

SAAJHI SAMAJH 11.0

Empowering Caregivers of PwDs

EVENT REPORT

8 DECEMBER 2023



Concept Lead: Empowering Caregivers of PwDs

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Panelists:

Mr. Anil Patil – *Founder and Executive Director, Carers Worldwide*

Mr. P. Madhusudan Reddy – *CEO, Sadhana Institute of Mentally Challenged*

Ms. Krishna Chowdhary – *Parent to a 4.5-year-old child diagnosed with Autism*

Major Mr. BV Ram Kumar – *Director, NIEPID*

Moderator: Ms. Prachi Deo – *Founder and Executive Director, Nayi Disha*

Anchors: Mr. Anji Reddy and Ms. Naima Urooj (R, M & E – Head, Tech Mahindra Foundation) and Indian Sign Language Interpreter Mr. Sundar Raju from Deaf Enable Foundation, Hyderabad

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Introduction:

Empowering Caregivers of Persons with Disabilities

At Tech Mahindra Foundation, disability is the third major area of intervention to empower all to Rise. The Foundation works relentlessly towards ensuring that People with Disabilities receive social inclusion and equal work opportunities for a better future. This is done through two premier disability programs - **ARISE+** (All Round Improvement in School Education for Children with Disabilities) and **SMART+** (Skills for Market Training for Persons with Disabilities). The Foundation mandates that 10% of all its beneficiaries are People with Disabilities. Currently, the foundation supports 5,050 children through 37 ARISE+ projects and plans to train 1,000 youth through 8 SMART+ projects.



About Nayi Disha

A pioneer organisation in the field of disability, [Nayi Disha](#) works as a lifelong partner for families of children affected by autism, Down syndrome, and other intellectual developmental disabilities. They help children reach their true potential by providing families with information, guidance, and hope through a reliable and evolving digital hub and a supportive online peer community. Nayi Disha hosts a digital platform with trustworthy and verified information and resources, expert networks, a helpline, and a supportive peer community.

Tech Mahindra Foundation has joined hands with Nayi Disha to release a compendium on schemes and policies for PwDs in the state of Telangana. It is expected to be a one-stop resource booklet for parents/caregivers of people with disabilities with verified information on national and state government schemes, information on service providers like counsellors, therapists, etc., and relevant phone numbers for easy access.

Saajhi Samajh - The Eleventh Edition

"Saajhi Samajh" (or Shared Understanding) is the Foundation's attempt to create a broader platform to enable advocacy through discourse and discussion on issues related to and relevant to the development sector in India. The previous editions of Saajhi Samajh were a resounding success, and details of them are available [here](#).

Saajhi Samajh - The Eleventh, initiated a discussion on "Empowering Caregivers of Persons with Disabilities" and their crucial role in ensuring PwDs live a life of dignity and independence.

Tech Mahindra Foundation has always encouraged the role of parents/caregivers in developing children with disabilities. With the assistance of committed organisations like Nayi Disha, the Foundation is hopeful of bringing the challenges of caregivers to the forefront and devising solutions to empower them in their arduous journey of being there for their loved ones.

The eleventh edition of Saajhi Samajh was held on December 8, 2023, and was hosted online by Tech Mahindra Foundation and Nayi Disha. It was followed by a formal launch of the compendium created by the organisations for caregivers in the state of Telangana. A diverse panel of speakers comprising key stakeholders across the board - organisations working with PwDs, caregivers, CSR professionals, and government officials addressed the importance of ensuring caregivers are equipped and their role in helping build an inclusive society.



Key questions to be discussed with our esteemed panellists

- 1) Over the 2-3 years of the COVID-19 pandemic, many experienced isolation and stigma; we could not step out of the house, go to theatres, or attend social events. What are some of the challenges faced by caregivers of PwDs?
- 2) How do the NGOs that primarily cater to people with disabilities involve their families in the process? What are the various ways in which caregivers can be provided with respite?
- 3) In the Indian cultural context, caregiving is primarily recognised as a woman's job, and women are disproportionately burdened with caregiving duties. How can we "de-feminise" caregiving?
- 4) Caregivers, as primary changemakers in their children's lives, play a crucial role in caring for and providing education and therapeutic support to their loved ones. To ensure meaningful family involvement, it is essential to focus on family-centric care. What does family-centric care mean for government institutions? How does one involve families in the care of the families?
- 5) How can we get more dedicated resources (funding/educational material) for caregivers? Can CSRs play a role in ensuring that the focus is placed on their caregivers along with the beneficiary?
- 6) One call to action from each panellist.

