

Autism News

People concerned about autism



tamana

If you have any suggestions, queries or requests for specific information, please write to :

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Helpline

Do you need to know more about autism ?
Or do you feel like talking to someone about your fears and joys?
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Views expressed in Autism news are not always held by us.
This is a platform to share experiences and keep you abreast of the latest methods and theories being practised

WELCOME

Tamana Silver Jubilee (1984-2009)



Three decades ago, after the birth of my daughter Tamana I had a dream to create a world of inclusion. It has taken 25 years of struggle by us to open the minds of Indian society to accept the disabled. As my daughter Tamana has grown into a well settled and independent adult, so

has the organization. This growth has been nurtured by our optimism in drawing out the excellence and potential of each child. We have observed that nothing is beyond them. They can walk the ramp, dance on stage and win medals at international sports events. They can also earn by creating art pieces and handicrafts, as well as work in offices, schools and shops.

However to achieve all this and optimise the potential we have to start the interventions very early in life of the special needs child. I did the same with my daughter Tamana, more than 3 decades ago, when services for special needs child were non-existent in India. Today it has been proven that the role of "Early Intervention and early Diagnosis" in any disability including autism is very critical. Especially, intensive treatment early in life can improve the development of useful speech and decrease the severity of mental retardation.

Tamana has put its best efforts to tackle and raise awareness about this aspect in India. Tamana was one of the first institutions in India to start "Early intervention and Diagnosis" unit in 2003. The Early Intervention Center (EIC) at Tamana has in its team an occupational therapist, physiotherapist, psychologist, speech therapist and special educators. EIC at the Tamana Autism Centre, School of Hope is specially designed to provide services to children from birth to 3 years of age who have a developmental delay or are considered to be environmentally or biologically at risk.

Since its inception the EIU has supported 54 children. The average age range, to which our EIU service has catered is between 18 months to 6 years. As per our records the average age of admission to our EIC is 3 years and 7 months. Although our unit caters to children with a range of disabilities, the major chunk (66%) of children availing services have been diagnosed with ASD.

Tamana is one of the largest centre for autism referrals in India. These referrals are from all over India from psychologists, pediatricians, neurologists, child guidance centres, hospitals, schools and from all other institutes working in the field of disability. We hope as the awareness of autism increases, more and more children will be diagnosed at an early age and will get referred for early intervention.

In the current issue of autism news we have focussed on early intervention and diagnosis. In the Nations' page Neerja Shukla has written about ABHI, a special School in Shimla. Purnima Jain, Coordinator of Teacher Training Cell at Tamana conducted an autism awareness workshop at ABHI. She has written about her experiences at ABHI. Supriya Malik, a psychologist at Tamana, describes a new technique Relationship Development Intervention. Also included are our regular columns- Book Review and Your Page. This time we also have contributions by parents in the form of two poems. The highlight of this issue is the speech made by the President of India, Her Excellency, Shrimati Pratibha Devisingh Patil at the Tamana Silver Jubilee function on 19th December 2009.

To commemorate our silver jubilee we also organised an international conference on Early Intervention in April 2010. The highlights and the report will be published in the next issue.

In our 26th year of existence we zealously continue with our mission of creating of awareness of autism in India.

Dr. Shayama Chona

SPEECH BY HER EXCELLENCY THE PRESIDENT OF INDIA, SHRIMATI PRATIBHA DEVISINGH PATIL AT THE SILVER JUBILEE CELEBRATIONS OF TAMANA ON THE 19th DECEMBER 2009, AT NEW DELHI

Ladies and Gentlemen and Dear Children,

It is a special occasion for me, as I participate in the Silver Jubilee Celebrations of the Tamana Association. I take this opportunity to applaud the work done by this organization over the last twenty five years in providing opportunities for education and holistic development to children with special needs. Seeing how these children work and perform only reaffirms the immense capacity of the human spirit to overcome obstacles and difficulties.

I consider this privilege to interact with such amazing individuals today which happens to be also my birthday. In my own life, I often recall the hard work and the effort that was required while working first as a lawyer and then in public life. Throughout this time, it was the values of perseverance and commitment that have been my guide. Moreover, there was always hope that the future held the promise of progress and prosperity for the people of India and for the nation. Indeed, it is eternal hope that is a driving force in a human being's life. It generates optimism and faith in their ability to face challenges.

I am encouraged when I see hope in the eyes of the children present here. This has been possible because of the hard work and patience of all those working with them. It is important that from a very



early age the concern of the children with special needs are identified and efforts made to work-out appropriate strategies. These children should be imparted training and given skills which would help their economic independence and rehabilitation in the society. The entire objective is to make them self sufficient and self reliant individuals who can pursue a career or vocation.

In fact, there should be no goal that is unattainable or any objective that cannot be achieved. There have been many examples where with great resolve and will power differently abled persons have been able to overcome the constraints of impairment. Tom Whittaker Climbed Mt. Everest with a prosthetic leg in 1998. It was a big accomplishment. Beethoven was completely deaf, when he composed his Ninth Symphony, considered as one of his greatest masterpieces of all times. Professor Stephen Hawking, who was diagnosed with motor neuron disease, was first disturbed, but soon realised that there were "a lot of worthwhile things" he could do. He went on to become an academic celebrity writing many papers, books and publications in the field of cosmology and quantum gravity including on "Black Holes". I am sure that many among you have the ability to overcome the impediments of disability and also to be innovative and creative.

Today, as I saw special children working on the computer, I was impressed with their capacities and talents. I am sure that they would go on in life to become people who would be a motivation for others. I would be amiss if I do not mention Tamana, who is the inspiration of this organization. Today, she is herself a teacher, as well as a spokesperson for the International Special Olympics. She has demonstrated that overcoming adversity, while a difficult task, is no barrier to making contributions to society and to the welfare of others.

The role played by family, especially parents, is critical in providing the necessary encouragement to the special child. It also means that their own lives have to become a mission. Social attitudes in this regard are extremely important. Civil society and NGOs can play a very bridging role in this regard. At one level they must create awareness in the society to treat the differently abled as normal children. They should bring to the public area the experiences and the success stories of differently abled persons.

