CATALYSING A GLOBAL CARERS’ MOVEMENT

Ten years of transformative impact with family carers in South Asia
Merck’s Embracing Carers® team congratulates Carers Worldwide on their ten years of meaningful work and support for South Asian family caregivers.

Dedicated to the memory of Maya Rani and Shima Rani, who are featured in the photo on the front cover along with their husband and father Monotosh.

Photo credits: Carers Worldwide, Carers Worldwide partners and Iqbal Hossain (pages 22, 25, 26, 30).
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A MESSAGE FROM
THE CHAIR OF TRUSTEES

All of us can expect either to take on caring responsibilities for our loved ones ourselves or to know someone with such a role. Needing to provide care to a loved one knows no social, economic or geographic boundaries. Caring for others whom we love is an honour and a privilege – but it all too often comes at a significant cost to the carer and more broadly. For carers in low and middle income countries, this burden can be almost intolerable.

This impressive independent report, marking ten years of tireless work to support unpaid carers in South Asia, sets out very powerfully the vital social impact that the Carers Worldwide Model is delivering to individuals, local communities and whole societies. The report shows just how much value the charity can deliver and also sets out well the range of social issues our work tackles. Like all brilliant inventions, the Carers Worldwide model is deceptively simple. This Model is borne from the professional and personal experiences of the team behind Carers Worldwide – not least, our impressive founder Director Anil Patil, whose personal experiences have been instrumental in the charity’s formation and development.

Crucially, the Carers Worldwide Model has been shaped by carers themselves. We know that it is carers that know best what they need in order to thrive. That is why carers sit at the very heart of this model. Having seen at first hand the work of Carers Worldwide projects, I am entirely unsurprised by the clear expert assessment provided in this report of the profound and transformative impact of the charity’s work. That we have invited external assessors to scrutinise our work in this way is illustrative of our focus to deliver the best possible social impact and to make the best possible use of every pound of donors’ generous support.

The commissioning of this report is also testament to our determination to build the strongest possible foundations on which to build our ambitious plans for the future. As proud of our achievements as we are, we know that we are only scratching the surface of the millions of carers in need of proper recognition and support. We are impatient to empower the vast numbers of family carers who could benefit from the Carers Worldwide Model. That is why we take impact assessment so seriously in order that we can be sure that we, and our local partners, can make the difference we want to see in so many more communities. And so that others can learn from our approach. We don’t jealously guard the Carers Worldwide model like a secret mix of herbs and spices, we offer it to any organisation serious about delivering true sustainable development!

The first ten years of Carers Worldwide, as evidenced by this important report, have been nothing short of remarkable. Our plans for the next ten years will, however, deliver a step change in our work. We are hugely excited by the journey ahead. I do hope that you will join us!

Jonathan Freeman MBE
Chair of Trustees

“The first ten years of Carers Worldwide have been nothing short of remarkable...”
A MESSAGE FROM THE FOUNDER AND EXECUTIVE DIRECTOR

Every year, more and more people take on a caring role. Most of the readers of this report will experience a caring relationship for themselves first hand. The enormous contribution of unpaid family carers makes an invaluable difference to the relatives and loved ones they support, as well as to society more broadly. This report recognises their vital role, demonstrates the significant inroads Carers Worldwide has made towards achieving their recognition in South Asia and urges others to come on board the journey towards a global caring movement.

Family carers are depended on by those they care for, family and community members, and health, education and social care professionals. What none of us must forget is that carers have their own needs too. We must be alert and responsive to those needs, or we risk compromising their health and wellbeing and, by association, the health and wellbeing of the others who depend on them.

At Carers Worldwide, carers are at the heart of all we do and the voices of carers are central. We are making carers visible, demanding action not just awareness and laying the foundations for sustainable change.

None of this would have been possible without the support and encouragement of everyone involved in the Carers Worldwide journey from its start. There are many to mention and all are remembered and valued for their contributions, but I will mention just a few here.

Ruth, my partner at home and at work, has been a pillar of strength. Without her enormous support and sacrifice, I would not have embarked on this journey and the organisation would not have reached this 10 year milestone in the strong shape it has. Asha and Maya, our beautiful daughters, have changed our lives for the better and continue to be a source of inspiration for me to keep exploring uncharted territories.

Chris Underhill, our founding Chair along with Siân Edwards, Sue Taylor, Sarah Ridley and Alastair Page our first Trustees have given unstintingly of their time and expertise, shaping the organisation’s strategy, approach and values and leaving a legacy which will sustain. Chris continues to champion the organisation in his role as Ambassador, for which we are immensely grateful. Reaching our 10th year and looking beyond, we are thankful to our Chair Jonathan Freeman and current Board of Trustees who, along with our Carers Worldwide India Trustees, continue to challenge us and celebrate carers every step of the way. The organisation started at our kitchen table, reliant on volunteers. We are proud now to have a small but dedicated staff team to whom saying thank you is not enough. They and the staff who have gone before them have fully embraced the ambitions of the organisation and always gone over and above to deliver them.

Our partner organisations in India, Nepal and Bangladesh are at the core of all we do and without them we would not have transformed the lives of 119,000 carers and family members in the ways that we have. Our early adopters - SAMUHA Samarthya, SACRED and NBJK –believed in my passion and allowed us to test the Carers Worldwide model. Their willingness to take that risk paved the way and sees us now working with 15 partners across 3 countries. Our sincere thanks go to the senior leaders and staff of each one of those organisations as they continue to be the voice of change, empowering carers and influencing policy and practice.

The journey this far would not have been possible without the investments of time and resources made by the range of donors and supporters who have believed in Carers Worldwide and our vision. Special thanks go to the Andrews Charitable Trust for seeing the early sparks of ambition back in 2012 and enabling us repeatedly to put words into action over the last decade. This report has been made possible by generous sponsorship from Merck, with whom we are delighted to work through their Embracing Carers initiative. We are grateful also to the team at MzN International for capturing in such an inspiring way the achievements of the last 10 years and demonstrating so decisively our incredible social return on investment: for every £1 invested, a return of £7.79.
Thank you to everyone who gave freely of their time to take part in the interviews and surveys that formed part of MzN’s research.

Last but certainly not least, our sincere respect and appreciation goes to all the carers involved in our projects over the last 10 years. They have opened their hearts and homes, shared their stories and allowed us to celebrate their gains alongside them. They are the living examples of change and we will continue to champion them as they take on the role of calling out for that change themselves. As we complete our first 10 years and look to the coming decade, society is starting to recognise the critical role of carers. This report demonstrates that Carers Worldwide has the experience and authority to take that recognition and shape the responses that need to happen. We urge everyone reading this report to reflect on their own spheres of influence and the ways they can commit to carers. Then join us in this global carers movement!

Dr Anil Patil
Founder and Executive Director

Carers Worldwide’s partners

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<th>In India</th>
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<th>In Bangladesh</th>
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<td>Self-help Group for Cerebral Palsy, (SGCP)</td>
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<td>Nav Bharat Jagriti Kendra (NBJK)</td>
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<td>Narendra Foundation</td>
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<td>Bijapur Integrated Rural Development Society (BIRDS)</td>
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Our core values

**WE CHALLENGE**
We constantly look for ways to innovate and evolve, and challenge others to do the same.

**WE IGNITE IMAGINATIONS**
We inspire ambition and bold ideas to tackle the issues facing carers everywhere.

**WE AMPLIFY VOICES**
We listen to and value everyone’s voice, amplifying the voices of those currently unheard.

**WE INSPIRE CHANGE**
We empower people and organisations to make lasting changes for carers and their communities.
EXECUTIVE SUMMARY

At the time of writing this report, the importance of unpaid family carers in our societies has been the recent subject of rare attention, a result of their instrumental and undeniable role being brought into the spotlight during the Covid19 pandemic. This recognition is long overdue; though family carers provide essential, often life-changing care to huge segments of population - in general between up to 15 – 20% – their contribution and stories remain largely invisible, for their contribution is commonly taken for granted and their own needs for support, services and attention largely ignored and neglected.

