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**Addressing the issues of unpaid family carers in low and middle income countries**

# Two experiences...

## Mental Health...





# Family...



# Purpose of the feasibility study

- To explore and consult on the needs of carers in in India and South Africa and how these might be addressed as part of the development agenda.
- To seek the opinions of experts within the sectors working with disability, mental health, HIV/AIDS, chronic illness and the elderly in both urban and rural communities.
- To verify an approach to address these needs and to identify an opportunity for developing future responses.



# The issues and problems facing carers

Carers are particularly hard hit in a number of different ways as a result of their caring role. These include:

- loss of employment;
- reduction in earnings;
- loss of education (in the case of children and young people);
- poor health;
- reduction in social contacts;
- reduction in opportunities to participate in family and socio-cultural activities.

*“We are voiceless, the most marginalised and excluded in every aspect of life.”*

Sabina, mother to a child with autism, Bangalore



In conclusion...

**Many organisations stated that they were already working with carers.**

But, this was only to meet the needs of the person being **cared for**, and did not look at the needs of the carer as an individual.

6 Million Carers in UK

1 in every 8 adults

=

£119B

saving to UK economy



1.2 Billion  
population of India



400%  
increased  
need  
for Carers

10+ million  
with severe mental illness

3.7 million  
people with dementia

20 million  
people with a disability



These adults  
and children  
all have carers...

...but just how many?



# Care: an unequal responsibility of women and girls

“....in most societies the norm is for women to be primary carers. This unequal distribution of unpaid care work arises from prevailing gender norms and values.”

(Chopra and Sweetman, Gender and Development, Vol.22, No.3, 2014)

**“Unpaid care work occupies large amounts of women’s and girls’ time, restricting participation in civil, economic and social spheres, and also in public life.”**

(Bulender, 2008, P13, The Statistical Evidence on Care and Non-Care work across six countries, Geneva: UNRISD)

\*Six countries: Argentina, Nicaragua, India, South Korea, South Africa and Tanzania

# Women's unpaid care work: the human rights framework

- The right to work
- Rights at work
- Right to health
- Right to education
- Right to social security
- Right to participation

But what about carers' rights?



The vision of Carers Worldwide is a world in which the **needs** of every carer are routinely met in order to achieve **physical, emotional, economic and social wellbeing** for each individual



Our mission is to enable carers, service providers, policy makers and other stakeholders to **recognise and respond** to the **needs of carers** in the developing world, ensuring balance and equal value is given to the needs of the carers and the person receiving care