All efforts should be directed towards the full integration of such persons in the society. Apart from ensuring that assistive devices are available easily and at affordable prices, Science and Technology must be used for the development of more user friendly systems for empowerment, rehabilitation and integration efforts. While speaking at the National Awards for the Empowerment of Persons with Disabilities on 3rd December this year, I spoke about the importance of education and skill building in this regard. Children with special needs should have access to education in an environment and format that caters to their needs, including material in accessible format and

barrier free schools. The success of educational programs for the impaired will depend upon getting many more of them in school and making it a learning experience for them. Here, I am reminded of Helen Keller who as the first deaf and blind person to earn a bachelor's degree in 1904. She was greatly assisted by her teacher, who taught her how to communicate. Keller went on to become an activist for many progressive causes in the world, including women's suffrage and worker's right. She understood the importance of human emotions and famously said, "the best and the most beautiful things in the world cannot be seen, nor touched...but are felt in the heart." Today, as I speak to you deeply from my heart, I want to convey my very best wishes to you for success and for progress in life. I am confident in the ability of each one of you to be brave in life, live with dignity and to bring joys to those around you.

I also convey my very best to Tamana organization as it continues its work in achieving what it visualizes, to set up a research and technology centre, set up a corpus fund which will provide a myriad of training and employment opportunities for its special students and to develop an aftercare facility that will step-in to constructively support the child when required. As I am completing seventy five years today, I am donating Rupees Seventy five thousand to this corpus fund, so that it can achieve its objectives.

With these words I once again wish all of you the very best.

Thank you,

Jai Hind!

TAMANA CELEBRATE ITS SILVER JUBILEE

WITH SHRIMATI PRATIBHA DEVISINGH PATIL, PRESIDENT OF INDIA

New Delhi, Saturday, December 19th - Tamana students presented a Cultural Programme at Le Meridien Hotel, New Delhi to celebrate its Silver Jubilee. Shrimati Pratibha Devisingh Patil, President of India was present, supporting our beliefs and cause.

On this special day, India's best and brightest came together to honour Tamana's journey of 25 years of relentless struggle and achievement. The President of India, Shrimati Pratibha Devisingh Patil, was not only in attendance, but made it more special by celebrating her birthday with the children of Tamana. Union Minister for Human Resource Development, Govt, of India Mr. Kapil Sibal presided over this ceremony, bringing to the fore India's commitment to ensuring that these inimitable children be accepted into mainstream society. He announced that the education of the disabled would soon become a part of the education bill and an amendment will be made in existing laws to

integrate autism, cerebral palsy and multiple disabilities in the mainstream school system.

The distinguished guests of honour- Mr. S.K Roongta, Chairman Steel Authority Of India, Mrs. Charanjit Singh, Chairperson M&D, Le Meridien, New Delhi, Mr. Pawan Jain, Chairperson, Board of Governors, Mangalayatan University, Aligarh, Mr. Rajesh Saxena, CEO, American Express, Mr. Satjiv Chahil, Senior Vice President, Global Marketing, Hewlett Packard Mr. Sunil Dutt, Vice President, Personal Systems Group, Hewlett Packard, Mrs. Shahnaz Husain- were in attendance to show their support for this extraordinary journey that spans 25 years - in pursuit of inclusion.

The students from Tamana School presented an unforgettable afternoon of dance and music choreographed and conceptualized by Shiamak Davar's Victory Arts Foundation. Tamana students also showcased their computer skills by making birthday greetings for the President of India on Touchsmart PCs donated by Hewlett Packard.



NATI ON

Action For Barrier-free Handicapped Integration (ABHI)

- Neerja Shukla

'ABHI' is one of the two NGOs' working for the rehabilitation of mentally challenged children in Shimla, Himachal Pradesh. The other one is a parent NGO, 'Udaan'. We are both fairly young, with ABHI being registered in 2004 and Udaan in 2002. This shows how recent have been the interventions in the disability sector, in our region, and how few.

ABHI is essentially an NGO of professionals-people trained and experienced in the field of special education and in the rehabilitation of the mentally challenged. We have eight special educators as members of ABHI and the core objective in the formation of our organization was to fill a gaping void and create a conglomerate of experts who would work together and along with the parents, towards evolving a sustainable model for the rehabilitation and integration of the mentally challenged.

ABHI works with the smaller children and those with severe or profound conditions. The mountainous terrain of Shimla is an added dimension to a difficult situation, as it makes it difficult to access the children since their homes are far from the road and very often on steep mountain faces. This makes it tough for rehabilitation workers to reach the children for home based intervention. Transporting the children out of their homes to the Centre, is

therefore another responsibility which our organization undertakes. We have employed two taxis for this purpose and the children travel with their teacher in order to ensure their safety. This has provided the parents some respite besides bringing a whole new world to the children's lives.

The lack of readily available expertise is the other problem we face here. The non-availability of occupational therapists, speech therapists, experts on Autism or Cerebral Palsy is another factor which compounds the problem for the parents who feel



quite alone and helpless and unable to cope with the responsibility of providing for their child's special needs. Our organization therefore has been inviting experts in these areas to assist ABHI and Udaan with programs for the

children. Since autism is invariably an interestingly difficult condition to deal with, we had Ms Purnima Jain from Tamana to assist us with the children's program and for parent counselling. She helped with individual programme planning with the parents and staff. After each case study and a review of what we were doing with each child with autism, Ms Jain helped us to work around the hurdles we were facing. As in the case of Gulshan, a 7year old girl with autism-the introduction of a picture book with family photographs has proved effective in gaining her attention. She identifies her family members

and can co-relate herself(in a mirror) with her photograph and even says her name!

ABHI runs a Counselling and Therapy Centre for children with various disabilities-autism, cerebral palsy, mental retardation and multiple disabilities. We have a full time physiotherapist for the children, along with two special educators and 2 helpers. The centre is not autism specific. We have four children with autism-one girl Gulshan; and three boys-Neeraj, Rajat and Abhishek. Individual time is given to each child when their specific goals are reinforced. For most of their school day the children work and play together. Prayer time, yoga, PT, games/puzzles and meal time form a part of their daily schedule. We have found that peer group training helps, as in the case of Rajat, an 8 year old boy with autism, who plays and eats with, Shalu a 13 year old girl with MR. He now sits with her and follows her instructions while eating. Individual ball play has also helped to increase Rajat's attention span and he can sit for longer periods with the educator while working. Neeraj now listens to commands and indicates his toilet needs with Abhay, his special educator, who has developed a rapport with him and has developed a vocabulary of basic

needs to which he responds-toilet, khana, come here etc. Abhishek, a 9 year old boy with autism can sit and do his colouring under the guidance of Manjula, an 8 year old girl with hearing impairment. Music and dance has been a great motivator in helping the children with autism to socialize.

