Ummeed’s Annual Report 2018-2019 is much more than just a listing of words, numbers and statistics of our activities of the past 12 months.

This year, the Report has sprung to life with artworks by some of our children, expressing themselves as only children can, trusting us with their hopes and dreams. Each and every artwork has a place in the Annual Report – our children have let loose with colours and emotions, and in doing so have inspired us to do the same.

The artworks represent everything that Ummeed stands for and values – families, love, hopes, dreams, diversity and inclusion. From rainbow splashes, to stars, to marine creatures, to families, to perfect landscapes, we have INCLUDED them all in the pages you are about to see, and we hope that you agree with us that nothing is out of place.

We thank our kids for sharing their love with us.

Front Cover and Back Cover Art by Aryan, 11 years
From the Executive Director and CEO

Vibha Krishnamurthy, MD
Founder & Executive Director

Anita Limaye, MD
Chief Executive Officer

The year gone by stands out as the year in which the Ummeed team became more aware of the power of our families. We have always been family centered, but that would end at ensuring that services were built around the needs of our families. In the past year, we went one step ahead – our families became our partners in services and care. This can be hard for an organization that is run by professionals, so we are indeed proud and humbled by the fact that we have been able to break this barrier!

It all started with listening to parent feedback which pointed out that we at Ummeed needed to make information about developmental disabilities more easily accessible to families. So we started proactively sharing such information on our notice boards and other avenues and based on this feedback went on to organize monthly Family Support Groups. Then, for the first time perhaps in India, a parent became a part of Ummeed’s expert team that trains pediatricians on how to better diagnose and support children with autism. Some of our older children with disabilities also became our partners in organizing fun clubs and leisure opportunities for younger children.

There is some truth indeed to the saying that teamwork can make the dream work! We believe that we have made a beginning towards a unique partnership between professionals and families, and that together we will be able to make the world a more inclusive place. We thank you, all our partners and funders, for being a part of Ummeed’s extended family, and for supporting us in moving forward!
Highlights of the Year

We have classified highlights for FY 2018-19 under the four verticals of Ummeed’s work: Clinic, Training, Research and Advocacy.

**CLINIC: Direct Services**

- Nearly 8000 clinical sessions offered to over 1300 children/families
- Eighty percent sessions at concessional rates
- Opportunity for leisure and support created for children and families
- Initiatives to make information about developmental disabilities more accessible

**TRAINING: Capacity Building**

- Over 1500 participants attended Ummeed’s training programs (including online trainings), representing over 200 organizations from 81 cities and 22 states in India, and 8 other countries
- Awareness through over 100 sensitization workshops attended by more than 5000 participants
- WHO’s Caregiver Skills Training program in India adapted and to be piloted by Ummeed
- Collaborations put in place — parents as trainers, creating trainee communities, working with the government and the GATI consortium for school inclusion
RESEARCH: Impact Measurement

» Second publication in a peer-reviewed journal (Acta Pediatrica)
» Study on impact of Ummeed’s training vertical shows “all respondents have shifted on the continuum of knowledge, skills, behaviour, and action”
» Study initiated on whether children with disabilities are able to effectively participate at home, school and in their communities

ADVOCACY: Awareness Creation

» Gateway of India lights up blue for World Autism Awareness Day
» Ummeed participates in “It’s Ok to Talk” — a youth advocacy initiative on mental health
Direct Beneficiaries

Numbers and Reach

Through its clinic, Ummeed offered assessments, consults and therapy services to 1318 children in FY 2018–19. Of the 7951 clinical sessions that were offered through the year, 6309 sessions (approximately 80%) were concessional for children from low- and middle-income families. There has been a nearly 9% year-on-year increase in sessions over the last two years as a result of improved efficiencies.
Early Intervention Center

The EIC offers a pre-school setting for children with moderate to severe disabilities. Its primary intention is to enable eventual school transition of the child. Through building communication, play and cognitive skills, children are helped in gaining independence in their daily living activities (such as self-care), thereby getting them school-ready.