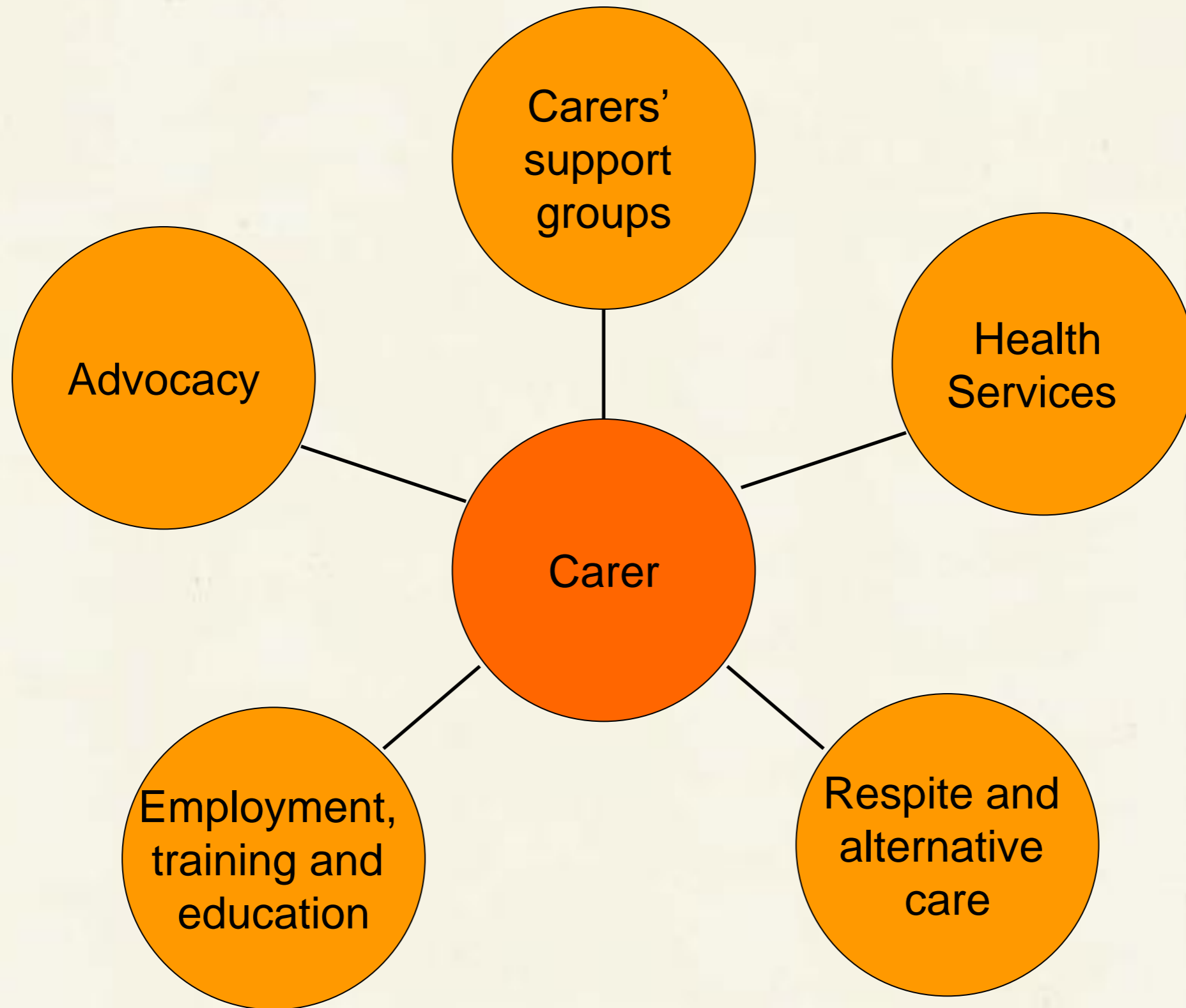
# How we operationalise our mission...

We serve as a **catalyst** to:

- **Bring about systemic change** in the work of various stakeholders so that they recognise and respond to the needs of carers in the developing world
- **Facilitate the provision of support** for individual carers and their families in the developing world, bringing them better health, wellbeing and economic security.







The Carers Worldwide **model** ensures **positive change** for carers

# What we do for Partners...

- Raise awareness
  - Design and develop programmes appropriate to the people they work with
  - Carry out training and capacity building
  - Carry out research to help 'build a case'
  - Help them to work at a broader policy level
- ⇒ Capability to work independently with carers





# Our work in action...

This is Gowri with her father, Srinivas. Her story is just one of millions...

- Her mother left because she couldn't cope
- Gowri became carer, cleaner and cook
- The family became destitute and Gowri had to abandon school
- She became ill through lack of female guidance and care





Now thanks to our work with our partner organisation...

Gowri has finally been able to return to her schooling

Srinivas has an income from selling mobile phone cards

Both of them are part of their local community again

“Life is still hard, but now we are better able to cope and finally feel we have a future...”



## Where we are now...

- 4 partner organisations, 3 states across north and south India, and Nepal
- More than 3,000 vulnerable carers and their families, touching the lives of 12,000 people
- 55% carers engaged in livelihood activities

<b>Carers:</b>	<b>Cared for:</b>
Female: 73%	Child with Disability: 55%
Male: 27%	Adult with Disability: 14%
Children: 11%	Child with mental illness or epilepsy: 5%
	Adult with mental illness or epilepsy: 26%



# To finish, comments from the field...

“The carers programme helped me to get a job looking after other children. I can do this alongside looking after my own disabled child. I have got a steady income and it means I can also get out of the house.”

***Parvati, carer supported in partnership with SACRED***

“We understand now that we need to include carers in government programmes. Your work is showing us how to go about that.”

***Local Development Officer,  
Kurnool district (SACRED  
project area)***

“This work is mandatory for us now. We have changed our whole approach. Now, we work with the carers first, strengthen them and then turn our efforts to the affected person.”

***Hampanna, Asst Director of  
Disability Programmes, SAMUHA***



For more information about Carers Worldwide:

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

[www.facebook.com/carersworldwide](https://www.facebook.com/carersworldwide)

[www.twitter.com/CarersWorldwide](https://www.twitter.com/CarersWorldwide)

Thank you!

