



**IMPACT REPORT**  
2020

## ABOUT US

**Carers Worldwide is the only organisation working exclusively and strategically with unpaid family carers in the Global South.**

Established in 2012, we implement a range of grassroots projects through partner organisations across India, Nepal and Bangladesh and engage in advocacy at national, regional and global level.

We draw attention to the poverty, vulnerability, marginalisation and exclusion faced by carers through lobbying local organisations, NGOs, governments and international agencies for positive change.

We also work to develop carer-inclusive initiatives that meet the emotional, physical, social and economic needs of carers.

## A MESSAGE FROM OUR CHAIR

**Chris Underhill, MBE**  
Chair



Carers Worldwide is making extraordinary progress and the Trustees and I are immensely proud of our achievements to date. As part of our policy work, we are delighted to report on the State Level Carers Forums which have formed in four states in India giving so many carers a voice for the first time. For a relatively small organisation to have this amount of influence is satisfying and a great way of demonstrating impact.

Women make up the bulk of carers everywhere and last year we launched a new project with LEADS Nepal, with the support of a Jo Cox Memorial Grant from UK Aid Direct. So far, we have organised over 1,000 women into self-help groups and 760 carers have been trained in new livelihood activities.

As can be imagined, the support of unpaid carers is clearly our main goal, but this, inevitably, leads to wanting to ensure that those people who are being cared for are also in a position to benefit, for example by looking after themselves more effectively and gaining some measure of independence.

Never has this been more important than during the COVID-19 pandemic. Through our partner organisations we have engaged in a range of activities, including checking regularly on carers by phone to maintain social contact at a time of great isolation and providing counselling where necessary. Emergency food packages have been delivered to carers and their families, and partners have worked hard on teaching communities about social distancing and effective hand washing in order to reduce the spread of COVID-19.

The Trustees have worked hard with the Chief Executive and staff to develop our new strategy for 2020-2022. This builds strongly on the work that we have reported on in previous years. The Trustees join with me in thanking Anil and Ruth Patil for an incredible year in which our staff at Carers Worldwide and the staff and Trustees at Carers Worldwide India have played such an important role together with our partner organisations.

A handwritten signature in black ink, which appears to read "Chris Underhill". The signature is written in a cursive, flowing style.



## A MESSAGE FROM OUR FOUNDER

**Dr Anil Patil**  
Founder and  
Executive Director

This year the global spread of COVID-19 has become one of the greatest challenges of our time. The scale and severity of the virus has created a particularly frightening reality for the millions of carers around the world who care for family or friends that are elderly, disabled, or living with long-term health conditions.

As a result of this pandemic, the importance of care has entered the global spotlight. This realisation makes our work more relevant and critical than ever, and it is my hope that we will emerge from this adversity in to a better, fairer world for all.

Despite COVID-19, I am proud to say that we have managed to achieve fantastic results during 2019/2020. It has been inspiring for me to visit our project areas in India, Nepal and Bangladesh where I have witnessed how our strategic partner organisations are empowering carers through the implementation of the Carers Worldwide model.

For the first time our annual income has reached over £300,000 and we have now transformed the lives of over 73,000 carers, cared for individuals and family members. Our sister organisation, Carers Worldwide India is making great progress, having secured grant funding from within India in its first year of operation.

Two stand out moments for me this year are the promotion of State Level Carers Forums (more detail on page 7) and co-hosting, in collaboration with the Commonwealth Foundation, the first ever international learning exchange workshop on accountable governance for persons with disabilities and carers. Held in India, leading international disability and development activists from seven countries shared strategies on how best to advocate for change.

We have now entered our 2020-2022 strategic phase which will see us expand both the reach and scope of our work. Everyone connected with Carers Worldwide - Trustees, staff, volunteers, partners, supporters and the carers themselves - have the passion, drive and commitment to ensure that big changes for carers will be secured during this period.

I would like to say a huge thank you to everyone who has supported us on our journey so far and I invite you to continue this exciting journey with us.

**“It is time for each one of us to play our part and bring carers to the forefront of everyone’s agenda”**

### LIVES TRANSFORMED SINCE 2012:



**12,264**  
carers



**12,499**  
people they care for



**49,056**  
family members

## CARERS ISSUE

**“Whoever we are, we will all one day be a carer or be cared for ourselves”**

At Carers Worldwide, we know that whilst caring for a loved one is a privilege and brings joy, it can also adversely affect the economic, social, mental and physical wellbeing of the person providing care. Whilst the challenges of caring are faced by carers globally, for carers in the Global South where social protection and support systems are limited and the provision of healthcare is inequitable, the challenges associated with caring are further exacerbated.



