in his eyes, a piece of steel in his spine and a prayer in his heart—that triple combination wrought a miracle as the courage of one man aroused millions to blind optimism and stubborn strength- the resulting vibrations melted the leadoff fear, and inspired the great victory of the Allies.

He refused to allow fear of defeat, get the better of him. He had faith and an inner conviction that things could work out “*Believe in yourself*”. *It would be a great pity if we submit easily to the situation and let our potential and those of our special children go unrealized.*

If fear was the basis of our life, we would never survive. We have to believe that when God created this being, He also made different avenues for it to be happy and healthy- we are there only to support and love this child till the end.

We have a son who loves our daughter to an extent

that mere words cannot describe. They have a greater bonding between them than I have as a mother. May be it is fortunate. But even then, we would never ask that our son care for her all his life as he has to lead his own. *Nor would we think of institutional care for our child.*

I have a vision of a huge village where only Down Syndrome adults live in harmony and love and care for each other. This village will have all the infrastructural features and this would give the children peace towards the end of their lives—music, drama and colours will fill their days.

I dislike the thought of my child being tucked away in an institution. You might say that a village is again cutting them away from the mainstream. Yes! But the fact remains that 99% of the world has no feeling for what is not the most “perfect” human being and I would hate it if people were forced to work for people they have no feeling for.

Residential care under my own supervision where the children will be loved for what they are is what I visualize. Why should we subject them to “so called” Down’s Syndrome workshops where they are made to sit like dummies in a corner? And those who are supposed to “Shelter” the poor darlings are either ridiculing or abusing them.

My daughter taught me that the happiest and safest place for her was with people of her own kind. “I am a person with Down Syndrome so why should I have to compare with someone else? She chose a life where her talent comes out with people who have the same affliction. Many a time she asked all of us to leave her room because she wanted to dance alone.

Life is what we make of it—man is a gregarious animal. In spite of this, I have found that at times I am very lonely even when there are 100 people in the same room. At other times I have found the eloquence of silence when nothing is spoken in the same room of 100 people. I have felt this with our Down's children. Some of the Down's Syndrome adults are happiest by themselves when they can relate with inanimate objects.

We have to learn that the so called “normal” being can have very negative effect if they cannot give these children the love and care they need.

#### **FAMILY LIFE :**

The root of the problem of our life is not so much the fact that we have special child on our hands but that we spend our entire life worrying what will happen to us as parents—will we drift apart? —after all, we are only human beings and are selfish, to a certain degree.



*But, remember the child has no one else but you!*  
So if you are going to be callous and imagine that this child is going to ruin your life, it is really unfair.

For years, my husband believed that our child was killing our relationship—she was going to mar our married life and leave no happiness in our lives.

I am glad that as a mother and a human being, I realized that this child was not going to take away anything. In fact she was the reason I wanted to live—*She gave me challenge and I am proud of what she is today.*

Yes, it was years of concentrated work and a lot of sacrifice. But then, I believe that life offers challenges and only the weak succumb. Not me!

The foundation for the child's very existence is in the hands of the parents. You can mould the child in the way you want to. Our daughter is a part of me. She talks, gesticulates, screams to be heard, makes plans for each day, is very organized, loves people, loves music and each of these attributes, she has taken from me. Unfortunately most parents with children with Down's Syndrome find their babies to be good and very quiet. So the mothers do not talk to their children as much as they should do. *Talk, talk for heaven's sake talk!* Even when you think they are asleep—the subconscious is more active than the conscious mind. If you are unable to talk all the time, then play music. As the child grows older, especially through their entire adolescence and adulthood it is even more important to communicate. *They might not respond for they might be very stubborn* as they grow older but we need to discuss ideas and daily situations with them.

Our daily routine is to spend time with Babli for an hour in the morning, discussing her plans for the day. At breakfast, she comes up with ideas for her free time in the evening. Most often, we end up doing exactly what she wants except if we have important prior commitments.

*No matter how a Down's teenager communicates with people around him/her—by speech, sign, touch or smiles, he/she must build up confidence in the belief that*

*people are interested in him/her and are willing to talk to and spend time with him/her.*

Most parents complain about the lukewarm response from their children to their efforts. My advice to them would be to continuously try communicating and the response will happen. It is equally important that parents should encourage their children, however handicapped they are to meet others of their own age at schools, clubs or any local organizations. *By getting to know people other than parents, brothers and sisters, the mentally impaired young people help their personalities to develop.*

They need friends, other than family members to share their problems with. *Babli has a world of friends.* All my friends are first and foremost her friends. They are the people with whom she can discuss her innermost feelings—her hurt, her pain or her happiness. I encourage that for the simple reason that every teenager needs a support. Parents can never be in sync with what a teenager needs a support. Parents can never be in sync with what a teenager is experiencing. To have good friends in whom you can confide in makes a world of difference. It is only through such friends that I get to know what Babli is going through. Wouldn't any normal teenager behave that way? I am very proud that Babli has friends who listen to her and advise her.

*When you were a teenager, did you always tell your parents everything? Did you find it easy to talk of who you were in love with? Did you feel they understood you? Did you accept their criticism of your dress, your behavior?* Babli has her latitude, her freedom and she emotes with people she is close to. I am proud of her.

*Being a parent is not just giving birth to a child.*

*It is about caring and loving, training and teaching, and preparing the child to take a place in the world, whatever his/her abilities be.*

I finally believe in this and that is the only reason why I exhort parents to care for this child till they are prevented by old age or ill health. And even then, the child should not be got rid of. Believe me, It is only after the child is 15 or 16, they start to love and shower affection on you more than your other children can ever do.

*Most parents of mentally handicapped children find it difficult to recognize that their children are growing up into adulthood with adult needs and desires.* Because, they have to help their child with some things that other children of the same age can do themselves. *It is very easy to think of them as children even though they look like adults.*

So it is very crucial for parents to stay in touch with how their child feels, what their child thinks and does. *The parent is the focal point.*

#### **LEARNING NEW WORDS :**

Although we can communicate without words, we cannot actually speak without a basic vocabulary which gives us a starting point in verbal communication. We learn a language by listening to those around us, by listening to TV and later on by reading.

Even if a young person has difficulty with speech, parents should encourage him or her to get to know as many words as possible so that the child can understand even though the words cannot be articulated at that time.

**IMPORTANT :** A word a day means

.....Seven new words a week

.....Thirty new words a month.



.....Three hundred and sixty five new words a year

.....Much better communication!

Even with the most handicapped child, it is crucial to encourage him to take as much part as possible in every conversation – He may not understand fully but *he will experience totally the feeling of being part of what is going on*. As he gains confidence with you, he will want to take part in conversations with friends.

#### FANTASY FRIENDS AND FANTASY PLAY

Many teenagers have other unusual features of language. These may be partly *a function of immature development or partly the result of social isolation*.

The first feature is a tendency to talk to themselves aloud in a self-regulating fashion. They may instruct themselves in practical activities like dressing up or to telling themselves how to behave, e.g.–“Don’t swear, don’t be naughty” *This may suggest a delay in the development of the internalized silent speech, inner speech or thought*.

*The second feature is the tendency to have fantasy friends and to talk to toys and dolls*. Often this involves acting out worrying emotional experiences and is typical of a normal four year old and seems to be a healthy mechanism for dealing with worries and anxieties.

#### **BROTHERS AND SISTERS**

The birth of a child always has some effect on the older siblings—good or bad depends on the way the child is handled. Babli’s birth was at first a shock to our son, Rahul who was nearly 4 years old when she arrived.

I had never imagined in my entire life that I would give birth to a handicapped child and so I was singularly

unprepared to handle both the children well. We all imagine that we would suffer immense financial strain when such a child arrives. How wrong we are! What we cannot beg, borrow or steal is TIME.

