

# Annual Report

**2015-16**



“ keeping families at the centre  
of child’s development ”



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## INTRODUCTION

*Nayi Disha Resource Centre* is a not-for-profit organization that aims to support families of persons with Intellectual Developmental Disabilities (PwIDD) by providing them with information and connecting them to a host of providers like schools, therapists, doctors and also with fellow parents. Nayi Disha has an online information platform with a knowledge bank and a searchable listing of various service providers such as schools, therapists and doctors.

## VISION

*"To enable Persons with intellectual and developmental disabilities achieve their full potential & improve their quality of life by empowering their families."*

## MISSION

- To provide verified and quality information in an easily accessible manner
- To build a supportive ecosystem of service providers, non-governmental organizations, and other families
- To form a strong community of families



# FOREWORD

Nayi Disha Resource Centre completed its first full year as a not-for profit organization in 2016. The past one year has been an amazing journey for all of us.

When Nayi Disha was started, it was little more than an idea to support families of people with intellectual and development disabilities (PwIDD). We knew that over 15 million people in India have some form of intellectual and developmental disability (IDD). We recognized that families, in most cases, end up providing a lifelong support to PwIDDs who are not usually self-advocates and in many cases are even unable to undertake self-care. Yet, there were few organizations that focused on providing support to these families. Our goal, and challenge, was to develop a solution for these family members of PwIDD.

As the idea took shape we began to structure our interventions under three pillars : i) providing a directory listing of service providers, ii) empowering parents through learning videos and workshops, and iii) creating strong parent communities (online and offline).

In the last one year, we have grown considerably. We now have a website which boasts of 350 service providers in Hyderabad, a network of over 500 parents that are connected to us, 4 WhatsApp communities across 2 cities (Hyderabad and Bangalore). We also conducted 12 parent workshops and support group meetings in Hyderabad and have started the process of converting the content of these workshops into learning videos. We have partnered with JP Morgan Chases's Force for Good programme to develop a mobile app that will complement our website. You will read about some of our progress in the following pages of this report.

The feedback from parents to these initiatives has been overwhelmingly positive, reaffirming our commitment to the vision and mission of Nayi Disha. We have managed all this on a shoe-string budget with the help of an army of volunteers, and a very supportive Board that has guided our vision and strategy through the year.

Our goals for the next year are to expand the service directory listing to three other cities, launch the mobile app for families and increase the content on our platform through online videos, blogs and tools to help families take more informed decisions. We are in talks with a number of individual experts and organizations to share their know-how through online videos and parent workshops.

We would like to thank our donors and supporters, especially our early stage volunteers, who stood by us and worked with us even when this was only an idea without a name. To all our experts who have given their time voluntarily to conduct workshops on behalf of Nayi Disha, you have our sincere gratitude and appreciation for your generosity. And lastly, a million thanks to all our parents - without all of you none of the work that we are doing would have been possible or meaningful. You inspire us with your dedication and joy for life.

It has been an incredible journey for all of us so far. We hope that in the years to come we are able to transform India into a truly inclusive society.

*Come join us and be part of this ambitious journey!*

*Message From*  
Nayi Disha Board and Founders



# OUR TEAM



**Prachi Deo**

**Prachi Deo** is a technology and project management professional with several years of experience in the software industry with companies such as TCS and Microsoft. She also led the IT department for a strategic marketing firm in Chicago where she built the offshore IT team and developed IT processes for the company with a wide client base in Europe. Prachi is a sibling and her brother, who has Downs Syndrome, is her inspiration for setting up Nayi Disha.



**Sudarsana Kundu**


**Sudarsana Kundu** is an expert on gender equality and development with more than 16 years of experience in the private and public sector. Sudarsana brings strong skills in programme management, review, evaluation and research and policy advocacy. She has advised several UN agencies, international foundations and NGOs to develop strategies and initiatives that bring about greater social impact. She has an MBA (XLRI) and a Masters in Public Administration from Columbia University.



**Reema Gupta**

**Reema Gupta** has an MBA from Babson College, US. She has worked for several years at the Indian School of Business, Hyderabad and with other private sector companies in the field of information technology. Reema is a firm believer in the concept of inclusion and creating social surplus through the transformative power of Digital Technologies. She is also the parent of a teenager with special needs and the founder of Anokhi Aasha, an NGO which worked with children with disabilities.