Carers Worldwide was founded in 2012 to fill precisely this critical gap in South Asia, becoming the first and only organisation working exclusively and strategically to support unpaid family carers in the Global South. As 2022 marks their 10-year anniversary, this report - Catalysing a Global Carers’ Movement - is motivated by the ambition to take stock of and reflect on the impact the organisation has had. The impact assessment exercise reviewed the broad impact the organisation has had in the lives of carers, and for the first time, robustly tested and provided additional tangible evidence of the social and material values its model has generated, using a Social Return on Investment (SROI) approach. Despite a growing body of literature examining the effect of different interventions to support unpaid family carers there remains a dearth of evidence regarding their cost-effectiveness and evaluation. This is an important gap and potential barrier to greater investment which we hope this report will contribute to addressing.1

The review completed to inform this report makes it crystal clear that investing in carers generates positive outcomes for many: for them, the people they care for, their family members, local health systems, communities, and government representatives. Not only do they generate crucial value, they are holding entire systems of care together, being effectively indispensable chain links without which these systems would indeed collapse. The Carers Worldwide Model stems from this very observation and the conviction that, if unpaid family carers are completely integral to public health strategies and community-based approaches, particularly so where they are expected to compensate for poorly funded health systems, it is both ethical and imperative that their wellbeing be also addressed, and in a systemic manner. The review of the Carers Worldwide Model brings crucial insights into how a simple, holistic model of intervention can make a significant positive difference in the health, social and economic areas of carers’ lives.

The SROI analysis reveals the extent of the exponential return these services generate: for every £1 invested, Carers Worldwide’s Model generates £7.79 of social and material return.

This finding complements key evidence of impact that the organisation has collated over the past ten years, and provides a robust and compelling case for investment. Due to the inherent participatory and inclusive approach underpinning SROI, the analysis provides unsuspected insights into the manifold and complementary ways the Carers Worldwide Model not only generates value for carers, but also for those they look after, other family members, communities and governments.

In the first part of the report, we outline the methodology used, sources of data and main conclusions.

The second section presents with specific examples the impact delivered by Carers Worldwide, organised across key areas of change for carers: their health and well-being, their employment and economic prospects, their opportunities for respite and socialisation and finally, their increased visibility and recognition. In a

In line with Carers Worldwide's mission to ensure every carer is valued and receives the recognition they deserve, this report celebrates the work and key results the organisation has achieved but also equally, the daily acts of kindness, support, commitment and dedication that permeate the rich and complex lives of carers. The work of Carers Worldwide and its local partners has not only shed light on the many challenges carers face, but also their incredible qualities: their dedication, effort, patience, knowledge, understanding, companionship, determination and compassion to transform the lives of the people for whom they care. The report is ultimately dedicated to the efforts of these women and men, girls and boys: spouses, parents, children, grandparents, neighbours and other community members making the world go round. By contributing to a greater understanding and acknowledgement of their invaluable work and resilience, this in turn will result in greater support and inclusion of unpaid family carers, the ultimate goal.

The Carers Worldwide Model: A holistic approach

**Carers’ support groups**
Reducing loneliness and isolation, creating social networks and supporting emotional wellbeing

**Health services**
Creating access to physical and mental health services including locally available counselling services

**Advocacy**
Strengthening the collective voice of carers at community, regional and national level to achieve changes in policy and practice

**Respite and short breaks**
Offering a break from caring responsibilities and developing alternative, high quality care options

**Employment, training and education**
Facilitating access to employment, training or education opportunities tailored to exist alongside caring responsibilities

“The Carers Worldwide Model not only generates value for carers, but also for those they look after, other family members, communities and governments.”

final and concluding section, we reflect on the broader significance of the organisation’s efforts in relation to the 2030 Global Goals and offer a set of predictions and strategic opportunities to further scale the organisation’s impact over the next decade.
INTRODUCTION

The report has been compiled by MzN International, a social consultancy firm entirely dedicated to supporting non-profit organisations thrive in delivering their mission through agile and effective business models and programmes. Tasked with completing a review of Carers Worldwide’s impact over the past 10 years, MzN embarked on a methodical investigation designed to meet two complementary objectives:

★ First, to systematically document, organise and synthesise the various ways in which the organisation has effectively delivered positive change in the lives of carers, as well as directly or indirectly impacted the lives of the persons cared for, carers’ families and communities and, ultimately, wider society. This effort was primarily informed by an extensive review of Carers Worldwide’s existing evidence, made up of baseline reports, technical notes, strategic documents, independent project evaluations and research pieces. Together, 26 documents were analysed. This exercise was further complemented by interviews with 8 respondents, picked for their knowledge of Carers Worldwide’s work but also their understanding of how the organisation inserts itself into the wider context of global development and other efforts towards tackling inequalities, exclusion, and poverty reduction.

★ Second, to assess and provide additional robust evidence of the cost-effectiveness and multi-faceted impact of Carers Worldwide’s interventions. To this end a Social Return on Investment (SROI) analysis was completed, engaging both quantitative cost data and a breadth of stakeholders to unpack their experiences of taking part in Carers Worldwide’s programmes, thereby understanding from their perspective both the material and social value generated. This exercise relied on data such as the costs of delivering activities from Carers Worldwide as well as inputs from a total of 21 carers, relatives receiving care, family members, community members, government representatives and partner organisation staff in India and Bangladesh who were interviewed in April 2022 and helped us critically validate or uncover anew the most valuable changes and outcomes experienced.

This report presents the summary and findings of this dual exercise. The first section presents the main findings of the SROI analysis, broken down by the key areas of impact or “change criteria” that guide Carers Worldwide’s work in support of carers and their families. Additional considerations and conclusions are presented in the second section: here we reflect on the organisation’s relevance in the broader ecosystem and, using the Global Goals as a reference framework, highlight essential contributions Carers Worldwide is making towards gender equality, reduced inequalities and poverty, access to education and good health and wellbeing for all. Finally, as the organisation comes to the end of an impactful, phenomenal first 10 years of work we argue that the vast evidence of impact this report demonstrates provides the perfect vantage point to prepare for the years ahead. The concluding and final section of this report offers recommendations on strategic opportunities and directions to propel the organisation into the next decade and help scale its impact exponentially in support of family carers worldwide.
A PREAMBLE: LEAVING NO CARER BEHIND

Before diving into the organisation’s accomplishments and in order to really take the measure of their impact, it is important to better understand who the carers are they target and support in South Asia. Reviewing the approach and model of Carers Worldwide, we find that there has been a constant preoccupation and commitment to contribute and establish, often for the first time, strong evidence on the needs and experiences of carers. This has been the case right from the moment the organisation started to plan and design its model of intervention, back in 2012.

The very nature of unpaid care means that the prevalence and characteristics of carers in a given country is at best estimated, but most often largely unknown. This leaves organisations and governments with little to no information about the extent and demographics of the carer population, let alone insights into the solutions and services they would require to navigate daily challenges and lead healthy, dignified and fulfilling lives. Yet when we consider that on average 15 to 20% of any given population needs a carer at one any given point in time or another in their lives, thus positing the carers population to reach a collective2 342 million across India, Bangladesh and Nepal, it becomes clear that carers form a severely neglected and excluded group, who need affirmative and inclusive action in order to have their needs adequately met, let alone to thrive.

Over the past 10 years, Carers Worldwide has understood this key barrier to stirring positive change and has led direct consultations with no less than 2000 carers. It is important to note here that Carers Worldwide has supported parents, grandparents, spouses, children, other relatives, neighbours and even child carers looking after relatives living with a mental illness, others living with a range of various disabilities, sons and daughters or siblings living with cerebral palsy, epilepsy or other neurological disabilities and family members with age related conditions. The point is that carers do not form one homogenous group and Carers Worldwide has

In one of the very first large-scale consultations Carers Worldwide completed, back in 2012, a respondent in India commented:

“In my opinion caregivers are an invisible community, sometimes even invisible to themselves. I think it is important to address this invisibility, which is the first thing that has to change.”

2 276, 33 and 5.6 million respectively
invested time and resources to uncover the multiple intersecting characteristics, such as gender, age, family composition and dynamics, educational background, and social status to name a few, that influence and define their experiences of caring. These have been critical to fill evidence gaps and help design interventions that are relevant and tailored to their specific needs, and is a crucial and important contribution in itself, in particular to the 2030 promise of leaving no one behind.

**Who are the carers?**

Worldwide the most accurate answer is that carers could be anyone, or rather anyone can become a carer at some point in their lives. But in the low and middle-income countries where Carers Worldwide has focused its efforts to date, a few important trends and characteristics emerge: these are families who do not have the resources to buy extra help, and simultaneously tend to live in areas where the government also does not provide much to help them. This is important to bear in mind when unpacking their experiences and needs and ultimately, assessing the impact of the solutions Carers Worldwide has implemented to address them.