Agenda

SS-11 - Event Flow			
Timing : 11:00 am - 12:20 pm			
11:00-11:03 am	Opening Remarks	Anchors of the events	3 mins
11:03-11:08 am	About TMF	Ms Neha Soneji Program Director - Child Development Tech Mahindra Foundation	5 mins
11:08-11:13 am	About Nayi Disha	Ms Aditi Koomar Manager-Donor Management and Partnerships Nayi Disha	5 mins
11:13-11:18 am	Speech & welcome address to the Keynote speaker	Mr Chetan Kapoor CEO, Tech Mahindra Foundation	5 mins
11:18-11:28 am	Launch of the compendium <i>Empowering Caregivers and Persons with Disabilities: A Comprehensive Guide for PwDs & PwIDDs in Telangana</i>	Chief Guest and leaders	10 mins
11:28-11:38 am	Speech by the Keynote Speaker	Mr Jayesh Ranjan IAS	10 mins
11:38 am-12:03 pm	Panel Discussion - Moderated by Ms Prachi	Ms Prachi Deo and esteemed panellists	45 mins
12:03-12:18 pm	Q/A from audience	Ms Prachi Deo	15 mins
12:18-12:20 pm	Q/A from audience	Ms Shormi Roy Choudhury Regional Head - East Tech Mahindra Foundation	2 mins



Welcome note by

Neha Soneji

Programme Director, Child Development, Tech Mahindra Foundation

Established in 2006, Tech Mahindra Foundation serves as the corporate social responsibility arm of Tech Mahindra Limited. The overarching vision revolves around empowerment through education, with a steadfast commitment to three primary focus areas: education, employability, and disability.

In the realm of education, active engagement is pursued to drive social change. Over the years, the Foundation has undertaken 50+ projects, collaborating with 90+ partner organisations across 11 locations in India. The SMART initiative, an acronym for Skills for Market Training, seeks to make youth self-reliant by imparting in-demand skills. Currently, eleven academies are operated directly, supporting 90+ centres through partner implementing agencies.

The Foundation has supported government schools, enhanced infrastructure, and provided skilled teachers to bridge educational gaps through the ARISE (All-Round Improvement in School Education) programme. With 18 ARISE programmes reaching around 5,000 children, the aim is to provide quality primary education to underprivileged and marginalised socioeconomic groups.

Shikshaantar, the flagship teacher development programme, strives to empower teachers and create safer, happier classrooms. In-service Teacher Education Institutes in Dilshad Garden, Shakti Nagar, and Delhi offer highly qualified teacher education, structured workshops, and a multidisciplinary curriculum.

To create an inclusive world, the disabilities vertical focuses on education and skill development for children and youth with disabilities. Currently managing 40+ projects with various implementing agencies, the goal is to provide a life of dignity and confidence to those with disabilities.

Last year, a collaboration with Nayi Disha resulted in a webinar on Disability Awareness and UDID schemes. This year, the partnership has deepened, and the two organisations have collaborated to develop a compendium of government-related schemes for PwDs and their caregivers. Neha shared the team's excitement for the event and expressed immense hope that it would be valuable. She also appreciated the support in helping the PWD community spread its wings. Neha then invited Ms. Aditi from Nayi Disha to speak a few words on behalf of the organisation.

About Nayi Disha

Dr. Aditi Koomar

Manager, Donor Management & Partnership, Nayi Disha

A warm welcome is extended to all the panellists and everyone attending Saahji Samaj 11, and we are thrilled to have everyone here today. Dr. Aditi Kumar from Nayi Disha, a tech-enabled organisation working with the community of persons with disabilities, expresses gratitude to Tech Mahindra Foundation for the opportunity.

Nayi Disha functions as a dedicated lifelong partner for families with children impacted by conditions like Autism, Down Syndrome, and other intellectual developmental disabilities. The mission is to help each child reach their true potential by providing families with information, guidance, and hope. The team offers a reliable, evolving digital hub and a supportive online peer community.

The digital platform hosts trustworthy and verified information, expert networks, a helpline available over the phone and on WhatsApp, and a supportive peer community that engages both in person and online. Active assistance is provided through WhatsApp groups, fostering a sense of community and collaboration. Nayi Disha is grateful for the opportunity to partner with Tech Mahindra Foundation and looks forward to a meaningful discussion.