Since 2012 we have been working in South Asia to highlight the important role played by carers and advocating for their inclusion in to mainstream development programmes. We are committed to transforming the lives of every carer and ensuring that their needs are recognised and routinely met.



The schedule of carers is often erratic. Many carers find it difficult to establish a routine in their own lives and constantly have to juggle and manage various responsibilities.



When caring is a full-time responsibility, the opportunity to earn a living is lost for the carer, just as much as it is for the person being cared for, which results in households falling further into poverty.



In the countries where we work, there is limited social protection available for carers and many carers are not aware of the schemes that do exist.

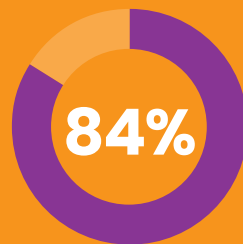


A lack of free time means carers often have to curtail social and leisure activities. Added to that, the stigma that communities attach to many health conditions often makes it safer for carers and those they care for to remain at home.

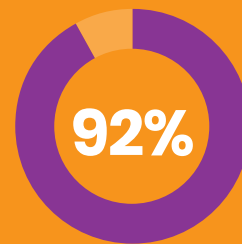


Carers often have their own health issues but do not seek treatment due to lack of time or financial constraints. If a carer's health deteriorates, they become unable to continue to provide high-quality care to their loved one.

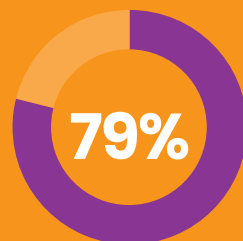
### KEY STATISTICS



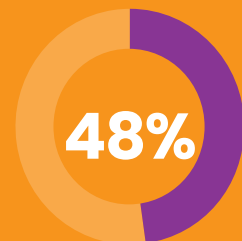
of carers are female



of carers worry about not having enough money to meet their family's basic needs



of carers experience anxiety or depression



of carers worry about their own health but do not seek treatment due to lack of time or money

Key statistics data comes from Carers Worldwide studies conducted in India, Nepal and Bangladesh

# PARTNERSHIP APPROACH

By forming strategic partnerships with local NGOs and other well-established organisations skilled in delivering services to the community, we act as a catalyst to facilitate rapid changes in awareness, attitudes and service provision for carers. Our readiness to work in partnership with local communities ensures our programmes are constantly evolving and always meet the needs of carers and those for whom they care. As of 2020 we are working with 7 partners in India, 2 in Nepal and 1 in Bangladesh. We also work closely with local government authorities in the areas where we operate with the intention of influencing policy changes that will promote the rights of carers.

## STRATEGIC GOALS 2020 – 2022

This year we launched our ambitious strategic plan for the next three years. Our goal is to change the lives of 30,000 carers and 120,000 family members in Asia by the end of 2022. We will do this by focusing on four key objectives.

- Increase **reach and impact** by **empowering existing partners** and **establishing new partnerships**
- Develop a **high quality, bespoke training and consultancy service** on carers and caring to deliver to national and international level NGOs, government agencies and the corporate sector
- Build up a **body of evidence** on carers to inform future policy and practice
- Engage in **policy and advocacy work** at regional, national and international levels in order to achieve recognition and inclusion of carers

# OUR MODEL

The key tool we have developed and utilised to transform the lives of carers is the 'Carers Worldwide Model' which consists of five core elements:



## OUR IMPACT AT POLICY LEVEL

- Establishing four State Level Carers Forums in Karnataka, Jharkhand, Odisha and Andhra Pradesh states in India, which will ultimately lead to the formation of an India National Alliance for Carers (INAC)
- Working closely with the Karnataka state government in India on implementation of the 'Rights of Persons with Disabilities Act 2018' and ensuring the inclusion of carers
- Securing a question identifying carers for the first time in the forthcoming Disability Census in Karnataka, India
- Publishing a review of existing legislation and policies in India that can be utilised or revised to promote the inclusion of carers
- Organising the first carers conference in Bangladesh, attended by local and national government officials who made commitments to take up the carers issue at policy level
- Advocating for the health needs of carers globally through the Commonwealth Civic Society Health Policy Forum
- Advocating for carers globally through our work with the International Alliance of Carer Organisations (IACO)