- Carers are predominantly women, representing on average 84% of people supported by Carers Worldwide (2021 Impact Report). In some projects supporting specific groups of carers, i.e., parents looking after a child with a disability, up to 97% were women.
- They tend to be of working age, most often between 20 and 60 years old, but some carers can be as young as 11 or as old as 80.
- On average 77% of carers live together with more than two men or more than one woman in the same household, yet carers recurrently report not having anyone who could relieve them so they can go to work, which hints at the weight of responsibilities placed on ‘primary carers’ in many families.
- Further nuancing the common assumption that people in low-income countries are more likely to live with extended family, Carers Worldwide’s data from working in urban areas in the Kathmandu Valley, for example, found that only 31% lived in “joint family arrangements” (Caring for Carers of Children with Cerebral Palsy in Nepal, 2017 Baseline study). This illustrates the growing trend of family nuclearisation in Asian countries, which is predicted to continue to rise.
- The carers supported by Carers Worldwide and their local partners in India, Nepal and Bangladesh tend to be located in rural, remote communities generally associated with limited or non-existent public services and infrastructure. For example, Carers Worldwide’s local partner LEADS works in the hilly and remote districts of Myagdi and Baglung in Western Nepal. Carers supported live in villages mostly inaccessible by road, with distances between villages measured in the number of days to walk. Other Indian local organisations and partners Ekta, SPREAD and WORD specifically target tribal populations living in hilly rural districts in the State of Orisha.
- Carers Worldwide routinely target families with the lowest income and/or facing additional marginalisation due to status, disability, or caste. Only a limited portion of them is literate. For example, in a recent project in Bangladesh, only 3% of 288 targeted carers were educated to the age of 16 or beyond (Testing an Approach to Social and Economic Inclusion of Impoverished Family Carers in Bangladesh, Baseline study report, 2020). As a result, carers supported in their programmes tend to live in poverty or extreme poverty.

Carers Worldwide’s extensive consultations and baseline exercises have thus been important to help governments and service providers better understand the prevalence and profile of carers and mobilise resources and investments that match the scale and needs of this population accordingly. Perhaps most importantly, the organisation has also repeatedly demonstrated that carers are able to articulate their hopes, ambitions, and plans. Listening to and documenting their needs reveals that more often than not, they are looking for simple, low-cost solutions to assist them in the short-term in order that they be enabled to sustain their often lifelong responsibility of caring for a loved one for themselves. The next section zooms in on the model Carers Worldwide has designed, refined and delivered in response.
FINDINGS FROM THE SOCIAL RETURN ON INVESTMENT ANALYSIS

Traditionally there may be a recognition or understanding that carers perform essential tasks and services for their families and communities. However, more often than not, people would not be aware of the extent of the tangible value, both societal and economic, that carers generate for society. This is compounded by carers often not feeling that they are doing anything extraordinary. The SROI exercise aims precisely to address this gap. MzN conducted a retrospective SROI assessment on the entire scope of work undertaken by Carers Worldwide, aiming to determine the full impact of its model for all those that benefit.

Retrospective SROI calculations are based on actual outcomes that have taken place over a given evaluation period. It is an outcome based measurement that aims to quantify social impact of past activities. The aim of the process is to monetise a range of outcomes to capture social impact in a form of cost-benefit analysis. The calculation measures impact against every £1 spent by the organisation and is expressed as a ratio of such. We acknowledge clearly that this process can only capture a narrow expression of the range of impacts an organisation has. Clearly though, the calculation adds significantly to the narrative of how Carers Worldwide creates value for its beneficiaries.

Methodology

SROI is based on a broad set of codes that are designed to create a robust and transparent process that is informed predominantly by stakeholders. The following is an outline of our approach used throughout this work.

Establishing Scope - To unpack what we needed to measure for Carers Worldwide we first had to understand who the stakeholders were and what they valued. It is the stakeholders that hold the true understanding of the value created by programmes. Identifying key stakeholders and setting clear boundaries about what the SROI would cover was the first step in the process. To ensure we covered the full breadth and depth of Carers Worldwide’s impact we collaboratively mapped stakeholders and tested and validated assumptions regarding reasons to include or exclude them from the analysis. Eventually this exercise resulted in identifying the following core stakeholders:

- Carers
- Relatives being cared for
- Family members of carers
- Community health workers
- The local community including where possible local government representatives
- Staff of Partner NGOs.

Data Collection - Through engaging with stakeholders with questions based around the five broad areas of the Carers Worldwide Model we created links between inputs, outputs and outcomes. To evidence the outcomes and to assign them a monetary value we created financial proxies. This allowed us to give an equivalent value to those outcomes that are not usually monetized. Alongside the quantitative data collection, we undertook 21 key informant interviews to verify and complement our understanding of impact experienced and the choice of proxy. Our range of proxies included (but were not limited to):
Establishing impact – Once we completed the data collection, we needed to determine which of the monetized outcomes or changes would or would not have happened anyway and also which uplifts were the potential results of other factors. As a team and based on the findings alongside wider demographic data we created a range of assumptions that helped assign attribution as well as understand the true impact of Carers Worldwide’s programmes, including the impact of time. Given the retrospective review considered activities that have in some cases been ongoing for 10 years, there was a necessity to consider wider changes to society and social services during that time.

Calculating SROI – Once the investment, the proxies and the assumptions were defined and established, the calculation could take place. The calculation is the sum of the discounted (accounting for net value factoring time, deadweight, and attribution) value of the benefits divided by the total investment made by Carers Worldwide. Given this was a retrospective review, there was not the requirement to calculate any net present value as per a forecast based SROI calculator, but more to acknowledge in the assumptions that impact may diminish over time.

SROI – The resulting calculation provided a figure, represented as a multiple of the base investment of £1. This figure provides insight into the likely social impact of the investment of £1 in programmes operated by Carers Worldwide. This report documents our SROI process as well as the outcomes of our assessment. The data used was supplied by Carers Worldwide and its partner organisations.

Findings

Based on our SROI methodology outlined above and explained in detail throughout this report we calculate an overall SROI for Carers Worldwide of £7.79. Taking 2021 as a reference and example, based on a total expenditure of £104,296 the value created was £812,465. Given the status of the beneficiaries that are provided for by Carers Worldwide we see an amplified value in some of the fundamental activities that Carers Worldwide provides. As part of our assessment, we calculated the SROI for the four key change areas and related activities of Carers Worldwide. The breakdown is as follows:

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<th>Activities</th>
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<tr>
<td>Health and Wellbeing</td>
<td>£6.07</td>
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<tr>
<td>Income and Livelihoods</td>
<td>£6.70</td>
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<tr>
<td>Socialisation and Peer Support</td>
<td>£11.25</td>
</tr>
<tr>
<td>Visibility and Representation</td>
<td>£7.18</td>
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We also separately calculated the SROI created for local and partner NGOs. Using a more limited range of data, and based on the amount of funding secured by partners along with increased visibility and capacity to support carers needs as a result of partnering with Carers Worldwide, we calculated that for every £1 invested in local partners (through grants or own funds secured by Carers Worldwide), local partners went on to generate £12.02 worth of support for their beneficiaries.

The following report provides detailed insight into the work that was carried out and how that was accounted for in terms of our SROI calculations.

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3 SGCP, one of the organisation’s local partners in Nepal, secured for example a grant of £50,000 from an international donor to continue independently the activities initiated together with Carers Worldwide.
OUTCOMES FOR CARERS

A. Health and wellbeing

A.1 Background and Context

Being responsible for the care and well-being of a loved one, from providing assistance in the completion of daily tasks to looking after their health, housing or finances can be immensely rewarding and fulfilling. But caring responsibilities also bring about a significant impact - physical and emotional - which over time, can build up to take a significant toll on carers’ own health and well-being. Though every carer's situation is unique and shaped by the particular needs of the person cared for, resources and personal family circumstances, there is ample evidence that the multiple demands placed on them can leave carers routinely tired, stressed and overwhelmed.