*When we have a child with special need, no amount of time is sufficient!* If you have to divide that time between 2 children, then even 48 hours a day are insufficient. Rahul and I were virtually inseparable for 4 years and we shared every precious moment. Babli’s birth brought with it jealousy and a bit of hate.

Babli was born with cataract and I had to be in hospital from the 6th week of her birth. Surgery after surgery was performed and this started wearing our son down. He felt he was losing me. Here I was, trying every method of therapy to improve Babli’s mental and physical growth—Magnetotherapy, Ayurveda, Homeopathy, Physiotherapy and all this without any formal guidance or help.

I honestly do not remember to have spent quality time with Rahul in the first six months after Babli’s birth. One day I got a call from his school. Rahul was slipping in his studies.

A student who had always excelled was not able to concentrate. I rushed to his school and met his principal Mrs. Cherian. Ever since then, she became a mother to me.

She understood my plight and took Rahul under her wing. I always believe that God arrives in so many forms—here he was as Mrs. Cherian. She had an intuitive understanding of what had to be done.

She asked me to encourage Rahul to get involved in some form of physical sport. Babli’s birth made Rahul

a sportsman, a National and International swimmer!

I pushed him into swimming to sap his energy as he was a hyperactive kid with a sister literally swimming against a tidal wave. He became one of the best swimmers of the country.

I was lucky that the school helped and recognized our son so much. Rahul is 20 year old today and adores his sister so much. But the love she has for him can never be equaled by the love she has for my husband or me. He is like a God to her.

*The Family Unit is very important. Family support at the time of the special child's birth is even more crucial.* The people in our families can be aggravating at times but when we need help over such a situation, we tend to turn to them to share our worry or happiness.

The idea of an extended family is slowly dying out—But when Babli was born we were a large family with a grandmother, uncle, aunts and cousins. All these people extended their help and but for the love of the cousins, especially my niece Rupa who was always with me to train and motivate Babli. I might never have made Babli talk the way she does today.

Unhappily, many families with Down's children might not be able to devote time to the child. Both parents might have to go to work or they might have other constraints. It is primarily for such parents that we have started the centre for Down's children which can provide the infants with the much needed stimulation.

It would not be possible for the mothers to give up their work and stay at home when there is so much financial strain. We at our centre encourage mothers to spend a few hours a week with us to get acquainted

with our programmes. Our main concern, apart from the children, *is to keep the parents relaxed and happy.*

### **The Older Child**

Being the eldest son in a family brings with it certain features—The eldest child is responsible and cares for the younger siblings much more than say the middle children. The eldest child definitely is the most practical.

Rahul has always been very caring and downright possessive about his sister. From the time she was born he would not allow the others in the family to keep her in their rooms. He did not want them to call her their baby!

When I was away attending my niece's wedding, I left Babli with my sister-in-law at Chennai. Rahul used to take her away to his room to change her diapers because he felt that anybody else might hurt her when pinning the diapers.

I was upset at his behaviour and then realized that he was only doing what he thought he had to do as an older brother. Moreover, diaper pins do look as big and menacing.

Even today he doesn't like her to be left alone. He checks all her clothes and if she wears anything slightly transparent, he insists on her changing at once. They do have arguments but these are easily resolved once she has been convinced or when Rahul gives in.

I have never had a problem leaving town and travelling without her because Rahul looks after her so well.

We take a family holiday once a year when we all do what Babli wants. The holiday is for her and she decides on the place and how she wants to spend the holiday

which must not be for more than a week.

*Babli's birth taught the entire family tolerance and acceptance.* One takes life for granted and we never realize how fortunate we are to be able to talk, walk and live normally. We constantly complain about minor worries like Rahul's colds, minor cuts and falls—Till Babli was born, I was always worried Babli's birth taught us to appreciate the facts that we were alive.

Since then we take one day at a time—we have taught Rahul the value of 'today' He is very practical and is appreciative of small gifts and for our time and attention.

Not all older siblings have felt the same way. In our centre most parents agree that the birth of a Down Syndrome child has taught the other children a sense of responsibility, tolerance and to be very protective. But a number of parents have felt that their children have felt lonely and missed their parents affection. They tend to go through a period of frustration and insecurity.

A number of siblings have felt very embarrassed when their friends come along visiting. Why does this happen? Telling friends about our child's Down's syndrome and the handicap is very important. The more we talk about the child and discuss the handicap with the other children, the more understanding they become. Rahul was so protective about Babli from the time we talked o him about her that we decided not to have any more children. I would obviously not be able to concentrate on Babli with any more children.

Rahul takes Babli to meet all his friends and there is a definite sense of pride in his introducing her to them.

Most people ask me what my job is in the centre that I run, called "*Mathru Mandir*". The name itself

conveys the meaning "A Mother's Temple."

To me, the mother is the focal point and I know as a mother exactly what it is to give birth to a Down's child. There are very few people who can really answer all the questions that keep piling up in our minds. As educated people, we need someone to answer all our questions patiently—even the most seeming irrelevant of questions.

Though Babli was born in Chennai and though I had a team of seven paediatricians as friends, and though I attended several seminars on Down's Syndrome, I did not find one person, even one person, who would answer all my queries. I had to make a trip to Shriver centre in Boston, U.S.A. to find the answers.

I did ask some stupid questions—whether they could do a blood transfusion as a cure! I had no idea what chromosomes were till I discussed with the doctors paediatricians, therapists and a genetic counsellor.

A detailed explanation was made of the cell system and about every human being having 46 chromosomes and that Babli had one extra chromosome in every cell. It took me years to understand what her body was being subjected to.

Then I managed to meet Dr. Penschel who was not only the head of the children's Hospital in Rhode Island, Providence but also the father of a Down's Syndrome child. I shall never forget his words—"*Your daughter, Babli has tremendous potential*". *That was enough for me.*

I started working on the baby day and night to make sure she reached her potential. It was words of encouragement like the ones by Dr. Penschel that kept me working hard to push Babli constantly.

My main area of concern has been and will always be the parent and family as a unit. *Strong family support helps the child develop to its maximum potential.* Unless the guidelines are clear to a mother, she can be totally lost in this huge, cruel world with no one to support or listen to her.

Of course every parent will feel the pain, the anguish at being inflicted thus and they obviously have a right to feel this. But once the initial pain and despair sets in, the parents have to start considering this child as any other child, only this child is definitely more of a challenge.

Whether the birth of a baby is planned or otherwise looked forward to or not, no parent to have a child who is disabled in anyway. So the birth of child who has some kind of difficulty would be seen as a disappointment or a “let down”.

*Parents in similar situations have told me they felt shunned, shocked and confused.* Not only is the normal child you expected not there, with the attendant grief, you know you have a child who is going to need special care of some kind from you.

You would have to provide services you probably do not even know about at that point of time. Quite possibly such services might not exist at all depending on where you live. And there could be major doubts about the child’s eventual ability to live a fully independent, adult life!

*Whatever the causes, whatever the circumstances, a disabled child puts great stresses on any marriage. These pressures could bring the husband and wife closer or they could do just the opposite.*

As the child grows up and begins to manifest the usual “teenage problems” it is generally the mother in the family who spends the most time with her child. As a result she has less time to spend with her husband during his leisure time. This leads to strain and could cause marital discord.

*It is however important to realize that you are a human being first and you must keep your well being in mind.* By looking after your needs, you will be ensuring care for your handicapped youngster in the future.

It is important to talk to someone close to you for airing both your positive and negative feelings. Sharing feelings and letting somebody see that you need advice or support can bring you strength irrespective of the type of relationship.

A number of parents find it difficult to share their feelings. But one must try. By staying in close touch with a confidante and with your own feelings and by satisfying your own needs, you are going to offer your child long term secure support and strength for the future.

### **Social Activities, Leisure and friendship**

Adolescence is the time when, for most teenagers, friendship become more important than family relationships. Much more leisure time is spent in the company of friends of their age.