### In the field, work with our partners has resulted in:



**1,512** Staff and Carers Trained

**557** Carer Groups

**81%** of Carers Earning a Living

**7** Carers Associations

**300+** Child Carers Back to School

**2** Carers Co-operatives

**22** Community Caring & Education Centres

**£58,589** in Carers Group Savings

**2,825** Carers accessing Respite and Short Breaks

**78%** of Carers with Improved Health

**£726,681** of New Government Support Accessed

**348** Health Professionals Trained

**More than 30,000**

carers and cared for individuals have participated in Carers Day Celebrations

**120** Barefoot Counsellors Trained

## OUR WORK IN ACTION

### Towards a South Asia Carers Alliance

Whilst working with individual carers to address their specific needs makes up a large part of our work, it has been our aim from the start to also bring carers together to create a strong civic voice that will influence policy changes and promote long term sustainable change for carers.

We bring carers together in local, district and state level groups, associations and forums, alongside key stakeholders such as NGOs working in sectors related to carers, academics, private companies, and government officials, so that the voices of carers can be heard by policy makers and practitioners at all levels and across sectors.

Our local carers self-help groups are the first step in bringing carers together. They have been a key tool in promoting carers connectedness with each other and provide much needed emotional support. Tulsi Ram Sapota, a carer from Baglung, Nepal commented:

**“Since joining my local carers group my life is no longer ‘in the dark’. I have a place where I can express my internal thoughts and pain. Bringing carers together makes us feel less depressed and happier.”**

Our cluster level committees and district level Carers Associations are focused on raising the carers issue with local government authorities and advocating for the rights of carers. Pradip Kumar Shrestha from Kathmandu Valley, Nepal became a member of his Carers Association. He said:

**“I want to be a representative for local Nepalese carers. It is my hope that carers will be able to receive financial support from the government for themselves, not just those they care for.”**

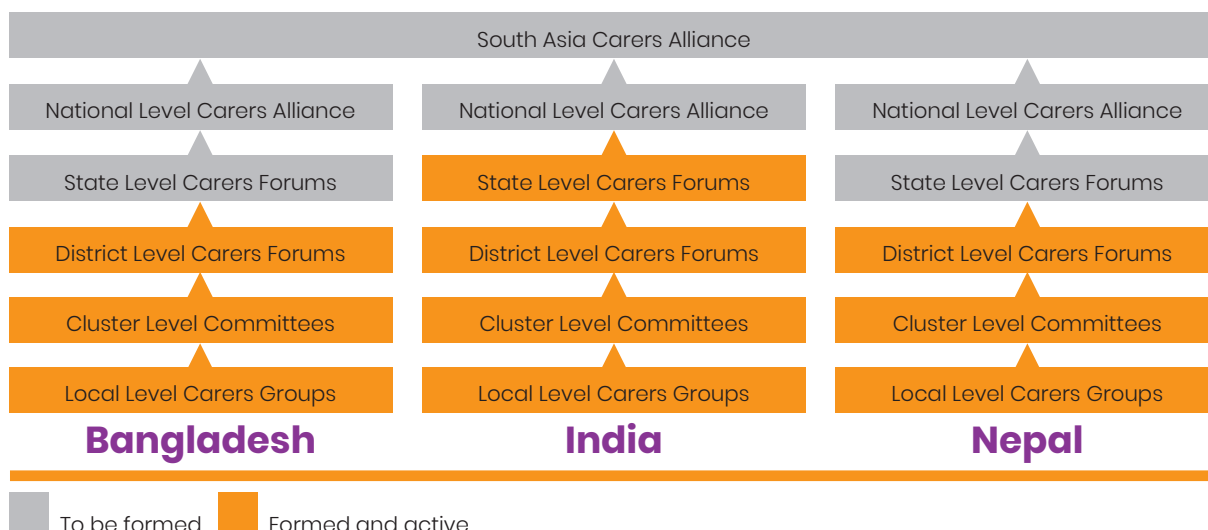
Last year we took our carers groups to the next level, launching State Level Carers Forums (SLCFs) in India. Working with our existing partners we have established SLCFs in four states of India – Karnataka, Andhra Pradesh, Jharkhand, and Odisha. Their purpose is to promote recognition of the existence and role of family carers; to raise the voice of carers and promote their inclusion; and to develop state level strategy frameworks for promoting and protecting the rights of carers.

