



Edition 35

Dear friends,

To embark on the journey toward your goals and dreams require bravery. To remain on that path requires courage .

The bridge that merges the two is commitment.

-Dr. Steve Maraboli.

As I compile this edition with interesting news of young minds trying solutions, the above said quote seems so true.

Happy Reading!!

Regards,

Bhavna Botta

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Tech for good: Class12 students develop an app to help the deaf, blind and mute communicate with ease

Originally featured in

Access and Inclusion through Technology

<https://yourstory.com/2019/01/students-app-deaf-blind-mute-communicate/>

Developed by three Class 12 students from Amity International, Delhi, the Practikality app provides an interactive mechanism for the differently abled - the deaf, the blind, and the mute - and is in its final stages of testing.

For seven-year-old Rohan Velanki, a partially mute and deaf child, the joy of social interaction was a limited experience. A quiet and reticent child, Rohan began interacting with Sugam, a non-governmental organisation (NGO), which works towards the betterment of abandoned and differently-abled children. Over the course of the next six months, he became a far more sociable and confident child. The key to this transformation was his new-found ability to communicate efficiently.



“Rohan carried a tremendous amount of emotional baggage. He would hardly attempt to mingle with other children. However, after using the ‘Praktikality’ application, what seemed impossible became possible. He turned out to be a more outgoing and light-hearted child,” says Saritha C, Vice-President, Sugam NGO.

Developed by Padam Chopra, Keshav Maheshwari and Aryaman Agrawal, three Class 12 students from Amity International, New Delhi, the ‘Praktikality’ app aims to empower people with disabilities.

While Braille helps the visually impaired to read and write, sign language aids the deaf and mute in expressing themselves. But, these can sometimes be a form of one-way communication.

The machine learning-based Praktikality app provides a fully-interactive mechanism for the deaf, blind, and mute to communicate with ease, and is in its final stages of testing. The app is scheduled to be launched on Android and on the web in March this year.

How it all started

Padam and Aryaman are classmates who had earlier worked together as a team for an event in 2016. They have also represented their college together in multiple competitions. Padam says that the push to develop an app like this came about when his grandfather lost his ability to speak clearly

“My grandfather could not even go to the chemist by himself. Since he couldn’t communicate properly, he used to depend on me for everything. He was feeling very helpless, and I wanted to do something about it. That is when I started thinking about the bigger picture, and of those people who do not have the ability to see, hear or speak,” says Padam.

A few months later, Padam got to visit a blind school, an experience that spurred him to commit himself to making the idea a reality. Both Aaryaman and Padam started on the research and development needed to build the application. After a few months, their classmate Keshav joined them to bring in some business acumen to the team.

“We spent sleepless nights learning to build algorithms and developing machine-learning models. But I am glad our efforts bore some fruit,” Padam recollects.

The Practikality app has three features - Voice, Easi, and Vision - to assist the differently abled.

VOICE: This solution can be used by the mute to convert text into voice. The user has to key in the message that he or she wants to communicate. The app converts the input which can be either words or Morse Code (a character encoding scheme) into audio, thereby facilitating communication between the user and the recipient. The icing on the cake is that VOICE produces the audio by closely matching it to human speech after taking into account five emotions – disgust, hate, anger, sorrow and joy.

EASI: EASI, which stands for 'Electronic Assist for Sign Interpretation', is for people who have a hearing impairment. It helps the user to convert the recipient's voice into text, which is in turn displayed on the app. To add to that, EASI also has an option to customise the database, which allows the user to add personal signs or gestures so as to reduce the time lag between interpretations.

VISION: VISION allows safe navigation for the visually impaired by allowing them to detect objects and people in the surrounding environment. It does this through environmental analysis and facial recognition. This solution also offers educational assistance by allowing the blind to store content within the app and refer to it later.

Padam says the app will be open for free subscription for the first 100,000 users. A minimal fee will be charged later for certain special features.

Understanding the challenges

The co-founders got in touch with many deaf-blind schools through the course of the testing phase. During the course of testing the app, the founders collaborated with many government schools and colleges meant for the differently abled.



“We interacted with about 150 deaf, blind, and mute students in order to understand their communication needs and difficulties, smartphone usage patterns, as well as their expectations from an app like Practikality,” says Padam.