The act of caring has repercussions on both their physical and mental health. For example, carers of children with cerebral palsy may suffer exhaustion due to their children's sleep disturbance, others looking after a relative with reduced mobility might experience physical strain such as back pain resulting from carrying or lifting them out of bed. At the same time, carers navigate daily a spectrum of emotions that can encompass feeling trapped (with no seeming end in sight in the case of persons needing lifelong care), helpless (to improve the situation of their loved one), guilty (about neglecting other aspects of home life or other family members) or angry (at the situation and a sense of injustice, and the loss of a previous life). The combination of demanding responsibilities and psychological stress can severely affect carers’ mental health, as Carers Worldwide has well documented.

![86%](86% of carers are concerned by their physical health (2021))

![89%](89% experience anxiety or depression (2021))

![48%](48% do not seek treatment due to lack of time or money (2019))

Despite this level of need, and in sharp contrast with the amount of time spent looking after a loved one, ensuring they maintain good health and are assisted in the performing of routine tasks essential to their development and well-being - such as feeding, hygiene, the administration of medicine and sometimes, additional care and exercises as part of home-based therapy - carers are not usually found to take good care of themselves. This may be because of lack of time, financial resources, or even complete unawareness of the impact that their caring role is having on both their physical and emotional health. Simply put, carers often tend to be so focused on taking care of the person supported that they end up neglecting their own health.

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4 From the data that is available, meta-analysis of 51 studies across 33 low-and-middle income countries (LMICs) found a negative impact on the social, mental, physical, and financial well-being of carers with 64% - 68% of carers reporting financial difficulties and 88% of carers reporting concerns of exhaustion and fatigue. (Thrush and Hyder, 2014).
To tackle this critical gap, Carers Worldwide has devised simple interventions allowing carers to become better aware of their health needs and access relevant support, ranging from general health check-ups to specialist consultations and access to subsidised medicines or assistive devices. Crucially, in order to be effectively accessed and used by carers these services and interventions need to be designed and delivered around the time and resources constraints they face. Carers Worldwide has responded to this through organising health camps taking place during carers support groups meetings or encouraging health professionals to deliver consultations at home or remotely over the phone. This has largely built on existing infrastructure through partnering with local health clinics to encourage them to expand their services to this largely underserved group and their unmet needs. As one recent consultation of carers in India has shown, an overwhelming majority (94.9%) would otherwise resort to alternative methods such as consulting a faith healer or seeking ‘religious treatment’ sometimes leading to inadequate remedy.

Training 458 community health workers, 152 partner staff and increasingly now carer representatives themselves to deliver barefoot counselling, carers have also been able to receive therapy, often for the first time, and access essential medicines to help relieve anxiety and depression. The latter is especially important in contexts where talking about mental health might be taboo and poorly funded in the first place, especially in the remote areas where Carers Worldwide supports carers.

### Health Provisions in Practice

At the end of a three-year project backed by the Commonwealth Foundation and supporting “the recognition and inclusion of carers of the disabled and mentally ill in India”, a final evaluation in 2017 found that carers experiencing anxiety or depression had dropped to 9% (from 61% at baseline), and that the intervention had significantly relieved their health worries (from 55% at baseline to 16%).

A project supporting 1578 carers in rural and isolated districts in western Nepal reduced the number of carers experiencing physical ill-health from 69% to 33% and those experiencing mental ill-health from 77% down to 33% (2017)

In Bangladesh, 97% of carers also reported improvements in physical and mental health (Impact Report 2021)

Besides accessing treatments or therapy that have often been life-changing for carers, it is worth noting how Carers Worldwide’s interventions to support community health workers have also helped transform their relationship with carers, resulting in better outcomes for all. Specifically, in resource-poor contexts where community-based rehabilitation is the preferred strategy to facilitate the care and social inclusion of people living with disabilities, carers play an instrumental role in delivering a range of activities, exercises, or home-based treatment to the person within their care. In this context, carers gain valuable skills or knowledge. However, in some cases carers have been labelled “non-cooperative” or singled out for failing to deliver one of the many steps of a CBR programme devised by health workers, doctors or therapists, without that professional understanding that the reason for this may be carer “burnout”. Ensuring health professionals are better informed and aware of the competing demands and emotional toll placed on carers results in them adjusting their communication and approach accordingly. This in turn has the potential to further improve the wellbeing of both the carer and the person receiving care.

“Previously [when working with people with disabilities] we were only looking through the curative lens to improve functioning…but supporting carers has helped us promote a feeling of working together, in tandem, with everyone benefiting. Now carers see taking care of themselves as an essential part of taking care of the person cared for”.

*Racheal Rayakumari, WORD, Carers Worldwide local partner in India*
A.2. SROI of Carers Worldwide Health Services

For every £1 invested we calculated a SROI of £6.07

The services delivered by Carers Worldwide and local partners include:

- Free health checks (health assessment camps) organised in partnership with local health clinics, typically conducted alongside carers support groups or project run community caring centres to take advantage of groups of carers already meeting
- Training local doctors and health workers to understand and take account of the needs of and constraints on carers
- Free or highly subsidised medicines
- Free or subsidised counselling through the growing network of barefoot counsellors and local specialists (where those are available in urban settings)
- Training of community health workers, partner staff and carer representatives in barefoot counselling
- Disseminating accurate information to carers about where to access affordable treatment or request support

The SROI for Carers Worldwide’s interventions to support carers’ health and well-being included the value for:

- Reduced anxiety and depression
- Improved physical health
- Access to treatment or treatment for persons cared for
- Increased income resulting from increased productivity/reduced absence at work

B. Income, livelihoods and education

B.1. Background and context

Looking after a relative or loved one affects all aspects of carers’ lives, and their ability to seek, perform work and earn an income is no exception. Because Carers Worldwide has specifically targeted the poorest households living in rural, remote and/or in other ways marginalised regions of India, Nepal and Bangladesh, the sudden additional financial impact of having a sick or disabled person in the family - including the costs of medicine and treatment, purchasing assistive devices and sometimes necessary housing adjustments to accommodate their needs - is an economic shock for families already living in or close to poverty.

In addition to new, costly, and often recurring expenditure, carers are faced with the irreconcilable dilemma of trying to continue to provide for themselves and the person(s) within their care, whilst struggling to maintain or access employment that is compatible with their caring responsibilities. This does not only affect women and men supporting children or relatives who may need ‘round-the-clock’ assistance. The multi-faceted and sometimes hidden demands attached to caring will vary for each family - from providing direct support at home, attending medical appointments, to being available at short notice to attend to emergency needs or experiencing illness or exhaustion as described in the health section above. Whatever the level of caring required, employment prospects and working patterns are almost always affected. In this situation, carers not only miss out financially but also on other important benefits of work such as the opportunity to socialise, develop professionally or gain occupational satisfaction, which in turn can fuel the negative mental health outcomes described previously.

The loss of income or additional barriers to access training or paid work resulting from caring thus represents an additional opportunity cost for carers and their families. Combined with the increased financial pressure from supporting the care recipient’s health, housing and other needs, family carers end up trapped or pushed further into poverty, a reality that Carers Worldwide’s investigation and surveys have evidenced persistently.

Against a complex backdrop and baseline situation - with typically up to 50% of carers targeted by their programmes having completed no education at all - Carers Worldwide’s interventions to improve carers’ financial resilience and security show that relatively small investments and well-designed solutions are not only possible, but impactful both for carers and their families.

With this in mind, the employment, training and education component of the Carers Worldwide Model stems from the finding that nearly all carers, when asked, express the desire to learn a skill so they can earn
an income. Although there are multiple reasons why paid work opportunities might be scarce or earnings unstable among the families targeted by Carers Worldwide (for example due to seasonal work or volatile yields from agriculture or rearing-related work), of significant importance is that on average close to 60% of carers state they are not able to find anyone to cover their caring duties if they were to return to work or engage in some kind of income generating activity. This suggests that while carers are typically excluded from the job market, many would be able, with adequate support and/or flexible working arrangements, to take on or continue earning activities.

In response to this, an important feature of the Carers Worldwide Model has been the linkages created with local, state or national government vocational training programmes in all three countries of operation. In India, working closely with local authorities the organisation successfully secured the inclusion of carers in the Jharkhand State Livelihoods programme, and the Mahatma Gandhi National Rural Employment Guarantee Act (MGNRGA). The focus is thus to encourage existing schemes to expand their reach to better serve the large and forgotten segment of the population made up of carers, rather than setting up new, parallel programmes.