Mrs Kasturi Mohapatra, Co-Chair of the Odisha SLCF, and previous Commissioner for Disabilities in Odisha, said:

**“I myself have needed care. Without my carers, I wouldn’t have been able to walk. Until now, I haven’t recognised the role of carers and their needs. It is important to recognise the significant contribution carers make and their voices need to be heard. This is a great initiative and a wonderful platform for them. I am glad to be part of this.”**

Beyond the SLCFs our vision is to establish National Alliances of Carers (NACs) in the countries where we work, beginning with an India National Alliance of Carers. Each national alliance will be committed to influencing policy changes for carers at a national level which will benefit all carers living in that country.

Ultimately, once the national alliances are established, we will bring them together to form a South Asia Alliance for Carers, resulting in a transformative effect for carers living across South Asia.



## OUR WORK IN ACTION

### From Carer to Co-ordinator



**When Nisha married her husband as a young woman, she was looking forward to a promising future. She was working for her local government's health department whilst at the same time completing studies in the medical field. However, just days in to her marriage she discovered that her husband had epilepsy and was alcohol dependent.**

Nisha was committed to her husband and dedicated herself to helping him recover. Despite her best efforts, over the years her husband's epilepsy worsened, as did his addiction to alcohol. The couple had two children together yet he would spend most of the family's income on alcohol and also started to become violent towards Nisha. With two children to look after as well as her husband, Nisha was unable to continue her employment with the local government or her studies.

As their situation worsened, Nisha and her family were stigmatised by their local community and became isolated. They had no money and Nisha became

**“Nisha has transformed from a woman living in exclusion, poverty, and domestic violence to a strong, empowered woman who is a role model for many carers. And her efforts continue...”**

**Padam Shrestha, LEADS Nepal Founder**

increasingly worried for her children's future. At her lowest point she contemplated suicide but somehow found the strength to continue.

When LEADS Nepal began supporting carers in Myagdi, Nisha received support from a social mobiliser who helped her set up a small grocery shop in order to earn an income to sustain her family. This gave Nisha new hope in her life.

As well as setting up a shop, the mobiliser encouraged Nisha to join her local self-help group for carers and within just six months she was leading the group. As her confidence grew, she became committed to supporting carers not just in her group but across her district. She trained other carers on making craft items, which they could do alongside their caring duties and sell for profit.

When a district level Carers Association and Carers Co-operative were set up through the carers project in Myagdi, Nisha was elected by her peers to be the president of both organisations. During her first year in leadership, she confidently visited government departments to request resources to be available for carers. She also arranged a market to sell organic products manufactured by carers in order to raise funds for the Carers Association. This money was then used to support some of the neediest carers in the district.

After seeing her leadership skills, innovative ideas, and vision for carers, LEADS Nepal offered Nisha a role as a district coordinator for the carers project. She is now excelling in this role and hopes to serve carers at a regional and even national level in the future.





# OUR WORK IN ACTION

## No more stress thanks to livelihood success



**38-year-old Kamruzzaman lives in Savar, a sub-district of Dhaka, Bangladesh. He lives with his wife, his mother, his mother-in-law, and 8-year old daughter Mim Moni.**

Kamruzzaman cares for his daughter and his mother: his daughter has cerebral palsy and his mother has a physical disability which has made her dependant on a wheelchair. His wife is a garment factory worker. Despite working long hours, her income is not enough

for the family to live on and so Kamruzzaman supplements their income by working as a rickshaw driver.

Kamruzzaman used to pay daily rent on a rickshaw meaning he had to work long hours in order to earn enough money to support his family, on top of the rent he owed to the rickshaw owner. This meant that he was unable to go home very often during the day to check on his daughter and mother. This caused him immense stress as he worried that something would happen to them while he was not there.

Staff of our partner, the Centre for Disability in Development (CDD), introduced Kamruzzaman to a local carers self-help group which was formed through our UK Aid Direct funded project. In this group Kamruzzaman met other carers who understood his challenges and who could offer him emotional support.

