

# Connect Special

## Editor's Desk

Dear friends,

Happy New Year to all of you !

One of the new year resolutions I made was to try and bring colour into the editions. I will try and adhere to it by bringing in varied reads.

Here comes the first edition of this year compiled for you and hope you enjoy reading it.

Happy Reading!!

Regards,

Bhavna Botta



### Special points of interest:

- \* AAC making inroads
- \* Pursuing dreams
- \* Essential plan for your dear one
- \* Accessible Technology

## In the news - A Pioneering Step

International Society for Augmentative and Alternative Communication- India chapter was invited for the first time to the 50th ISHA conference , held from 5<sup>th</sup> to 7<sup>th</sup> January, 2018, at Mysore, to deal at length with AAC among speech Language pathologists from all over India.

As part of the programme, an interactive workshop by special educators, speech therapist and an AAC user was held as preconference. The participants had opportunity to understand how the AAC user could communicate at ease through low tech to high tech devices. They also were able to interact with an active AAC user

Through an array / display of various AAC devices available in the market , the participants could get an hands on experience as to how best they can be used among the AAC users. The programme demystified lot of their doubts.

The Plenary session in the main conference had a panel discussion dealing with AAC In India which looked into ISAAC in India, the impact of AAC, problems faced in inclusive set up, technology development so far and the future path.

# From The Heart

## Our Monalisa

Meet Ms.Monalisa, model, actor and motivation speaker.

### 1. Your work -your challenges and success, aspirations

I was in media. And acting and modeling my full time passion. I had opportunity to act in few serials, short films .I did some add shoots and photo shoots too. I was a busy bee!

I was diagnosed with multiple sclerosis in 2015. It was a huge shock but I realized there was very little awareness about MS. I am pursuing my passion of modeling on one hand and at the same time creating awareness about MS in the society. It's a jugglery but I think I am putting in my best.. I also do Motivational speeches to bring positivity and awareness about Multiple sclerosis.



### 2. Your support system-family and friends and community in general as a person as a professional

My big support is my mom and my family. If my mom was not there at all my bad times I wouldn't be here now. She is my greatest support.

### 3. What is the one thing you would like to see changed in this community for equity?

Multiple sclerosis and the medical emergencies have taught me so much. I feel there needs a systematic change and medical treatment should be equal and common for all.



### 4. Your views on inclusive education and on access for PWDs -are we moving forward or backward?

My view is that there have been no changes and the status of PWDs is yet to move even a little forward.

### 5. About MS and the need of the hour

About multiple sclerosis, I believe more awareness is needed. And support needed from the family, friends and society.

<https://youtu.be/XVsr-nCPYDg>

## A plan which every parent has to make

***Without a proper plan, your child with autism may face an uncertain future after you are gone. Chitra Iyer, Treasurer and Trustee, Forum for Autism, spells out reasons why it is absolutely necessary for parents to prepare a Will. While this may apply to various disabilities, the focus for this article is mainly on children with autism and keeps in mind the legal requirements in India.***

What if something were to happen to me tomorrow, how can I ensure that my child with Autism who is now an adult is well taken care off?

How will I know that my money that I have set aside and have accumulated over the years will be used for my child for his needs, for his comfort?

Can I tell people what I want and how I want my money to be used for my child after I am gone? Can I tell them who should take care of my son? How should he be taken care off?

Can I protect my wealth for my child and only for his needs without anyone else encroaching on it after I am gone?

These are some of the fears that every parent of a special needs child always has at the back of his or her mind.

It is through a written WILL that a special needs parent can address most of these fears and feel a little assured about the most important duty towards their child as being addressed.

### **Why should a parent of a child with Autism prepare a WILL?**

A proper Will lists down all the assets and liabilities that you own or owe based on documents to prove your ownership that is being WILLED to the next generation. When you want your assets to be clearly used to look after your child you need to write very clearly about how the assets need to be used so that he or she is well looked after.