When government programmes are not sufficient or available in certain project locations, Carers Worldwide supports its local partners to deliver livelihood trainings that are grounded in carers’ personal interests and local environments and are either within their skill level e.g. agriculture, poultry, or animal husbandry; or lead to suitable income generating activities that can be easily performed at home alongside caring responsibilities, such as tailoring and knitting. Where deemed necessary, carers receive additional start-up support such as equipment or small capital to purchase livestock, materials or seeds. To ensure alternative caring arrangements free up carers to attend training or conduct paid work, inventive solutions - such as groups sharing daytime caring for each other’s relatives with those earning paying those who do the daytime caring, thus resulting in income for both groups - are implemented. Increasingly, Carers Worldwide’s innovative Caring Community Centres have also become integrated hubs where skills trainings are organised while children or other relatives are being looked after, saving time and resources with activities being delivered simultaneously.

Where appropriate and possible, the relatives receiving care are also involved in the income generating activity, thus providing a form of occupational therapy as well as increasing earning potential for the family. The results of various projects that have deployed these simple interventions are a testimony to their feasibility, appropriateness and impact in the lives of carers and their families. Typically, since the activities are heavily context-driven they require only low-entry capital and a flexible time investment. Of particularly notable impact is the encouragement for carers to diversify their income by securing revenue from different business activities where feasible, which is a key driver of resilience to shocks and sustainability.

**Case study**

We provided Bhola with two goats and training on how to rear them, so that he could start to earn a steady income. The income he generated from selling his goats meant he could purchase and raise chickens for sale as well. Bhola then attended training on fruit and vegetable production and additional support from our project helped him to set up an irrigation system on the land around his house. This has meant he can now grow more vegetables and also kiwi fruit which are incredibly popular in the local area. Bhola’s daughter has also been able to access treatment and her condition is currently stable.

The final evaluation of the UK Aid Direct funded two-year project *Promoting Social and Economic Empowerment of Carers by Strengthening Women-led Carers Associations* found that 80% of the participants were lifted above the poverty line by the end of the project, as compared to 85% of the targeted carers living in extreme poverty at the start of the project (2021)
Over 10 years, 312 young carers are back in education
8,834 carers have taken part in livelihoods activities
(2021 impact report)

The impact of tailored training and flexible working arrangements is evident for all carers, but it is worth mentioning the additional benefits reaped for specific groups. First, when we know that up to 82% of carers are being financially helped by other family members, it is clear that improving the income prospects of a carer will bear positive impact and financial relief for other family members too. For women, who make up the overwhelming majority of carers supported by Carers Worldwide (upwards of 84%) improving their economic status can have transformative effects within the household. Project evaluations showed that women report enjoying an increase in their bargaining power resulting from their earnings (Promoting Social and Economic Empowerment of Carers by Strengthening Women-led Carers Associations, Project Final Evaluation, 2021).

Finally, Carers Worldwide has also supported a uniquely vulnerable group that see their life trajectories deeply affected by the caring responsibilities they have been entrusted with child carers. Just like adult carers see their ability to complete paid work compromised by the time and resources spent looking after someone, children’s education prospects are deeply affected by the often-irreconcilable demands deriving from caring. To resolve this, Carers Worldwide supports its local partners to facilitate alternative care arrangements, lobby schools to raise awareness among teachers and train community-based services to better support child carers, allowing them to re-enrol into education and access tailored support which minimises disruption to school attendance and learning outcomes.

“Carers Worldwide has focused on changing the whole system and architecture around carers so they are not dependent on handouts. It is about making it possible for them to care for their loved ones, whilst also pursuing their hopes and dreams.”

Jonathan Freeman, Chair of the Carers Worldwide Trustee Board

B.2. SROI of Carers Worldwide Training, Education & Livelihoods Activities

For every £1 invested we calculated SROI of £6.70

The services delivered by Carers Worldwide and local partners include:

- Delivering training to increase carers marketable skills such as literacy support, business development skills or budgeting
- Facilitating access to government livelihood training schemes
- Providing equipment or start-up capital to purchase materials, equipment or livestock
- Training employers to propose more accommodating working hours to support carers
- Supporting child carers to resume education, including paying for school fees, extra tuition to help them to catch up lost learning and running peer support clubs to allow child carers to meet each other
The SROI for Carers Worldwide’s interventions to support carers’ improved access to livelihoods included the value for:

- Increased income
- Improved living conditions
- Enhanced feeling of self-esteem / reduced anxiety
- Increased skills

“"We carers are very supportive of one another. While I was sick the other members of my Carers Group motivated me and it helped to establish my emotional wellbeing."”

Deumaya, Nepal

C. Socialisation and peer support

C.1. Background and context

As Carers Worldwide’s work and extensive consultations have demonstrated, carers face significant time and resource constraints on their ability to pursue essential activities, such as maintaining employment or looking after their own health. As a corollary and unsurprisingly, carers also commonly find themselves with little to no time for socialisation or respite, with the consequent risk of becoming socially isolated as a result of their caring role. This is a consequence not only of material lack of time, but also the real or perceived absence of resource persons carers feel they could entrust to watch over their child, parent or spouse as we have already highlighted. Even when there may be other suitable or capable members of the family within a household, caring roles and responsibilities tend to be so rigidly assumed and imparted (most often, by and to women), that carers have virtually no credible option for someone to substitute and relieve them.

Globally but especially in the regions where Carers Worldwide works, this de facto situation is further compounded by misconceptions and the stigma often surrounding disability and mental illness, where communities may associate these to a “curse” or wrongly believe that certain conditions - such as epilepsy or mental disorders - are contagious. Known as “courtesy stigma” or stigma by association, the ignorance about and/or rejection of persons with different needs within the community can end up also negatively affecting the rest of the family, and primary carers in particular. In concrete terms, this frequently means carers feel less inclined to enter the public sphere or attend social gatherings, let alone publicise their difficulties or ask for help. The combination of anticipated, self and effectively experienced stigma thus fuels cycles of marginalisation difficult to break, trapping many carers in loneliness and ostracisation.

In a consultation conducted among 334 parents of children with cerebral palsy, Carers Worldwide found that carers’ greatest concern was, for 76% of them, not receiving support from friends and family. Over half also worried about their friendships drifting apart and “feeling isolated and lonely as a result of their caring responsibilities”. Understanding the huge unmet needs of carers in accessing emotional support and opportunities to interact with peers, a central feature of the Carers Worldwide Model has been the creation of carer support groups. Spreading and consolidating steadily from 15 groups first set up in India in 2013, Carers Worldwide and partners today count 631 groups collectively supporting 11,358 carers.

Meeting monthly for a couple of hours, the carer-to-carer support meetings offer a welcoming and relaxed space where participants of the same locality or village come to know that they are not alone, find encouragement and access practical advice. The meetings may take place in a community, under a tree or outside the home of a member. Taking into consideration the cultural operating context and, particularly, reluctance among men towards their local community becoming aware of their “caring” status, groups sometimes also take place inside homes where male carers might feel more comfortable speaking openly.

The groups, each one made up typically of 10-15 members, allow carers to share their immediate concerns, reflect on their challenges and leverage collective problem-solving. Due to the prominence of the participants’ concerns in relation to their financial situation and security or lack thereof, more often than not the groups also become a vehicle for group-based savings and livelihoods activities.
Of course, some carers need access to alternative caring arrangements to be able to attend the group meetings, something that Carers Worldwide has creatively responded to, for example by encouraging family members to take up and fulfil a "secondary carer" role in the household or in the case of children receiving care, exploring options for inclusion into school, even on a part-time basis, depending on the child’s needs and local capabilities.

Another key innovation of the Carers Worldwide Model has been the introduction of Community Caring Centres, with 24 centres up and running across India, Nepal and Bangladesh to date. With initial set-up support from Carers Worldwide and the training of local staff and volunteers, the centres offer a local, affordable and quality day-care solution for parents of children with disabilities which ensure their child is not only looked after, but provided with tailored, relevant occupational, speech therapy, physiotherapy and special education input. The centres also provide paid work opportunities for local carers whose skills and experience are particularly suited and valuable, in addition to offering flexible working arrangements reconcilable with their own caring responsibilities.