When everything in the environment 'failed' to cater to the needs of special children, then we looked for answers in philosophy and religion. ABHI has put a philosophy for rehabilitation in place, in order to move beyond the many barriers and provide some relief to the children and parents. We work primarily at emotional and spiritual development, giving the children's life an element of joy in order to make them blossom to their individual potential. We have chosen to work with the commonality of needs rather than focus on special needs, because we feel that the answer to rehabilitation lies here. We have chosen to work with what is available rather than create a special environment for our children. We follow the Buddhist principle of creating harmony by establishing fun-filled platforms which bring us all together, in order to move beyond the insurmountable problems and find some meaning and hope in life.



VISIT TO SIMLA - AN EYE OPENER

- Poornima Jain

When I received an invitation to visit Simla from ABHI (Action for Barrier-free Handicapped integration), an organization which is working with children with special needs in Himachal Pradesh, to hold a workshop on autism for the parents and teachers my delight was two-fold. The idea of going to Simla in the summer was thrilling in itself and with it, to talk about autism and to be of any help to all those who are involved in the teaching and training of children with autism was an added bonus. Autism is an area, very close to our hearts at Tamana. At Tamana we have been very fortunate as we have been involved in ongoing training programmes on autism, both formal and informal; conducted by our various directors (who had been trained at that time in US when there was no training in India) and series of workshops and international conferences held at Tamana. I was looking forward to this and I must say I was not disappointed at all.

Compared to Delhi schools, the ABHI centre seemed very small from outside. But as we entered through a narrow walkway, it opened up inside. Like the city of Simla, it has different ascending levels utilizing the space to the maximum. There were homogeneous classes with children with various types of disabilities but similar levels. Apart from the academics, emphasis was also on the training of

daily living skills and different vocations. The teachers there, some new and some who have been working there for quite some time, were highly motivated. All the work that was being done was really inspiring. You do not need a fancy building, or expensive teaching devices to teach, what you need is dedication and intent, this was so obvious.

After the round of the school, a small meeting was fixed to interact with the parents and the teachers. This was such a humbling experience, to realize that there are parents who have travelled almost a hundred kilometres to learn from us. We in big cities may have more access to know how, but how many of us here put all that into use. Meeting parents, grandparents, who may not be having degrees and qualifications but having the knack of putting into use whatever they know about autism to teach their child was an eye-opener. I shall always be grateful to ABHI to have given me an opportunity to think beyond big cities and degrees.

The statement that only people from big cities are aware about autism does not hold good any longer fortunately.



ASSESSMENT TOOLS USED AT TAMANA

- Dr. Reena Bhattacharya

DIAGNOSIS AND AFTER

At the Tamana outreach and child guidance cell, older children usually come with a diagnosis, and once reconfirmed, they now want intervention and guidance. It is when very young children are referred (usually by hospitals or paediatricians or other affected parents/friends), we come across shock, disbelief, arguments, justifications, etc. Parents often and not surprisingly feel as though there is a mistake in the diagnosis. Long and gentle counselling sessions aid acceptance.

The earlier the better is the motto for all disability treatment. Because of brain plasticity, i.e. new neural connections that are still being formed in very young children, new strategies and skills can be taught and imbibed easily by the brain.

However, with regard to the early diagnosis of autism or any other spectrum disorder the difficulty lies in "labelling as something definitive or not labelling". Certain features are still developing and yet some get resolved over time, while some take another form. So, keeping the 'triad of impairments' in focus, along with sensory integration issues, lack of joint attention and/or shared attention, stereotypical play and interests and problem in regulation of eye gaze, we can safely arrive at a diagnosis of spectrum disorder or PDD even by the first 18 months. This done, intervention should start to address social, communication and cognitive deficits.

AIDING ACCEPTANCE

Primary caregivers will often argue and sometimes try to justify deficits (e.g. aberrant communication) as natural to a small child. They will cite individual differences and family history. Therefore one has to be cautious and share the diagnosis gradually during the session. We discuss their child's skills on various play and activity items one by one. As we always have the parents with us when we see the child, the deficits can not be argued away. We reconfirm what they have already reported about the child's responses to sensory issues, pain interests, anxieties, fears, etc. Problem behaviours that were

cited are discussed again. And then the possible diagnosis is stated. We never label definitively but keep it broadly categorized. The implications of a spectrum disorder are discussed; including the skills and strengths of the child. Also shared are examples of, famous people who had autism but over-came their limitations, the various therapies and educational facilities now available.



After this, need for immediate intervention is stressed. We talk of the developing brain, better capacity of the young child to learn and overcome weaknesses. Most parents are by now receptive and also know that they are not alone but the team is with them. Though they go home and cope with their extreme distress, each in their own way, the hope held out to them is also recalled.

Families are not called back immediately- giving them time to work through their feelings and think of the possibilities held out to them. Usually, within a fortnight parents come back to get advice on the Early Intervention Program. It is usually in this session they ask about future prognosis. Since there are never definitive answers to that, the stress is on what is usually achieved, how Early Intervention helps the child cope and learn, and what problems surface, if intervention is not given.

TOOLS AND INSTRUMENTS

There are various tests available for screening and diagnosing PDD (Pervasive Development Disorder). The CHAT (Checklist for Autism in Toddlers) or a modern version of CHAT is the oldest screening schedule and is given to children ages 18-24 months. It is a quick five minute test that can show a care giver or a medical provider if a child has several markers that may indicate the presence of

autism spectrum disorder. This was published by the Cambridge Autistic Centre and is used all over the world. This is however not a diagnostic tool but a screening test only.

For Diagnosis, M-CHAT consisting of 23 questions is used to identify possible PDD difficulties. We at Tamana have a Hindi version of it also. This test is given to children ages 16- 30 months.