Welcome and Launch of Compendium by

Mr. Chetan Kapoor and Mr. Jayesh Ranjan

Chetan started his speech by sharing his optimism for a better future and showing gratitude to everyone. He shared that he is immensely grateful to the founders of TMF, who in 2007 realised the importance of working for Persons with Disabilities, and it was decided that at any given point in time, at least 10% of TMF's beneficiaries would be Persons with Disabilities. He added that the Foundation ensures ample representation and that 20% of its funding is devoted to projects for PwDs. Mr. Chetan shared that Tech Mahindra Foundation, over the years, has taken significant steps. They began by assisting organisations that promoted PwDs' access to education and employment, and as a result, they significantly enhanced the value of their devoted and committed partners' work. He shared that the foundation has decided to move to a life-stage approach of working with PwDs. They have already introduced projects in early detection and intervention. They will focus on the 18+ age group with higher education projects, career counselling, entrepreneurship, and innovative options for skill development for PwDs. Chetan then highlighted the importance of collaboration while working for PwDs and the need to first scale deep before going wide. He expressed appreciation for the collaborations with like-minded organisations like Nayi Disha and the desire to create compendiums with schemes for PwDs for all states, leading to a nationwide repository.

Chetan highlighted the need for collective awareness, sensitisation, empathy, and decisive, impactful action. He shared that the compendium would be a big step in that direction. He expressed his heartfelt gratitude to Prachi and the team at Nayi Disha.

Chetan encouraged everyone to join this journey, paving the way to a better life for PwDs. He then invited Mr. Jayesh Ranjan and Ms. Prachi Deo to release the compendium.

Demo of the compendium by

Ms. Priya from Nayi Disha

Shanmukha Priya from Team Nayi Disha expressed heartfelt gratitude to Tech Mahindra Foundation for their collaboration, which marks a crucial step towards breaking barriers. Special thanks were extended to Mr. Jayesh Ranjan for accepting the invitation and joining the event.

This compendium is designed to guide and inform caregivers and individuals with disabilities about valuable details regarding services and benefits. It covers topics such as the process of obtaining a SADARM certificate, various educational benefits and scholarships, health care support systems like NIRAMAYA and ADIB, social security schemes including loan finance and pensions, facilities, income tax rebates, skill development, employment opportunities, legal entitlements such as voting rights, obtaining legal guardianship, and provisions like travel concessions. It encompasses everything for individuals with disabilities in Telangana.

This tool fosters independence and ensures that everyone in the community is well-informed and empowered. This compendium will be accessible in Telugu within the next couple of months. Priya also walked everyone through some of the essential parts of the compendium.

Following this, Mr. Jayesh Ranjan, the Special Chief Secretary of the Industries & Commerce (I&C) and Information Technology (IT) Departments of the Telangana government, was invited to formally deliver the keynote address. Mr. Ranjan holds degrees in psychology, business management, and public management. He has worked in the field of education and is well-versed in the non-profit sector. Mr. Ranjan has undertaken various international assignments, earning prestigious scholarships and accolades, such as the Royal Order of the Polar Star from the King of Sweden in 2019. He is deeply involved in shaping policies, attracting investments, and promoting digital empowerment. Beyond his official roles, Mr. Jayesh Ranjan is actively engaged in the fields of technology and innovation and actively supports numerous social, cultural, and charitable causes, contributing to various boards and advisory committees.



Keynote Speech



Mr. Jayesh Ranjan

*Principal Secretary to the Government of Telangana
Industries & Commerce (I&C) , Department & Information Technology
Electronics, and Communications (ITE&C), Department*

Mr Ranjan started by extending acknowledgements to all panellists, invitees, and members of Tech Mahindra Foundation with special thanks to Nayi Disha. Thrilled to be part of this initiative, he highlights his association with Tech Mahindra Foundation, adding his long active support for social and charitable causes.

He recounted his involvement in the Abilities Mela Initiative, collaborating with various organisations, including Tech Mahindra Foundation & Nayi Disha. Being aware of Tech Mahindra Foundation's engagement in the disability sector, he was not surprised at their collaboration with organisations like Nayi Disha. Having worked with people with disabilities for over a decade, especially those with intellectual disabilities, he emphasised the challenges they face in securing gainful employment, making caregivers' roles crucial.

He suggested focusing on technology as a solution and proposed building a compendium of assistive technologies' information on accessibility, affordability, and adaptability. Addressing caregivers' concerns about the future, especially as they age, he suggested a few possibilities for sustaining a good quality of life for persons with disabilities beyond the caregivers' lifetime.

In conclusion, he encouraged discussions on achievable solutions and the role of government, the private sector, philanthropies, and technology developers. While dropping off, he requested updates on outcomes and potential implementation opportunities. He extended his heartfelt congratulations to both Tech Mahindra Foundation and Nayi Disha, appreciating their efforts and wishing them success in future endeavours.