# OUR BOARD



**Arun Pereira** is Clinical Associate Professor at ISB and has over 30 years of experience researching, teaching, and consulting in the area of marketing. He is also Emeritus Faculty at the John Cook School of Business, Saint Louis University, St. Louis, USA.

**Vivek Subramanian** is the Co-founder and Executive Director at Fourth Partner Energy. Vivek has an MBA from INSEAD and brings his in-depth experience of strategy, operations and financial management to the Nayi Disha Board.

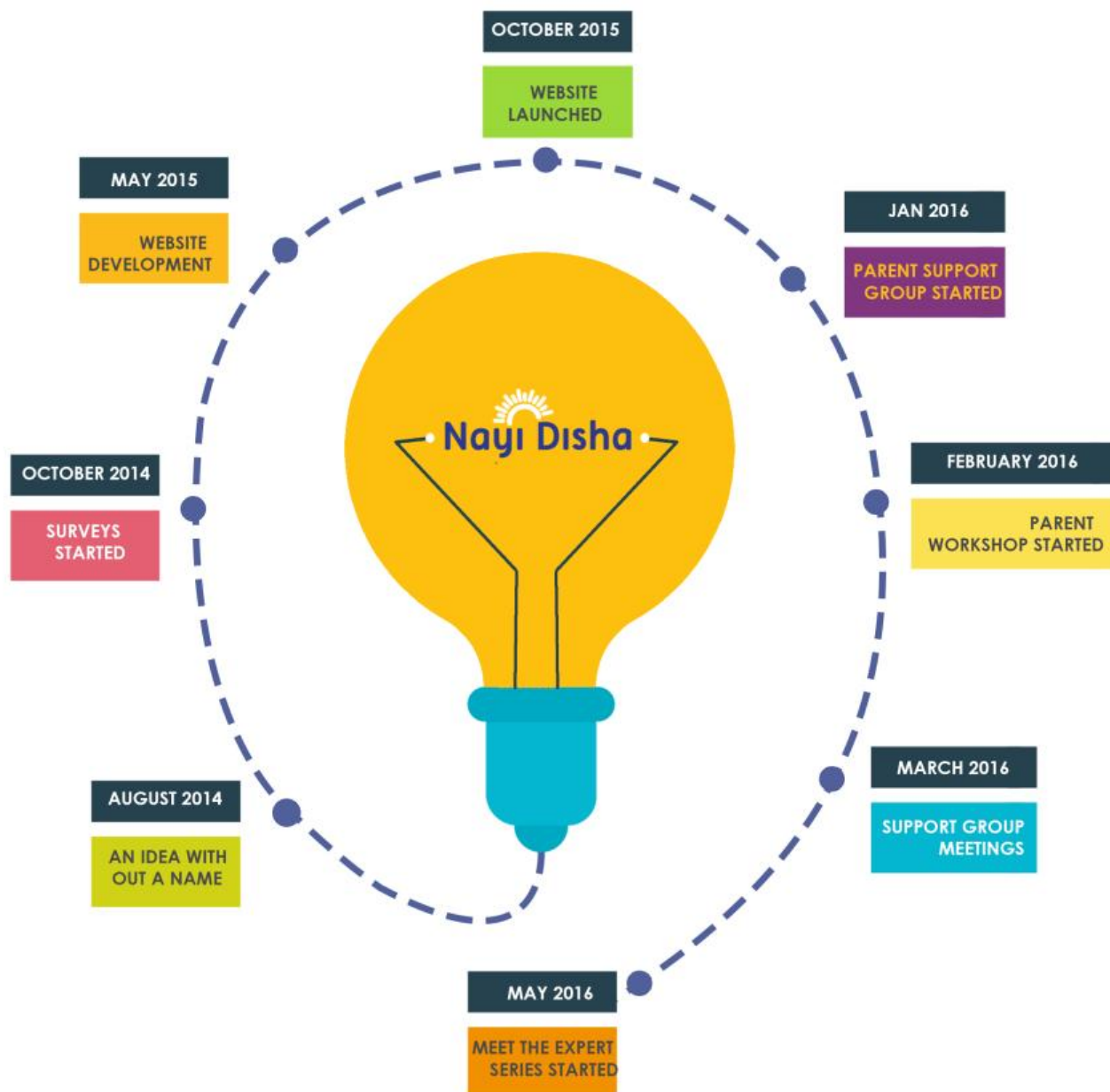
**Shyamal Kachare** is a parent of a special needs child. She was Vice President at Goldman Sachs before leaving the private sector. Shyamal is closely connected with other similar parents in India through a support group that she started.