The DSM IV criteria and CARS (Childhood Autism Rating Scale) are usually used. CARS is a diagnostic assessment method that rates children on a scale from one to four for various criteria, ranging from normal to severe, and yields a composite score ranging from non-autistic to mildly autistic, moderately autistic or severely autistic. The scale is used to observe and subjectively rate fifteen items, categories, relating to:

- relationship to people
- imitation
- emotional response
- body use
- object use
- adaptation to change
- visual response
- listening response
- taste-smell-touch response and use
- fear and nervousness
- verbal communication
- non-verbal communication
- activity level
- level and consistency of intellectual response
- general impressions

Now a days a new tool ADOS is also used for diagnosis. The Autism Diagnostic Observation Schedule -Generic (ADOS-G) is a semi-structured play method assessment of communication, social interaction and play or imaginative use of materials for individuals suspected of having autism or other pervasive developmental disorders (PDD). It is a combination of two earlier instruments: the Autism Diagnostic Observation Schedule (ADOS: Lord et al., 1989), a schedule intended for adults and children with language skills at a minimum of the three-year-old level, and the Pre-Linguistic Autism Diagnostic Observation Scale (PL-ADOS: DiLavore, Lord & Rutter, 1995), a schedule intended for children with limited or no language, as well as additional items developed for verbally fluent, high-functioning adolescents and adults.

The ADOS-G consists of four modules, each of which is appropriate for children and adults of differing developmental and language levels, ranging from no expressive or receptive language to verbally fluent adults. These modules are labelled with numerals 1 to 4, with each activity numbered within its module. The ADOS-G offers clinicians and researchers the opportunity to observe social behaviour and communication in standardized, well-documented contexts. These contexts are defined in terms of the degree to which the examiner's behaviour structures the individual participant's response and social initiative. For purposes of diagnosis, use of this instrument should be accompanied by information from other sources, particularly a detailed history from parents whenever possible (see Lord, Rutter & Le Couteur, 1994).

Hence ADI-R(Autism Diagnostic Inventory-Revised) is administered before starting ADOS. It is a structured interview used to gather information from parents for diagnostic purpose. Its goal is to provide standardized contexts in which to observe the social-communicative behaviours of individuals across the life span in order to aid in the diagnosis of autism and other pervasive developmental disorders.

THE EARLY INTERVENTION UNIT

Early Intervention unit is devoted to very young children showing deficits which prevent them from developing as they should. The assessment is done in an informal play situation and check for indicative behaviours and habits of the child to see if he comes under the autistic umbrella. The children who are not picking up from social cues, are not responsive to another's voice commands and who have sensory integration problems come under this category. One of the early signs of detecting autism is the communication impairment in the child. The child will not have speech or would have echolalia i.e. automatic repetition of vocalizations made by another person. The child may also have meaningless self talking speech and problems in regulating eye gaze for communication. Child would also be showing deficits in joint attention sharing, and be somewhat restless in behaviour.

A non verbal child may not have any pointing or any gestures to compensate for their communication deficits. All these children do not pick up cues of others needs and interest. They are seen to be self absorbed and non compliant and have serious spells of aggressive behaviours.

The Focus of Early Intervention are:

1. Reduce developmental delays and deficits through therapies such as Occupational Therapy and Speech therapy.
2. Reduce certain behaviours which interfere in learning and attention (e.g. sensory motor behaviour like hand flapping, head nodding, hyperactivity etc.)
3. Teach Pre Academic Skills to prepare the child for school.

The Play-way activities are planned in ways to develop:

- Attention to voice to respond to name, when he is called.
- To follow simple commands, this is the basic to all learning
- Share interest with primary care giver and later the teacher.
- Social Skills- autistic children don't respond to/like interacting with other children hence are made to sit in situations where they have to work and play in a group to develop the association of feeling pleasure in group activities.
- Imitation- Imitation is basic to most of our learning, but as PDD children do not readily

imitate others, imitational skills have to be taught.

- Play- Children with autism usually have an idiosyncratic play or repetitive play. Appropriate play skills have to be taught for enjoyment and to increase cognitive skills and motor skills. While teaching play, social and non verbal communicative skills like gestures etc. are built up. Children learn to appreciate success and also become aware of other pleasures and joys too. Concept of Turn taking is taught slowly through ways that are enjoyable like games etc.
- Communication- autistic children lack proper communication skills, so to express themselves they show behaviours like banging on the walls, hitting someone etc. This is not appropriate. So we have to teach them simple actions to express their needs like just bringing their hand forward for "give". In their turn the children need to understand the concept of "Wait".
- Eye Contact - Autistic children generally have poor or fleeting eye-contact, which hinders social communication. Hence developing eye-contact is also important.

(Reena Bhattacharya is a Senior Physiologists at Tamana and Incharge of Diagnostic Centre)



How To Tell Parents That Your Child Has Autism

- Poornima Jain

When I was asked to write an article on "how do we tell the parents that your child has autism", I initially brushed it under the carpet, as we do with all the questions that are difficult and tricky, with the excuse, that as special educators we do not do the diagnosis and it is the job of a psychologist or a pediatrician. When we meet the parents of the child, he/she already has a diagnosis of some sort.

But the fact is, for the parents it is just a name or label given to their child. How many parents in India (accept on big metros) have actually heard of autism, leave alone know about it. And to make the situation more confusing, they hear the term PDD-NOS, which is being used more often now as a diagnosis (understandably to be on the safer side).

I would like to quote this comment from one of the parents from the internet "What the heck is PDD-NOS? It stands for pervasive developmental disorder not otherwise specified, which for most of us means very little. It actually MEANS developmental delay that is not diagnosed as autism-- even though it is on autism spectrum?"

The point I am making is, that even after the diagnosis. Does it really help the parents?

Just explaining the diagnosis may take quite some time, because it is just so hard to explain.

If the child has been fortunate enough to be diagnosed at an early age, i.e. before 3, (and that is a big if in India) and we talk about the symptoms that the child is showing (putting things in a line, recites video clips, shifts sand through fingers instead of playing with other kids) we hear responses that "all kids do this, he will be fine". The key word is NEVER. All kids do 'this and that' but with kids with autism, it is the autism-twist that makes it different, and that is what we have to explain.

How do we explain depends on whether the parents are knowledgeable about autism. If they are, then we may take the line that autism is a spectrum disorder varying from mild to severe. Regardless of where your child falls on the spectrum there are

interventions and treatments for their symptoms. The sooner interventions and treatment are initiated the better the outcome. The parents need to take measures to prepare their child for a life with the disorder and to ensure that they are living with autism and not surviving it. It is a life long disorder.

Raising an autistic child, depending on the severity of the disorder, can be an extraordinarily difficult task that can take both an emotional and physical toll on parents and family members. However, there are forms of treatment and interventions that can truly help. So the sooner a child is diagnosed, it becomes easier to cope if the interventions and treatment can be started faster.