Thank You Remarks

Mr. Chetan Kapoor, Chief Executive Officer, Tech Mahindra Foundation

Chetan expressed gratitude to Mr. Jayesh Ranjan for his thoughtful insights into assistive technology and the need to reassure caregivers. He acknowledged the relevance of these points and committed to translating these ideas into actionable initiatives at Tech Mahindra Foundation. He also showed keen interest in collaborating with Mr. Jayesh to create replicable models that can be implemented nationwide. He emphasised the essential decision to spotlight caregivers and their often-overlooked role, particularly that of mothers, in supporting individuals with disabilities.

Thank You Note by

Mr. Sudheer Babu, Programme Director, Youth Empowerment

Mr. Sudheer Babu thanked Mr. Jayesh Ranjan and Mr. Chetan Kapoor for joining despite their busy schedules, highlighting Jayesh's eagerness to attend the event. He echoed Chetan's thoughts about technology's potential to assist caregivers in Telangana. The Tech Mahindra Foundation is committed to delving deeper into creating a compendium of available technologies. Sudheer Babu acknowledged Mr. Jayesh's passion for positively impacting society and expressed wholehearted support for his work. Mr. Sudheer Babu showed interest in collaborating further with Mr. Jayesh and explored ways to progress initiatives during his next visit to Hyderabad. Sudheer Babu thanks Jayesh once again for his valuable insights and continued support.



Panel Discussion

Moderator



Ms. Prachi Deo

*Founder and Executive Director,
Nayi Disha*

Ms. Prachi extended greetings to everyone who had joined today's event. A heartfelt thank you was conveyed to Mr. Jayesh Ranjan for his insightful remarks, emphasising his understanding of the cause and commitment to supporting families and individuals with disabilities. Mr. Ranjan rightly highlighted the importance of assistive technology not only for persons with disabilities but also as a means to empower caregivers.

Gratitude was extended to Tech Mahindra Foundation, Chetan, and Neha for the invaluable partnership and the opportunity to launch the compendium today. The work ahead involves distributing the compendium to families and organisations in need. The upcoming panel discussion on empowering caregivers holds particular significance for Nayi Disha.

She quoted Rosalind Carter, "There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need a caregiver." This succinctly captures the societal roles all may play. As the founder and executive director of Nayi Disha, Prachi is also a caregiver to her 50-year-old brother with Down syndrome. Her caregiving role has evolved over the years, from a playmate to a companion, a partial caregiver, and now a legal guardian and full-time caregiver to both her brother and parents.

Caregiving is not easy, and the statistics reinforce its prevalence. With 62% of people with disabilities requiring caregivers, and considering India's 15% population with disabilities, it means there are 132 million caregivers. This staggering number, 9.3% of the population, underscores the urgency of the discussion. Prachi introduced and invited each of the esteemed panellists and began the conversation.

Prachi initiated the discussion by addressing Ms. Krishna, a parent who recently took up her caregiving journey, to share her experiences and challenges over the past two and a half years.



Highlights



Ms. Krishna Chowdhary

*Parent to a 4.5-year-old child
diagnosed with Autism*

Krishna extended a warm welcome and expressed her happiness about participating in the meeting. Her journey as a caregiver has been marked by numerous challenges, particularly after learning that her son has Autism Spectrum Disorder (ASD). Living in a village with no therapy centre, Krishna faced difficulties enrolling her son in school due to safety concerns. Despite initially accompanying him to school, the demands of managing the household compelled her to relocate to Raipur, leaving her husband behind.

In Raipur, Krishna found a therapy centre and initiated classes for her son when he was just 2.9 years old. He has progressed to the sentence level, bringing her immense joy. However, Krishna stressed the challenges she faced without a support system, after moving to Raipur alone. With no family support, the difficulties have persisted, preventing her from returning home for a year. Krishna faced complex challenges in school and therapy, with inconsistent sessions adding to the hurdles. Social acceptance remained a hurdle, as society often failed to understand her son's special needs, making it challenging for them to feel included. Despite the hardships, Krishna stands resilient, caring for her son single-handedly, demonstrating the strength and determination required in her caregiving journey.

Prachi appreciated Krishna's courage to share her story. She shared that the strength of families like Krishna's amazes her, tackling isolation and stigma at every turn while striving to unlock their children's true potential. Beyond these challenges, there is a critical aspect often unspoken - the concern about "what comes next" for children with disabilities. She shared that she recognises the gravity of this issue and, with that, invited Mr. Madhusudhan Reddy to share his thoughts and experience of running an NGO for persons with intellectual disabilities.