The teenager is becoming an independent adult, establishing a distinct identity, values and beliefs. It is time to discover their own skills, interests and to start exploring one’s personal and sexual identity.

If a person with a handicap is to take his or her place in society, then, they must also go through a realistic, healthy adjustment to life despite the shortcomings.

*They also need the opportunity, most importantly, to seek out and sustain friendships; real friendships based on mutual warmth and respect so as to enable them to grow as people and to value themselves.*

LEISURE—the most popular activities for a Down child during teenage years are watching TV, listening to music, playing in the garden, riding a cycle. Swimming or playing tennis is enjoyed by a small percentage of teenagers.

Drawing, doing jigsaws, playing board games with family members are also very popular. Doing household chores is common among the children. Most of the children in our centre help their parents in tasks like cleaning, making beds, laying the table, washing clothes and vessels, etc.

Babli has a number of interests. She is busy throughout the day. She spends most of her time watching video tapes of her favorite film stars. Or she does a lot of taping from video to audio or from audio to audio. She also loves to go for her dance lessons where she has integrated with regular dance groups. The older children here guide and help her to perfect the steps.

Indian classical dance is not easy and involves a lot of “mudras” or expression through the eyes and hands. The feet have to be constantly tapping to the beat of the music. There has to be a constant coordination between hands, feet and expression.

She also spends an hour in the swimming pool doing twenty to thirty laps. Her favorite stroke is the breast stroke and she is a National breast stroker in the Indian Special Olympics.

Now at the age of 16, she loves to sing and talk loudly while she tapes. Her only demand is a new audio

cassette every day to sing into. It upsets her when we comment that her voice is very low or unclear. She asks her music teacher to help her sing clearly.

She loves to dance by herself in the privacy of her room. Not many parents can afford to give their children a room for themselves. *It is vitally important to provide some place for this since the child tends to spend increasing periods of time on its own away from the family, either alone or with friends.*

## ADOLESCENCE

Adolescence is the time when friends of one's own age become increasingly important as young people gravitate away from the family and begin to establish their own independence and identity.

A lack of such friendship in our teenagers must be a cause of concern for most Down's children, their own brothers or sisters seem to be their only source of company. They anyway do not have great many friends, and tend to spend a great deal of time amusing themselves in passive activities. Many parents are becoming aware of this increasing social isolation. The child is more and more restricted socially as it gets older because of non-acceptance by other children. Most of the time is spent watching TV.

Up to about two years ago, other children were happy to include one such child at games but they soon outgrew the child and there were no younger children to replace them.

I had the same problem with Babli. She replaced one cousin with the next till I realized that all of them had grown too old to play her type of games. I immediately introduced her into two new groups of children so that

she could make more friends.

One group of children was from her dance class while the other was the swimming pool group. With 30 children in the dance class and 60 children in the swimming pool group, Babli could interact with a large number of children and start making her own friends.

She now has a large circle of friends from all walks of life and many of them spend weekends with her. She organizes picnics, visits to the museum, the zoo and theme parks. Most of her friends treat her on par with anybody else.

*Parents must encourage their children to join various clubs, music or dance schools.* This definitely holds their interest and they get a fantastic chance of meeting people and making them own friends.

## **SEXUALITY**

One of the major worries that many parents have about encouraging their teenage children to go out and socialize with others of their own age, is that they may get into trouble, sexually.

*The whole issue of sexuality is one which is difficult to handle since there are lots of undercurrents. It has always been a sensitive area, socially.* Many women are brought up to believe that sexuality is something which cannot be discussed.

*Some parents find it difficult to admit that their child is growing up into an adult with normal sexual needs like the rest of us.* Many people say “I was never taught about sex and it hasn’t done me any harm”.

However, sexuality is now becoming a more open topic. People are willing to discuss and learn. Women are seeing sexuality and pleasure as their right within a relationship.

*Down children who are labeled “mentally handicapped” are actually not so. They are also healthy people with active minds, whose bodies grow and take adult characteristics almost identical to the normal teenager.*

As a result their adult needs and desires also grow. *They become interested in the opposite sex and need information and sympathetic instruction on how to understand and cope with their new feelings.*

Sexuality is the most basic aspect of our life. It is obvious to even the slowest of slow learners that there are men and women in the world and there are differences between them.

Sexual attraction, the lead-up to and the symbolic consummation of the sex act is shown in somewhat graphic detail on our TV screens. On some embarrassing occasions, which can neither be anticipated or avoided, kids are exposed to such scenes on TV and manage to think that it is desirable.

It has been found that as the level of mental impairment increase, the sex drive tends to drop. However, many successful and satisfying marriages have taken place between quite severely handicapped couple.

It is interesting to note that many Down’s affected youngsters are interested in sexuality and knowing more about it at our centre. But they try to “please” their parents by showing no interest in lurid TV scenes at home!

Teenagers should know their bodies and have the opportunity to fulfill their physical needs within the religious and moral principles around which they have been brought up.

*One way many teenagers do learn about their own sexuality is by masturbation.* This can present certain problems for parents who might feel that it is wrong to

allow their child to masturbate or they might have a child who does not understand that 'there is a time and place' for it.

Many mentally impaired youngsters do not understand the feelings they experience which make them feel they want to masturbate.

*If they are prevented from doing so, they could feel frustrated and exhibit irritability and resort to fits of temper and tantrums.*

Just because a youngster's mind may not work as adequately as a normal one, it does not mean that his or her bodily functions are retarded. Mentally handicapped boys would still, have nocturnal emissions and erections. They would need to learn to shave. Girls would obviously menstruate and develop breasts. *And because of their impaired understanding they have an even greater need of education in sexuality, We cannot pussyfoot around this.*

There is a definite risk of an unwanted pregnancy which can be avoided by educating the girls about the real implications of allowing sex to take place. Beyond this, parents might want to take the precaution of continuously making the girls use contraceptive devices or better still, to go in for sterilization. This is preferable for girls who do not fully understand the events or implications.

We have to realize that sex and sexuality play an integral part in our lives and much psychological, emotional damage has been done by lack of knowledge. This would have caused a lot of worries most of which might have been completely unfounded.

Sexuality is one important area of our lives where we all should have the opportunity whether we take it or not, to make informed choices or decisions about our behaviour.

The fear and risk of pregnancy is now thankfully easily tackled by modern contraceptive methods so that young, mentally handicapped people can now have, with sympathetic guidance and information, the opportunity to experience a satisfying and fulfilling personal experience.

*Every single human being is different with his or her own personal needs and desires. Everyone has his/her own limitations and problems. By helping such growing teenagers to develop skills in as many areas as possible, parents and professional are providing them education for life, which can be difficult even at the best of times.*

But we have to concentrate on what we can do rather than moan about what we cannot do. No one can do everything, I agree. But it is a fairly useless and depressing exercise to think about what we cannot do.

### **SEXUAL DEVELOPMENT AND BABLI**

Babli has always had a very normal approach to boys and has fallen in and out of love a couple of times. Her body development has been as normal as any girl of her age and she is able to care for herself.

Her greatest love was for her cousin who she was keen on marrying. She was very jealous of the girl who he was in love with. She wanted to marry him so much that she even claimed that it was okay for a man to have two wives! All this information had been absorbed from the TV and movies.

Being a movie buff has added to her vocabulary substantially. Her choice of words for men she has a liking for are very apt.

She manages her menstrual cycles fairly well but she does have bouts of depression. At times she prefers privacy and sleep by herself. She must have music to be able to sleep. It is important that, while on the subject of

sleep, I mention that Babli has had many periods of acute disturbed sleep. She sleeps for few hours, then gets up and watches TV or listens to music till she can manage to go back to sleep. Most Down's Syndrome children have this problem which may stem from fear of the dark or from fear of being alone in the dark.

Most parents reported a slowness in getting undressed before bed or displaying other delaying tactics like asking for water, numerous trips to the toilet, etc. Some children would play quietly with their toys often in the early hours of the morning.