After collating data points and feedback from them, the team used machine learning and a self-trained ‘Convolutional Neural Network’ to constantly improvise the app's features to reach one step closer to their goal.

“I was in constant touch with the co-founders throughout the testing of the app. As and when I was exposed to the voice-to-text feature, I felt independent since I didn’t have to rely on anybody’s help. The real-time conversion of ongoing conversations was great,” says Alok Bansal, a user with a hearing impairment.

Last year, the Practikality app was also recognised at the Microsoft Imagine Cup Indian Nationals as the ‘Best Project on Accessibility Track’. The team was also a national finalist at the Intel IRIS National Science Fair in 2017.

From The Heart

In conversation with Mr iftikhar Zia ,a parent who has taken on himself a mission to create awareness about Rare Diseases through his work in ORDI ,Chennai .

What is ORDI

Organization for rare diseases India ,ORDI, co founded by Mr.Prasanna Shirol , is a national umbrella organization representing the collective voice of all patients with rare diseases in India with a vision to make rare diseases easily diagnosed and treated as other common diseases. It works towards public-private partnership to accelerate diagnosis and treatment for patients, advocating for mandatory new born screening, Policy development and implementation to cover rare diseases, undiagnosed and genetic diseases patients in India. Such as Rare Disease Policy and Orphan Drug Policy, facilitate and encourage research and orphan Drug development.

Please explain the term rare disease

A rare disease is a health condition of low prevalence that affects a small number of people compared with other prevalent diseases in the general population. It is estimated that globally around 6000 to 8000 rare diseases exist with new rare diseases being reported in the medical literature regularly.

However, 80% of all rare disease patients are affected by approximately 350 rare diseases. 1 in 20 is the expected prevalence in India with one rare disease or the other 80% of rare diseases are genetic in nature. Globally, the last day of February is commemorated as Rare Diseases Day since 2008

Tell us about Rare Disease Care Coordination Centre

RDCCC is a shared opportunity and responsibility for all stake holders. Major work is finding patients of Rare Diseases and giving families hope through diagnosis, expert advice , access to potential treatment and lifestyle enhancement. It brings collective experience and expertise of specialists , creating better understanding and awareness. Pharma companies offering orphan drugs or doing research get correct data. And if they have more data it will help them further their research faster. First RDCCC has started in Bangalore, next set up is in Mysore. Chennai will soon be having RDCCC.

Are people with debilitating rare Diseases being covered under disability quota

Yes....if they come under the list of disabilities notified. For invisible disorders it is difficult to get. And the disability certificate mentions Challenged...but not Rare Disorder

what about insurance coverage

Though Insurance is supposed to coverthe rules have not been implemented. It is difficult to get coverage.

what are the various facilities or provisions being extended for education like scribes etc

If they fall under the notified disabilities, they get .In my son's case....we did get a scribe , but it is was a long process. As Ataxia is not a notified disease or disorder.

How much aware are the medical professionals

Slowly some awareness is being created. Sometimes the doctors are not aware and are clueless. Genetic disorders , are usually not known to many. The reason why we are trying to create awareness.....is to first make others know about the prevalence of such diseases and disorders

What is the budget allocation for research and for subsidies

Rare Disease Policy was notified in 2017 , and a 100 crore budget was kept asidewith 60 ; 40 sharing between Centre and State. States started their own committees to find out rare Diseases patients and forward to Centre for allocation of funds for treatment.

But in a sudden and unexpected U turn , the govt recalled the policy and said revised and new policy has to be done.PIL had been filed in the court asking why the policy has not been implemented. Recently Supreme Court had issued a notice to the centre and the states.

How do you spread awareness in public

We hold many events like Race for 7 is an awareness run about rare diseases, to empower patients and their families with access to national and international resources.

Race for7 symbolically represents the 7000 rare diseases with 7000 people running for 7 kilometres. In Chennai it is being conducted on 24th Feb 2019 at Olcott School Besant Nagar at 6.30 am



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CHENNAI
24th Feb 2019
5th year Anniversary

ORDI
Organization for Rare Diseases India
RACE FOR 7
7000 Rare Diseases | 7000 Miles

IN THE RACE AGAINST RARE DISEASES, WE ARE GAINING GROUND.