For those parents who have no idea or a very little idea about autism, basic psychology suggests that when you approach someone about a potentially troubling situation it is better for all concerned if the situation is handled in a gentle manner. Obviously, if you are going to tell a parent that you believe their child is autistic, and what all it involves, it pays to be sensitive. Remember many people do not fully understand what autism really is, so it will be up to you to explain the disorder and answer any of their initial questions. Be straightforward and discuss the matter in a calm, sensitive way. Many parents who first hear the words "Your child has autism" are shocked and dismayed and may react angrily and deny the suggestion that their child is autistic, so it is probably a good idea to have some literature with you to explain to them what is autism. It is also important to explain the different levels of autism and their effects. There are many negative aspects of autism but there are the positive ones too, what strengths and the special skills that their child may have or may show later should be put on the board in front, along with the negative ones.

When your child has autism it can be a very difficult situation to deal with. Many times, parents may suspect there is something developmentally wrong with their child, but consciously coming to grips with the situation can be extremely hard to accept. There are many cases where an autistic child is

treated as if he or she is a completely normal child, out of a sort of blind, but wishful thinking; and these situations can be particularly troubling for parents and child.

In addition, autistic children, like other children with developmental disabilities, have special needs. If you really want to help, you should be ready to provide information on how to access services that address the special needs of the child in question. When a parent faces the fact that her child may be autistic, it can be an overwhelming sensation due to the fact that the resulting changes will be life-altering for the people directly involved. Make sure you know enough so you can answer the majority of

questions that will be thrown at you. Most importantly, be yourself and make sure the person knows that you care and are concerned for them and their child.

Try to offer information about methods of treatment that will shed some positive slant on autism. Inform your friend or family member that there are thousands of scientists and researchers working on ways to treat autism better. You should also have a list of resources available. This list can include websites, local clinics, cutting-edge research and anything else you feel can give a realistic, but positive approach to autism..

THEY---Ode to our special children
Is it really too much to ask?
That the 'special' be included in every task?
That those of us who are joyful and whole,
Will do much more than just console....
We'll not stand by, look away or ignore
Their pleas.... for a piggy back ride to the shore....?
They have brought laughter into our eyes,
With their mischievous antics and innocent ploys--
The joy and contentment of the unknowing....
The comfort of the unquestioning and unprobing-
From their acceptance of life with its constraints
... They're living the moment and day, sans restraint...!
They fly unburdened, embracing all in their fold
Fleeting memories and delicate minds, unable to hold
Grudges, disappointments or malice...anger and pain
Their transient emotions are careworn to retain.
Tomorrow is a lifetime away---
Inequities and inabilities will not mar today...!
They force us to redefine the meaning of success
As their accomplishments go unnoticed, in mankind's progress-
They falter and fumble, in their attempts to attain
To make that small step---try again and again!
Achievement and fulfillment...is to have done
To hope and believe----is to have won!
They are not in the race that man has made.....
But to walk alongside, with faith and aid
Are we not the learners...as to us they smilingly beseech?
That to strive and enjoy the moment-is Life...They teach!
We are blessed for each day we see
In every child the spirit.....that's Thee....

-Neerja Shukla

Early Diagnosis and Early Intervention in Autism Spectrum Disorders

- Alycia Halladay and Geraldine Dawson

The growing awareness that signs and symptoms of autism spectrum disorder (ASD) can be identified in infants and toddlers has spurred the development of intervention techniques that can be implemented before 24 months of age. This focus on earlier ages has provided new opportunities to characterize the developmental trajectory of ASD and answer questions such as whether early signs and symptoms are predictive of later diagnosis and outcome. This emergent focus also makes it possible to consider how early environmental factors can influence the developmental trajectories of young children at risk for ASD.

While retrospective studies using parental reports and videotapes have proven helpful in identifying early signs and symptoms of ASD, prospective studies of the infant siblings of children with ASD, who are at higher risk for developing the disorder, have distinct advantages for examining multiple ranges of functioning, determining the impact of early delays in one domain on later development, and identifying relevant biological and behavioral markers during development (Zwaigenbaum, 2001; Zwaigenbaum et al., 2005; Zwaigenbaum et al., 2007).

The use of high-risk samples, especially infants who have an older sibling with ASD, has been instrumental in helping researchers and clinicians identify warning signs for ASD before a formal diagnosis can be made. A number of screening tools are now being validated that are developmentally appropriate for infants and designed to identify features that may predict later diagnosis of ASD. These tools include the Autism Observational Scale for Infants (Bryson et al., 2008; Brian et al., 2008), the Infant Toddler Checklist (Weatherby et al., 2008), The First Year Inventory (Watson et al., 2007) and the Early Screening for Autism Traits questionnaire (Swinkels et al., 2006).

In a recent review article, Rogers (2009) outlined a set of developmental characteristics exhibited by infants who are later diagnosed with ASD that appear between 12-18 months of age but

have not been consistently observed at earlier time points. These characteristics include atypical motor movements or object exploration, deficits in gross and fine motor skills and joint attention, atypical visual attention and temperament, and deficits in receptive and expressive language at 14 months of age (Chiang et al., 2008; Landa and Garrett-Mayer, 2006; Loh et al., 2006; Ozonoff et al. 2008; Presmanes et al., 2007; Yirmiya et al., 2007; Zwaigenbaum, et al., 2005; Yirmiya, 2006). Individual children show different onset patterns, such that the timing and onset of the specific behavioral autism phenotype differs from child to child. Certain infants exhibit "early onset" symptoms whereas other may show a decline in skills and the onset of symptoms during the second year of postnatal life (for review see Rogers, 2009). Using the findings of children who show early signs and symptoms of autism, early interventions for infants and toddlers at risk for ASD are being developed. Autism Speaks has funded several clinical trials that are exploring approaches to early intervention with children at risk for ASD who are less than 18 months of age. These new protocols currently under study utilize manualized interventions with a strong parental and family component. All of the newer studies involve parent coaching or parental use of daily interventions in a variety of settings. In most cases, the studies involve a phase of clinician-parent coaching followed by support via manual, videotape, or telephonic clinician contact to ensure that the intervention is being used properly and to provide support to parents in various situations. Also of primary importance are the individualized activities designed to meet the needs of each child. While different intervention protocols target similar behaviors, it is generally understood that the



heterogeneity of the disorder will not be conducive to a "one size fits all" approach.