Reviewing the impact the groups have had in carers’ lives, it is clear they have been a source of comfort and peer support, but also that they have emerged as essential gateways for carers to access relevant and sometimes life-changing information. Participants have been able to tap into the collective wisdom of others facing similar challenges in the provision of care, with some even leveraging the groups’ “authority” and expertise to convince spouses or other family members about the importance of a certain treatment or equipment. Participating in the groups has also enabled many to hear, often for the first time, about grants, insurances and schemes available to them. Group members are better positioned to receive structured information and advice from professionals, or meet with other stakeholders such as local administrators, community leaders and disabled people’s organisations to advocate for improved local provision and inclusion for both carers and those receiving care.

The benefits of the groups go yet further than the instrumental access to a newly found support network and carers’ social capital. Following the popular model of Village and Loans savings associations, they encourage members to deposit personal savings into a shared bank account with interest. Members whose group belongs to a Carers Cooperative may also access highly subsidised loans to weather economic shocks or invest in an income-generating activity or be eligible to apply for government funding towards livelihood activities or microcredits. A notable example is a project Carers Worldwide implemented in Nepal, in which over 1600 carers enrolled into support groups secured no less than 34 grants from local authorities.

In summary, the groups have become an essential feature of Carers Worldwide’s community-based approach in support of carers, with a positive impact on their mental, economic, and social well-being. Available on carers’ doorsteps and shaped by the members’ own communities, they are geographically and financially accessible, in addition to being socially relevant. Drawing on strong organising and community mobilisation models, Carers Worldwide has successfully promoted the groups not only as a critical entry point to support and information, but also the start of a journey for carers’ greater visibility and representation, which we zoom in on in more detail in the next section.

“Carers Worldwide’s group approach is quite unique. In many ways it is not too dissimilar to what you may find in the UK, but to establish such a framework in low-income settings, is really ground-breaking”

Callum Manson, Risk and Performance Manager, Mannion Daniels - UK Aid Direct Fund Manager
C.2. SROI of Carers Worldwide’s Socialisation & Peer Support Activities

For every £1 invested we calculated SROI of £11.25

The services delivered by Carers Worldwide and local partners include:

- Mapping to identify carers and forming local support groups
- Delivering training in human rights, leadership, facilitation skills
- Conducting regular activities in support of/together with support groups
- Facilitating groups access to savings schemes, loans or benefits
- The setting up of community caring centres

The SROI for Carers Worldwide’s interventions setting up and strengthening carers support groups included the value for:

- Access to key information on eligible benefits, schemes
- Access to peer support and collective problem-saving
- Reduced isolation, feelings of loneliness
- Opportunities for socialisation
- Access to respite breaks

“Now I feel valued and part of the decision making in the family as a result of Carers activities in our community, recognising us and what we do. I am now also a leader of the Carers Support Group in my community.”

Jesmin, Bangladesh

D. Visibility and representation for systemic change

D.1. Background and context

The previous sections have helped map and understand the multi-faceted repercussions of becoming a primary carer in the context of India, Nepal and Bangladesh, and how Carers Worldwide has responded to mitigate them. One more less immediately obvious but no less important effect of significant caring responsibilities is how they limit people’s ability to participate in social and political life, a situation that has been described as a “crisis by design”. In contrast with their overwhelming need for support and recognition, the combination of time, resource constraints, and social marginalisation too often trap carers in inaction, fuelled by a lack of confidence and knowledge of how to challenge the status quo. Yet for carers to be truly empowered, they need the information, capacity and space to articulate demands and influence government, and in turn to promote systemic and lasting change.

Understanding how a widespread lack of awareness about their rights directly undermines carers’ ability to claim and access services they might be entitled to, the Carers Worldwide Model harnesses support groups as key entry points to supply crucial information about allowances, benefits or schemes available to carers. Through research and interactions with local authorities and policy makers, the organisation has mapped key pieces of legislation directly relevant to the situation of carers and the persons within their care, highlighting key provisions and summarising in simple and accessible language ways to leverage them. In such an exercise
In a recent project supporting **1500 carers** to form and join **115 groups** in the state of Odisha, India, the groups, Carers Worldwide and local partners WORD, SPREAD and Ekta identified and supported carers and their family members to access **30 types of schemes or social advantages** ranging from disability allowances, scholarships, adaptive home equipment such as accessible entrances or toilets, widow or single parents’ pensions to start-up seeds or the allocation of land. Over the 24 months course of the project, the project secured **562,227,288 Indian Rupees** worth of support for its participants.

Over the past **10 years**, the work of Carers Worldwide and their partners have unlocked over **£850,000** worth of government support and investment.

“**WORD is one of very few organisations working in the remotest districts of the State [of Orisha]. Through our work with Carers Worldwide, we secured a visit from the Disability Commissioner at State level for the first time in history. Following on from this a State-level workshop was organised and carers were included in a Disability Forum. Authorities have pledged to take similar action in other districts**”

*Racheal Rayakamuri, WORD, Carers Worldwide local partner in India*

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conducted in India in 2019, Carers Worldwide identified and analysed no less than a dozen pieces of legislation spanning employment, disability allowances, pensions, populations living with HIV, rural employment or income tax.

Though a small number of allowances and benefits do exist in India, Nepal and Bangladesh, they are typically dependent on the presentation of official documents or bureaucratic steps that most carers targeted by Carers Worldwide might face difficulties navigating or face logistical barriers to completing. For example, it is estimated that less than one in every four persons with disabilities in India have been able to secure the Unique Disability Identity Card, a prerequisite to attest their eligibility and claim social benefits. In this context, groups offer an ideal forum to assess each carer and their families’ unique situation, with Carers Worldwide’s local partners then able to process applications on carers’ behalf and/or assist them throughout the process. As unpaid family carers by their very nature do not access financial compensation, ensuring households do not miss out on welfare claims is all the more crucial with both carers and persons cared for benefiting.

Besides accessing crucial and often life-changing information, groups have, even more importantly, become a space and lever for collective action led by carers themselves. In contexts where carers have traditionally been neither the subject nor target of government interventions, routinely overlooked and as a result holding little to no power or influence, Carers Worldwide has harnessed the evident potential of groups to promote and amplify their voices. Following on from carers bonding, discussing, and articulating shared concerns and objectives, carers become progressively more aware and confident of their increased bargaining power as a group. Upon inception, groups receive training in gender, social inclusion and human rights, alongside leadership and

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5 2019 India Policy Review
6 Tangled in red tape: the disability ID card process is steeped with gender barriers, accessed on 27/04/2022
facilitation skills. They are further supported to make links with community leaders, raise awareness of their needs and leverage resources.

Today, Carers Worldwide’s power and influence rests on 631 village groups, organised in over 40 cluster groups at block level, collectively representing the voice of around 12,000 carers. They are further represented by 8 Carers Associations in India - four at divisional level, four at district level - three in Nepal and one in Bangladesh, themselves comprised of carers representatives who have been elected by the village level-carers groups. The Associations meet quarterly to formulate responses to issues raised in the groups, plan engagement with government officials and to take part in capacity strengthening training. Registered as independent entities with local authorities, the Carers Associations are increasingly accessing local funding sources to further sustain and expand their reach. They also organise and take part in roundtables and high-profile events such as Carers Day Celebrations or the International Day of People with Disabilities. Through consistent investment and support to build their organising, lobbying and influencing capacity, the Carers Worldwide Model enables carers’ grassroots demands and preoccupations to be elevated to duty-bearers and gain visibility and traction in decision-making spaces. The ability of carers supported over two years to form and join 20 carers groups in Savar, Bangladesh and deliver the first-ever Carers Conference attended by the Ministry of Social Welfare, demonstrates the quick gains in visibility and recognition that can be secured from carers’ joint efforts and collective voice. Only 2% of the carers targeted were participating in any type of self-help group before the start of the project.

Crucially, Carers Associations’ collaboration and coordination with local government is increasingly turning carers into integral partners in local development initiatives, whilst also leaving them better positioned to secure carers’ inclusion in mainstream initiatives and political support. In the State of Karnataka, India, where Carers Worldwide is registered as a trust, the organisation has been recognised as a domain expert on the topics of caring, disability and mental health. Of notable importance is how the organisation, along with the State Level Carers Forum it has promoted, was able to leverage its weight of authority during the Covid19 pandemic, alerting the government to the unique needs of carers and securing priority access for over 140,000 carers to be vaccinated.