Of 16 children enrolled in the EIC in the year under review, 11 graduated and entered the school system; 5 continued at the EIC for the following year.
Opportunities for Leisure and Support

Fun Club

For most children with disabilities, evenings and weekends are spent at therapy sessions and tuitions. There is no opportunity for them to be active, have fun, listen to music or simply play with other children. Not having enough outlets and spaces for fun and leisure can affect one's mental health and well-being. Thus, when the Ummeed team conceptualized the Fun Club or a “space for fun”, it was envisaged as a “protected time” for young people to have opportunities to be good at and/or feel good about something, use their skills and capabilities, and take their first steps towards believing in themselves and in the changes they can effect in their own lives.

“I love Fun Club. Because I get to play there and do whatever I want,” says Priyankar Ganguly, who is a regular at Fun Club sessions. “I have made so many friends there. I look forward to meeting them every month. If you send me to Fun Club every day, I will go. Can we have Fun Club every day?”

A parent shares, “My daughter has cerebral palsy. Fun Club is like a change from her everyday life when she constantly needs to go for therapy sessions. She has found friends that she can play with, share her thoughts with. She’s much more confident about expressing herself by learning about things from other kids.”

Over the course of the year, monthly Fun Clubs including Summer and Winter Camps were hosted. About 70 children participated in activities such as movie time, cooking and baking and art. What was also enriching was the presence of the volunteers who themselves experience developmental disabilities, thus giving the Ummeed team an opportunity to make them allies in creating such a space for younger children!
Family Support Group

Being the parent of a child with a disability can be a very lonely experience and there is no one who can understand your experience better than a parent going through a similar journey. The Family Support Group is a space where families come together every month to connect with and support each other through the sharing of problems, hopes and dreams. In this year, monthly meetings were held focusing on themes such as leisure, speaking to young people about their diagnosis and other relevant topics. Over the year, about 80 parents participated in these meetings. Sessions where young people came in and talked about their experiences were a highlight; when parents saw that young people experiencing disabilities could speak with hope, it made them optimistic for their own children.

Here’s some of the feedback:

“एक दूसरे से बहुत कुछ सीखने मिला।”
“We got to learn from each other.”

“एक दूसरे के बच्चों के बारे में बहुत कुछ जानने मिला।”
“We get to know about each other’s children.”

“मार्गदर्शन मिला और सहयोग मिला।”
“We received support and guidance.”
Information about Developmental Disabilities | Onsite and Offline

Using Ummeed’s Notice Boards Effectively

In a survey conducted in 2017, 154 parents visiting Ummeed voiced a need for information on developmental disabilities to be made more accessible.

Based on this feedback, a small team began working on presenting information about developmental disabilities and related topics to families that visit Ummeed’s clinical space and training facility. This has been done by creating informative collaterals which are then put up on the notice boards in the reception area of both facilities. In FY 2018-19, bilingual collaterals – in Hindi and in English – on Cerebral Palsy, Family Centered Care, World Disability Day, Early Childhood Development, and Down Syndrome were created and posted.

Tapping the Internet: Making Information about Developmental Disabilities Available Online

The Ummeed team is also keen to leverage technology to make information about developmental disabilities more widely accessible, not just to families that come into Ummeed, but also to those who live around the city and across India too. Our own searches on the internet have shown that currently, most of the information is in English – very little (if any) is in local Indian languages and culturally relevant to low- and middle-income Indian families. In addition, the quality of information is variable, with incorrect and contradictory information across different sites. Ummeed’s intent is to leverage the widespread availability of the internet and the growing penetration of smart phones in India, to provide information on developmental disabilities which is simple to understand, in local Indian languages and from a trusted source. Towards this end, a pilot for an online information platform has been initiated.
Outreach Clinical Services

In December 2018, Ummeed initiated clinical outreach services in a low resource community situated in the vicinity of the Ummeed clinic, so as to promote play and early childhood development in this community, as well as to diagnose and intervene early for delays and disabilities.