*Chitra Iyer is a mother of 18-year-old happy go lucky Shravan who has autism. She has been associated with the Forum For Autism, an NGO and a parent support group for children since the year 2002. She is also a Trustee and Treasurer of the Forum for Autism.*

*She is a Cost Accountant and Certified Financial Planner with 20 years experience in the Financial Services Sector*

Ensuring that what you own goes to the correct person, that is, for your child with disability or to the guardian of your disabled child or a trust for your disabled child can be done through a WILL.

If this is not clearly written in the WILL and left to chance we have come across enough instances where relatives or others miscreants have claimed right to the assets and stalled the entire process of flow of assets to the lawful inheritor.

The WILL helps you write down who should be the executors and who should be the beneficiaries of your wealth. You can also write down who will replace whom as guardians or as beneficiaries in the WILL. When you have more than one child and you have other family members to whom you wish to leave your assets the WILL helps you clearly right down to whom you wish to vest which portion of your wealth.

You can be specific about who you wish - either a specific family member or a residential center or a care giver or a friend - to take care of your child. This should be done lawfully as required. Otherwise, in absence of clear instructions the law will have to take its course to decide who should take custody of your child.

(..CONTINUED IN NEXT PAGE)

## A plan which every parent has to make

You could take a lawyer's help to draw up a WILL, especially if you are anticipating any problems in the care of your special needs child. Writing a WILL is actually very simple. You can use a format of a WILL to write one and get it signed by two witnesses. It is an absolute MUST and should be considered as a priority that you owe to your child!!!

### Every parent should create a WILL. Why is the need for children with special needs greater?

In order to protect the interests of the person with disability ...and to ensure they get their share of the inheritance, it is imperative the parents write a Will. Autism being a disorder with some social and cognitive deficits, all persons on the spectrum may not have the skills to navigate legal and financial issues independently and make decisions that protect self-interests in these areas.

### Is a guardian always required?

Although legally one does not need to take guardianship post turning 18, the National Trust Act for CP, Autism and MR in India provides for us to take guardianship to take decisions on behalf of the adults with challenges.

Why this was introduced could be understood with some examples below (though may not ap-

ply to all in a lifetime, it is more of a good to have rather than not to have.)

- As parents if and when we need to take decisions for e.g.
- In a hospital to sign on a surgery form as guardian
- At a police station in case of an accident it becomes necessary (we had a case where a flower pot was accidentally pushed off a higher floor by a challenged Autistic person. A person walking below was badly hurt. The police nabbed the Autistic adult, who the parents could prove they were guardians to and the parents could do the talking on his behalf)
- The need to take decisions on residential options when the adult with autism needs to live in a home
- To be able to sign on documents that are needed financially or for government identification

### Is there something in the default inheritance laws in India which exclude children with disabilities?

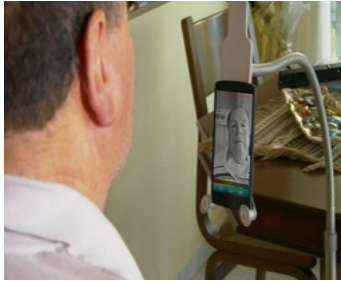
Generally No. But once assets are passed on by way of inheritance, the guardian of the special needs person is required to have been appointed to manage them on his/her behalf... this can be detailed in a WILL.

*Originally published at [Patientsengage.com](http://Patientsengage.com)*

## Tech Corner

### Open Sesame

<https://ablethrive.com/life-skills/sesame-enable-smartphone-controlled-head-movements>



The Sesame Enable Phone is the world's first truly hands-free device that allows users to control a smartphone with head movements.

#### HOW IT WORKS

Sesame Enable's app tracks head movements using a front-facing camera. A cursor appears on the screen, and the user can fully operate the phone using head movements and voice commands.

There are three options on their product page:

**Android App:** Download the app from the Google Play store and install it on your existing Android phone (available for Android 7 and up) with a 30 day free trial!

- No additional hardware required
- Total control using head movement
- Personalized customer care and support



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