The review of Carers Worldwide’s advocacy demonstrates that carers’ participation in advocacy and mobilisation activities is not only their place and right, but an important driver of improved confidence and self-esteem. In an investigation of the impact of Carers Worldwide’s groups on participants’ empowerment in Nepal, the researcher notes that whereas carers previously used to hide away or sit at the very far back of community events, they now enjoyed a renewed sense of status and belonging, with community members more aware and respectful of the important role they play within society.

This fight for due recognition has been central to Carers Worldwide’s challenging the very inconsistencies and unfairness surrounding the lack of compensation for carers, despite governments making them de facto partners and crucial components of their policies - for example as part of national ageing strategies - so clearly. Carers Worldwide’s ability to secure policy change recognising for the first-time carers’ right to financial support in India’s Rights of Persons with Disability Act and Mental Health Bill shows the pertinence of requalifying the undervalued work of carers so it can be identified as “eligible” and be rightly remunerated.

The next stage of Carers Worldwide’s advocacy efforts focusses on strengthening State Level Carers Forums across India and building National Alliances of Carers in India, Nepal and Bangladesh. Discussions about a South Asia Carers Alliance are also underway. Co-ordination at this scale will further embed and scale up the changes required for long term transformation of carers’ lives.

7 Testing an approach to the social and economic inclusion of impoverished family carers in Bangladesh, Evaluation Report, 2020

“What is really unique about Carers Worldwide is the combination of their 'boots-on-the-ground' work and engagement with policy-makers. As part of the Embracing Carers initiative, they are the only organisation doing such work in South Asia”.

Jasmine Greenamyer, Vice-President of Global Partnerships and Initiatives including Embracing Carers, EMD Serono
Carers Worldwide is also regularly feeding into relevant conversations at international level - for example, participating in the Commonwealth Civic Society Health Policy Forum or Global Disability Summits and more importantly, increasingly shaping agendas and global initiatives. The organisation is an active member of the International Alliance of Carer Organisations (IACO) and at the peak of the Covid19 pandemic provided crucial insights into the needs and experiences of carers as part of the Global Carer Well-being Index, as one of ten members of the global Embracing Carers initiative.

**Case study: The Government of India’s Rights of Persons with Disability Act 2016**

Though the legislation stipulates that a “caregiver allowance” should be available to carers of persons with disabilities who have high support needs, Carers Worldwide found that out of an estimated 400,000 – 600,000 carers in the Karnataka state who may be eligible, none of them were claiming it.

In collaboration with local partner NGOs, community-based organisations, disabled persons organisations and carers associations, the organisation engaged in intensive coordinated advocacy efforts to address this. This included raising awareness of the caregiver allowance among government officials, public health workers and rehabilitation staff via circulars and meetings, disseminating materials to government representatives and following up with face-to-face meetings, mentoring teams of carer representatives at district level to engage in local lobbying with government and community workers and information sharing with other carers. As a result of this strategy, Carers Worldwide secured commitments from the Mangalore City Corporation, Udupi City Corporation and Bagalkote City Corporation who agreed to develop the processes for granting the caregiver allowance, resulting in more than 1,500 now in receipt of the allowance. Applications from more carers continue to be submitted to the authorities in other districts in Karnataka.

As this section clearly highlights, Carers Worldwide’s focus on equipping carers to influence and shape decisions affecting them has critically paved the way for a carer-powered movement, effectively capable of advocating for the rights of carers and taking matters into their own hands.

“This project guided me in the way to lead my life. Since I have been attending my Carers Group I have built my courage. No matter how difficult it may be, I have the strength and courage to lead a life.”

*Balamma, India*
D.2. SROI Carers Worldwide’s Visibility and Recognition Activities

For every £1 invested we calculated SROI of £7.18

The services delivered by Carers Worldwide and local partners include:

- Delivering training in human rights, facilitation and leadership skills to groups
- Conducting regular activities in support of/together with support groups
- Organising carers day celebrations and other high-profile events
- Facilitating meetings with key stakeholders including State officials
- Convening regional civil society workshop for learning and exchange

The SROI for Carers Worldwide’s interventions promoting the visibility and recognition of carers has taken into consideration the value of:

- The benefits and allowances secured as a result of revised legislation
- The increased visibility and funding gained for carers initiatives
- The increased social cohesion and participation of carers in community activities
- Increased knowledge of carers’ needs at government level

“The carers’ project is a blessing for me and my child. I have never been respected as a human being and the carers’ project has taught me to recognise myself and live as a carer, a human being. Now I am not ashamed to be a carer, being a carer is my first identity.”

Nazma, Bangladesh
As the impact review and Social Return on Investment analysis of Carers Worldwide’s work have clearly demonstrated, the organisation’s model of intervention impacts virtually all aspects of carers’ lives, creating the conditions to improve their emotional, physical, mental, and economic well-being and functioning. These in turn have ripple effects on the persons they care for, their families, community members as well as community health workers and government agencies whose work critically depends on a healthy, sustainable and resilient carer workforce population. With this in mind, it is both relevant and important to zoom out and situate the impact of the organisation in a larger perspective and reflect on its significance for the broader objectives of social justice, equality and national development.

Using the 2030 Global Goals as a key reference framework, it is evident that Carers Worldwide’s contributions are cross-cutting several Sustainable Development Goals. Carers naturally represent a significant segment of national populations entitled to quality, relevant and affordable healthcare in their own rights, making investing in their well-being directly relevant to SDG3. Given how unpaid carers largely subsidise governments by providing essential support to national populations in need of assistance due to frailty, illness or disability, supporting their physical and mental health is both a condition and an enabler of realising good-health and well-being for all. With recent research estimating that greater investment in care could create almost 300 million jobs by 2035, it is clear that supporting carers to secure adequate and practical livelihoods is also key to realising inclusive growth, and decent and productive employment for all (SDG8), as well as to reducing poverty (SDG1). In line with Carers Worldwide’s approach, this includes both providing carers with employment opportunities that are compatible with their caring responsibilities, whilst simultaneously recognising that the services they deliver constitute valuable and productive work. The organisation’s tackling of both barriers to the job market and the effective realisation of carers’ right to benefits and allowances, makes them an important contributor to reducing inequalities (SDG10) too. The Carers Worldwide Model indeed challenges the multiple exclusion and discrimination points carers may face, and lobbies to ensure they are equitably and adequately included in social protection policies. Other specific initiatives such as those in support of child carers, ensuring they do not have to make a critical choice between their caring responsibilities and attending school further supports progress towards SDG4. Indeed, such interventions allow inclusive and equitable access to education for a group that is, without appropriate affirmative action and investment, particularly likely to be left out of mainstream policies and programmes.

“Carers, by virtue of their caring trajectories, needs and experiences, touch multiple intersections of the Global Goals. Women, who make the majority of carers, are of course regularly consulted to shape the programmes: what they want to work on is up to them, and they usually want to access livelihoods and economic independence. Carers Worldwide’s model ensures their involvement in food production and agriculture... they are in turn able to generate income and actively participate in the economy”.

Chris Underhill, Founding Chair of Trustees and Ambassador of Carers Worldwide
Last but not least, with the overwhelming majority of the providers of care being women, Carers Worldwide’s commitment and very mission to design, secure and deliver carer-specific services and policies, constitute an indisputable contribution to achieving the promise of SDG5: gender equality and empowering all women and girls. Indeed, where the expectation that caring is to be performed by girls and women behind the scenes effectively allows boys and men to pursue formal, paid employment, facilitating carers’ access to employment opportunities and financial security is fundamental to tackling persisting gender inequalities. Alongside the immediate benefits of raised income, feedback from women carers taking part in Carers Worldwide’s programmes highlights the transformative change in household dynamics following on from participating in carers groups and conducting income-generating activities. This is a result of changing perceptions among family members, including husbands and partners, who become increasingly aware and more prone to sharing care responsibilities but also critically of a greater sense of agency and self-efficacy among women themselves, as an evaluation of Carers Worldwide’s work in India perfectly illustrates.

The above sought to highlight the relevance of Carers Worldwide’s model for the Global agenda. The connections highlighted show that the links are multiple, and that supporting carers is not a mere contribution but a potential key enabler of gender equality, justice and the eradication of poverty in low- and middle-income countries. Increasing calls for supporting “an ecosystem of transformative care policies, which would have benefits for workers (both women and men), children, businesses, societies and the planet” show that the movement towards investing in carers is gaining evidence and momentum, and rightly so as making the right to care and to be cared for a reality for all has overarching implications for the sustainability of humanity.