Highlights



Mr. P. Madhusudan Reddy

Chief Executive Officer

Sadhana Institute of Mentally Challenged

Mr. Reddy started by congratulating Tech Mahindra Foundation and Nayi Disha on releasing the compendium guide for PwDs and their caregivers in Telangana. As the Secretary-General of the Federation of Organisations working for Disabilities in Telangana, he applauded the initiative.

The holistic support approach was mentioned, encompassing educational facilities, vocational training, healthcare, and community involvement for families. Utilising a family-centred approach, families are actively involved in planning and decision-making, and academic training is provided to enhance their understanding of their children's needs. Initial assessments using technology, such as NIPED's functional assessment tools, help explain a child's present level of functioning to caregivers.

The crucial role of networking and peer group involvement in intellectual development in society was emphasised. Creating awareness about disabilities is deemed essential, involving schools and collaboration with professionals like special educators and health workers. As a caregiver for the past three decades, he recognised the significance of respite care, especially in today's scenario where working parents need support. Daycare centres, residential care centres, and partial respite care homes are considered vital resources. Community integration programmes and school involvement enhance societal understanding and respect for intellectual disabilities. He recommended that this valuable information be included in the compendium to highlight the services available in Telangana.

Prachi expressed her appreciation for addressing crucial points. The challenges of acceptance are acknowledged, as observed in the work at Nayi Disha, where parents' initial reactions rarely involve immediate acceptance. The importance of shifting the conversation to focus on the child's strengths was highlighted. Krishna's example of Hassan's love for playing with a ball and his proficiency in English and reading books underscores the importance of identifying and nurturing these strengths.

The significance of peer groups came up repeatedly. Connecting with other parents on similar journeys provided invaluable support. The crucial nature of parent training programmes was highlighted, as families would play a pivotal role in a child's development at home, beyond school and therapy hours.

With this, Prachi invited Mr. Srinivasu to share NIEPID's approach to family-centric care. The inquiry involved understanding how family-centric care permeates through NIEPID and its partner organisations, like CRCs. He was also asked to share information regarding the initiatives to support caregivers in the organisation.



Highlights



Mr. Srinivasulu

Head of the Department

The National Institute for Empowerment of Persons with Intellectual Disabilities

Srinivasan represented NIEPID (The National Institute for Empowerment of Persons with Intellectual Disabilities), headquartered in Secunderabad. He advocated a lifecycle approach to intellectual disabilities that offers interdisciplinary and multidisciplinary services at all stages. The institute, operating under the Department of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment, Government of India, has a widespread presence with three regional centres in Noida, Kolkata, and Mumbai, and three Composite Regional Centres (CRCs) in Nellore, Damanagiri (Karnataka), and Rajanathigam (Chhattisgarh).

Mr. Srinivasan shared that the comprehensive services addressing intellectual disabilities included assessments, diagnosis, intervention, training, and employment services for individuals of all ages. Integral components of the offerings included IQ assessments, interventions, respite care services, and autism intervention centres. The focus extends to associated conditions and probabilities, with need-based services tailored to diverse needs.

As the Coordinator and Head of the Department for Adult Independent Living, he conducts vocational training programmes for individuals over the age of 18. The programme covers computer training, agro-based training, manufacturing setups, bookbinding, and office assistant training. The Skill Council for Persons with Disabilities has approved and endorsed these courses.

He added that support is extended to younger age groups for livelihood sustenance and self-employment endeavours, with the facilitation of loans on various scales. The commitment extends to supporting organisations through project proposals, registrations, and collaborative initiatives, including vocational expansions. Active engagement with implementing the Persons with Disabilities Act and the national vocational and skilling support action plan is emphasised.



In response to Prachi's query about relevant information regarding any government orders or schemes for the supporting families, Mr. Srinivasan shared about the specialised provisions under the National Trust. The provisions included early intervention services, encompassing a range of services such as medical support, speech therapy, physiotherapy, and occupational therapy. The Disha, early intervention support, is available for families seeking medical services at the in-panel level. Additionally, families in remote areas without access to professional support can benefit from respite care services provided by the NPC centre. These services cover a spectrum of needs, including medical support, therapeutic services, behavioural assistance, IQ assessments, and vocational training for families dealing with intellectual and developmental disabilities, including associated conditions like autism and ADHD.

