



Nothing about us, without us!

Stories of empowering
organisations of
people with disabilities

Funded by European Union



Contents

Acknowledgement.....	1
Introduction.....	2
Elections and equality.....	4
Beyond borders.....	6
A ramp to dignity.....	8
Certification challenges.....	10
Enabling scorecard for inclusive education.....	12
Now or never.....	15
Disability pension – right to independence.....	18
A lifeline during the lockdown.....	20
‘Never-say-die’ spirit.....	22
Securing livelihoods in the pandemic lockdown.....	24

Acknowledgments

We would like to thank all the OPD members from Chhattisgarh, Jharkhand, Madhya Pradesh, Odisha and Rajasthan who agreed to share their stories and testimonies around, accessibility, livelihoods, entitlements, participation and empowerment. Their voices bring deeper insights to understanding the challenges, concerns and triumphs of people with disabilities in rural India.

We salute them for their honesty and courage in sharing their stories. It's been a privilege to participate in their journey of accessing rights and entitlements.

A wholehearted **acknowledgment** to all the state project team members especially Asit Kumar Behera, Jijo Mathew, Lokapriya Priyadarshini Kanungo, Manjeet Kaur, Mohit Pahalwan, Gaurav Jain, Jitendra Kumar, Harshal Jariwala, Tushita Mukherjee and the state programme leads. Without their attention to detail and meticulous review, it would have been impossible to capture the notable work done by all the OPDs.

We express our special thanks to Namrata Mehta, Programme Manager, Sightsavers India for her immense contribution in conceptualising this book, leading the process of collating information and providing valuable inputs at each stage to make this book a reality.

We also acknowledge Prasannakumar PN, director - programme operations, for his support and oversight of the entire documentation process. Special thanks to Sarah Bourn for thoroughly reviewing and facilitating the finalisation of the book.

We are deeply grateful for the financial support of the EU for the whole project implementation of Building Partnerships for the Sustainable Development Goals – Empowering Organisations of People with Disabilities, and for supporting the publication of this booklet in particular.

We appreciate the invaluable support provided by the communications team at Sightsavers India for ensuring the book was written and designed by competent professionals. We acknowledge Avijit Dey, director funding and marketing for identifying an experienced writer for the stories. A big thank you to Pritika Malik, the designer for making these stories come alive visually. Rishibha Gupta, manager, brands & communications for bringing enthusiastic guidance to the final process of integrating visuals to content and Arya Vatsa, communications officer for the support she provided in the initial coordination.

Heartfelt gratitude to the writer of this book Salma Veeraraghav, for breaking the barriers of the pandemic lockdown with her efficient online documentation system, which ensured thorough details were gathered from the field for all ten stories. Each story has a clear message and captures the remarkable achievements of the OPDs with sensitivity and lucidity in expression.

Finally, we acknowledge every reader of this book because without your time and effort to read this, the world will not discover the amazing people with disabilities who are changing India with every step they take.

Sincerely,
Sightsavers India Team

Introduction

As the world endures the dark clouds of the pandemic, the outstanding work of organisations of people with disabilities (OPDs) in 15 districts of 5 Indian states is a silver lining. In this booklet, Sightsavers India captures ten empowering stories to highlight the remarkable work of OPDs in the states of Chhattisgarh, Jharkhand, Madhya Pradesh, Odisha and Rajasthan.

Each story presents the different grassroots challenges that were overcome to support people with disabilities in realising their potential in remote corners of India. When you read Husaina Bi's story, **Securing livelihoods in the pandemic lockdown**, you will discover how women with disabilities can be skilled professionals in delivering high-quality, affordable food to underprivileged people, even during a national emergency. The women featured in the story even rise above the fear of contracting the deadly disease to do their job of running government canteens efficiently.

These ten stories cover crucial issues faced by people with disabilities. Beginning with certification challenges, these stories cover accessibility woes and livelihood struggles.

Stories like **Certification challenges, A ramp to dignity** and **Never-say-die spirit** demonstrate how people with disabilities are capable of making an extraordinary contribution to society as a whole.

We hope these stories will also inspire people with disabilities to realise that an accessible world is their right. An inclusive world is a better world for every individual, with or without disabilities.

There are remarkable stories, like **Enabling scorecard for inclusive education** and **Elections and equality**, that highlight how people with disabilities can lead the way in

making the world's largest democracy an inclusive space for people with visual and mobility impairment.

All these are not just stories of amazing individuals; each one of them has been supported by the power of OPDs. These democratic and voluntary institutions are created of, by and for people with disabilities and demonstrate the power of being organised.

OPD members have been trained on their rights and entitlements under the European Union funded Sightsavers project, Building Partnerships for Sustainable Development Goals – Empowering Organisations of People with Disabilities.

These training workshops made OPDs aware of the Rights of Persons with Disabilities (RPWD) Act 2016, the United Nations Convention on Rights of People with Disabilities (UNCRPD) and the Sustainable Development Goals (SDGs). Special emphasis was also laid on gender and disability assessment. These assessments facilitated clear roadmaps for institutions and administration to support people with disabilities.

OPD members are also trained in the advocacy and communication skills needed to liaise effectively with the government. The stories in this booklet show the tremendous capacity of OPDs, once equipped with knowledge of their rights, to tenaciously persuade and collaborate with the government for empowerment.

Since 2018, Sightsavers' project has been working towards ensuring that women and men with disabilities engage, shape and monitor the implementation of the Sustainable Development Goals in India. While working with 15 OPDs, the project is strengthening

policy dialogue and partnership between Indian OPDs and the European Disability Forum.

The story titled **Beyond borders** captures the marvellous impact of exposure visits to Brussels during European Disability and Development Week in December 2018. This visit was an eye-opener for OPD members in India as it gave them a fascinating window to the world and allowed them to explore ideas that could be adapted for local needs. While OPD members were greatly enriched by their European visit, they also inspired representatives from other countries with their grassroots work and achievements, despite not having the resources that are provided in European countries.

This targeted capacity-building and advocacy project in 15 districts and 5 states of India has facilitated certification of disability for 11,152 people, provided disability pensions to 8,144 people and supported the issuing of voter IDs to 8,450 people with disabilities.

The ten stories shared here stand testimony to the fact that when necessary support is provided through capacity-building initiatives, people with disabilities can organise themselves to advocate for their rights and ensure there is 'Nothing about us, without us!'

There is an urgent need to scale up the work of OPDs to benefit India's huge population of people with disabilities. As per the 2011 census in India, there are about 26.8 million disabled people (56% male and 44% female). Of these, about 69% are people living in rural areas and 31% are living in urban areas.

The OPDs are successful grassroots initiatives that advocate for people with disabilities rights and entitlements. Empowering OPDs will fast-track India's march towards the Sustainable Development Goals that are focused on quality education (Goal 4), decent work and economic growth (Goal 8), reduced inequalities (Goal 10), sustainable cities and communities (Goal 11) and partnerships (Goal 17).

Elections and equality

Elections and equality

What stake do disabled people have in the world's largest democracy? The first step in answering this question is to make the democratic process physically accessible. To do this, the Election Commission of India chose the motto, 'No voter to be left behind' and emphasised that the voting process must be disability-inclusive.

But a motto alone does not make a difference – it is the tireless efforts of organisations and individuals that turn an intention into reality. In 2019, OPDs who were supported and trained by Sightsavers played a crucial role in re-orienting the election process to become friendly to disabled people during the legislative assembly elections in the state of Jharkhand.