The team collaborated with a local organization known as Ansh that helped identify 14 children upto 3 years of age. These children and caregivers received monthly visits from the Ummeed team, aimed at supporting them in enhancing skills such as play, communication and responsive parenting. The child's development is monitored using the international Guide for Monitoring Child Development (GMCD), a tool Ummeed helped develop and that has been published in *Lancet Global Health* as well as *Acta Paediatrica* (for more details see page 16).

We would like to acknowledge the support of our generous donors – Axis Bank Foundation, Bajaj Finance Ltd., Charities Aid Foundation for Oracle, Deutsche CIB Center Pvt. Ltd., Hardik Pandya, Oman India Joint Investment Fund, Reliance Foundation and United World College of South East Asia – for making it possible for children from low- and middle-income backgrounds to access clinical services that would otherwise not be affordable to them.
Over the last few years, Ummeed has steadily increased its investment in training and capacity building of individuals and organizations working in the child development and disabilities space. In FY 2018-19, 1577 participants attended Ummeed's skill-building and long-term training programs, including online trainings. In addition, 5815 people were sensitized through more than 100 sensitization workshops.

**Indirect Beneficiaries**

**Numbers and Reach**

Over the last few years, Ummeed has steadily increased its investment in training and capacity building of individuals and organizations working in the child development and disabilities space. In FY 2018-19, 1577 participants attended Ummeed's skill-building and long-term training programs, including online trainings. In addition, 5815 people were sensitized through more than 100 sensitization workshops.
In the previous year, Ummeed piloted an online training using the ECHO (Extension for Community Healthcare Outcomes) model, that works on the philosophy of transferring knowledge instead of people, through case based rather than didactic learning. Nine ECHOs run in the year under review have helped Ummeed reach 44 cities in India and its neighbouring countries.

Ummeed is privileged to be piloting the World Health Organization (WHO)-Autism Speaks Caregiver Skills Training (CST) program in India.

The CST program has been developed by WHO and Autism Speaks to train parents of young children with autism in countries with limited or no access to therapists. Currently this is being field tested in more than 30 countries worldwide to ensure that it meets the needs of parents across cultures. Ummeed is leading the effort in India, with its therapists being trained by Autism Speaks to become “CST-Master Trainers”.
Parina Khetan is a parent of a child with autism. She has been a part of Ummeed’s ECHO hub team that provides online training to pediatricians about how to better diagnose and support children with autism and their families. In addition to Parina, the team includes pediatricians, an autism intervention therapist, and the support team. This might be one of the most unusual instances in India where a parent serves as an “expert” to train doctors, voicing the experiences of children with disabilities and other parents like herself.

This is what Parina had to say about her experience:

“The ECHO program and being a part of the team has brought a confidence in me. Reliving certain moments again (diagnosis, early journey) only strengthens my will, and makes me realize how blessed we were to have all the help that was needed. The panel of doctors is so eager to learn and this brings a certain type of joy in me as I feel the world will be better tomorrow. Every session is a new learning experience and a bank full of knowledge.”
Creating Communities of Trainees

One of the hopes that our trainees of mental health programs have shared over the years is to have a safe space, a community in which they can discuss their post-training ideas and work, and continue to have conversations. In response to this need, Ummeed’s mental health team began hosting monthly narrative gatherings. These gatherings are open to participants from all our past mental health trainings. At each gathering, members from the narrative community present an innovative idea that they are currently working on, providing others in the group an opportunity to witness new work, brainstorm and connect with each other.

There were 12 gatherings held in FY 2018-19, each gathering had 20-25 attendees, with some participants who joined in online from other cities.