**Dr. Amaresh Rao Malempati** is a Cardiothoracic Surgeon at Nizam's Institute Of Medical Sciences in Hyderabad. Dr. Amaresh is an active Rotary member and passionate about social causes and delivering healthcare to those who need it most.

**Hari Babu** is the former CEO of Ana Labs Pvt Ltd, a leading services provider in the field of Environmental Consultancy. Inspired by his son, who has Downs Syndrome, he has set up Sai Krishna Teja Foundation, a charitable trust, working for the welfare of persons with special needs.

# OUR STORY

Here is a quick snapshot of *Nayi Disha evolution* till date and how it all began.



Given the strong IT background of the core-team, the design and development of the website began way back in early 2015, even before organization was christened and registered. The first phase of the website was launched in Oct 2015 with a facility to search providers, knowledge bank and upcoming events. The initial response and feedback of families has been very appreciative and about 330 parents in Hyderabad are registered on the website. The website allows users to view details like clinic or school timings, facilities or therapies available in the school/clinic/hospital, fees, qualifications of the providers and importantly reviews from other parents.

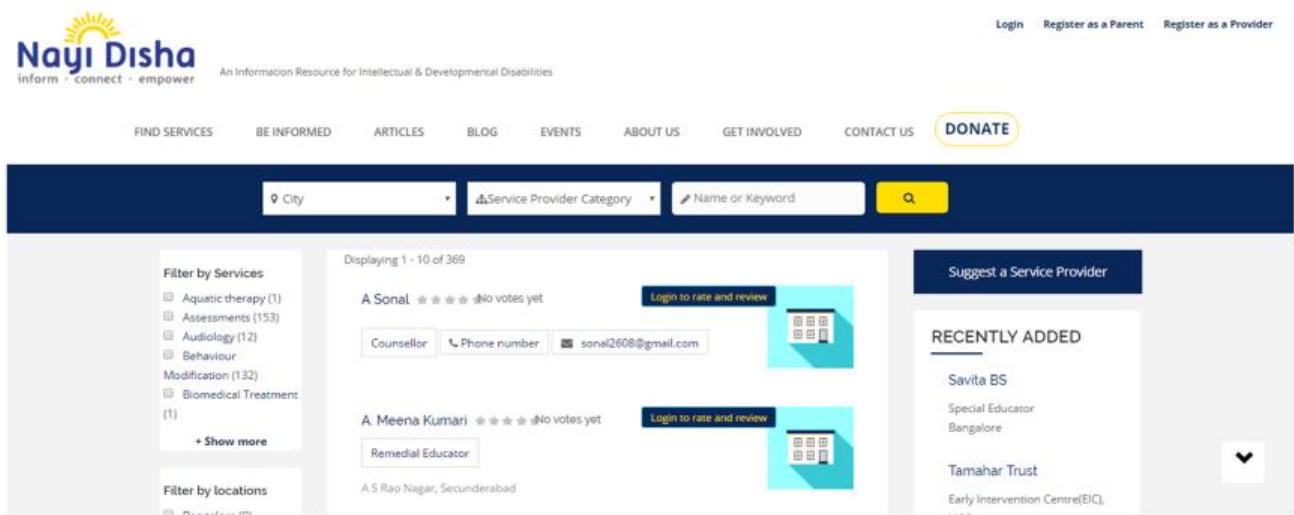
The website gives prime importance to user reviews and recommendations to help parents make informed decisions and find the right resources for their child. The website also has an option to suggest therapists/organizations that work with PwIDD or post an upcoming event in the city. A knowledge bank is being created with information on the various disorders and different government schemes available for families of PwIDD.



## Service Provider Listing

Nayi Disha website was first launched with a listing of 60 schools and therapy centers surveyed through field visits.

Over the last one year, Nayi Disha volunteers and interns have conducted field visits and telephonic surveys to build a comprehensive and verified listing of about 365 providers for Hyderabad alone. This is the only online resource that provides such a comprehensive listing of service providers bearing in mind all the various service requirements of families with IDD, right from sports coaches, music teachers to neurologists and developmental paediatricians.



Parents are now rating and reviewing the providers, We believe this will help fellow parents take informed decisions on choosing the right service for their child and also help providers understand their areas of excellence and areas of improvement.