Parent-mediated interventions are likely to be cost effective and more widely available to a variety of countries with cultural adaptations. Other dissemination methods may make these interventions even more widely available. For example, Vismara and Rogers (2009) are currently piloting a telehealth program for training parents via webinars, teleconferences, video conferencing, and videotapes. The results have been quite positive and parental satisfaction rates are high. While programs involving early intervention of autism (before 24 months) have just begun, they are built on a strong framework of understanding infant behavior, the importance of parent-child interactions, and the need to continually manage or monitor progress over time.

While new approaches for very young children with ASD are being developed, evidence continues to demonstrate that early intensive intervention during the preschool years can improve children's outcome. Recently, meta-analyses have been performed across several studies and protocols to determine the efficacy of current preschool early intervention programs that use teaching strategies based on applied behavioral analysis. Some of these programs focus on Discrete Trial Learning while others use a more naturalistic, developmental approach (for review see Rogers and Vismara, 2009). Analyses have shown that these interventions can be effective in improving IQ as well as some core symptoms of autism (Eldevik et al., 2009; Reichow and Woolery, 2009). While these interventions may differ slightly in their approach, they typically address similar domains of functioning: language, motor skills, joint attention, socialization, and communication.

The availability of early intervention for young children with ASD has resulted in improved outcomes for them (Dawson, 2008; Altemeir and Altermeier, 2009). As early interventions become available at even earlier ages, it is hoped that it will be possible to change the trajectory of early behavioral and brain development so that symptoms of autism can be reduced or even prevented, in some cases.

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Relationship Development Intervention® (RDI®)

- A New Paradigm

- Supriya Malik

RDI® was developed by internationally renowned psychologist couple Dr. Steven Gutstein & Dr. Rachele Sheely and is a powerful step-by-step growth model based on typical development. It tries to restore the Guided Participation Relationship (GPR) between the individual with ASD & the caregivers, thereby giving the family a second chance to successfully engage in this universal developmental relationship, which for no fault of their own, was not successful the first time.

Relationship Development Intervention® is a philosophy. Although it is a parent based remediation program, it has a strong theoretical basis embedded in developmental psychology & autism research. The intervention is primarily based on the belief that individuals with ASD are capable of a lot more. RDI® believes in giving individuals with ASD better developmental tools to cope with the constantly changing, ever-so-dynamic environment. It stresses on developing the true deficits of ASD flexible, critical thinking, perspective taking, multi-channel communication, collaboration, self-regulation, spontaneous joint attention, reciprocity etc. It also empowers parents/caregivers by helping them learn the tools for guiding their child to succeed in forging meaningful relationships.

Some things for you to try at home...

Has it ever happened that you ask a question but get an answer only after a few minutes or sometime later in the day?

Does he/she avoid situations/activities?

Do you have to repeatedly ask your child to look at you?

Do you repeatedly ask/instruct the same thing over & over again?

Is he dumping/asking for information only and not sharing experiences/feelings with you?

If your answer to all the above is Yes, then I am sure you are tired and disappointed and so is your child. As a parent, one needs to remember that an important influence on your child's thinking is YOUR interaction & communication style. Therefore, if you truly want to help your child then it's time you modify your interactions.

One of the families enrolled in the intervention aptly

described their boy by saying "He avoids challenges." This holds true for all our kids however mild or severe they are on the spectrum. Children with ASD, due to a breakdown in Guided Participation Relationship, do not develop the adequate developmental skills to cope with the dynamic challenges our environment poses. Therefore, they end up becoming 'control freaks' as that allows them to control every bit of uncertainty or challenge they are faced with. I am sure your home often becomes a battle ground, where you & your child are constantly struggling for control over the other. An easy way to handle avoidance and control is by making the environment/activity less challenging. As soon as they are able to see that they can succeed, children with ASD readily start approaching and completing tasks.



Research shows that children with ASD have slow processing speeds (Schmitz et al, 1997). Therefore, any incoming information language, non-verbal communication or actions will take them longer to

process and respond to. Slowing down your actions & language will then, automatically help them give time to process and respond better. For example, if I am teaching my child to learn twisting-hand motion, I would have both of us hold a bottle each and then with just a simple instruction "Let's open the

bottle", I would slowly start twisting the bottle-cap. After each rotation, I am going to pause to give him/her time to process and complete the action. If he/she is successful in only one rotation, I am still going to praise him for it as this will motivate him/her to try the task again.



Similarly, "spotlighting" becomes crucial in an interaction i.e. highlighting for the child what he did well and what he was unable to accomplish. It becomes very important for us to modify praise with spotlighting because spotlighting is more specific. When you do say "good job" are you sure your child knows what you have appreciated him for? Therefore, we encourage our parents to be more and more specific when they spotlight, for example, "You opened a bottle yourself! Wow!" Through spotlighting the child is aware what the stars, well-dones and good jobs mean. It will therefore help him /her assimilate knowledge more cohesively and think about what he/she has done.

Something else we stress on in RDI is "framing". Framing or structuring a task becomes very important. Like a frame brings out the most important features in a painting, framing an activity helps to keep child focused and bring out the most important concepts in the activity. Whenever you are going to start an activity, it will be important for you to think about various things: a. What is my goal and target skill; b. What am I expecting him/her to do; c. Is it above or below his/her competence level; d. What may be a possible distracter; e. Which activity to chose in order to achieve the goal; f. How

should we be sitting or standing and g. What instructions do I give him/her. Like spotlighting, framing aids in concept formation and thinking.

Lastly, something for you to think about. Are your conversations always a question-answer session or do they also include commenting and sharing? It is important that you start including some sharing & commenting in your talk so that your child can understand what typical communication is like! We need to provide children first with a model so that they at least know what an interaction truly is. If the only thing they have experienced is question-answers, they will not learn any other way of communication.

If you have found these suggestions helpful, please feel free to contact me for further information on RDI®:

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AUTISM AROUND THE GLOBE

The NLM Family Foundation is pleased to announce the launch of a new website project titled Autism around the Globe (<http://www.autismaroundtheglobe.org>).

Autism around the Globe is an interactive web-based project which focuses on raising public awareness of how autism affects those in different parts of the world. The goals of the project are to:

Raise global public awareness of autism, increase understanding of how cultural variations affect how autism is viewed and experienced, provide information about autism and a directory of international autism resources, develop supportive networks of families and professionals in autism communities around the world, and encourage international research collaboration in autism-related fields.