The GATI Consortium for School Inclusion

In FY 2018-19, Ummeed’s school outreach team was part of GATI (a disability focused accelerator consortium of Atma – http://www.atma.org.in/gati). The purpose of the consortium was to drive high quality education for individuals with disabilities by improving the resources and knowledge available to school practitioners while fostering sector coordination. As a part of this consortium, Ummeed’s school outreach team has engaged in 3 activation workshops towards building awareness about inclusion and supporting children with disabilities in the mainstream school context. These workshops have reached out to approximately 70 affordable private schools.

We would like to acknowledge the support of our generous donors – Azim Premji Philanthropic Initiatives Pvt. Ltd., Cipla Foundation, H T Parekh Foundation, IQVIA, JM Financial Foundation, Morris Foundation, Narotam Sekhsaria Foundation, Trafigura Foundation and our Early Childhood Development and Disability partners – Apnalaya, Forbes Marshall group, Setco Foundation and Tara Mobile Creches for their continued support towards our training and capacity building initiatives.
Research & Impact
Is What We Are Doing Working?

Publication in Acta Pediatrica

Between 2010 and 2015, Ummeed represented India in a 5-year international research project with 3 other countries (Argentina, South Africa and Turkey). The project had several path-breaking outcomes, including evidence that child development milestones are remarkably similar across the world. The project also helped develop a tool known as the Guide for Monitoring Child Development (GMCD). The findings from this research study were published in Lancet Global Health in March 2018, and in November 2018, were published in another prestigious and peer reviewed scientific journal – Acta Pediatrica: [https://onlinelibrary.wiley.com/doi/10.1111/apa.14661](https://onlinelibrary.wiley.com/doi/10.1111/apa.14661)

Impact of Ummeed’s Training Vertical

Ummeed collaborated with Start Up! (an incubator, accelerator and leadership springboard for social entrepreneurs) in August 2018 to conduct an assessment of its training journey to date. The study was designed and executed from September 2018 to April 2019. The analysis of responses is underway but a key finding is that Ummeed’s training programs have successfully, and without exception, demystified the concept of the “expert” in treating developmental disabilities and created a conviction in the recognition of the parent/family as the expert. The final report of this assessment is expected in FY 2019-20.

Study Initiated to Measure “Participation” in Children with and without Disabilities in Mumbai

Children with disabilities and their families hope for outcomes similar to typically developing children – which is to be independent, have opportunities to socialize with family members and friends, have fun and learn at home, at school, and in the community. In order to measure how children accessing services at Ummeed are doing on these very important outcomes, Ummeed is collaborating with researchers from CanChild ([https://www.canchild.ca/](https://www.canchild.ca/)), a reputed non-profit research center dedicated to applied clinical and health services research on children and youth.

This is probably the first time that such a study is being undertaken in India. Findings on how children participate in different activities in the 3 areas – home, school and community – will help bring in a new perspective and approach to interventions for children with disabilities. It will tell us how our children integrate in real world settings, and how the environment supports or hinders their participation.
INCLUSION IS WITHIN EVERYONE’S ABILITY
Awareness and Advocacy Towards Creating a More Inclusive World

“Gateway of India” Lights Up Blue for World Autism Awareness Day

For the last 3 years, Ummeed has actively participated in the World Autism Awareness Day (WAAD) campaign, inspiring many others to participate and create awareness too. In 2019, the team at Ummeed, planned and executed our biggest campaign so far, under three themes – Light It Up Blue, What Have I Done to Light Up Blue, and Outreach. A key highlight was that the iconic Gateway of India lit up blue on April 2, along with 13 other Mumbai landmarks. The social media campaign was very successful, with people from across the city and the country participating to create awareness. The outreach program included an art therapy workshop for children with autism and other disabilities by a renowned Indian artist, a street performance by the Symphony Orchestra of India, and talks/sensitization workshops. A radio station visited Ummeed and engaged with the kids and broadcast a program on WAAD.
It’s OK to Talk

It’s Ok to Talk (http://itsoktotalk.in/about-us/) is an initiative to overcome stigma around mental health and to create safe spaces for young people to talk about their mental health. One of Ummeed's younger members from the mental health team, Yashna Vishwanathan, participated as a Youth Advocate, along with other advocates from different parts of India. Post a training that covered topics such as community mental health, law and policy making, intersectional identities, mental health conversations on social media, etc., these young advocates were asked to undertake a community project within their respective contexts.