*On returning to India (Hyderabad), I looked for a speech and language therapist for my son for many months. He has been diagnosed with developmental delay because of epilepsy. Finding Nayi Disha was the best thing that happened to us. Not only did it guide us to the right remedial work for my son, it also connected me to other parents with similar needs. Thank you Nayi Disha!*

*When my husband got transferred to Hyderabad, the my first thought was "Oh God how to find a school there!". From my experience, it is difficult to find schools for senior kids that too autistic. I searched on net, called some of them and was worried about it.*

*Then someone told me about Nayi Disha and shared the link to the website. I got information regarding the schools, their location, reviews etc. It helped me to find a school for my son, Kenaz Mathew. I found the website very useful and I thank Nayi Disha for making the website. It is really helpful for people like me, who land up in a new place. I wish Nayi Disha team all the success for the future.*

*I am a parent of a teenage son who is on the Autism Spectrum. I homeschool him and take him for therapies. I was having a stressful day where nothing was going according to the schedule. I was nearly in tears and questioning my decision to home school my son. In desperation, I sat at my computer and googled special educators in the hope that I would be able to find help online. The search result led me to nayi-disha.org. I was surprised to find a list of special educators in the area I lived in. I was also thrilled to see detailed information on the therapists such as their qualification, experience, geographic location, contact details and area of expertise. It is a very comprehensive database and a lot of effort has been made to include relevant details so that a parent can make an informed choice. Until then I had not seen any website that listed special needs resources that were exclusive to Hyderabad area. Finding the web-site and knowing that help is available calmed me down and made me very happy. Kudos to the team at Nayi Disha and much appreciation for all their hard work in setting up such a useful website.*



## Community Building



We have observed that families of persons with IDD, are often stranded and are left to handle their ward with the sole inputs of the physician/professional treating them. They have very limited information and support in this phase. In line with our motto to bring parents together and foster a culture of emotional support and information exchange, we are facilitating an online group of parents, where information is exchanged almost every hour. Nayi Disha has also organized a couple of support group events to encourage parents to meet in person. A parents' meet has been organized in March, September and November. One such event, interestingly, led to a group of parents in a close locality finding a sports coach and arranging group sessions for their kids.

On **5th November**, Nayi Disha conducted a fun family outing at Mrugvani National Park. It was a great opportunity for families to bond. Kids also had a lot of fun exploring nature. Many of the families informed us that this was the first event of its kind where families of children with IDD came together to go on an outing. Parents told us that the event was stress buster and they enjoyed every activity as much as their child. This event was organised in association with Dirty Feet.









# Parent Empowerment Workshops

Parent empowerment workshops are targeted towards families whose kids are attending special schools. While special school management recognize the need of parent support and education, they find it extremely difficult to find the right experts and organize such events due to lack of resources.

Our **first series** of Parent empowerment workshop was conducted in partnership with I Read Foundation. These sessions were focused on communication with children and behavior management.



Our **second series** of parent empowerment workshops was on the neglected topic of nutritional requirements for children with IDD. It is often found that children with IDD often lack of several micronutrients. These workshops were conducted at different special schools and parents were informed and encouraged to focus on a nutritional diet for their kids. We were able to reach 70 parents through these workshops.



Our **Third series** of parent empowerment workshops was around epilepsy and seizure management. Epilepsy is common in people with intellectual and developmental disabilities (IDD) and parents have many questions about first aid in event of seizures. Dr Anil Israni, MD, DM (Pediatric Neurology) from Maxcure Hospitals conducted a workshop on Epilepsy in children and its first-aid on 15th October 2016. . About 20 parents attended this workshop.



We have also attempted to make an informal connect between families and experts in fields like developmental pediatricians, neurologists, psychologists through a "Meet the expert Series". It provides a platform for families to get pressing questions answered. In our series of meet the expert events, Dr. Ram Kairam, MD, pediatric neurologist from New York, gave a talk on Neurology- Autism and other developmental disorders. The talk was aimed at helping parents and caregivers demystify common myths and misconceptions about autism and other developmental disorders.





# ACHIEVEMENTS

## 2015-16



Network of 900  
parents and providers



300 families  
reached through  
workshops & meets



Online  
communities  
across 2 cities

# FUTURE PLANS



Expand Service Providers  
directory to 15 Cities



Expand Knowledge  
Bank



Parent Empowerment  
Workshops & Meets



Develop a New mobile  
app to increase outreach



Connect with  
30,000 Parents

# OUR SUPPORTERS

JPMORGAN CHASE  
& Co.

JPMorgan Chase & Co.



Fourth Partner Energy



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