A classic example of this effort is evident in the case of 25-year-old Neha Khaton. Born with a physical disability, Neha had never had the use of her legs. This young girl in the state's Hazaribag district fought social stigma and showed grit in every stage of her life.

As a graduate, Neha had to struggle to go to a college that was six to seven kilometres from her home. Hiring a rickshaw to commute was very expensive and Neha recounts how her brother supported her by dropping her at college. Later, she got a tricycle that she could pedal by hand, but travelling the long distance would make her exhausted and affected her concentration.

A supportive family of eight, as well as help from her teachers, ensured that Neha graduated. She met representatives from Sightsavers during a door-to-door visit in 2017.

Since then, Neha has been a part of Divya Jyoti Divyang Samiti (DJDS), an organisation of people with disabilities in Hazaribag, which has a membership of more than 300 people.

Though she had difficulty walking, Neha and other DJDS members became crusaders in carrying democracy to people with disabilities. Neha immersed herself in a state-wide awareness campaign to make the election process more disability-inclusive.

There are more than 35,000 people with disabilities in Hazaribag, and though 11,246 of them are entitled to vote in an election, very few actually do.

Difficulties in the registering process, inaccessible offices and materials, inaccurate or incomplete information and difficulties in voting on their own due to a lack of support from staff are some of the key reasons why the people with disabilities do not exercise their right to vote.

Social attitudes are regressive and, in several cases, family members do not help or assist people with disabilities to cast their ballot.

Neha and DJDS began to work closely with the State Election Department to help change these realities, not just in Hazaribag, but in the whole of Jharkhand. Their mission started after an invitation was extended to Sightsavers - supported OPDs by the chief electoral officer in Jharkhand. The election officials relied on the understanding and in-depth networks of Sightsavers to make the election disability-inclusive across Jharkhand.

Supported by Sightsavers, leaders from the OPDs (like Neha) conducted intensive training sessions for 24 master trainer nodal officers. These 24 officials were appointed to each of the state's 24 districts to address the issues facing people with disabilities during the elections.

The training given by OPD leaders was essential to sensitise officials to the needs of people with disabilities.

Several other activists, teachers and officials were also present at the training sessions. The OPDs even provided assistance to the Election Department by creating and printing documents in braille to ensure blind people could vote independently and privately.

Sightsavers helped make ID cards, voter slips, voter guides and even trial ballot sheets in braille. More than 18,000 braille voter slips were printed and OPD leaders like Neha ensured that they were distributed around the state to people who required them.

It was an enormous feat to train staff, reorient the system, create the necessary infrastructure and ensure that everything was conveyed to voters with disabilities. Voter lists of people with disabilities were finalised for each of the districts and there was a media campaign to increase awareness.

All this was done within a very short period of time ahead of the legislative assembly elections in 2019. The result of this extraordinary effort was visible in the numbers. 283,038 people with disabilities cast their vote across the state; this was more than double the number of votes recorded in the parliamentary elections held just six months earlier.

Neha personally mobilised more than 500 voters with disabilities and was actively involved on polling day in monitoring and supporting voters with disabilities who required any kind of assistance at polling booths. She also coordinated efforts in other districts and spearheaded new initiatives.

As a pilot initiative, postal ballots were sent to people with disabilities in seven assembly constituencies. Forms were sent to every voter marked as a person with a disability, with the option to vote by mail or come to the polling booth. They were given training on how to vote and oriented towards the process.

In total, 1,394 people were given the postal ballot and 1,338 used it – an extremely encouraging turnout. In fact, this is proof that the best way forward is to take democracy to

disabled people instead of forcing them to come to the polling booth.

Several media reports recorded the stellar support given to disabled people in the elections.

Bipad Barn Gosh, who is blind and hails from Jamtara in Jharkhand, says, ***“Last time I returned without voting because of the long line and no arrangement for blind [people], but this time I cast my ballot with pride and dignity.”***

Many such voices endorsed the efforts taken by the OPDs and the Election Commission. In many ways, this was not only about ensuring votes for people with disabilities, but also changing attitudes and stereotypes. Most importantly, it ensures that people with disabilities have a stake in the democratic process and in building an inclusive society.

After all, if democracy is of, by and for the people then it has to become of, by and for **all** the people.



Beyond borders



It was a defining moment for 42-year-old Ajit Kumar when he was chosen by Sightsavers to be part of a delegation from India to attend the events organised in Brussels during the European Disability and Development Week in December 2018. During the visit, he realised there was a world of opportunity that existed beyond national borders. He also realised that the world recognised the achievements of people like him in India, who were working with scarce resources.

A spirited campaigner for the rights of people with disabilities, Ajit was born with visual impairment in Ranchi, the capital of Jharkhand State. His condition worsened progressively and despite medical attention, he became completely blind by the age of 21.

Fortunately for Ajit, his parents and siblings had financial resources and supported him through school and college. He completed a bachelor's degree in education and went on to complete a master's degree in social work. Social service was an instinct for Ajit, so he immersed himself in it even during his college days and took to activism full-time after completing college.

He says, "I was into grievance redressal and individual advocacy till 2015 when I came across Sightsavers and its programme in the state. I realised how policy advocacy at state level was the need of the hour, says Ajit."

He joined the Divyang Adhikar Manch (DAM), an OPD supported by Sightsavers in Ranchi with more than 500 members, and was trained by Sightsavers in legislation, advocacy and rights for people with disabilities.

As an individual, Ajit recounted that he had to struggle to get his own train travel pass for 18 months and the authorities would not give him much of a hearing. But with proper training, backed by an organisation, and a national network of contacts through Sightsavers, he could effectively ensure that his voice was heard.

Ajit worked tirelessly to educate people with disabilities about their rights and ensured that many could get certificates and access to organisations with resources. This was essential as in a largely tribal and hilly state like Jharkhand, lack of awareness is a challenge.

Some of the key initiatives taken by Ajit include organising events across the state on days marked for people with disabilities, like the International Day of People with Disabilities, White Cane Day and World Sight Day. He actively used social media to spread messages on issues faced by people with disabilities and wrote several blog posts, which helped him connect with a national and international network of activists.

It was because of his ability to articulate and advocate for people with disabilities that Ajit was chosen by Sightsavers to be part of the delegation from India to go to Brussels for European Disability and Development Week. This visit was part of the European Union project, Building Partnerships for Sustainable Development Goals – Empowering Organizations of People with Disabilities.

To be part of a global event like this was a dream come true for the young man from Ranchi.

Ajit and the team were exposed to how several European countries deal with issues faced by people with disabilities and the policies they have created. This was an eye-opener for them and being part of the annual conference hosted by the European Commission, in partnership with the European Disability Forum, gave them a fascinating insight into ideas that could be adapted for India.

Ajit also got to meet and interact with organisations like the European Network on Independent Living and the European Union of the Deaf. He presented issues faced by his team in India and heard about interventions – like awards for the most accessible city and discussions at EU level – which emphasise the participation of OPDs.

The physical meetings in Brussels led to a strengthening of Ajit's global network and now he regularly interacts with people from around the world through online platforms to exchange ideas on various issues.

On 13 April 2021, Ajit participated in a virtual learning event facilitated by the European Disability Forum. It focused on inclusive policies and equal rights of people with

disabilities. Ajit presented the work done by the team at DAM in Jharkhand, under the project with Sightsavers. His presentation showcased the remarkable work on the disability inclusive scorecard in the state.