A crucial aspect to highlight is the significance of obtaining a UDID (Unique Disability ID) for persons with disabilities (PwDs). Many parents are unaware of this scheme, which offers free-of-cost services, including medical support and continuous rehabilitation services tailored to the individual's condition. To all stakeholders, organisations, and parents of PWIDs, it is essential to register for UDID. NIEPID provides support through its four registration centres, ensuring individuals can access future services seamlessly at the institute and government levels, covering various benefits, including medications and OPD services, all at no cost.

Prachi thanked Mr. Srinivasan for highlighting the crucial aspects of the services available to caregivers. Firstly, the respite care service at NIEPID provides families with a supportive option during emergencies, allowing them to address urgent matters while ensuring the well-being of their loved ones. Additionally, the provision of NIRAMAYA health insurance is significant in supporting and alleviating the financial burden for families. She then invited Mr. Anil Patil, Founder & Executive Director – Carers Worldwide, to share his insights.



Highlights



Mr. Anil Patil

*Founder and Executive Director
Carers Worldwide*

Mr. Patil extended greetings from Carers Worldwide, expressing gratitude to Prachi and Neha for the invitation to participate in this insightful panel discussion. He extended congratulations for the launch of the compendium, recognised as a much-needed resource for service providers, parents, and caregivers. He hoped that it would soon be available in multiple languages for organisations nationwide.

He appreciated that Tech Mahindra Foundation maintains that 10% of their beneficiaries are persons with disabilities. He encouraged CSR initiatives to extend their support not only to individuals with disabilities but also to their caregivers, emphasising the crucial role caregivers play and the importance of their well-being.

The discussion, initiated with a quote from Rosalynn Carter highlighting four kinds of caregivers, emphasised how everyone would eventually become a caregiver or be cared for. The impact of caregiving is highlighted as non-discriminatory based on wealth, profession, or background. The work of Carers Worldwide in supporting unpaid family caregivers in India, Nepal, and Bangladesh is shared and rooted in Mr. Patil's personal experience as a caregiver.

Considering the projected increase in the need for caregivers, he drew attention to the critical need to address their concerns, with the WHO predicting a 400% rise in caregiver demand by 2030. He presented a model focused on empowering family caregivers, including elements such as emotional support groups, addressing mental health issues, providing respite care, focusing on employment and training, and establishing a platform for caregivers through associations at various levels.

In a short period, Carers Worldwide has played a significant role in policy changes, contributing to the Rights of Persons with Disabilities Act and the Mental Health Act. The organisation serves as an advisor to the governments of Karnataka and Tamil Nadu, influencing policy decisions and advocating for caregivers' rights. Mr. Patil shared some of the achievements for the families, including Karnataka providing caregivers' allowances and Tamil Nadu initiating a similar pension for high-dependency care.



In conclusion, he emphasised improving caregivers' health and well-being and engaging policymakers to bring about systemic changes in the countries where Carers Worldwide operates. Prachi expressed gratitude for sharing these insights, concluding to allow space for other panel members to contribute.

Prachi extended her appreciation to Mr. Anil for addressing a crucial point. The discussion was heading towards the financial burden faced by caregivers, and Mr. Anil's insights provided valuable input in this regard. As Krishna mentioned, family caregivers play a significant role in educating and providing medical support at home, alleviating pressure on education and medical care systems. However, this often leads to caregivers giving up their jobs, adding to the financial stress at home. While acknowledging the positive step, there is room for pension amounts to increase. Advocating for caregiver pensions is considered a valuable effort. The conversation then shifted to de-feminising caregiving, and Ms. Krishna was invited to share her three most important aspects as a caregiver.



Discussion - Round 2

Krishna spoke about the crucial nature of financial support, which was emphasised due to the high fees for long-term therapies, beyond reach for many middle-class families. The importance of knowledge and guidance became particularly important in situations where other family members' support had been lacking.

She shared how looking after a person all day puts incredible strain on the caregiver. The panellists agreed about the importance of pensions, especially in planning for the child's future and addressing concerns about their future. They committed to work towards understanding and addressing these aspects of caregiving.

The focus shifted to other essential aspects, such as legal guardianship, written documentation, and financial arrangements. The emphasis lies in ensuring provisions for the child's future, without necessarily involving substantial assets. Making these arrangements becomes paramount for full-time caregivers, whether they are mothers or siblings. Ms. Krishna mentioned how she had got support from her brother, which is unconventional. This prompted the question to Mr. Madhusudan Reddy regarding the advocacy for a more active role for fathers in caregiving, taking into account Anil's observation about the predominance of women as caregivers.