Babli has evinced a desire to get married and have babies.

#### **GENERAL BEHAVIOUR AND PERSONALITY**

The many physical changes which occur during adolescence are accompanied by changes in behaviour and feelings. It is a period during which transition occurs from childhood to adult status and brings many changes.

*The adult status requires the specific role of taking on the responsibility of making a living and fulfilling one's sexual and family life.*

During their progress from childhood, our expectations from our children's behaviour alter. We expect them to abandon their infantile traits and to accept responsibility for themselves and others and to behave in ways which are socially acceptable.

*The most important question is whether the child is generally a happy person.* Most parents usually say that the child is very content and happy. They feel that the child is always cheerful and a joy to have around. They feel that this young person evoked feelings of warmth and a positive response from the family. They are loved within

the family and are physically independent or are not, in the majority of cases, needing a lot of supervision.

*The usual experience among parents was that Down's Syndrome children seemed to be particularly sensitive to other's feelings.*

Most parents say "My child gets upset by arguments or raised voices." "If any of us is depressed he will try to cheer us up." He has a good sense of humour and tries to make people laugh. "She gives a lot of affection."

"When on holiday with her school friends, she has an amazing ability to cheer up other teenagers who are moody." This was about our daughter, Babli.

*As far as personality goes, the average Down syndrome child is generally placid, outgoing, compliant and affectionate.* The majority of them are able to occupy themselves without bothering parents constantly through passive and solitary activities such as watching TV, colouring or playing alone in their rooms.

Some Down's children can be difficult or naughty. This could be related to them getting cross when not being able to get their own way or frustrated at not being able to make themselves understood.

The majority of the Down's teenagers are not passive. This is applicable to some of the more dependent teenagers with poor communication and inadequately developed skills. These handicaps would not permit them to actively engage in leisure and social activities.

#### **DIFFICULT BEHAVIOUR**

**OVER ACTIVITY:** Over activity is a complex subject and is sometimes more related to the level of tolerance of the parents than to observable quirks. Most of the boys are considered too lively and excitable whereas the girls



are not. Most of the hyperactive teenagers appear to be on the go, loud and noisy, easily overstimulated and very demanding.

*PROVOCATIVE BEHAVIOUR: Behaviour such as stubbornness, swearing, throwing tantrums, etc could be interpreted as being deliberately annoying. This could also be reactions to frustration or as attention seeking devices which are common among Down's teenagers.*

Such behavior becomes more and more unacceptable with increasing age and interferes with normal aspects of social development. Throwing tantrums and other forms of *attention seeking behaviour are usually successfully dealt with by completely ignoring them while at the same time rewarding socially acceptable behaviour.*

Other types of annoying behavior include ignoring parent's instructions and repeating requests parrot-like instead of complying with them.

#### FEARS AND PHOBIAS:

Most of the Down's Syndrome adolescents have a fear of sudden loud noises, thunderstorms and strange dogs. A small percentage of them are frightened in the presence of people arguing loudly and



some teenagers still have a fear of the dark.

None of our children at the centre show behaviour which could look bizarre or as manifestation of mental illness of any kind. Most Down's Syndrome teenagers are pleasant loveable and affectionate.



*While most Down's children are friendly and appealing there are a number of problems faced by parents on this score. Most of these children are very trusting. They go with anyone as a rule and should never be left alone until their behavior has indicated that they would remain in the proper areas. This problem can be eased with increasing age and training.*

A characteristic that all parents and teachers of Down's children have noted is obstinacy. The degree to which this appears, varies with the intelligence but nearly all adolescents are stubborn to some degree.

There are several reasons for this. Some of it arises from a limited understanding of what is expected or it could be caused by difficulties in communication. But, most of the time I repeat, such obstinacy is only to gain attention. We have found the child much easier to handle at our centre than at home with parents.

At times it has been observed that the child's mental process does not permit rapid changes from one conscious activity to another. One must gauge whether obstinacy is deliberate or if it pertains to a situation.

*The other common characteristics of the Down's adolescent is that they have a tendency to be restless and get distracted easily. This is related to the level of mental*

*development and we have found them to be impulsive—a feature that stems from their power of reasoning being less developed than their emotions.*

*Complex powers of thought and reasoning are the last to develop and this is the slowest in the Down's child. The part of the brain governing bodily functions, feelings and emotion is more advanced than the part of the brain governing conscious thought and reasoning. Therefore the child will have a lot of affection, sympathy and sensitivity to others. But reasoning is not its forte.*

*The one characteristic common to all Down's children is mimicry. This process has many advantages but there can be pitfalls too. It is important that one keeps an eye on the company they keep. Undesirable examples should be kept away. The main reason to start a centre exclusively for the Down's Syndrome children is to develop them to their fullest potential.*

When Babli was born, I was told to put her with the deaf and dumb, with the spastics or with the mentally retarded. All this surprised me since I had read that Down's children had the uncanny knack of imitating their peer groups. If the group was autistic, spastic, or deaf, these children would never behave like normal children. Our centre trains these children from infancy to three years and then we send them to regular schools or play groups. The main reason is that they can imitate their normal peers in regular schools and in various situations.

*Language and habits are taught from early infancy. If these children are kept with slow learners or children with learning difficulties they will remain slow and have minimum stimulation. They need to be given exposure to normal children even if it means that they might be naughty and mischievous. This should be done as it allows*

them to gain an experience of the real world. After the age of ten, they become very lethargic and their curiosity and desire to explore diminishes.

Babli was put into a regular play group at the age of two years and ten months. The reason for integrating her early was simple. I compared her to the average child who goes to the play groups. Children in that group are required to be toilet trained and have a simple, understandable language. Spoken language comes later for most children and only after they meet other children.

*Babli was already having a sight handicap. If I had kept her away from her normal peers she might never even have heard children talk. She might never have behaved like regular kids. She had no formal spoken language but she understood most of the instructions issued to her. Her high level of reasoning and good social behaviour happened only because she was made to analyse every situation from a very early age.*

Most Down's syndrome children are very sensitive to other people's attitude towards them and shy away from people who they feel, are indifferent towards them. They are comparatively well behaved and generally do not exhibit severe anti-social activities such as violence, drug taking or wanton destruction. We rarely find any behaviour which can be associated with mental illness. However, problems such as swearing and annoying behaviour are fairly persistent. One important characteristic is their sensitivity to the feelings of others.

This emotional perceptivity is appreciated by the families and is seen as a positive contribution to family life. This may be partly responsible for a large number of families who keep their teenagers with them. They are seen as generally happy, cheerful and warm individuals.

## PHYSICAL DEVELOPMENT AND HEALTH

*All chromosome disorders produce a wide variety of physical defects but in general, these tend to be milder in Trisomy 21 (Down's Syndrome) than in other disorders.* The most serious physical problems are present at birth and by the time early teenage is reached, many of them can be treated one way or another. Modern medicine and surgery have made enormous improvements in handling congenital, cardiac, gastrointestinal, and other problems.

In the pre-antibiotic era, the mortality in Down's syndrome was very high with average life expectancy being around nineteen years. *However, with the discovery of antibiotics, the life expectancy of those who have overcome the medical problems of early life, has altered dramatically. With proper diagnosis and treatment even the most serious infection can be successfully treated. Life expectancy for Down's children can reach sixty years while some may even live to seventy.*



**GROWTH :** It has been mentioned that Down children are usually shorter and smaller than normal children. In India, research confirms that on an average, most of our teenagers are shorter than their peers and they also reach physical maturity earlier. The normal range for the first menstrual period would be between ten to twelve years after birth.

**PHYSIQUE :** Most Down's Syndrome people have been described as being short and obese or at least being stickily built.