Learning events like these help hone the skills of activists like Ajit and are a major confidence booster. They are also important platforms to exchange ideas and understand solutions to issues faced by people with disabilities. Ajit has helped establish the DAM as a resource and information centre. The capacity-building of advocacy activists has created a pressure group to monitor the implementation of the Sustainable Development Goals, government schemes and entitlements under the Rights for Persons with Disabilities Act 2016.

During the lockdown, Sightsavers organised several webinars and the OPD did stellar work in ensuring pensions were paid to people with disabilities, distributing relief and personal hygiene kits. They also ensured that migrant people with disabilities reached their hometowns safely.

Even government stakeholders now reach out to Ajit and the Divyang Adhikar Manch to get their input on policy and implementation issues. This has helped in serious policy changes like relaxation in the age limit for people with disabilities in taking examinations for government jobs, the establishment of a disability trust fund by the state government and even an increase in the pensions that are disbursed.

“We treat the problems of every person with disability as our own and ensure that we give logical solutions and fruitful results” says Ajit. While he and his team were greatly enriched by their European visit, they also inspired representatives from other countries with their grassroots work and achievements despite not having the resources that are provided in European countries.

It was truly a breaking of national barriers for people with disabilities around the world to meet at one event and Ajit has ensured that he has brought back a world of knowledge to Jharkhand!

A ramp to dignity

The Rayagada railway station in India's eastern state of Odisha was once almost impossible to navigate for people with physical disabilities and challenges. A steep flight of stairs to the overbridge connecting different platforms was the only way to reach a train arriving or departing the station.

Even people without disabilities found the climb exhausting and many people with disabilities had to endure the indignity and ordeal of crawling up the filthy stairs. Ignorant officials did not find it necessary to build a ramp.

It was not just people with disabilities who suffered. Older people, people who were unwell and even pregnant women found catching a train at the station difficult and distressing.

In fact, most of them did not even entertain the idea of taking a train at Rayagada. But 39-year-old Rakesh Chandra Himirika, who is blind, took action to change this and became a symbol of light and hope to people with disabilities in Rayagada.

Shy but courageous, Rakesh, who was born without sight, was a fighter since his childhood. Dedicated and hard-working, he met all challenges head-on and passed his 12th standard. He runs a small grocery shop and lives independently with his caring and supportive wife, Rashmi.

Rakesh came in contact with Sightsavers in 2007 through partner organisation, Adivasi Krushi Swasthya Shikya Unnayan Samiti (AKSSUS) and was inspired by the late Kishor Chandra Patra, a staff member at the project. He mastered braille as part of the Sightsavers programme and it bolstered his confidence.

The innate leadership skills Rakesh displayed were honed in several Sightsavers training workshops organised under the European Union funded project, Building Partnerships for Sustainable Development Goals - Empowering Organisations of People with Disabilities.



The workshops are aimed at creating awareness about the The Rights of Persons with Disabilities Act, 2016 the United Nations Convention on Rights of People with Disabilities (UNCPRD) and the Sustainable Development Goals (SDGs). He was also trained in the advocacy and communication skills needed to liaise effectively with the government.

Gaining knowledge of disability rights and entitlements made Rakesh determined to work for people with disabilities in the area. His enthusiasm helped to establish the Rayagada Bhinnakhyam Mahasangha (RBMS), an OPD in the district.

Records show that there are more than 28,334 people with disabilities in the ten blocks of the district, which has many remote hilly areas.

Most government buildings, like the railway station, are inaccessible for people with physical challenges. And social insensitivity to people with different requirements is conspicuous.

Having become the president of an OPD, Rakesh decided to challenge the realities and ensure that he and the 372 members of his organisation would make a tangible difference. He decided to start with making the railway station more accessible and hoped that it would become the symbol for other government buildings to follow.

A simple ramp was all that was needed. But getting it constructed and making sure the authorities understood the need for it was not that simple.

Rakesh and the eight-member executive board of the RBMS first discussed the matter with the district social security officer and the sub-divisional social security officer. After these discussions, it was decided that the right authority to contact was the divisional railway manager (DRM).

They approached the local station manager and, through him, obtained contact details for the DRM. While the DRM met the entire team, little action was taken after the initial meeting. Rakesh, along with the team from RBMS, built support for a ramp at the station through news reports in the local press and signature campaigns. They reached out to senior citizens' associations, as older people were also affected by the absence of a ramp and ensured that many of these associations signed the petition.

Rakesh ensured sustained engagement with the officials by supporting his team to draft several petitions to the authorities. He created awareness that it was the responsibility of the government to make public places easily accessible to people with disabilities.

The ramp was not a favour, but a right for people with disabilities, guaranteed under the RPWD Act, 2016. Rakesh's awareness of the law, much of which came from advice and orientation in Sightsavers' programme,

helped in convincing officials to understand their responsibility and realise the pain and suffering people were experiencing.

Finally, a ramp was sanctioned – but the construction process was slow. So the OPD team met the DRM again in 2018 to speed up the process. After this meeting, the pace of the work improved and the ramp was eventually completed in 2019.

Sameer, a person with disability in Rayagada, says, ***“Earlier, I completely avoided using trains as it was impossible to board one for a person like me. But thanks to RBMS we finally have a ramp and I can travel by train. We are very grateful to Indian Railways for building the ramp.”***

RBMS and Rakesh did not stop with the building of a ramp and ensured that free wheelchairs were available for passengers with mobility impairments, pregnant women and senior citizens at the station. In many ways, the station is a symbolic start for the journey to make every public office more accessible.

Rakesh and the RBMS team, which included the secretary of RBMS, Amarendra Nath, and advisors Uma Shankar Padhi and the late Kishor Chandra Patra, had reached out to several government offices to make them more accessible.

In the remote and rural Rayagada district, this effort is also about re-writing social apathy and sensibilities to people with physical disabilities. It is not just a question of accessibility, but also of dignity and self-respect to citizens with different requirements.

Certification challenges

Tragedy struck Amarendra Nath (known as Amar) when he was just ten days old. His caring parents had put their baby boy to sleep on a cot when a fire accidentally started in the middle of the night. Amar was trapped. By the time the lantern blaze was put out and the baby was rushed to hospital, his right hand was severely injured, causing a permanent disability.

The devastated family gave their baby endless love and affection. His three brothers supported Amar every step of the way. This ensured that he went to school and passed his 12th standard. He was motivated to help other people with disabilities who did not have the family and financial support system that he had.

This desire brought Amar into contact with Sightsavers in 2013 and he became part of the Rayagada Bhinnakhyama Mahasanga (RBMS), an OPD with more than 300 members.

At that time, Amar recalls, ***“People asked how a person with disability like me could help other people? They could only see my disability and not my determination to help society.”***

Sightsavers gave Amar the backing he needed and educated him on the legal provisions and rights guaranteed to people with disabilities.

He was also made aware of several government schemes for people with disabilities.

It is during this process that Amar realised that the most important step for people with disabilities is gaining access entitlements such as a medical certification. Without a certificate, millions of people with disabilities across India cannot access their rights and entitlements such as a disability pension, travel concessions, assistive aids and government reservations in higher education and jobs.

Amar and the RBMS decided it was time to create a strategic plan to ensure that people with disabilities in Rayagada were made aware and could get access to certification.

People like Amar with physical disabilities needed certification from an orthopaedic specialist appointed by the Government Medical Board. However, Rayagada district did not have an orthopaedic specialist and the chief district medical officer would arrange a visit from a neighbouring district once a month, for just three hours. This meant that thousands of people in need of a certificate would have to queue for hours and several cases were turned down for want of time.