A major feature of this website, is that it shares compelling personal stories from contributors around the world whose lives have in some way been affected by autism. It features multiple perspectives, highlighting the thoughts and experiences of parents, siblings and individuals with autism themselves as well as educators, researchers, social workers, therapists, and other professionals.

A great deal of cultural variation is expected particularly with regard to definition and view of autism, typical referral and diagnosis process, impact on daily life, educational options, access to autism research, and long-term life planning options for adults. It is hoped that elucidating these differences as well as sharing commonalities will lead to a greater understanding of how autism is experienced across cultures and an increase in the exchange of knowledge and resources between countries. We hope that you find these stories to be as enlightening, thought-provoking and inspiring as we do.

Submissions of personal accounts of autism from anywhere in the world. If you are or know any individual with autism, parent, caregiver, family member, or professional involved in your local autism community who might be interested in submitting a short story for inclusion on our web site, please visit http://www.autismaroundtheglobe.org/submit_story.asp for information on how to participate, and email info@nlmfoundation.org if you would like us to add your autism organization to our Autism Resource Directory.

Please feel free to forward this information along to those in your autism community or any others who may be interested in learning more about autism around the globe. Thank you.

A visit to U.K. - A report

- Rashmi Wahi
Principal
Tamana Special School

This visit was aimed at strengthening bonds between Tamana and different schools in U.K. This visit helped in developing an understanding of the educational system being followed in schools there.

I visited Gibside school in New castle, St. Christopher in Wrexham and I also attended the conference on Understanding and Supporting Child on Autistic Spectrum in Devon

At New Castle I visited Gibside School that caters to children upto 13 years of age. All rooms were very large and divided into two parts- a snack area and class area. The snack area also had a wash basin where children washed their plates after having their meal. Each class had about 8 students, one main teacher, two assistant teachers and one volunteer-an impressive 2:1 ,student-teacher ratio. The learning and response was faster when the child was given a low student teacher ratio. The classrooms were equipped with a computer, printer and access to the internet.

Gibside implements inclusion by organising visits by students from regular schools to interact and work with special children. The Gibside students also go to the mainstream school for specific sessions, once a week. There is a joint planning and review between 2 schools i.e. between the inclusion co-coordinator and key staff. The staff from Gibside also provides information to pupils and staff of mainstream schools on disability awareness.

The whole school gathers for lunch in the main hall at 1:30 p.m. There is a canteen in the main hall. Each class has their table assigned for lunch .They would assemble in a line, pick up their fork, plates and spoons and take food from the canteen.

The weekly assembly was very interesting especially the concept of "Star of the Week Award" given to a child from a particular class. The goals are sets for a week which were further divided into smaller tasks (task analysis). The theme star of the week did not

focus on major achievements but only moving one step forward e.g. one of the severe CP child got the star of the week award because she was able to lift her head and respond to the teacher by giving eye contact .

Most children were using PECS for independence in communication skills.

Gibside shared the following material with us: -

1. Derbyshire Language Scheme Picture Test
2. Art and design scheme of work (planning and execution)
3. Physical education scheme of work (planning and execution)
4. Annual review of statement objective
5. Inclusion Planning Sheet
6. School Report

The second place I visited was St. Christopher school in Wrexham. At St. Christopher school children were from 11to 18 Yrs. Here, I saw the different protective aids and accessories designed and developed for children with special needs that have made their life more meaningful, aiming towards independence.

1. They had standing frames (which help the child from supine to standing position.) With board activities attached with it.
2. Book keeping, budgeting, savings, handling petty cash - each child had an individual exercise book to keep records.

St. Christopher provides a much needed vocation for young adults. Different ways are used to help



students acquire and develop skills towards a particular goal, based on their ability and interest.

Some key programmes are as follows -

1. An environmental task force to work in the community. The staff (in-house) is trained to pick up the children and bring them back at the end of the day.
2. Millennium Eco Centre that support work experience placement.
3. Car wash centre
4. Café' for in house and For Public
5. Fair trade shop
6. Hair and beauty salon
7. Food Technology Unit
8. Day placement at Behaviour support unit for working parents
9. The school provides placement at St. Christopher to students who do not perform well in primary and secondary schools (it is a Joint key skill program)

Students are also given an opportunity to be a part of different clubs- such as Breakfast Club (which had an opening to the road also). Adults here make snacks and drinks that are used by the staff and the public. Bungalow Club- was aimed at providing a life skill program for pupils with low ability level e.g. how to lay the table, make a bed, cook a snack and develop skills in socialisation.

Some other clubs that were also there were the After School Club and Weekend and Holiday Club.

They shared some print material of plans from their school-

1. School development plan
2. Cognitive abilities test

Keeping in mind the goals of our organization and aiming to provide a child centered environment, I learnt more about special education programs for autistic children, the usage of latest technology, teaching aids, curricula, assessment techniques, latest interventions and the IEPs(Individual Educational Programme).

As a part of Religious Education (RE) I talked about families', school and religion in India and also taught some basic yoga exercises.

I was introduced as a head teacher in India. Suddenly a child got up and said "She is Brown"

A very interesting education imparted to children (apart of curriculum) is that, they had different stone structures of different religions (Christianity, Islam, Hinduism, Buddhism zorastiasm) in their garden.

After my visits to the school I went to attend the conference at Devon-Understanding and supporting the Child with Autism organised by NASEN, focused on improving outcomes in mainstream schools and issues and solutions on autistic spectrum. One of the workshops was on Building attention skills for children with autism spectrum disorders. The presenter Gina Davies was very informative as her topic focused on practical strategies for supporting children.

I believe, that networking with some good speakers of U.K. will be helpful for Tamana in the future forums.

I bought 3 books on Autism

1. Behaviour Management
2. Challenging Behaviour
3. Aspergers Syndrome

I really learnt a lot and enjoyed my stay in U.K. I hope to interact more with the schools through emails and learn more about the new developmental technology.

Book Review

Autism in the Early Years - A Practical Guide, Second Edition

-Prithvi

Authors: Val Cumine, Julia Dunlop and Gill Stevenson
Publisher: Routledge, Oxon, UK



The first edition of this book was published in 2000 and has been considered as a good source of information. This updated edition has been published in 2010. The book is aimed mainly at professionals working with young children of Kindergarten and first class. The authors suggest that the book can also be used for parents who have children at this age. They ensure its accessibility by writing in simple language and an easy to understand format.