Hypothyroidism is associated with people who are overweight. *Both obesity and deficient thyroid function is common in Down's Syndrome.* It must not be assumed that obesity, with or without sluggishness is purely because of Down's Syndrome. *It is always advisable to assume that all people with Down's Syndrome may be hypothyroid and to have the thyroid tested regularly.*



Most parents are concerned about their children being overweight and are constantly wanting advice on how to control the weight problem. Babli at sixteen, has started putting on weight but she does not suffer from hyperthyroidism. So she could be overweight because she is very fond of yoghurt, dosas and coffee. So we realized that the only way to keep her weight down was to take her swimming.

Every time she puts on weight, her walk is altered and her gait gets worse. She becomes very lethargic and prefers to sit in her room, watching TV.

## MOTOR SKILLS

Good control of one's body is an integral part of human development. *Physical ability is obviously important in terms of its relevance to self-help skills, mobility, weight control, vocational abilities and the enjoyment of leisure pursuits.*

It has been observed that motor development in people with Down's Syndrome lags behind that of a normal group of the same age. Good musical tone definitely helps people to have motor development, social skills, mental functioning and language acquisition.

Early intervention centres today concentrate on

skills important for everyday life such as walking, climbing stairs, riding a bicycle, kicking, throwing catching a ball etc. if these basic skills are not developed we find that the children are definitely hampered in motor development. We also found in our centre that unless heart diseases, hearing and visual defects are not diagnosed and treated early enough, the children are unable to reach their full physical potential.

*Today, there are several programmes to help improve the physical performance of a Down's syndrome child. Almost any muscular activity is beneficial and whatever the child finds enjoyable should be definitely and positively encouraged.* Competitive sports are becoming increasingly popular and many Down's children enjoy dancing which too is a form of exercise which tends to benefit neuromuscular perceptual conditions.

Children in our centre all participate in the special Olympics. Most of our boys opt for soft ball throw, throw ball and 50 meters dash. We encourage them to form their own teams and they are all actively into a sport of their choice. Only two of our children have a fear of water and they are made to routinely tread water. Water can be a terrifying experience for most children, so the coaches must be very patient and encouraging. This year, fifty Down children and adults were in a camp and they all learnt to swim!

We have a large cricket team. Boys imitate their favourite cricket heroes and they decide who the batsman and the bowler is.

*The general flaccidity of muscle tone and looseness of ligaments and joints in Down's syndrome is associated with extreme physical flexibility.* This flexibility enables

them to sit on their feet in a way that would be awkward or painful for others. They can control their bodies in unusual ways.

There are a number of people who suggest that most forms of exercise should be avoided because the lax ligaments in the two top vertebrae at the base of the skull could become vulnerable (a condition known as Atlanto-occipital dislocation). This is however untrue and the best way of protecting against this occurrence is by developing good, strong muscles in the neck and base of the skull area. Only those activities which might directly injure this area such as diving should be avoided.

#### **COMMON ILLNESS**

In the past, infectious diseases were the main cause of illness in Down's Syndrome. *The most common of the illnesses were coughs, colds, sore throats, ear and skin infections and stomach upsets.* At our centre we find that most of our children are rather healthy except for some who are susceptible to upper respiratory tract infections. Most of our children wear glasses to correct their vision. *Most of the children have long sight but we have also found short sight, astigmatism, strabismus and various other visual disorders.* This high incidence of visual disorders is important because this is likely to delay all aspects of their early development. *Regular testing of vision right from childhood, is crucial for all with Down's Syndrome.*

Babli was born with bilateral cataracts. She is the only baby on record at our centre to have had congenital cataracts diagnosed at birth. Because the cataracts were very dense, surgery was performed when she was just six to seven weeks old. Even today she has only seventy percent vision and could not take to contact lenses.

She suffers from nystagmus and it was actually suggested by an optometrist to implant lenses in her eyes. However, we were not willing to subject Babli to one more surgical procedure at that stage.

### **HEARING**

Hearing is the most important of the senses concerned with learning, communication and social interaction. It should be regularly tested and every effort made to improve it as much as possible. Children at our centre are all tested at least once in six months for hearing.

Those who fail to cover the goals set for them are routinely tested for hearing as it is one of the crucial senses for development. Some of the children are very sensitive to loud noises and tend to drift to a place where screams and loud laughter are absent. Such children also need to be regularly tested.

### **THYROID DYSFUNCTION**

It has been known that Down's children generally have defective thyroid function. In fact, over seventy percent of the children at our centre suffer from this. A routine test is done once a year to check the levels because, once again, this can play an active role in the overall development of children with Down's Syndrome.

*Missing the diagnosis of hypothyroidism is an extremely serious matter since the treatment is extremely effective and without side effects. It so happens that diagnosis is comparatively easy. Thus an overweight sluggish child can metamorphose into a lighter and active one.*

### **CARDIAC DISORDERS**

*Eighty percent of the children at our centre have*

*heart defects.* The incidence of cardiac disorders in Down children is particularly high but modern cardiology has encouraged and changed the outlook for the majority of the cases. Corrective surgery is usually carried out in early childhood.

### **ALZHEIMER'S DISEASE**

*Alzheimer's disease is a degenerative neurological disorder characterized by progressive memory loss, personality deterioration and loss of functional motor capabilities. It is far more common with Down's Syndrome than with the general population.* However not all individuals with Down's Syndrome will develop Alzheimer's disease and even those exhibiting the symptoms may not actually suffer from it since other conditions can mimic the symptoms.

It is recommended that people with down's Syndrome take a baseline test of the cognitive function at the age of thirty and then repeat the test annually to check for any deterioration in this function. Some Alzheimer's disease symptoms can be treated although there is no current cure or ways to even arrest the disease.

### **ACHIEVING INDEPENDENCE IN EVERYDAY LIFE**

Every Person has a right to feel worthwhile and must be as self sufficient as possible which is normally the goal of every parent with a handicapped child.

*Each person is not only unique but each one would like to feel good about himself. It does not matter how slow one is or how handicapped one may be. We all need to maintain our self-esteem and build up confidence in our own value and worth.*

One of the basic ingredients of feeling that we are worthwhile is that realization that we make a choice or

help to choose or are asked how we live, where we live, what we do, etc. which we are able to answer.

I have found that in our context (the Indian community at large), the average handicapped person has no control over his or her lifestyle. They are subject to controls from family, professional and institutions where there is little thought or consideration of consultation with the person for whom many vital decisions are taken.

*However we try very hard to create a feeling of independence in the Down's Syndrome adult because the most important thing to realize is that they have feelings.* They are very sensitive to how people react to them and pick up feelings of being cast aside, ignored or treated badly.

*The word "independent" means different things to different people. We all have different levels of ability.* Being as independent as possible for any individual is to be allowed to do what he can for himself, and to try and develop skill which others may take for granted. These skills expands the ability of that individual and enhances his feeling of achievement.

The growth of independence however minimal begins early in a child's life in any areas. *It is the prime responsibility of parents and professionals to encourage the development of skills in six crucial areas.* These are skills in dressing, eating, hygiene, mobility, communication and sociability. Training and practice in each one of these sets of skills goes on regardless of how old a child is. Parents have what is a unique opportunity to prepare their children for making their own way in life as adults to the extent they are individually able to.

### **What should the child wear?**

Dress and appearance makes up for most of our handicaps in every way in the world that we live in, people constantly scrutinize your clothes, your skin ,your nails, your hair, your shoes.....if a child dresses badly, this goes against him or her immediately. Cleanliness and hygiene are very important and we should consider the climate and temperature before helping a child to choose his or her clothes.

In India, considering the heat and humidity, the ideal clothing would be fresh cottons and light colours. Underwear must be chosen carefully. Remember, the child has very sensitive skin and so, one has to help the child choose appropriate clothing. Polyester and silk underclothes can cause sweat and irritate the skin.