Lalita, a young girl with a physical disability, recounts, “We had to stand in line for hours without food or water and our own families got fed up and blamed us for having to go through the process.”

In fact, on one such occasion, an angry crowd of people who had waited for many hours to get a disability certificate were frustrated and turned violent. They damaged some portions of the district hospital, but Amar and the RBMS members stepped in and controlled the situation tactfully.

This incident only bolstered Amar’s determination to set things right. Sightsavers had empowered the RBMS team with awareness of the procedures and strategic planning techniques to develop a campaign for achieving their goals. Amar and the RBMS team, which included the president Rakesh Himirika and other advisors, put a step-by-step plan in place.

Each member of the team was given a specific responsibility and the first step forward was to hold discussions with district level officials, including the district social security officer.

Amar organised this discussion and then reached out to state level officials to raise issues that needed to be addressed.

While getting an orthopaedic specialist was the main objective, there were other issues that needed to be addressed as well. For instance, to apply for this certificate, applicants had to go through an online process. Many people found this difficult as they were not comfortable using technology.

Jana Seva Kendras, centres that service citizens are set up to facilitate this process often charge a lot of money – in most cases much more than the fixed price of INR 70 for an application. The RBMS team discussed this with officials and then launched a campaign asking people to go directly to the block offices where they ensured that government officers would fill in the applications free of charge.

However, the demand for an orthopaedic specialist remained a challenge. The team decided to take the matter up with the top officials in the state and sought a meeting with the commissioner and secretary of the Health and Family Welfare Department.

Despite having gone through severe hardship to travel all the way to the state capital of Bhubaneswar, resistant government officials did not allow the team to meet the officer. Finally, after several attempts the team's sustained efforts paid off.

A concerned official helped the team to get an appointment with the director of the National Rural Health Mission. She promised them that a specialist would be appointed for the district. The jubilant team was confident they had achieved their goal, but six months passed and no appointment was made.

The team did not give up and took the matter up with the mission director when she visited the district. Finally, the orthopaedic specialist was appointed.

Sightsavers' training programmes had taught Amar and the rest of the team how to create documentation records, approach officials and

build advocacy for a cause. These trainings were organised under the European Union funded project, Building Partnerships for Sustainable Development Goals - Empowering Organisations of People with Disabilities.

All this helped build confidence and awareness among team members to achieve their goals. Today, more than 200 disability certificates are being issued a month by the specialist, compared to only 50 that were being issued earlier.

Madhuri, a young girl with a physical disability, says, ***"I could not get a certificate in 2019 as there was no specialist here and because of that I could not get college admissions. But in 2020, after two specialists were appointed, I got a certificate and admissions into the women's college."***

With their tireless efforts and support of Sightsavers, Amar and the RBMS team are ensuring thousands of people with disabilities get access to certificates – the first key that opens the gates to a million opportunities!



Enabling scorecard for inclusive education

Born with sickle cell anaemia and into a poor family in the Raipur district of the central Indian state of Chhattisgarh, Nomesh's condition was left undiagnosed for many years. He would constantly fall sick as a child and had extremely poor immunity. He was seven years old when he was diagnosed with a genetic disorder.

Nomesh's mother would often donate blood for his transfusion to keep her son growing and alive, but he had multiple disabilities, including visual impairment, and would often be physically drained. When Nomesh was just 14 years old, his mother passed away and his father remarried.

Despite his personal and physical difficulties, Nomesh struggled through till 9th standard, but after that, he left his father and began living with his grandmother. He would sell vegetables for a living, but as he grew older his body could not take the stress of very hard labour.

Fortunately, a free Sightsavers training programme that providing livelihood skills for people with disabilities helped Nomesh become an electrician. It was a window to a whole new world for him. Apart from just the technical training, the programme got him in touch with several other people with disabilities and he got involved with Divyang Kalyan Sangh (DKS), an OPD in Raipur supported by Sightsavers.

His eagerness to serve the people and his sharpness in understanding issues ensured that he soon became president of DKS. This is when Nomesh began to see his full potential. From struggling to earn his daily bread, he realised he could now be the torchbearer for change all over.

One of the key questions that thousands of activists, like Nomesh, seek an answer for is whether it is possible to objectively assess the programmes, policy and interventions made

to support people with disabilities. Without objective and accurate assessment, most initiatives will not have the desired impact and will lack focus on issues of importance.

The disability inclusive scorecard (DISC) aims to give an objective assessment to ensure a better understanding of problems and achieve targeted interventions. The scorecard is a participatory, community-based monitoring approach that helps people assess, monitor, and evaluate services.

It empowers people with disabilities and increases the accountability of decisions being made for them. Led by OPDs as equal stakeholders in the implementation of the Sustainable Development Goals, the aim is to strengthen collaborative engagement with local and district administrations.

Sightsavers, as part of the project supported by the European Union, had organised capacity-building programmes for 15 OPDs, including DKS. Awareness of the Sustainable Development Goals, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the Indian Rights of Persons with Disabilities Act 2016 was a key element of these programmes.



After these sessions, almost all OPDs identified inclusive education as a crucial area in need of intervention, but a concrete action plan was not possible without a disability inclusive scorecard. In September 2019, 30 participants, including Nomesh, attended a training session on the scorecard. Nomesh would take all this knowledge back to Raipur.

Arriving at a DISC is a multi-layered process that starts with people with disabilities presenting evidence around the level of provision of services and linking this with the Sustainable Development Goal framework, United Nations Convention on the Rights of Persons with Disabilities and The Rights of Persons with Disabilities Act, 2016.

The disability inclusive scorecard can be specifically tailored for various sectors. In November 2019, a DISC process was conducted to understand issues of school education in Raipur, Chhattisgarh as part of the project called Building partnerships for Sustainable Development Goals: Empowering Organisations of People with Disabilities. The DKS team implemented this DISC for inclusive education and it led to remarkable results.

To start with, Nomesh and his team identified early childhood care centres as well as primary and middle schools and assessed the status of services available to children with disabilities, including parameters such as accessibility, infrastructure, teaching aids and attitudes of staff and fellow students.

Preliminary meetings were held with school administration and education officials at block and district level, OPDs, parents and children. They were all introduced to the DISC process. The OPD members in the facilitation team were then trained on the process, their roles and the rights of people with disabilities.

The three-day programme included OPD members, children with disabilities and their parents, school teachers, principals, Anganwadi (childcare centre) workers and district education officials. The participants were divided into different focus groups, including a separate focus group with women.

First, common challenges were identified and converted into indicators. This was followed by a voting process. Then an interface meeting with OPD members and district government officials was held where final scores were shared to highlight inclusion challenges in mainstream education.

Finally, an action plan was developed on the findings of the scorecard and the interface meetings.

Since the DISC process was new it required several meetings and orientation sessions to train members properly. Nomesh's contribution in this regard was stellar and he further convinced community members and government officials to be part of this exercise. This was a huge challenge as it needed a total change in mindset towards understanding the issues faced by people with disabilities.

All the pain and efforts that Nomesh and his team took reaped rich rewards. After the DISC process, OPD members and parents were exposed to the entire education system and its shortcomings. They could advocate for specific solutions based on the issues that emerged with department officials and demand rights under the Right to Education act.

Accessible environments at school premises emerged as the key priority and the OPD demanded that Panchayati Raj Institution members construct ramps, toilets and other accessible infrastructure.