Mr. Reddy shared that the majority of caregivers are mothers. This trend is observed not only in families but also in organisations providing care for individuals with intellectual disabilities. In their organisation, too, they predominantly have women caregivers. It is essential to rethink and highlight the roles fathers can play in taking responsibility for their child's care. His organisation has been actively training fathers. They promote joint training sessions for both parents, stressing that it is not solely the mother's responsibility. Their approach involves making parents understand the value of dedicating time to enhance their child's skills. Mr. Reddy added that they are exploring avenues such as modelling, creating father support groups within parent support groups, and providing examples for fathers to witness and feel inspired to contribute.

Transitioning to the discussion on respite, Mr. Srinivasulu mentioned NIPID's respite care.

Srinivasulu shared how Respite care facilities vary across regions, and there are well-established models in Western countries, particularly Europe. Daycare centres' overnight stays and policies that allow caregivers to access respite care for a specific duration are standard. Some places even provide paid leave for caregivers to take vacations. Another practical approach is assisted living, where individuals can stay in trusted environments, and primary caregivers get the opportunity to spend quality time together. Additionally, models like nursing homes and community care centres have proven successful.

Community care centres, an innovative model, involve two adult carers contributing to the operation. It not only provides respite for primary caregivers but also acts as an entrepreneurship model for some carers who contribute to its sustainability. Collaborative efforts involving organisations like Tech Mahindra Foundation and the government can contribute to developing culturally appropriate models to address the diverse needs of caregivers. Proposing policy changes at the state and central levels can have transformative impacts on the lives of caregivers, providing the necessary support and recognition for their critical role. As we move to the Q&A session, each panelist is asked to share one word encapsulating what they believe is crucial for empowering caregivers.



Krishna Chowdary

Caregivers are incredible individuals who continuously work, provide care, and manage everything. They can be called powerful because "incredible" implies that they are not ordinary people. They possess a unique strength as they take care of a special child, and it is a divine gift that enables them to handle such responsibilities efficiently. In a nutshell, caregivers are genuinely incredible.

Madhusudhan

Creating confidence in caregivers is paramount. Thank you.

Srinivasulu

Capacity building is crucial for caregivers, enabling them to provide valuable support to those in need.

Anil Patil

Caregivers are the catalysts for the success of therapy. Their pivotal role in implementing interventions and driving positive outcomes should be acknowledged. Second, many caregivers, despite being unable to read and write, possess invaluable expertise in caring for their loved ones. Recognising and appreciating them as experts based on their lived experiences is essential.



Q&A by audience

Question to Mr. Anil Patil

Q: Mr. Patil, could you kindly share a specific case where Carers Worldwide significantly impacted caregivers' lives? Additionally, highlight the key factors that contributed to the success of that particular case.

A) Mr. Patil shared a compelling case involving a caregiver named Parvati. She had two children, and the second child's health condition went unnoticed for the initial three years. Tragically, during this period, her husband passed away in a truck accident, leaving her burdened with loans and challenges. Overwhelmed, Parvati attempted suicide three times. Carers Worldwide, through their support group, intervened. They approached Parvati, empathised with her struggles, and requested just 60 minutes to share their experiences. In that crucial hour, she pledged to the group that she would never attempt suicide again. Today, Parvati is a caregiver champion, having won the state award for the best caregiver in Karnataka. She leads a carer association, inspiring thousands with her resilience and determination. This success underscores the transformative impact of caregiver support groups. It highlights the importance of emotional connections, understanding, and shared experiences in helping caregivers navigate challenges and find renewed strength.

Post the Q/A, Mr. Chetan Kapoor expressed his heartfelt gratitude to each of the panellists and the moderator, Ms. Prachi. He shared that this has been one of the most enlightening and insightful discussions he has witnessed. Caregiving is an area that demands additional focus, and it is clear that attention needs to be shifted here. He added that he could resonate with Ms. Krishna's choice of "incredible caregivers". However, the challenge is empowering these incredible individuals even further. He took away insights from the discussion, such as ways to collectivise caregivers and strengthen them emotionally, aligning with the work on social, emotional, and ethical learning at Tech Mahindra Foundation. He once again thanked everyone for their insightful perspectives.