The book starts with a brief introduction to autism and then focuses on diagnosis and assessment in the next two chapters. As part of this some of the characteristics of autism and the differences between the various labels used for diagnosis purpose are described. This would be of help to professionals working with younger children as it highlights the behaviours that they should look for, if they suspect a child has autism. The second chapter further explains the different diagnostic tools that are used.

A major strength of the book is that, there are a number of case studies which helps in relating the theory into practice even when complex theories such as Executive Function Deficits or Theory of Mind

were explained. The authors then highlighted what the implications of these theories would be in practice when working with small children. It similarly assesses the different intervention methods that are available in the UK and the rationale for using them.

The chapters that parents and professionals might find most useful are the ones focusing on behaviour interventions. I thought that in these chapters the causes of the behaviour, how to identify them and some strategies that can be used are explained very clearly. The final chapter with the observation checklist would be useful in assessing the child, which can then lead to identifying the areas that need to be developed.

The main limitation of this book is that it is aimed at parents and professionals in the UK. Therefore people outside UK may not find the chapters focusing on the legislation or the early years curriculum of much relevance. In spite of this limitation I think this is a good introductory book for professionals new to working with children on the autism spectrum with lots of case studies that they can relate to.

Your page

Question and Answer

- Q. Shalu is a 7 Yrs. old girl who has Autism. She keeps food in her mouth for a long duration and does not chew. I discussed it with an Occupational Therapist, but according to them she has no sensory issue related to the behavior mentioned above.
- Ans. If, according to the occupational therapist, Shalu has no sensory issue then it could be that she has no motivation to eat. You can try following things.
1. Give her the bite with her favorite food.
 2. You can keep her favorite food in front of her with her meal. Initially you can start with a small amount of food and tell her if she finishes her meal then she can get her favorite thing.
 3. Sometimes if children are not hungry they show this kind of behavior also. So give a gap between meal times and try not to give any other things to eat in between.
- Q. My child does not sit, is hyperactive and throws tantrums when forced to sit still. What should I do? (His age is 4 Yrs.)
- Ans. First of all see if the child likes swings and likes to jump more than other children. If yes, then you need to visit an Occupational Therapist. This is an vestibular issue and the therapist would need to check if there are any additional sensory issues. But if no, then you have to accept that it is difficult for child also to sit for long time. Try to make a note of all the things, food items etc. in which the child is interested and plan a task which is small like finishing one row of alphabets or numbers. After he completes the task award him with any of his favorite food or toy or short game. Again ask him to finish the next row of alphabets. Slowly with every day and week that passes, the amount of time your child sits will increase. You can use different constructive toys and games, make a small area in a room where the child can spread things and play freely. Don't forget to award him for not cluttering the whole house.
- Q. My child dislikes going in crowd, shouts, sometimes even pushes others. He cries a lot, and keeps his hands on his ears. What should I do?
- Ans. This thing definitely indicates towards your child having some auditory issues. Your child has, or may be having a few tactile and proprioceptive issues (as he is pushing others). For addressing his auditory issues, check if your child likes soundless environment and see if he produces humming in soundless environment. If yes then consult an Occupational Therapist and use selective music (like music with high tones for e.g. jingles, using rhythm and beats) and see if child responds positively. Avoid crowded places and if going to such places is unavoidable then prepare the child by telling him beforehand so that he is ready and knows what to expect. To facilitate this, you can use ear plug or muffs. Give it to your child so that he can wear those in crowded places to decrease the noise. Use ear pressure by both hands (yours) for 10 seconds and release it for 2 seconds, do this for 5 minutes twice a day. You can also acclimatize the child by adjusting the home environment by bringing few friends to house and make a small crowd to prepare/train the child.
- Q. My son is 8 years old high functioning Autistic child. He does not allow anyone else inside the elevators in our society when he travels in it. He screams and pushes everyone out from the elevator. To avoid embarrassment we have to climb the stairs which is always not possible when carrying heavy bags in hand. Please help us to tackle his behavior.
- A. This behavior could be due to various reasons. One of them is that the child has not learned sharing, which needs to be taught from a very basic/elementary level. Another reason could be that the child wants to do things himself as he has just learnt it and wants to be independent but with another person in the lift, he is not allowed to do so and he pushes everyone out.
- Most of the children with ASD are visual learners and they understand concept through visual clue better than any other mode e.g. You can draw a picture of the lift and tell him that some times other people can also go in lift with you. As you mentioned that he is a high functioning Autistic child, you can write a social-story on the same topic in small sentences and encourage him to read it. When he shows positive behavior, praise him.

A parent's Tribute to Tamana

*Hamari Tamana ke yeh bachche,
Aapki Tamana main pale bade.
Hamne to inhein janam diya tha
Aapke yahan yeh parwan chadhey.*

*Jab yeh chote the,
Hum inki chinta main raat bhar nahin sote they
Jitna yeh rote the,
Usse Zyada hum inke liye rote they.*

*Tabhi andhere main,
Asha ki ek kiran jagmagai.
Is kiran nain,
Hamari sari chintayen mitai.*

*Humne aapke school ka naam suna,
Hamare dil nain bhi is school ko hi chuna.
Hamnain inhe aapke yahan dakhil karaya,
Aapne inhein inki kshamta ke anusaar paraya.*

*Aapke yahan par kar,
Yeh bachche insaan bane.
Yeh Tamana school,
Hai hi itna pyara.
Ismain nahin koi bachcha,
Abhaga ya bechara.*

*Kahin Jyotsna Kalra ke pita,
Kahin Prerna Gupta ki Maa,
Kahin par Prateek khara hai,
Kahin khara Satyam Ojha.*

*Ab hum inki nahin,
Balki yeh bachche hi hamari pehchan bane.
Tamana main parne wale bachchon ke,
Hum abhibhavakon ki yeh dili tamana hai.*

*Itna chamke tamana ka suraj,
Ki damak sara aasmaa pare.
Maine jaisa jo bhi likha hai,
Par bhav hamare sachche hain.*

*Hum pare likhe, haath pair walon se,
Yeh bachche hi acchhe hain.
Itne bhole, itne nishchal ki,
Dikhe inme bhagwan parey.*

*Hamne inko janam diya tha,
aapke yahan yeh pale bare.
Aapke yahan yeh parwan chadhey
Aapke yahan yeh parwan chadhey.*

*-Neelima Ojha
Mother of Satyam Ojha
(Student of Tamana School)*