During the DISC process, some of the state level officials from the education department took part and they also realised the problems faced by children with special needs and their parents. As per the government record, from April to December 2019, ramps were introduced in 44,353 primary and higher secondary schools and accessible toilets were constructed in 32,472 primary and higher secondary schools.

A delegation of seven OPD members, including a few parents, participated in a meeting called by the education department – all this was a result of the DISC process. Some of the crucial decisions taken in these meetings included the following:



- Block resource persons will support the OPD members to enrol children with disabilities in schools and Aanganwadi centres
- Awareness and training of parents of children with visual and hearing impairment will be conducted
- These decisions will be included in the yearly plan of the education department
- It was also decided that the OPD members would be invited for their feedback in all meetings of the education department in the district

The DISC initiative has enabled Nomesh and his team to complete an accessibility audit in four schools in the district. Parents were encouraged to bring back children with disabilities from residential special schools to mainstream schools. Aanganwadi workers were sensitised to ensure children with disabilities were enrolled.

The DISC process also helped children to demand an accessible environment not only in schools but also in public offices. The School Development Management Committees discussed the creation of facilities for children with disabilities.

In schools where toilet construction was going on, it was ensured that the facility was made accessible for a wheelchair user. To aid the

learning process, the education department's digital library made accessible learning books available that could be easily downloaded on smart phone devices.

OPD members facilitated some families in getting disability certificates – these are necessary for accessing assistive aids under government schemes. Assistive devices were provided for children with visual impairment. Cycles were also arranged for some girls.

Above all, the attitudes of several parents who perceived their children's disability as a lifelong burden have shifted. They now believe children with disabilities can be independent and self-resilient with proper training and motivation. OPDs are now considered part of essential human resources in the education department, which is a good beginning in their journey towards cooperation.

These are extraordinary steps forward in creating a society that is more accessible for people with disabilities. Trained by Sightsavers, Nomesh and his team are torchbearers in this process of change and in turning the DISC process into a grassroots reality!



'Now or never' is Santosh Katara's slogan that has motivated people with disabilities in the small town of Dungarpur in Rajasthan, and supported them to overcome their fears and demand their right to a dignified livelihood.

Affected by polio at the tender age of one, Santosh has lived his life in poverty with physical impairment. His work as a tailor was the only source of income for his family (which includes his father, who has cancer, his mother and two unemployed younger siblings). He worked hard to look after his family but was struggling to pay off the debts incurred for his father's treatment.

It was in this situation, in 2018, that Santosh's friend Dikshanth, who also suffers from an orthopaedic disability, introduced him to the Viklang Adhikar Sangathan, an OPD supported by Sightsavers.

The two friends embarked on a journey that was to change the lives of people with disabilities living in this area. The OPD trained Santosh and made him aware of his rights and entitlements under The Rights of Persons with Disabilities Act, 2016. It helped him get a disability certification from a medical professional, based on which he was able to apply for a disability pension. The steady income from the pension helped stabilise his financial crisis.

The OPD also nurtured his natural talent in public speaking by enrolling him in advocacy and communication training sessions. These were organised under the European Union funded project Building Partnerships for Sustainable Development Goals - Empowering Organisations of People with Disabilities.

Attending various workshops and meeting a wide network of people through the OPDs work with the government enhanced his tailoring work as well.

Soon, he acted as a resource person for the tailoring workshops under the livelihood component of the social inclusion programme, to share his craft with other people with disabilities. Today, with the tailoring and social security pension, he earns around INR 10,000 (approximately 97 GBP) a month and has ensured his brothers finished their education. They are both employed, bringing prosperity to the family.

This personal transformation became Santosh's inspiration to find ways to secure livelihoods for people with disabilities in his area. He immersed himself in the livelihood training organised with the support of the OPD and now conducts regular training in making artificial jewellery, herbal gual (coloured powders used in Holi festival of India), pooja thali (prayer plates where all prayer materials are accumulated and decorated), spices, paper plates, tailoring work and more.

Initially, the workshops used to be held at the premises of an old partner organisation, Astha Sansthan, but as the work expanded the need for a dedicated training hall emerged. Santosh and his team struggled organising meetings in different locations. Often, the rent for a new venue was unaffordable and scheduled dates were cancelled because the owner would give the hall to weddings for a higher rent. Most importantly, these places were not accessible for people with disabilities.

Santosh and his team needed a resource centre dedicated to the needs of people with disabilities. They realised that a devoted, accessible space would not only provide the much-needed livelihood training but could also become a space for many people with disabilities to bond and give emotional support to each other when they faced domestic or social abuse.

As one female member put it, “The regular meetings in one venue used to be my second home as I had so many friends with whom I could share my daily life problems. Now that meetings are organised in different locations each time, I am unable to attend half of them.”

The irregularities in the follow-up meetings also affected the morale of several people and they became uninterested in continuing to attend them.

Santosh, with his powerful public speaking abilities and training in advocacy by Sightsavers, decided to lead the campaign for a dedicated space for people with disabilities. For support, he reached out to his friend Dikshanth in the state OPD, who was working closely with the government.

With Dikshanth’s help, Santosh got to meet the government officials at a Sightsavers livelihoods training session at a rented hall in 2018. The closing ceremony of the training was in the presence of the CEO of the Zila Parishad, Dungarpur and officials from the Department of Social Justice and Empowerment.

During the ceremony, Santosh made a powerful speech and presented the challenges of conducting training in a rented space to the government officials. He made an ardent request for a resource centre. The CEO acknowledged it with a smile and was impressed by the speech but did not make a commitment.

While the team was disappointed, Santosh proposed that they meet the chairman of the Municipal Council of Dungarpur to further their demand. Most of the members were intimidated by the idea of meeting a senior political leader, but Santosh inspired them to fight for their rights and needs.

As the leader of the district OPD, Santosh took the initiative to convince the members to make a representation and gave the slogan, ‘Aaj Nahi to Kabhi Nahi (Now or never)’. The slogan was to inspire the members to fight their fears and have the courage to get past their disadvantaged backgrounds. Sightsavers supported their decision by providing financial aid for travel and meeting the government officials to make the representation.



The determined team was able to secure a meeting with the chairman of the Municipal Council. They made a presentation of all the training workshops, inclusive elections and disability pension work they had been doing under the OPD. The chairman was impressed to see the high-quality work they were producing and allotted a dedicated space to the OPD within 15 minutes of the meeting. The team was elated with the success.

However, as they moved into the new resource centre, they discovered that it was inaccessible and that many people, including people with orthopaedic disabilities, had to crawl to enter and exit.

Sightsavers' training on accessibility had made the community aware of their rights so they decided to make another representation to make the centre accessible under the Accessible India campaign. While discussing the accessibility issue, Santosh took the opportunity to highlight the need for equipment to facilitate production.

The chairman granted their requests and provided the machinery and furniture worth INR 650,000 (approximately 6300 GBP) for the resource centre to make it an accessible space for people with disabilities. The team enthusiastically began producing high-quality products for sale.

But now they were faced with the challenge of inaccessible markets. This seemed like a deadlock. The team was not hopeful of any further support, but Sightsavers' training to stay focused on the problem helped Santosh to motivate his team for another meeting with the chairman.

They met him with the samples of their work and to their surprise, the chairman once again gave them a wholehearted response. He allotted a newly made cabin at a prime location in the heart of the city in the name of Viklang Adhikar Sangathan, Dungarpur.