Yashna came back and started a Young People's Club to initiate conversations and document young people's everyday knowledge about mental health, based on the uniqueness of their life values, contexts and lived experiences. Her hope is to pool this knowledge and create a handbook that shines light on the “little-big” skills used by these young people to support their own mental health.

Says Yashna,

“It was so much fun to work with youth advocates across India at the Delhi training, and to get to know about mental health from their contexts. Back at Ummeed, it was exciting to have the support of the mental health team to shape the Young People's Club initiative which was informed by narrative ideas and my learnings at It’s Ok to Talk.”
**Fund Raising Events**

Ummeed’s annual event, the “55 Km Walk for Ummeed” was held in Goa on 12th January 2019. One hundred and eighteen enthusiastic walkers participated in this event and raised an amount of Rs. 1.85 crore. Ummeed would like to express its gratitude for the support received from all the participants and their supporters.

Sixteen individual runners and corporate-led participants from MHFC ran in the Tata Mumbai Marathon and helped raise Rs. 3,71,667. We are grateful to all the individual participants and MHFC for their support in raising funds.
Staff Matters

THE UMMEED TEAM

Ummeed is now a 90-member strong team of employees and consultants. Additionally, we had 14 volunteers, 13 observers and 23 interns, support our work as well as come in to learn and observe.

Feedback from an observer

“My experience at Ummeed was ‘life-calling’. I entered as a confused person who wanted some clarity on how to practice in my career and I landed up getting a lot of fulfillment and enrichment. It reinforced the vision I bear for children - to provide a space where each and every child develops to the potential that they are born with. I could in reality see each and every person at Ummeed working to the best of their capacity whether it’s the therapists or counsellors or doctors or even the staff at the front desk or cleaning staff - all were working together as one loving family for children. It was an overwhelming experience being there and a total example of goodness and warmth in this world. I dream of replicating these values wherever possible in my life for children.”

Feedback from an intern

“I want to take this opportunity to thank you for the wonderful learning experience it has been for me at Ummeed. The philosophy that Ummeed stands for is so very precious and is something that has overwhelmed me over the past couple of months. It has truly been a pleasure to have been associated with Ummeed and the people of Ummeed. As I move forward, I know there are a few important life lessons I’m picking up from this place to take ahead with me for which I will be grateful to Ummeed.”
EMPLOYEE HIGHLIGHT

Raviraj Shetty, who is a part of Ummeed’s mental health team, was invited to speak at a TEDx event organized by The Orchid School in Pune in August 2018. Raviraj shared stories of what becomes possible by the simple act of asking with curiosity. Here is a QR code and link to his talk:

https://www.youtube.com/watch?v=M7QURkRf_Ls

IT SYSTEMS IMPLEMENTATION

Towards making Ummeed more IT enabled, a project to roll out systems for most of Ummeed’s operations – clinic management, training management, human resource and donor management – has been initiated. These systems will be implemented over a period of 3 years.

We would like to acknowledge the support of our generous donors – Big Tree Entertainment Pvt Ltd., CAF UK for Douglas L Miller & Audrey T Miller Charitable Trust & Miller Minots Funds, Connell Brothers, Fidelity International Foundation, Mascot Dynamics Pvt Ltd., Pallavi Shah, Tanya Dubash, Teritex Knitting Industries Pvt Ltd. and several other institutional and individual donors for their continued support for Ummeed’s activities.
DIVERSITY IS BEING INVITED TO THE PARTY; INCLUSION IS BEING ASKED TO DANCE

