Dream On

- Health

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Rejected by the 'perfect world' these kids have carved a perfect world of their own at Zaiba Appa. **Saima Rashid** *spends one quiet afternoon at this south Kashmir facility housing specially-abled children to tell their story*

Zaiba Appa Institute of Inclusive Education: Afla and Jasmeen, two best friends and two best dancers at the special facility for the specially-abled children in South Kashmir.

Five-year-old Aiman is the youngest entry at Zaiba Appa Institute of Inclusive Education – a special facility for differently able children in Bijbehara town of south Kashmir's Islamabad district. She suffers from rare Rett Syndrome – a genetic disorder found in one among 20 thousand girls. Aiman hardly makes eye contact with anyone, neither does she interact. She lacks any verbal skills. All she can say is her own name.

Rett Syndrome is never inherited from the parents; it happens because of a chance mutation in a girl's DNA. So far there is no treatment available for Rett Syndrome and life expectancy of a patient is very less. "She was born normal," says Aiman's mother Wahida Akhter.

After a brief pause she continues, “When she turned two, her coordination power weakened, hyperactivities were predominant. There was loss of speech and she would become uncontrollable as well.”

At that time Aiman’s family was in Saudi Arabia. “My husband worked as an Assistant Professor there.” Aiman’s father took her to a doctor who diagnosed told him that his daughter is suffering from Rett Syndrome.

After coming back from Saudi Arabia Aiman’s mother started teaching at a Srinagar based school. But soon she had to leave her job as Aiman’s condition worsened. Then Wahida came to know about Zaiba Appa. “It was functioning from my hometown,” says Wahida. After some self convincing, Aiman was admitted at Zaiba Appa in May 2015. But soon Wahida realized that staying away from her only child was not as easy as she had thought earlier. “So I started working here as a teacher.”

The only way to increase Aiman’s chances of survival was to put her into a rehabilitation institute where she will learn to coordinate, feels Wahida. “But then some things are out of my control. Like when she is hyperactive she starts eating her own skin,” says Wahida.

But not everybody’s story is as pathetic as Aiman’s. There are many other specially-abled children at the institute who despite their disabilities have found a way to live their lives respectfully.

The story of brother sister duo: Mehran Syed and Afla Syed, born deaf and dumb, is one such example.

Mehran, a bright boy who studies in 4th standard, can copy dance steps of Prince, one of the participants at Dance India Dance TV show, flawlessly.

“He is good at motion style dance. When he dances it is hard to tell that he cannot speak and hear,” says Rifat Sadiq, a psychologist working with Zaiba Appa. “For him dance is a way of expressing himself.”

The institute helps these children to participate in various dance competitions to boost their morale. “We have a huge collection of certificates and medals won by these kids,” says Rifat.

Mehran’s sister Afla is friends with Jasmeen, one of the most beautiful girls inside the facility. She too is deaf and dumb like Afla and her brother.

“Without exchanging a word they (Afla and Jasmeen) understand and coordinate with each other,” says Rifat.

Both the girls are exceptional dancers besides being good at studies. While dancing they are perfectly in sync with each other without even looking at each other.

Aiman is suffering from Rett Syndrome – a genetic disorder found in one among 20k girls, not inherited from parents.

In 2005 the Zaiba Appa Institute was stated by Javid Ahmad Tak, a specially-abled person who manages the facility despite being confined to a wheel chair. “I wanted to get these kids out of the darkest corners of their houses and give them a respectable space to live,” says Tak.

These differently-abled kids have created a small world of their own in this institute, a world different from the one outside its doors. “These kids are not burden but a source of happiness for me,” says Tak emotionally.

But managing these kids is not an easy job always, says Tak.

A small room located at the corner of the institute is out-of-bounds for everyone including visitors. The room belongs to nineteen-year-old Misbah. Her unpredictable behaviour has forced teachers to isolate her from other kids. She is mentally retarded. “She has no idea of modesty. Once she gets violent she starts tearing her clothes,” says Rifat. “Things get worse during her monthly menstrual cycles.”

Before coming to Zaiba Appa for specialised care, Misbah’s parents has kept her chained in a room. “She was not allowed to meet anybody,” says Rifat.

Since last few months Rifat is studying Misbah’s case keenly.

“A girl in her teens goes through many hormonal changes; and out of these changes arise certain desires. While a normal human being can exercise self-control to overcome such desires, Misbah cannot.”

Rifat feels that these desires might have made Misbah’s parents to keep her in chains at home. “Here we stand like a wall between her and such desires,” says Rifat.

For Zakia, 14, who suffers from retina cancer, life is nothing but fragments of a shattered dream. Zakia wanted to become a doctor, but was booed down by her relatives telling her that she won’t be able to do anything in life with such an ailment. “She was a classical case of hopelessness. People around her had made her believe that she is not worth anything because of her ailment,” says Farhat Shah, an intern psychologist at Zaiba Appa. “We helped her believe in herself.”

Within no time Zakia started responding to her Farhat. “I told her, ‘what if you cannot become a doctor. You have soulful voice; you can be a great singer’.”

In next few days there was a visible change in Zakia. She has now set her eyes on Radio Jockeying (RJ). “She is fluent in English. She can host shows in English as well. Nothing is impossible for such a bright and talented girl,” feels Farhat.

Misbah’s case is under special attention at Zaiba Appa.

Not all are as fortunate as Zaika. There are some who cannot afford to send their specially-abled children to Zaiba Appa for lack of resources. Seven-year-old Irtiza, who suffers from Down’s Syndrome, is one such unfortunate soul. “She has exceptional IQ level. But she had a habit of spitting on everything and everyone when she was brought here,” remembers Farhat.

Within a few days Irtiza started responding to her psychologist and stopped spitting at people. “It was good to see her behave like normal kids. She was very responsive,” says Farhat.

After spending a year at the institute Irtiza stopped coming to Zaiba Appa as her parents couldn’t afford the monthly fee and other expenses. “It was sad to see her leave. But it is not possible for us to retain everybody either,” says Tak.

At Zaiba Appa, treating an ailment by using conventional method of prescribing medicines is the last thing on their mind. “We have realized that therapies like music, play, dance etc. are more effective compared to prescribing medicines,” says Farhat.

In order to make them feel special Zaiba Appa has gone out of its way to help these children. “We have given each one of them an ipad so that learning becomes fun.”

The institute also encourages regular interaction between these students and people from the ‘outside world’. “It helps them stay connected with the world,” feels Farhat