In March 2019, the OPD members inaugurated the cabin and started selling their products. There are around 40-50 people with disabilities coming to the resource centre to earn their livelihood. Around 50-60 people with disabilities come regularly to the district level OPD meetings that help address the problems faced in creating sustainable livelihood opportunities.

Every month around 10-20 people also come to take support for accessing government benefits. Around 100 people have benefitted with the livelihood activities of this centre. Santosh clearly has proved the power of 'Now or never' and has led the way for all other members to shed their fears and demand their rights.

Disability pension – right to independence



It was a horrendous case of medical negligence that left Jamuna Patel with a mobility impairment at the tender age of five. A local doctor administered the wrong injection on him and this one mistake led to a lifetime with physical impairment for Jamuna.

In the rural confines of Bhatadon village, in Jabalpur district in the central Indian state of Madhya Pradesh, the case went unnoticed and Jamuna's family had to endure the fallout. They depended on agriculture for a livelihood and Jamuna has four siblings.

His physical impairment did not deter him from attending school and passing the 10th standard exams. Fortunately, the family's five acres of land ensured a secure source of income and Jamuna stayed with his parents (who are dependent on him).

Having got his basic education, Jamuna was always keen to explore social issues and it was in 2017 that he came in contact with Sightsavers' social inclusion programme.

Following this, he joined the Divyang Kalyan Sangh (DKS), an OPD in Jabalpur district. DKS works with several smaller units at the village level, like the one in Jamuna's village.

While there are 2,675 members in DKS, Jamuna's commitment and abilities ensured that he was chosen to be the district level president who coordinates and works with village level units. Sightsavers had trained him on advocacy and educated him on the rights and legal provisions for people with disabilities. This training was essential to ensure that Jamuna could carry out a leadership role.

One of the key challenges in remote rural areas is that people with disabilities are not even aware of their rights and legal provisions. Even those who were aware do not have the necessary documentation and certification to claim their entitlements, like the disability pension offered by the state and central governments.

Madhya Pradesh offers INR 600 (approximately 6 GBP) a month to people with disabilities below the poverty line through the social security for the disability pension scheme. For those who are not covered by this scheme, there is also the Indira Gandhi National Nishakta Pension Yojna which ensures another INR 600.

Thousands of people were not able to access these funds. Jamuna decided to put all his training into practice and created a step-by-step plan to spread awareness, ensure documentation and get the pension scheme for those in need.

He and the district level team made door-to-door visits and confirmations through phone calls to identify people eligible for the scheme. They used village level OPDs to organise Samasya Samadhan Shivir a problem-solving camp, in several villages where people with disabilities came with their documents and the district level staff then submitted these documents to the relevant officials.

The key to the success of this exercise was galvanising the power of village-level units. Jamuna, hailing from a village himself, was aware of the grassroots realities. He knew setting up bank accounts and the documentation process was a huge challenge.

Several meetings with district level office bearers were organised to put a detailed plan in place. The training to plan and run a campaign of this nature is a crucial part of the workshops conducted by Sightsavers under the European Union funded project.

A series of meetings were conducted by Jamuna with various stakeholders. Two were held with the social justice department, one with the district disability rehabilitation centre, two with banks and three with Janpad Panchayats. In these meetings, he was accompanied by his OPD core team members and they ensured that the collected documents were submitted to the relevant officials at the Lok Sewa Kendra.

An essential aspect was the organised manner in which the entire process was executed and help was provided in cases where people needed certificates. Each government department needed two or three rounds of meetings to set things in motion and the team was both dexterous and patient during this time.

Jamuna alone submitted 230 forms for pensions from people with disabilities and ensured that every one of those applicants started receiving a pension. Together, with all other OPD members, more than 470 people with disabilities eligible for the pension have been brought under the scheme.

This was a life saver during the lockdown. Even during the lockdown period, Jamuna continued his work and ensured that 28 people with disabilities who were in need of money started receiving their pensions. The entire process was efficient and transparent and has bolstered the confidence of hundreds of people in the system.

Raju, one beneficiary of the scheme, says, "I was trying for the past year roaming from office to office to start my pension but Jamuna and his team got it started in just one week's time and [did this] during COVID lockdown, when I needed it the most."

A monthly pension gives both social status and independence to people with disabilities and often their families treat them with dignity because they are a financial asset. This is a crucial step forward in bringing about social justice and Jamuna, along with his team, has led the march in Jabalpur district.

"Earlier, there was no one to look up to when we were in need and this OPD of Jabalpur has changed that and given me confidence and fame too. I don't think there is any top politician or government official left in Jabalpur who doesn't know the OPD or my name," shares Jamuna with pride gleaming in his eyes!

A lifeline during the lockdown

The sudden and strict nationwide lockdown imposed in India in March 2020 to contain the COVID-19 pandemic was a debilitating blow to millions of people living below the poverty line. The worst affected were those with physical disabilities, many of whom had no money or support. Thousands of people had to wait for days before help arrived and several were starved of food until relief reached them.

It was during this enormous humanitarian crisis that three young OPD leaders, supported by Sightsavers in the grassroots of the central Indian state of Madhya Pradesh, proved to be life savers for thousands of people with disabilities.

38-year-old Santosh Gujar, 45-year-old Rajju Patel and 33-year-old Ramawati Watti are names that are celebrated by people with disabilities in the Hoshangabad, Jabalpur and Betul towns of Madhya Pradesh. Each of them has a story of grit and courage and rose above personal challenges to lead organisations of people with disabilities (OPDs) in these three towns.

Santosh leads the Viklang Ekta Sewa Samiti OPD with 3,675 members, Rajju leads the Divyang Kalyan Sangh OPD with 2,675 members and Ramawati leads the Navdeep Divyang Kalyan Samiti OPD with around 1,345 members.

The three of them, and members of their OPDs, have received extensive training from Sightsavers on legal frameworks, rights and government schemes to help people with disabilities. They have also learned how to run campaigns and plan for a crisis situation.

These trainings were imparted under the European Union funded project Building Partnerships for Sustainable Development Goals – Empowering Organisations of People with Disabilities. The capacity-building initiatives enabled them to address the gaps in



the representation and participation of people with disabilities. The training also ensured that they became an articulate voice of OPDs in mainstream civil society organisation platforms, at the local government and in national level planning.

All this preparation helped during the nationwide lockdown and these three grassroots warriors realised the crisis that was about to unfold as soon as the announcement was made. The first step was to call for a virtual meeting between the three of them and it was useful that all had prior training in the use of computers and gadgets to hold the meeting.

The aim of this meeting was to get the process started. Soon after this, the leaders held online consultations with their core team members. They realised that food shortages needed to

be addressed urgently, followed with spreading awareness about the pandemic. They immediately started disseminating information and dos and don'ts to people with disabilities and others. This included the need to wear masks and sanitise hands.

Following this, a telephone survey was initiated to identify those in dire need. Phone calls were made to thousands of people with disabilities asking about their status and requirements. The survey helped them to prioritise persons with disabilities from below poverty line families.

As soon as the details were collected, Santosh, Rajju and Ramawati contacted the relevant officials, including the sub-divisional magistrate of the blocks concerned and CEOs of the Janpad Panchayats. The people with disabilities who were starving were highlighted as a priority and food packets were immediately dispersed to them. Following this, self-help groups and OPDs helped to make more than 8,000 masks from cloth supplied by the government. Some of these masks were also given to people with disabilities.

Where the government officials faced challenges to supply food and masks, the OPD leaders contacted private organisations and ensured that help was reached. Since there was no public or private transport on the roads, one of the key challenges for people with disabilities was the lack of mobility due to COVID restrictions, and this was coupled with complete confusion and lack of awareness about the pandemic. Getting access to resources was virtually impossible.