Shoes must be chosen carefully so that it does not restrict or make the gait any wider. *Clothes can be a bone of contention between parents and children. But if a growing teenager is always told what to wear, he or she will never develop the skill to choose comfortable and appropriate clothing.* It can be difficult to let a teenager go out wearing clothes which parents feel, are less than appropriate. It may be embarrassing for parents if their friends laugh at the clothes. Or friends may assess them as parents who do not care enough to dress their children suitably.

On the other hand it is important for teenagers to experiment a little and try out different kinds of clothing. It helps them to build their identity and helps them express themselves as individuals.

Parents do not always understand what young people like to wear since they really are not aware of what

young people are wearing these days. *They can further disable their children by sending them out in something that actually makes them “different” from what they aspire to be.* Sometimes parents can hinder more than help!

It may be helpful to discuss with your child aspects like colour combinations, choice of colour to suit the skin and hair styles, etc. suitable clothes and looking good need not cost any more than necessary. More thought and time devoted as a parent can stimulate and maintain your youngster’s interest in what he or she is wearing. The crux of the matter being to stimulate and not to stipulate.

You are actually helping to build self-confidence and self-esteem; one of the greatest gifts and skills you can pass on.

Babli loves good clothes and spends a lot of time matching her clothes with her shoes, her hair band, her bangles, etc. she loves to look good and will not allow me to choose what I wish her to wear. During her travel to different parts of the world, she spends time picking her clothes and shoes. She loves soft fabrics and the Indian dress called “pavadai” is her favorite because she can wear a lot of jewellery with it.

## **FOOD**

Down’s children sometimes live to eat instead of the other way around and most of them become compulsive eaters and never know when to stop. This leads to obesity which can give rise to other related problems.

It is very important that for a Down’s child right from birth, one monitors the intake of food. This child needs large quantities of proteins, vitamins, amino acids all in the right proportion to help replace tissues and to replenish every stores. The child needs to be helped to choose and decide what is best for his or her individual system.

*Today in 1998 we have learned that these children need nutritional metabolic therapy to combat the effect of the extra chromosome.* For this, Dr. Jack Warner of the Warner House.U.S.A. has discovered what he calls HAP CAPS, *a cocktail of vitamins*, which every child must be given at birth. With this very recent *breakthrough*, a lot more advances have been made in enabling a Down’s child to realize his/her potential much more fully.

Talking of a diet, it is really the parent who has to decide on a planned intake of food for a Down child. Fresh vegetables, sprouted grams, enough roughage, are essential in tropical climates like India.

Babli’s intake of food has always been very poor. She is a vegetarian and dislikes the smell of eggs too. We have kept her on soups, vegetables and all dairy foods. Since her interest in food is low, she has to be necessarily coaxed into eating what we think is good for her. As such we have never been able to introduce her to a variety of food. Even today, at times, one has to feed her as she finds it a tiring job.

She loves coffee and yoghurt. Amongst food, she loves dosas (Indian pancake) with sambar.

To enable a Down’s adult to be self-sufficient, it is crucial to teach him or her to prepare a simple meal for themselves when they are hungry and there is no one around.

For this, in our centre, we have an adult group who are taught to make sandwiches and cut salads. We avoid making the children use the gas as it can be very risky. Many feel that we are not giving proper kitchen training but the fear of gas and fire has made me keep the children away from it.

## **HYGIENE AND HOUSE WORK**

From an early age it is necessary to teach these children daily washing and cleaning routines, and to develop good toilet habits. *Understanding and accepting the responsibility for his or her own personal cleanliness gives the young person dignity and builds self-esteem.* This is one more step towards maturity.

Even when there are physical and practical difficulties of handling taps while taking a bath, it is worthwhile to let the youngster do as much as possible on his or her own. Being clean is part and parcel of being socially acceptable. An interest and care for personal hygiene can also be extended, with encouragement, into the home and surroundings.

Responsibility for various household duties is not exploitation of young people with special needs. It is a recognition that they are members of a family and society and that they have a valuable contribution to make to it.

## **OUT AND ABOUT**

Most school children have the opportunity to develop expertise on transport services on their way to school. But down's children attending special school mainly miss out on this since they are "bussed" to and from or they are taken to school by their parents in a car or two wheeler. Most Down's teenagers by the time they are sixteen or more, may want to exercise their independence by wanting to use public transport like buses or trains.

When we think about it, using public transport is a fairly complex operation. We have to make sure that we are at the right place, the right time, be able to identify the correct vehicle, exchange money and finally disembark at the desired destination. This may not be possible for our Down's teenager.

In India, the crowds are massive and there is so much jostling and pushing that it is a marathon job to get in to a bus.

Girls can be hackled and molested and this can be very risky. Parents can help their children by taking them around in local buses a number of times to make them confident. However I feel it takes a lot of courage to allow our special children to go by any public transport all by himself or herself.

As I have said repeatedly, the most important concern is that of social skill and social interaction. At our centre too, I constantly stress on the necessity of *good communication* which must become the basis of all programmes. Actually it should form the base of the entire educational pyramid. Many teachers have complained that they are too busy teaching them to read or write to be bothered with something like that.

For me, interaction is the most important part of any education however short. The confidence to speak is absolutely a must for special people. Most of them are shy but we have to make an effort to make them join in a conversation.

Social skill must be developed and for this, one can use the video recorder to show the child where he/she is making mistakes or even to encourage him/her. Babli loves to watch herself on video and any small improvement is recorded or photographed so that she can visualize all her movements.

We find that most of the down's adult group have a very limited span of concentration when it comes to academics and they tend to get bored. It is also terrible to be confined to a small room or to be sitting at a desk on a



clear and sunny day. My advice to the staff at my centre is to take them out to the park, departmental store etc. and hold a conversation about what they have seen or would like to see. Slowly but surely I have seen their confidence grow.

We had a swimming camp for all the children at our centre and though all the children might not have learnt to swim, they were all outside the classroom atmosphere. They were so communicative that it surprised all of us.

Being in different surrounding and seeing a wondrous kaleidoscope of colours especially at the theme park, or on the stage, or in the van, these children are totally different.

### **CONCLUSION**

It is surprising that people have the strangest notion about mental handicap. Some people assume that mental handicap and mental illness is the same thing.

I am averse to labeling children who are special. They are different in the way you and I are different. Many people ask me what is the matter with your child? Can she talk, can she ever be normal?

Now, I find that difficult to answer. So I only say “she is just a person.” A person who feels hurt, laughs like you and me. I do not worry about what she cannot do. I look at Babli who can do everything you and I can. That much is enough !

Social attitudes to mental handicap and towards special children is however improving in comparison to what they used to be. Over the years, “special” people have undergone and been subjected to a number of differing conditions. In larger institutions, they were kept and cared for but had very little to do.

The role of the care staff was custodial and had

no developmental inputs at all. The general public could look at these institutions and feel satisfied if they had given some form of donation. They felt that they had done their bit.

Fortunately the late seventies saw the beginning of a major rethinking in this area. Professionals began to talk about ‘integration’ and ‘normalisation’. They realized that Down’s children are special and possessed innate skills and abilities that should and could be developed.

Art, music therapy, yoga were introduced into many of the large centres as an option to the monotonous and boring work they were earlier made to do. They were allowed to move around freely and mix with others.

When Babli was first integrated into a regular school, people were shocked, I did this only because I felt she needed to be with children of their own age, for her to develop any form of spoken language. The school was so very supportive and she was there for over eight years!

She developed her social skills, behaviour and her capacity to mingle with people from all backgrounds.

Attitudes change but parents must face the fact that they will be hurt and angry at other people’s reaction to their child. People may laugh at our children, may ignore them or simply stare at them. After some time we learn to be more tolerant and it stops bothering us.

I believe that if the people of this world who are so educated do not understand or care for special people then it is a crying shame. Those who have no compassion or understanding of children with special needs are not worth bothering about, in my opinion. We need to stop being embarrassed because of our children.

We need to treat them like any other child and allow them to develop their potential to the maximum.

Responsibility lies also with the parents of other children. They need to educate their children to develop positive, healthy views towards these special children.