Vote of Thanks by

Mr. Parveen Kumar, Tech Mahindra Foundation

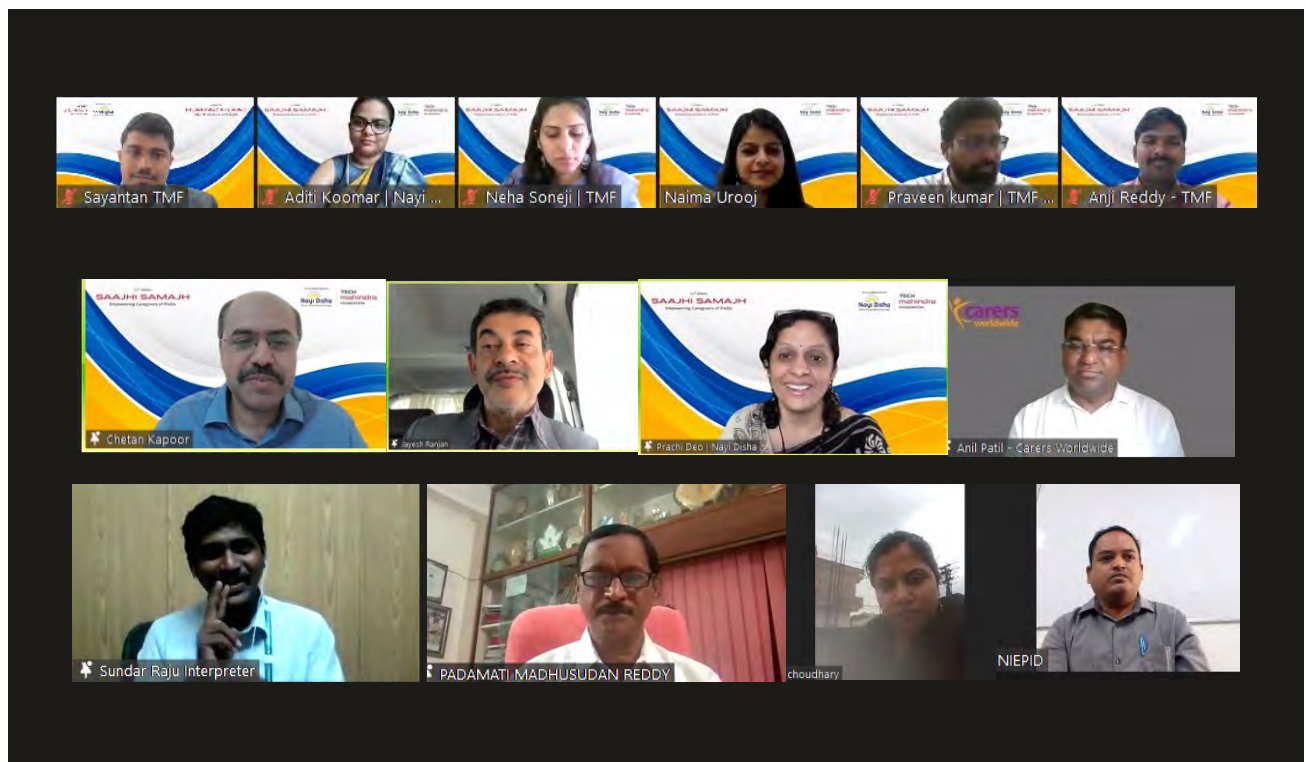
As the 11th edition of Saajhi Samajh concludes, heartfelt thanks are expressed to the distinguished speakers, panellists, and esteemed keynote speakers. The insights provided have illuminated our understanding of the challenges faced by caregivers and the pivotal role they play in ensuring the dignity and independence of persons with disabilities. Sincere appreciation was given to the panellists, Mr. Anil Patil, Mr. P. Madhusudan, Ms. Krishna Chowdary and Mr. Srinivasulu. Diverse perspectives and experiences enriched the discourse and shed light on the multiple aspects of caregiving.

A special acknowledgement was made to the moderator, Ms. Prachi Deo, for steering the panel discussion and ensuring a meaningful exchange of ideas. Special thanks were extended to the Nayi Disha team for their valuable contributions to the compendium. The Tech Mahindra Digital Studio team, led by Miss Anjali Datha and including Sukesh, Vamshi, Rohith, and Abhishek, did a commendable job designing the compendium.

Heartfelt thanks were expressed to the Tech Mahindra Foundation team, including Chetan Kapoor, Sudheer Babu, Neha Soneji, and Anji Reddy, for their continued support and commitment. Special thanks were extended to the presenters, Naima Urooj and Anji Reddy, for hosting this event, with special mention given to Mr. Sunder Raju for providing interpretation in Indian Sign Language.

Gratitude was expressed to all the attendees for their active participation, insightful questions, and unwavering commitment to building an inclusive society. The spirit of Saajhi Samajh needs to be carried forward, and the valuable insights gained during the event should be implemented into actionable initiatives. Praveen ended by emphasising that contributions can be made to creating a society where caregivers are adequately supported and people with disabilities lead lives of dignity and independence.

Glimpses of the Event



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