To tide over this situation, Sightsavers developed and distributed accessible audio awareness materials through the OPDs. Meetings with the disability commissioner and other high-level officials were also organised to make them aware about the challenges facing people with disabilities.

“There was no food left at my home when I received a call from Hoshangabad OPD. I live with my mother who is very old and dependent on me. When I told the OPD members that

I don't have any rations left at my home they did something and the very next day some government officials came to my home and gave me rations for a week free of cost,” says Nandkishor from Madhya Pradesh.

This was the impact of the work by Santosh in Hoshangabad and there are hundreds of similar testimonials from Betul and Jabalpur as well. In all, more than 2,000 phone calls were made to people with disabilities to spread awareness and seek information on their status. Of these 376 were made in Betul, 976 in Hoshangabad and 709 in Jabalpur.

In Betul and Jabalpur, the OPD members facilitated public distribution system shops to distribute three months free rations to people with disabilities. Details of more than 500 people with disabilities who did not have rations or BPL cards, but were in desperate need, were shared with the authorities. Masks were ensured for 2,734 people with disabilities free of cost, and Raju, along with his team, even helped set up a COVID-19 information stall in Jabalpur.

All these measures not only helped people with disabilities in need but also created livelihood opportunities for them through making masks and conducting other activities. One of the key achievements of the OPDs was to bring to attention the plight of people with disabilities in the lockdown situation and ensure that they were a focus group in the fight against the virus.

Sustained advocacy measures are needed to ensure that decisions such as future lockdowns and measures to contain the pandemic take into account the impact on people with disabilities.

Had it not been for the OPD leaders like Santosh, Rajju and Ramawati, thousands of people would have fallen off the radar and not received timely support. This is what makes the three leaders lifesavers in the remote areas of Madhya Pradesh.

'Never say die' spirit

'Never say die' spirit



During the sudden nationwide lockdown announced in 2020 to control the coronavirus pandemic, some of the people worst affected were those people with disabilities who lived below the poverty line and had no source of income.

"My husband and I are daily wage labourers, but now we don't have any work because of the lockdown," reported Shanti, a woman with a physical disability. "For four months I received an advance disability pension and spent the entire amount on my family. We have six people in the family; how will I meet their needs?"

The stress of uncertainty led to serious domestic disputes. Manguli, a woman with visual impairment, said: "This is the first time that everyone has had to stay at home for an extended period of time. Men folk are not used to it, so they sometimes vent their frustration and anger on us."

Santosh Moharana, who is visually impaired, has been a fighter all his life and embodies a 'never say die' spirit. When he heard about the suffering of many people during the lockdown, he decided it was time to step in and address the situation facing people with disabilities. He found the courage to take action in desperate situations through his own life experiences. Santosh was in 10th grade when he suddenly started experiencing blurring of vision and within three days, he lost his eyesight completely. It was an unbearable trauma.



His parents tried to save his vision through an emergency surgery which restored it for six months and then, all of a sudden, he lost it again. Doctors treating Santosh told his parents there was no hope.

"They told my parents I will be confined to my home now, indicating I had no future left," he recalls. It was his 'never say die' spirit that got him through those dark days to complete his education, start a small business and become independent.

He was able to move ahead because of a strong family and Sightsavers' former partner NGO, the Centre for Community Development, which helped him to learn braille and complete his post-graduate degree in Odia language. It also helped Santosh establish Samarth, an OPD that serves the impoverished tribal population in the Gajapati district of Odisha. Santosh leads the OPD, which has 3,115 people with disabilities as members.

As soon as the lockdown was announced, he decided to mobilise his core team of nine members to provide emergency relief and livelihood support to people with disabilities.

Working in such unprecedented times required strategic planning and action. Santosh was well equipped with these skills through Sightsavers' training sessions in leadership, advocacy and communication techniques. It was his ability to articulate on behalf of people with disabilities that helped Sightsavers select him for an

exposure visit to Brussels for the European Disability and Development Week.

These trainings and exposure visits were conducted under the European Union funded project, Building Partnerships for Sustainable Development Goals - Empowering Organisations of People with Disabilities. Knowledge of The Rights of Persons with Disabilities Act, 2016 along with global exposure empowered him with a strong legal understanding of the rights of people with disabilities.

Conscious of the value of information, the first thing he did was to set up a telephone communication system with the help of community volunteers at block and district levels. They created awareness about necessary safety measures like washing hands, wearing masks and social distancing among people with disabilities.

A telephone survey was also conducted to understand the needs of people living in particularly difficult situations. Without work, several families of people with disabilities were living with the fear of running out of food and meagre savings. Emergency relief services and livelihoods were identified as two key areas to provide immediate support.

Santosh and his dynamic team coordinated through phone calls and connected a women's self-help group, who were administering community kitchens, to 1,350 people with disabilities who were struggling without food. The team tracked the media to know about all government orders related to COVID-19 emergency relief and shared them with people with disabilities. They even helped several people receive a four month advance of their disability pension.

People with disabilities often require regular medical support as well. During the complete lockdown, the OPD supported several people with disabilities with medical emergencies. They helped them get urgent permission from local administration to travel to district hospitals for treatment.

As migrant workers across the country rushed back home, unemployment increased and every family had a larger number of mouths to

feed. It became imperative to secure livelihoods. The government announced employment through the Mahatma Gandhi National Rural Employment Guarantee Scheme (MGNREGS). But most people with disabilities were unaware of how to access this opportunity.

Enabling people with disabilities to get their rights and entitlements required Santosh to rely on his outstanding relationship with the government. Over the years, Santosh and his team had made regular visits to the district social security officer and block social security officer, the Integrated Tribal Development Agency and all other relevant departments to advocate for the rights of people with disabilities. This regular networking was effectively leveraged with Santosh's calibrated strategy to create pressure on the government to take speedy action.

At one level, the OPD team drafted representations highlighting the needs of people with disabilities and conducted several telephone and online follow-ups with the government to help people with disabilities to get jobs under the MGNREG scheme. Simultaneously, the OPD encouraged all people in distress to file complaints about their problems of food scarcity and livelihood challenges on government helplines.

The large number of complaints filed along with mainstream media and social media coverage created indirect advocacy for all the emergency needs of people with disabilities. This well thought out strategy worked and 132 people with disabilities are now employed under the MGNREG scheme and receive an income of INR 207 (approximately 2 GBP) per day.

The relief is well expressed by Ajikiya, a man with a physical disability, who says, ***"During the initial phase of the lockdown, members of Samarth reached out to me. They advised me to wear a mask or gamuchha, to wash my hands frequently with soap and water and to avoid roaming around unnecessarily. They assisted me in obtaining advance pension funds, masks and dry rations. With the help of Samarth, I enrolled myself for the daily wage labour under MGNREG scheme and now I am working in stone bonding. This enabled me to meet the needs of my family."***

Securing livelihoods in the pandemic lockdown

Life was never easy for 46-year-old Husaina Bi, who lives in the Mewar region of Rajasthan. But her bold and lively spirit helped her navigate all the ups and downs of life. Husaina Bi has had a physical disability since childhood. After separating from her husband, she moved in with her parents and her married brother, who are all daily wage earners. Her mother works as a house help and the brother tries to make ends meet by painting and repairing houses. Her father is too old to get work.