And we, as parents of these special children, should not hide away our own children but bring them out into the open. We should demand that they be allowed to live as normal a life as possible.

There have always been people with special needs and always will be. Despite advances in modern medicine, in improved ante-natal care, we may be able to bring down the number of children born with special needs but we cannot eliminate the problem altogether.

With society as it stands at present, services will have to be available in a fine tuned manner to that section of society dubbed 'mentally impaired' to give them as high a quality of life as possible.

For this to happen, a large educational process would have to be undertaken with both professionals and general public. Professionals need to come to terms with the fact that those who are mentally impaired are people as well.

*They are normal people with needs, desires and wants. They need food and warmth just as we do, they fall in and out of love and they want as much out of life as we do.*

By making decisions for special people, professionals are taking too much upon themselves, too much responsibility and devote little thought to the consequences. They need to keep in mind that just because a person has been labeled as handicapped in one area, it does not necessarily imply handicaps in all other areas.

The general public too must begin to have a realistic idea of what mental handicap is all about instead

of simulating the ostrich with its head under the sand. Existing publicity and media coverage has begun the process but much still remains to be done to explore the mysteries and myths surrounding mental handicap.

The process of deciding what is the best living situation may be an agonizing and painful process for families. But it is imperative to realise that this person is first and foremost *your child*. He/she has all the feelings that any other person has. It is *your duty* to keep him/her as comfortable as possible and facilitate him/her to integrate into our society without this debilitating feeling of being different.

I firmly believe that even after sixteen or twenty, the child will always remain a child and be innocent and loving.

It is left to every individual parent to find the best lifestyle for his/her child so that he/ she can be a valued and contributing member of the community, not within his/her own limitations but within his/her ability.

THINK OF THE ABILITIES  
NOT OF THE DISABILITIES.



## CHAPTER SEVEN

### Mathru Mandir & Genetic Lab

#### 1. MATHRU MANDIR

Mathru Mandir is a project of the Down's Research Society (India) and sponsored by Rotary Club of Madras Southwest Charitable trust in 1984. Mathru Mandir is a school cum day care centre for rehabilitation of children suffering from Down's Syndrome.

#### Genetic Lab

The genetic lab is an unique feature of **The Down's Research Society (India)**. This is the first lab of its kind to be established for service and research on Down's Syndrome and other allied genetic abnormalities. This project is sponsored by the members of Rotary Club of Madras Southwest, Rotary club of Balwyn, Western Australia and The Rotary Foundation of Rotary International.

#### 2. AIM & OBJECTIVES

1. To diagnose and identify every Down's baby born
  - a. Clinically
  - b. By chromosomal confirmation.
2. Register all these babies and to expand the registry to anyone who wants to avail of its services.
3. To find out the exact incidence in our population
4. Training and rehabilitation of these children.
5. Parent education about Down's Syndrome
6. Prevention.
  - a. Genetic counseling
  - b. Education regarding marriageable age group
  - c. Finding out carrier status
  - d. Type of chromosomal disorder which can be passed on to offspring

7. To take up research studies.

8. Collect scientific information and documentation.

#### 3. DOWN'S SYNDROME

Down's Syndrome means that the child has been born with one extra chromosome. This extra chromosome could have come from either parent, so neither should carry blame for the child's condition.

A Child with Down's Syndrome has typical features like:

*Small head*

*Upward slant of one eye*

*Sunken nasal bridge*

*Protruding tongue*

*Short stumpy fingers*

*Single transverse palmar crease*

*Short incurved little finger*

*Gap between the big and second toe*

All Down's children look alike as if they are siblings, but a Down's child need not have all the features mentioned above.

#### Mental faculty

Down's children are of low intelligence with individual variation. They are friendly, lovable children. They usually have no behavioral problem. These children have a great liking for music. One encouraging feature about these children is their ability to imitate whatever they see. And this helps very much in their training programme.

#### 4. INCIDENCE

The general incidence of Down's Syndrome is 1 in 600-800 live births. That is one Down's baby is born every twenty minutes. This reveals the magnitude of the problem.

## 5. RECENT CONCEPT

Previously, when a Down's baby was born, the parents were told that.

- a. Very little could be done for these babies.
- b. Left alone, these children improved as they grew up

But recent advances in western countries show that by "Early stimulation" technique the mental faculties of these children can be greatly improved and they can be brought to near normal.

## 6. EARLY STIMULATION TECHNIQUE

Early sensory training in hearing, smelling, emotional reaction, physical exercises should be started from birth onwards. The first month of life and the early years are absolutely vital to the development of a Down's child and much can be done to improve its reactions and hold on life.

## 7. TRAINING SCHEDULE

After registration, the child is sent to Mathru Mandir for assessment and further training. Each child is different. Hence, individual assessment is done and a training schedule is programmed for each child. Reassessment is done periodically every six months for the child's improvement.

**8. Parent Counselling :** A parent counselling meeting is held in MathruMandir. The syndrome is thoroughly explained to them. The attitudes of the parents towards such children, what they want to do for them and their problems, are discussed.

1. Some parents are not aware they have a Down's child.
2. Some parents are ignorant about the fact that their child is mentally subnormal and presume that in

due course, it will walk and talk (especially parents who have a 2 year-old child).

3. Some parents feel that their children will become normal as the grow up.
4. They feel that it is enough if the child is put in school at the age of 3-4 years.
5. They are not aware that these babies have to be put in special school.
6. 50 percent of the parents are cooperative and are willing to do anything for their babies.
7. Some parents are curious to know whether there is any medical or surgical treatment to make them normal.
8. Misunderstanding on this account is not uncommon in the lower socio-economic strata.
9. They cannot stay with the baby at Mathru Mandir since they have to look after the siblings.

## 9. PARENT EDUCATION

Parent education is very important in our training programme. Parents are told that these are special children who need more affection, intensive training and constant attention. They should try and encourage their children to meet more people, more children, and overcome their inhibitions. We request the parents to choose the medium of instruction, and parents should talk to the child only in that language. We emphasize the importance of social behaviour and toilet training. It is their cooperation which is really going to help these children. All this is done at Mathru Mandir.

## 10. DIETARY ADVICE

A dietician visits MathruMandir every fortnight. A diet chart for each child is drawn up depending on whether the child is overweight or underweight and the parents are advised to follow this chart'

## 11. GENETIC LAB

A chromosomal analysis of not only the Down's children but also of their parents (also the sibling if necessary) is done to find out carrier status and to prevent further Down's babies being born.

## 12. GENETIC COUNSELLING :

Parents with a Down baby , if young, are advised to follow temporary abstinence for a period of two years. If they wish to have another baby, their chromosomal patterns are analysed for carrier states. If they are found to be normal, the chances of having a normal baby are high. More details can be had from :—

Mathur Mandir

Down's Syndrome Federation of India

Chennai – 600018

Phone : +91-44- 2498 6824 / 4211 2249

Fax : (91) 44-2852 0717

### About The Book

This is not a book about a SYNDROME, but a programme for special children. Children have some chromosomes which happen to be arranged in special ways and the arrangement is referred to as Down Syndrome. It is our aim that these children be looked at as individuals and given an opportunity in society, like any average child.

—During the course of our experience, we have come to know of a number of families who have a child born with Down Syndrome. Their lives would have been enriched, their child's physical and social well being would have improved, if only they had had access to the information available to us today. In this booklet, we have prepared a programme for both the parents and the child. We have tried to answer the most common questions asked of us. We hope we have been of assistance to parents by helping them help their special one.