Racefor7, an initiative championed by ORDI helps raise funds and awareness for rare disease patients in India. And we at ORDI are quite literally, going the distance.

Join Racefor7 today. Help keep the momentum going, and make the voice of rare disease patients heard.

Date: **24th February 2019** Start time: **6:30 am**
Venue: **Olcott School, Besant Nagar, Chennai**

for registrations please log on to www.racefor7.com
<https://registration.racefor7.com>

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Accessible Election Update

Ms. Smitha Sadasivam, Accessibility consultant ,Election Commission

These are some election updates

1. Free transport / pick up & drop facility for voters with disabilities which had been tried out in the recent state legislative assembly elections.
2. Revised notification on Braille EVMs VS Braille candidate sheet to facilitate voters with visual impairment that relieves tactile confusion in case of more than 15 contesting candidates as every EVM has only 16 buttons to vote for 15 + NOTA or 16 candidates and lacks continuum in subsequent EVMs, if numbers exceed 15.
3. Accessible elections mobile app had been designed by ECI as well as few states to facilitate voters with disabilities.
4. Specific efforts to enrol maximum number of persons with disabilities are being taken.1950 is all India number for details on enrolment including enrolment of people with disabilities
5. The focus right now is more on refinement, like ensuring standards and access guidelines in polling booths, engaging signage's and sign language interpreters, mapping persons with disabilities for every polling booth to figure out the need for wheelchairs / volunteers and provide adequate number of wheelchairs and volunteers to facilitate them, etc

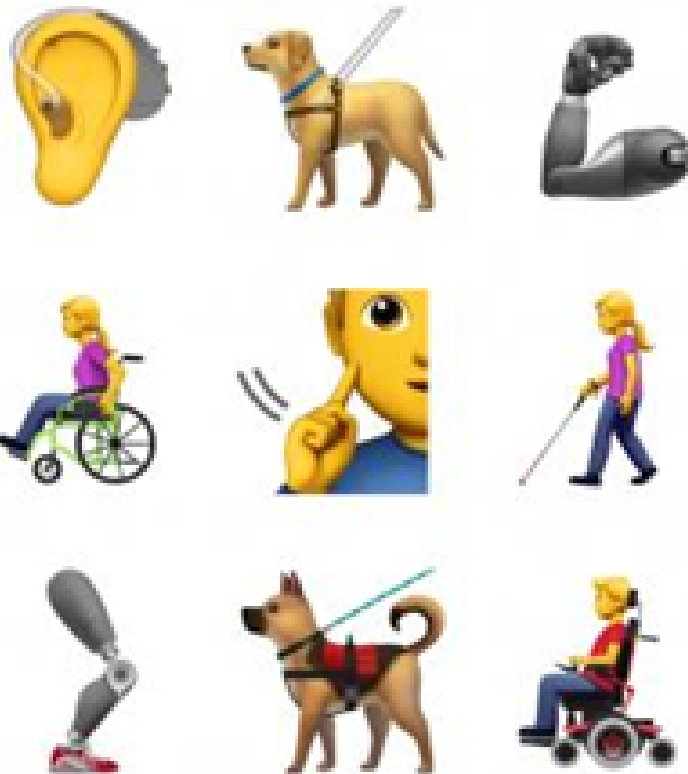
Be the change maker Employer

5 Musts if you are employing a person with disability:

- 1.** Equity and equality are pillars of inclusion-let this become the vision and mission of you as an employer
- 2.** Sensitization about disability -Remember information is awareness and changes attitudes of fellow workers
- 3.** Ensure complete access -do not compromise on it because this will go a long way in changing attitude from charity to right
- 4.** Invest in the best technology as reasonable accommodation for the employee with disability, this is the best way to get the optimum contribution from the employee
- 5 .** Remember equal job - equal pay - equal appraisal builds self esteem of the person with disability and builds a healthy work atmosphere.

The new emojis

The Unicode Consortium, which standardizes how letters and characters appear on your computer screens, just finalized the new roster of emoji that Apple, Google, and other tech vendors will add to your devices .



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