Husaina Bi has always been hard-working and never saw her gender or physical disability as a disadvantage in fulfilling any responsibility. She is inherently fair so she was keen to share equal responsibility with her brother to look after their aging parents.

The search for a suitable livelihood to support her family got Husaina Bi involved with Mewar Viklang Sewa Sansthan (MVSS), an OPD in the Chittorgarh district. Her physical disability had impacted her legs so mobility was a major impediment in fulfilling her dreams. The OPD helped her to get a disability certificate and apply for a motor scooter under a government scheme.

The unique scooter helps a person with a disability balance and operate it easily. It gave wings to her dream of augmenting her family's income. With it, she could move around freely and she joined the Mewar Viklang Sewa Sansthan supported self-help group that sold spices.

With a hunger to learn, Husaina Bi attended several training sessions conducted by Sightsavers that helped her take up a leadership role as the secretary of the district OPD. This position, along with a steady source of income, gave her dignified independence in a conservative society that is quick to dismiss a woman with disabilities who is separated from her husband.

However, life had its own plans to challenge Husaina Bi's grit with the sudden nationwide lockdown that was imposed in March 2020 to contain the pandemic. As the nation came to a grinding halt, the daily wage earners were the worst affected.

As Husaina Bi recalls, "The self-help group had to stop its operations and my brother and mother also could not go to work. Suddenly we had zero source of income. Sitting at home jobless was becoming depressing and we were really worried how long our meagre savings



would last. And this was not just my story alone, several self-help group members were in the same boat, as for most of them, this work was their only source of income.”

Husaina Bi continued to keep in touch with the self-help group by phone and soon they came up with an idea to produce masks as there was a shortage. The group decided to work from home and produce masks to sell. Their high-quality masks got the attention of the district administration which was falling short of masks for its employees. Husaina Bi and the team got the opportunity to make masks for the local panchayat and other vendors too. They soon realised the demand for masks was high but not everyone could afford them, so they made masks from spare material and distributed them free of charge to people in need.

While the mask mission gave temporary relief from the financial crisis, Husaina Bi was acutely aware of the fact that this income would not tide her family through the uncertain COVID-19 times as she was the only earning member in the family. Regular income was the need of the hour for all self-help group members. Support came with Puran Mal Sharma, the president of the All People's Network Organisation (APNO), a state level OPD established to improve the interaction between people with disabilities and government officials.

He came across an opportunity to take up contracts for running three Indira Kitchen canteens operated by the government to provide meals at affordable rates. Puran asked if Mewar Viklang Sewa Sansthan would be interested in applying for the contract. Husaina Bi, supported by Priti Taneja (the President of MVSS) took the lead in applying but as they began the process, they discovered they had only a day left to submit the application.

With their limited literacy skills, the opportunity seemed to be slipping out of their hands. They shared this with Puran who quickly helped them complete the online application process. The security fee was paid through the deposits of MVSS. The entire

OPD team was mobilised by Husaina Bi and Priti to ensure all formalities were fulfilled in just a day!

Puran continued to support Husaina Bi and Priti in the rest of the process by conducting regular follow-ups with the government. They met the district supply officer and even had a meeting with the commissioner of the Municipal Council. The government recognised their efficiency from the mask mission and appreciated their social commitment. This helped them secure the Indira Kitchen contracts, a three-year contract giving the entire team long-term financial security. Such a big contract allotted to people with disabilities irked several prominent businessmen and many canteen agencies tried to bribe Husaina Bi to get the contract.

However, Husaina Bi declined the offer without batting an eyelid because along with her team she was determined to secure the livelihoods of people with disabilities. The team was inspired to ensure no person with a disability and below the poverty line walked away hungry from their canteen.

Though she was elated about getting the contract, Husaina Bi was also concerned as the team had no prior experience of running a food canteen and cooking for such a large population. The daunting challenge brought to the fore the team's organising abilities. These abilities have been nurtured over the years through Sightsavers' capacity-building workshops conducted under the European Union funded project Building Partnerships for Sustainable Development Goals - Empowering Organisations of People with Disabilities.

These workshops built Husaina Bi's leadership abilities along with resource mobilisation skills. They give special emphasis to building communication and advocacy skills that are essential for people with disabilities to access their entitlements under the various government schemes.

Husaina Bi and Priti mobilised the entire team to inaugurate the Indira Kitchen Canteen on 20 August 2020. The three canteens were inaugurated by four dignitaries – a cabinet

minister from Nimbaheda, the district collector of Chittorgarh, the commissioner of the Municipal Council of Chittorgarh and the MLA of Chittorgarh. All three canteens serving people with disabilities are located in prime areas like the government district hospital, the cement factory in Chanderiya village and the government roadways bus depot.

The canteens employ 17 people, including five people with disabilities. This includes four people with physical disabilities and one with low vision. The OPD members have responsibilities like collecting cash and issuing tokens, preparing meals and housekeeping. The government provides all equipment for the kitchen and monetary assistance to the OPD for each meal. Currently, the OPD makes a profit of INR 12 per meal (approximately 0.12 GBP). It is estimated that a minimum of 150 meals are provided in the morning and 150 in the evening at each canteen. The women members of the OPD are currently selling approximately 700-900 meals per day and earning a profit of INR 8,000 - 10,000 per day. The income earned from working at the canteen has helped OPD members in supporting their families and becoming self-reliant.

Securing a livelihood has motivated Husaina Bi and Priti to continue working against all odds to keep the kitchen running. This canteen serves many people whose family members are battling COVID-19 in hospital. This makes everyone working in the canteen vulnerable to the disease.

Naturally, there is a fear of getting infected, and looking at dead bodies going out of the hospital is heartbreaking and unnerving for everyone working there.

As Husaina Bi recalls: ***“Several times I had thought of closing the canteen for a few days to give the women a break from the stress of working in these conditions. But I could not make up my mind because one question always bothered me – who will provide food for people in need at the hospital if we take leave? So, I decided to motivate the canteen staff by reminding them that we are people’s only hope to support with meals while so many are fighting***

death. Looking at the doctors, nurses and other hospital staff working relentlessly for COVID-19 patients, it boosted our morale and encouraged us to continue working for the people.”



Copyright: ©Sightsavers India, 2021

Writer: Salma Veeraraghav

Design: Pritika Malik

Cover image: ©Shutterstock

Other images: ©Sightsavers

Disclaimers:

Sightsavers India has made every effort to provide accurate information. However, if any inaccuracy is found it is inadvertently committed. The author and Sightsavers disclaim any liability in connection with the use of this information. Sightsavers provides the opportunity for individuals to be acknowledged in this publication in case of any unintentional omissions.

This publication was produced with the financial support of the European Union. Its contents are the sole responsibility of Sightsavers India/European Disability Forum and do not necessarily reflect the views of the European Union.



Share [SightsaversIndia](#)



Follow [@SightsaversIN](#)



Watch [SightsaversIN](#)

Registered office

A-3, Shivdham, New Link Road,
Kanchpada, Malad (west)
Mumbai – 400 064
Phone: +91 22 28820808/ 1919

Country office

45, Second Floor,
Okhla Industrial Estate, Phase III
New Delhi – 110 020
Phone: +91 11 42267202 / +91 11 42384572
Email: indiaweb@sightsavers.org

Other offices

No. 86, II Floor, Platinum Project
Coles Road, Frazer Town,
Bangalore – 560005

GC 104, Sector III, Salt Lake
Kolkata – 700 106
Phone: +91 33 40086225

E -1/136, Arera Colony
Bhopal – 462016
Phone: +91 755 4292807