## PINGALWARA DIARY

(UPTO January, 2018)

Services rendered by Pingalwara Institution for the service of the suffering humanity are:-

### 1. Homes for the Homeless

There are 1809 patients in different branches of Pingalwara now a days:-

- |  |                    |
|--|--------------------|
| (a) Head Office, Mata Mehtab Kaur Ward,<br>Bhai Piara Singh Ward | 359 Patients       |
| (b) Manawala Complex   | 876 Patients       |
| (c) Pandori Warraich Branch, Amritsar                            | 99 Patients        |
| (d) Jalandhar Branch   | 39 Patients        |
| (e) Sangrur Branch   | 228 Patients       |
| (f) Chandigarh (Palsora ) Branch                                 | 115 Patients       |
| (g) Goindwal Branch  | <u>93 Patients</u> |

Total 1809 Patients

### 2. Treatment facilities

- (a) **Dispensary & Laboratory:-** Pingalwara has a dispensary and a laboratory for the treatment of patients. It has an annual expenditure of about Rs.1 Crore 30 lakhs. Medicines are also distributed free of cost to the poor and needy people.
- (b) **Medical Care Staff:-** Experienced medical staff like Nurses, Pharmacists and Laboratory Technicians are available for the care of the Pingalwara residents.
- (c) **Blood-Donation Camps:-** A Blood Donation Camp is organized on Bhagat Ji's Death Anniversary every year. The blood is used for Pingalwara residents and road accident victims.

- (d) **Ambulances:-** Ambulances with basic Medical aid are available for victims of road accidents on G.T. Road, round the clock and provide facilities for taking Pingalwara patients to the hospital.
- (e) **Artificial Limb Centre:-** There is an Artificial Limb Centre at Manawala Complex, dedicated to the memory of Bhagat Ji which provides free of cost Artificial Limbs to amputee cases and calipers to paraplegic ,hemiplegic or polio affected people. 8757 needy people have benefitted till November 2017.
- (f) **Physiotherapy Centre:-** A Physiotherapy Centre equipped with State-of-the-art equipment is functioning in the Manawala Complex since June 2005. On an average 80 patients are treated everyday.
- (g) **Operation Theatres:-** There is a well equipped Operation Theatre in Bhai Piara Singh Ward Amritsar for general surgery and A Micro Surgery Operation Theatre in Manawala Complex where Cochlear Implants and major operations are carried out.
- (h) **Dental, Eye, Ear & Ultrasound Centres:-** These Centres have been set up to provide these services to Pingalwara residents, sewadars and their families.

### 3. Education

Pingalwara Society is running five Educational Institutions for the poor and needy children.

- (a) **Bhagat Puran Singh Adarsh School, Manawala Complex:-** This school provides free education to 771 students from the poor and deprived sections of the society. They are provided with free books and

uniforms. Children being brought up by Pingalwara Society are also studying in this school.

- (b) **Bhagat Puran Singh Adarsh School, Buttar Kalan (Qadian):-** This school is dedicated to the sweet memory of Bhagatji. 461 students are getting free education under the able guidance of well qualified teachers. The school also provides financial help to students who have finished their school studies and are aspiring for higher studies.
- (c) **Bhagat Puran Singh School for Special Education, Manawala Complex:-** This school is providing Special Education to 169 Special children.
- (d) **Bhagat Puran Singh School for the Deaf:-** Bhagat Puran Singh School for Deaf Children is functional at the Manawala Complex since May 2005. The school is equipped with state-of-the-art training aid and has 180 children on its rolls.
- (e) **Bhagat Puran Singh School for Special Education, Chandigarh (Palsora):-**This school caters to the needs of Special adults of the branch.
- (f) **Vocational Centre:-** This Centre is providing free training in embroidery, stitching, craft work, making washing powder, candle making and painting, etc. Young girls from the villages of surroundings areas are the main beneficiaries.
- (g) **Computer Training:-** Computers are available in all the schools for academic and vocational training.
- (h) **Hostel facilities:-** There are separate hostels for boys and girls in Manawala Complex. Many girls are

pursuing higher studies in different colleges.

#### 4. **Rehabilitation**

**Marriages:-** After being educated, boys and girls at Pingalwara are married to suitable partners. 40 girls and 4 boys have been married off till date.

#### 5. **Environment Related Activities**

(a) **Tree Plantation:-** Bhagat Puran Singh Ji was deeply concerned about the degradation of the environment.

A vigorous campaign of tree plantation is started every year on Bhagat Ji's Death Anniversary. Each year trees are planted in various schools, colleges, hospitals, cremation grounds and other public places. These include Amaltas, Kachnar, Behra, Champa, Arjun, Sukhchain, Chandni, Zetropa, and Kari-patta, etc. These are distributed to different institutions.

(b) **Nursery:-** Pingalwara has its own Nursery where saplings of various plants and trees are prepared. Every year, the aim of nursery is to grow more than 54 different kinds of saplings.

#### 6. **Social Improvement Related Activities**

(a) **Awareness:-** Pingalwara has played an important role in spreading awareness about the evils in the society. This has been done by printing literature on religious, social and environmental issues at the Puran Printing Press, Amritsar and is being distributed free of cost. Annual expenditure of printing and publicity is about 1 crores 50 lakhs rupees.

(b) **Puran Printing Press:-** The Printing Press has been updated with an Offset Press.

(c) **Museum and Documentaries:-** A Museum, and a number of documentaries have been prepared on Pingalwara activities as well as on zero budget natural farming. The C.D.s are freely available from Pingalwara.

A feature film produced by Pingalwara Society, Amritsar on 30 January, 2015 EH JANAM TUMHARE LEKHE (Punjabi) on Rev. Bhagat Puran Singh Ji, founder Pingalwara and his struggle not only for selfless services of wounded humanity but for Environment Crisis also, will prove a beacon for the generations yet to come after us.

#### 7. **Help to the victims of Natural Calamities**

Pingalwara makes an effort to provide succour to the victims of natural calamities like floods, earthquakes and famines. Aid was sent for the earth-quake victims in Iran, Tsunami disaster victims, Leh landslide and flood affected areas.

#### 8. **Cremation of unclaimed dead-bodies**

Pingalwara cremates unclaimed dead bodies with full honour.

#### 9. **Dairy Farm**

180 cows and buffalos at Manawala Complex provide fresh milk to the Pingalwara residents.

#### 10. **Old Age Homes**

Old age homes at Sangrur and Manawala Complex of Pingalwara caters to the needs of elderly people.

11. **Expenditure:** The daily expenditure of Pingalwara is more than 6.5 lakhs.

**Other Details:**

- a) All India Pingalwara Charitable Society is a Registered Society, registered by Registrar of Companies vide letter No. 130 of 1956-1957 as amended vide No. A-28/4540 dated 07-07-1998.
- b) All donations to Pingalwara are exempted under Section 80 G of Income Tax-II Amritsar letter No. CIT-II/ASR/ITO (Tech.)/2011-12/4730 dated 11/12 January, 2012.
- c) PAN Number of the All India Pingalwara Charitable Society is AAATA 2237R
- d) FCRA (Foreign Contribution Regulation Act) 1976 Registration No. of Pingalwara is 115210002

Wahe Guru Ji Ka Khalsa

Wahe Guru Ji Ki Fateh

***Dr. Inderjit Kaur,***

***President,***

All India Pingalwara Charitable Society (Regd.),

Tehsilpura, G.T. Road, Amritsar. (Punjab).

- \* Preserve natural resources.
- \* Service of the poor and destitutes is the service of God.
- \* Plant trees to save environment.
- \* Wear Khadi clothes to lessen unemployment.
- \* Simple living and high thinking is a bliss.
- \* Use less of diesel and petrol.
- \* Exercise restraint in your living habits.
- \* Don't forget to plant trees. They are the sign of prosperity of a nation.

—Bhagat Puran Singh

K.M. Munshi writes that Matsya Purana says: "One who sinks a well lives in heaven for as many years as there are drops of water in it. But to dig ten such wells equals in merit the digging of one pond; digging of ten such ponds was equal to making a lake; making of ten lakes was as meritorious as begetting a virtuous son but begetting ten such virtuous son had the same sanctity as that of planting a single tree."