VERNA MYERS
### FINANCIALS

**Balance Sheet as on 31st March, 2019**

<table>
<thead>
<tr>
<th>Particulars</th>
<th>As on March 31, 2019</th>
<th>As on March 31, 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EQUITY AND LIABILITIES</strong></td>
<td></td>
<td></td>
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<tr>
<td>Shareholder’s Funds</td>
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<td>Share capital</td>
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<td>100,000</td>
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<td>Reserves and surplus</td>
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<td><strong>CURRENT LIABILITIES</strong></td>
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<tr>
<td>Other current liabilities</td>
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<tr>
<td><strong>TOTAL</strong></td>
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<td>123,622,009</td>
</tr>
<tr>
<td><strong>ASSETS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Current Assets</td>
<td></td>
<td></td>
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<tr>
<td>Fixed assets</td>
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<td></td>
</tr>
<tr>
<td>Tangible assets</td>
<td>28,679,430</td>
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<td>Intangible assets</td>
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<td>276,801</td>
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<tr>
<td>Long-term loans and advances</td>
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<td>3,240,536</td>
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<tr>
<td>Other non current assets</td>
<td></td>
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<tr>
<td>Current Assets</td>
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<td>Short-term loans and advances</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td>138,423,037</td>
<td>123,622,009</td>
</tr>
</tbody>
</table>

**Auditor’s Report**
Signed in terms of separate report of even date
SLM & CO LLP
Chartered Accountants
Firm Regn No: W-100030

**For and on behalf of the Board of Directors**

Sanjay Makhija
Partner
Membership No: 042150
Date: 19 July 2019

Ashish Karamchandani
Director
DIN: 01894569
Date: 19 July 2019

Rajnish Inderjit Dhall
Director
DIN: 02146708

**For and on behalf of the Board of Directors**

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DIN: 01894569
Date: 19 July 2019

Rajnish Inderjit Dhall
Director
DIN: 02146708
## Financials

**Statement of Income & Expenditure for the year ended 31st March, 2019**

<table>
<thead>
<tr>
<th>Particulars</th>
<th>As on March 31, 2019</th>
<th>As on March 31, 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions and grants</td>
<td>93,719,846</td>
<td>77,180,439</td>
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<tr>
<td>Other income</td>
<td>3,244,527</td>
<td>3,291,368</td>
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<tr>
<td><strong>Total</strong></td>
<td>96,964,373</td>
<td>80,471,806</td>
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<tr>
<td><strong>Expenditure</strong></td>
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<tr>
<td>Expense on activities</td>
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<td>72,546,035</td>
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<tr>
<td>Administrative expenses</td>
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<td>6,468,620</td>
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<tr>
<td>Depreciation and amortisation expense</td>
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<td>1,081,329</td>
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<td><strong>Total</strong></td>
<td>87,304,167</td>
<td>80,095,984</td>
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<tr>
<td>Surplus Before Exceptional and Extraordinary Items (I-II)</td>
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<td>375,822</td>
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<tr>
<td>Exceptional item</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Surplus Before Extraordinary Items (III-IV)</td>
<td>9,660,206</td>
<td>375,822</td>
</tr>
<tr>
<td>Extraordinary items</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Surplus/Deficit</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Surplus for the year from operations</td>
<td>9,660,206</td>
<td>375,822</td>
</tr>
</tbody>
</table>

**Auditor’s Report**
Signed in terms of separate report of even date
SLM & CO LLP
Chartered Accountants
Firm Regn No: W-100030

For and on behalf of the Board of Directors

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DIN: 02146708

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Ummeed Board

Ashish Karamchandani  
Chairman & Founder

Arun Jethmalani  
Board Member

Rajnish Dhall  
Board Member

Merry Barua  
Board Member

Ujwal Thakar  
Board Member

Art by:  
Aarav, 5 years
Please use these artworks as a greeting card, a postcard or put them up in your space – as a reminder of our wonderful and talented children.
Perforation for tear out postcards
Our Ummeed Family

Creating a world where all children reach their maximum potential!