<table>
<thead>
<tr>
<th>Carers Worldwide’s change criteria</th>
<th>Additional / related metrics of interest in “carers” community, stakeholders and donors (for example: IACO’s principles for carers)</th>
<th>Contribution to SDGs: Leaving no One Caring Behind</th>
</tr>
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<tbody>
<tr>
<td>Health, well-being and functioning</td>
<td>Reduced loneliness, increased mental health</td>
<td><img src="image" alt="SDG1" /> NO POVERTY <img src="image" alt="SDG3" /> GOOD HEALTH AND WELL-BEING</td>
</tr>
<tr>
<td>Levels of income of carers’ households</td>
<td>Financial security, financial literacy, fair and dignified working conditions and compensations</td>
<td><img src="image" alt="SDG4" /> QUALITY EDUCATION <img src="image" alt="SDG5" /> GENDER EQUALITY</td>
</tr>
<tr>
<td>Strength and functioning of carers’ groups</td>
<td>Increased participation and voice, representation, enhanced skills, and knowledge</td>
<td><img src="image" alt="SDG8" /> DECENT WORK AND ECONOMIC GROWTH <img src="image" alt="SDG10" /> REDUCED INEQUALITIES</td>
</tr>
<tr>
<td>Levels of change in policy and practice</td>
<td>Improved data and understanding of the needs and rights of carers, increased accountability,</td>
<td></td>
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* Care policies are defined as public policies that allocate resources in the form of money (including income), services or time to caregivers and to people who need care. International Labour Organisation, Care at work, Accessed on 12/04/2022
THE NEXT 10 YEARS: SPARKING A CARING REVOLUTION

Reviewing Carers Worldwide’s work over the past ten years has provided key insights into the many ways the organisation has impacted carers and the dependents and loved ones they look after in India, Nepal and Bangladesh. We have seen how the organisation has captured and responded to the needs and demands of carers, examined and documented the effectiveness of the Carers Worldwide Model and witnessed how carers’ voices, supported to organise themselves and influence change, are fuelling a growing and ambitious carers’ movement. Backed by solid evidence and fruitful partnerships secured with local NGOs and government partners, Carers Worldwide’s ten-year anniversary provides a key vantage point from which to reflect on tactical alliances and strategies to further pursue in order to scale up the impact of the organisation and reach even more carers over the next decade.

With the population in need of care projected to continue steadily increasing worldwide by 2050 as a result of ageing, other shifts such as changing family structures, labour force migration and increased female participation in the workforce, the demand on family carers is projected to increase particularly dramatically in low-and middle-income countries. Whilst this shows that organisations such as Carers Worldwide will remain and in fact become increasingly important and relevant in order to champion the investment needed to support family carers in a dignified and sustainable manner, the size and scale of the challenge ahead calls for the quickest and most efficient ways to achieve the level of change needed.

Firstly, building on the growing network of local NGO partners – currently 15 and set to increase - that Carers Worldwide works with will remain an essential feature and driver of efficiency to ensure more and more carers are reached. Even though the organisation focuses primarily on low-income, tribal and rural populations, typically severely underserved due to a combination of scarcity of public infrastructure and services which may exist in the areas where they live being oblivious to their needs, carers are unlikely to exist completely ‘off the grid’ from government programmes or local community-based initiatives. Rather, carers are likely to interact, whilst remaining largely invisible, with a range of organisations or services focused on the needs of the persons cared for, a situation largely confirmed by the history of Carers Worldwide’s partnering with local NGOs who had been working, sometimes for decades, for persons or children with disabilities without developing specific initiatives benefiting the carers looking after them. Owing to the relevance and prevalence of situations where vulnerable groups might find themselves in need of long-term care - whether due to ageing, disability, mental illness or the range of chronic health conditions - there is tremendous untapped potential for Carers Worldwide to support ‘mainstream’ organisations to include carers in their existing programmes, incorporate carers-specific services, or both. This could be easily achieved through training and knowledge sharing, with an opportunity for Carers Worldwide to sell its expertise and model as part of a social franchise or consultancy package.

Two groups of organisations appear as strategic allies to achieve impact at scale moving forward. Disability-focused organisations, already a partner of choice of Carers Worldwide (presently 11 out of their 15 local partners support people living with disabilities as their primary mission) offer prime entry points to unpaid family carers, in addition to having much to gain from including packages of support for parents and other family members playing a crucial role in the lives of people with disabilities. Adopting a whole-family approach,
ensuring carers are adequately supported to deliver the care and linkages to other services (such as doctor visits, legal or administrative appointments) they are de facto expected to provide, is key to building a strong and sustainable supportive system for people with disabilities in the long-run.

Women’s rights organisations, and any parties interested in gender transformative programmes and advancing equality evidently share overlapping and complementary objectives to those of Carers Worldwide too. With the provision of unpaid care worldwide relying disproportionately on women and girls, investing in practical services and solutions ensuring carers do not have to renounce employment or education as a result of bearing the majority of caring responsibilities, is quite simply an essential requisite to enabling woman to pursue opportunities according to their choices and preferences, and to fulfil their life potential. The recent commitments made by the Generation Equality Forum to provide care for carers as one of five core objectives underpinning its Global Acceleration plan to make gender equality a reality by 2030 further illustrates these crucial links. Carers Worldwide’s track record of promoting carers’ economic independence and the subsequent impact on improving the balance of caring responsibilities and family dynamics make them a key resource partner whose expertise would directly support efforts aimed at reinventing a more gender equal approach to care.

In the ecosystem of healthcare, and the care economy in particular, the private sector is poised to become an increasingly important stakeholder, both in the delivery of paid-for care and in the provision of flexible working arrangements that take into consideration the juggling of caring responsibilities that is a reality for so many potential workers. Already in its early stages, Carers Worldwide’s endeavour to train employers to deploy “carer-friendly” policies - for example facilitating peer support and offering more flexible working hours - has significant potential to continue expanding livelihood opportunities for carers and enabling carers already in work to remain employed, whether they live in rural areas or more urban centres. At the same time the organisation is in a unique position to pioneer, refine and scale up a social enterprise model of paid-for care, through which payment for care made by households with higher incomes would be reinvested in the organisation to enable continued partnership working with families in lower-income settings, whilst at the same time developing a workforce of high calibre, paid carers and offering relevant employment opportunities that will remain in high demand.

Finally, the commitment of Carers Worldwide to respond to unique individual needs resulting from the variety and diversity of experiences of caring for a loved one is set to lead the organisation to continue developing inclusive and innovative solutions that respond to carers’ ever evolving needs. Looking at demographic and urbanisation trends in a 10-year horizon, this will include continuously tracking developments and tailoring services to support, for example, ageing persons providing care as well as the next generation of carers who are more likely to be educated and seek to reconcile careers and caring responsibilities. Building on a vast

“People with disabilities entire lives depend on carers. Whatever services we initiate, carers are part of the solution. We can strengthen government support and services, but who will take them to the services? Carers act as a bridge between families and service providers. Not looking at them will never be sustainable”.

Noman Khan, Founder and Executive Director, Centre for Disability in Development, local partner in Bangladesh
experience of conducting routine consultations with carers and their families, co-designing projects and responding to participants feedback, all of which has become standard practice for the organisation, Carers Worldwide is well positioned to continue supporting carers into the future, shaping support and ambitions in a spirit of co-production with both carers and partner organisations. The ultimate aim is to overturn the exclusion and invisibility of groups finding themselves at the intersection of multiple disadvantages, and in turn contribute to preventing and dismantling growing inequalities.

Of course, carers themselves will continue leading the way to voice their demands for equality and recognition, drive change and steer the direction of the organisation. The incredible gains in visibility and representation Carers Worldwide has achieved for and with carers in just ten years demonstrates the capacity of carers to organise, challenge injustice and write a different story for themselves and society. Steady investment in the capacity of carers groups, cluster groups, Carers Associations and all the way to national alliances of carers, ensuring resources and advocacy capacity are well channelled, and the safeguarding of civil spaces all have the potential to unlock unyielding progress for carers and their families. A global carers’ movement is mostly truly well underway.