Through the project, Kamruzzaman also received financial assistance to purchase his own rickshaw meaning he no longer has to pay rent on a borrowed vehicle. All the income he earns can now be spent on his family. This has given Kamruzzaman more flexibility in his working patterns meaning he can be at home more during the day to care for his daughter and mother. He no longer feels the stress that was created by constantly juggling working and caring.

Kamruzzaman is keen to support other carers and is doing this by taking children with disabilities in his rickshaw each day to the local Community Caring Centres that Carers Worldwide and CDD have set up. This service is of great use to other carers and he is proud to do this work.

It brings us great joy to hear how our work has supported carers such as Kamruzzaman and made meaningful changes to their lives.

**“I am happy to see my father’s smiley face.”**  
Mim Moni,  
Kamruzzaman’s daughter



## OUR FUNDING

**We are pleased to announce that our income for 2019 increased to over £330,000, a significant step up from previous years.**

This increase in funding has enabled us to reach even more carers and implement activities that will make long term sustainable changes in their lives. We would like to thank our donors and supporters for recognising the importance of our work and providing us with the funding required to deliver our impact.

Making sure money donated goes to the people who need it most, the carers and their loved ones, is essential to us. 98.3% of all the money we raise is spent on charitable activities with the remaining 1.7% going towards fundraising and governance.

Our approach offers excellent value for money because:

- We focus on carers
- Our projects are targeted
- Our approach is low cost and replicable
- Sustainability of impact is a key factor at all stages
- We do not work in isolation
- Evidence-based approaches are at the heart of what we do



## CARERS WORLDWIDE INDIA

In December 2018 Carers Worldwide India was launched as an independent Trust registered in India. Over the last year Carers Worldwide India has raised over £77,000 from the Live Love Laugh Foundation and the Rangoonwala Foundation (India) Trust, which has been spent directly on project activities in the state of Odisha.

# CARERS WORLDWIDE AND COVID-19

At the time of writing this report, the emergence of COVID-19 has had an unprecedented global impact, resulting in severe restrictions on movement and the lives of everyone throughout the world. We have adjusted our programme activities and approach in order to respond rapidly to the current situation. Our project activities throughout India, Nepal and Bangladesh have all

As well as our emergency relief efforts, we have implemented measures to combat the increased loneliness and anxiety that carers may be facing during the pandemic. Field staff have been working from home and making phone contact with as many carers as possible. Developing ways to keep carers in touch with both staff and other carers remotely is providing a



been adapted to ensure the health and safety of our staff, partners' staff, the carers they work with and those they care for.

Carers and the loved ones they care for are particularly vulnerable during these times so we have been working alongside our partners to ensure that carers and their families are receiving the support they need. At times this has meant engaging in activities that are new to us, and we have learned a great deal along the way. Staff from our partner organisations have been distributing essential medicines, food packages, and sanitation packages to sustain families, as well as holding community meetings to raise awareness on COVID-19 and ways to reduce its spread, such as social distancing measures and adopting effective sanitation practices.

lifeline to carers, ensuring they can maintain social contact with persons outside of their immediate household for support.

At this stage, the long-term effects and consequences of COVID-19 are difficult to predict. There will certainly be ongoing disruption to the short-term and mid-term operations of our organisation. We anticipate that some of the adaptations to programmes will remain for a significant length of time. We have learnt that some of the changes we have initiated have actually improved the connectedness of the most isolated of carers, and these will stay.

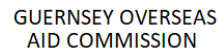
We expect to face a significant reduction in immediate funding and future funding opportunities. Despite this, we remain committed

to ensuring that carers are not forgotten and to promoting and supporting carer well-being. This crisis has shone a light globally on the importance of carers and we want to ensure that carers are recognised for their huge contribution to society. Carers deserve even more of a voice as we all move forward together.

It has never been more important for national, regional, and international action to be taken to support carers and the people they care for. As an organisation, in collaboration with our partners, we will consult and reflect on how we can best continue to promote the recognition and support of carers and their families both during and after COVID-19.

## Thank you to our Donors

Our work is not possible without the individuals and organisations that support us



## Thank you to our Partners

Our committed and dedicated partners make our vision a reality



## Contact Us

### Carers Worldwide

30 Lodgefield  
Welwyn Garden City  
Hertfordshire  
AL7 1SD

**w:** [www.carersworldwide.org](http://www.carersworldwide.org)

**e:** [info@carersworldwide.org](mailto:info@carersworldwide.org)

**ph:** +44 (0) 7745 608 438

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