

FC2 along with Action For Autism looking forward to an evening of music for a cause

MERRY'S CHILDREN



Come January 20, the folks of Delhi can look forward to an evening of Urban Folk Music with Sushmit Bose along with the children of Action For Autism and Pitch Blend.

"The concert is partly a fund raiser, but the big thing is raising awareness," says Merry Barua, the founder of Action

For Autism, the organisers of the concert. "What we do is we get a well-known group or individual to come and sing. People come to listen to that person. When they do that, we show a short film on autism, about 10 minutes long so people won't get bored. Then we get some of our kids to perform. People get surprised, 'We thought they were disabled'. They see the families are all very happy even if some of them lead the most incredibly difficult lives that you can imagine because autism is a very hard disorder to live with. It's not a disorder that if you have money, you can hire two people to look after your kid. They see the families and this creates a lot of awareness. We've had concerts at which groups like Indian Ocean, Just Us, Parikrama have performed for us. This way, we get all these young people to hear of autism. This year we've got Sushmit Bose and Pitch Blend to perform. Pitch Blend is actually a small group of

students from the North-East who are medical students, architecture students and stuff like that. We usually have two people so our kids can perform in the middle so as not to break a performance. Pitch Blend is performing, then our kids and then Sushmit at the amphitheatre, Habitat World."

Many of us haven't even heard of autism, let alone be aware about it. "Autism is a neurological development disorder that primarily affects a person's ability to use and process communication and to understand, learn and use social skills for social interaction. It is also an impairment in the use of imagination. It means that they are not able to imagine what things could be like. They cannot figure out how you would be thinking in a lot of situations. They say that people with autism are *mind blind*. When you cannot imagine, it is impossible to imagine a lot of things, like abstract things. There are very able people with autism who don't know what you mean by the glory of the country. Or in the Lord's Prayer you have the power and the glory. One of them says 'I still don't know what that power means. I only know that power is power lines. When I think of glory, I think of rainbow.' They have to fix it to something concrete. This makes life very complex. People with mental retardation can learn how to go to a shop and buy things,

they know how to do the *yeh chahiye* (I want that). They'll have difficulty with the calculation. People with autism will do the calculation like that in their heads, but that social skill of how to ask that man, which moment to wait for, is completely lacking in very able people with autism."

A really complex disability and "this is the only organisation in the country that specialises in autism in every area - education for kids, training of teachers, all-round specialisation. We've been trying to get land from the DDA to set up the National Centre for Autism. They suggested we should get the land at maximum concession because of the kind of work we are doing. But we've been told that even if you do get the land, you will not get it at a concession. Right now our funding comes from parents raising the money and from a television channel who do quite help."

Action For Autism runs a number of programmes for the children and the parents. "Our focus is on parent empowerment. If a mother knows what to do with a child, they can make more significant changes. There is the Day School Programme to which the kids come. It is a regular day school where kids get a very structured kind of teaching, one-on-one, along with group activities. They learn various skills and academics. We've got other programmes to help as many families as we can. There is the Weekly Intervention Programme where a family comes with a child. All our classrooms have windows. We

ought to change in the way they were working. This is for kids who are not going anywhere. Many of the kids go to other schools because schools in Delhi take in some children with autism. Then we have the three-month Programme which is for parents who live outside Delhi, who cannot therefore get the intervention programme or the mother-child thing. They come and stay for three months. They usually do it if they have a relative or someone to stay with. The child is put in the day school, the mother learns and gets feedback and experience to go back wherever they are from and implement it."

"We've changed the face of autism in the country since we started. We've been doing awareness in the media,





work inside and the parents observe what we are doing. Then we have the feed-back session and discussion. We are not only telling them what to do, but they are actually observing. Then we have Home Programmes for those who live either outside Delhi or they live too far away in Delhi. They come once a month or twice a month to get an update on what they should do. They go back and implement what they've learnt. Then we run something called the Mother-child Programme where the mother and the child they come and work together. They do it just like the schools. They have morning assembly, attendance, *et cetera*. Then each mother sits and works with her child. All the while, one of us, a trained person observes them. After the closing song, the mothers get the feedback on what to teach next, how to go about it, what are the things they

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writing in the newspapers. We have changed legislation. We've got ministry to acknowledge there is something called autism. I've heard senior people tell me that it's a western disorder. It's been said very recently by a very leading physician. We also bring out a journal that goes all over the country. Our website is very widely accessed. We conduct workshops very frequently."

Merry is all smiles. There is so much going on there at their place. Preparations for Christmas. The concert. Laughter. Fun. "Working with these children is a great deal of fun. Nobody here thinks that they are doing this great work for people. Mothers don't think that they are martyrs for their children. The organisation has a philosophy - learning to change your belief systems and learning to be happy, accepting and not being judgmental. It's exciting to see every little step that the child takes and how far the mothers have travelled. We want people who want to come for fun because they think it is interesting and not because they want to make their contribution to humankind. 'Hey, let's do it.' That's the spirit we want."