



REGIONAL LEARNING EXCHANGE WORKSHOP

Caring for Carers: Creating a Network of Support



SUMMARY OF WORKSHOP

DATE: 26TH SEPTEMBER 2019

LOCATION: BANGALORE, KARNATAKA

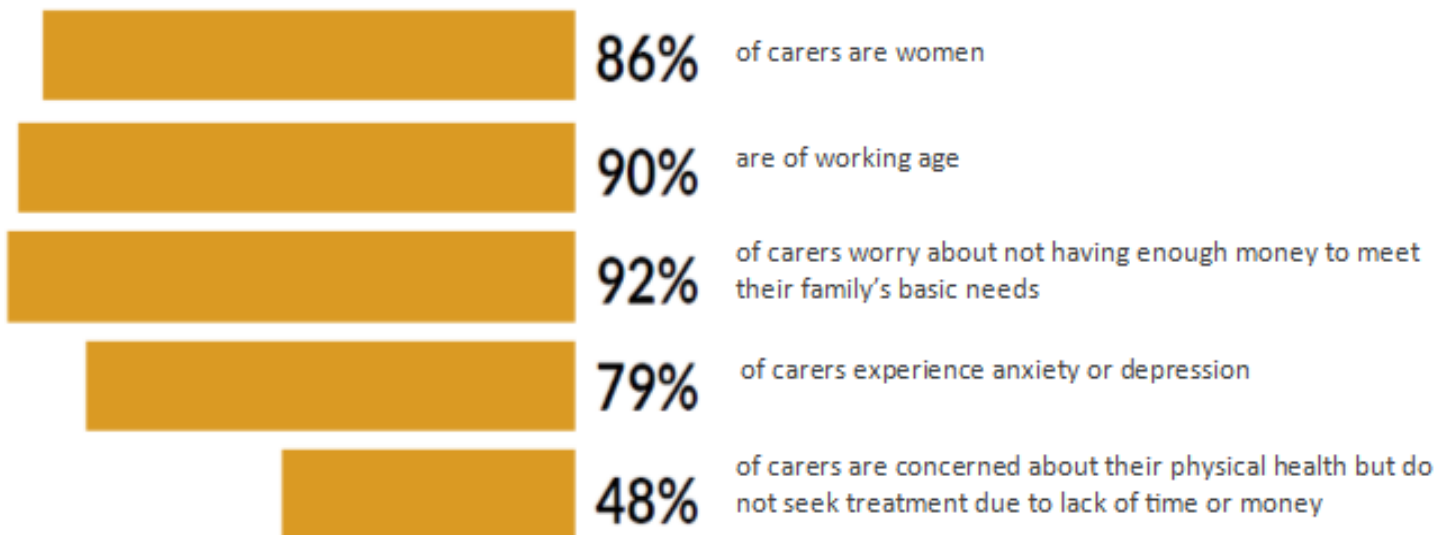
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WORKSHOP BACKGROUND INFORMATION

Caring is a global issue that impacts us all. Whilst many organisations assist people with long term illnesses or disability, the needs of their carers – most of whom are unpaid family members – are widely neglected.

FACTS ON CARING



Caring can be a rewarding role for but at the same time it can have a negative impact on the physical, mental, emotional, social and economic wellbeing of carers. In low-and-middle-income countries (LMICs) there are very few NGOs or government resources that provide support to carers.

“Carers are the invisible army of people keeping everything going. They are among us but we don’t have eyes to see them.” - Anil Patil

In LMICs such as India, the demand for care is continuing to increase. People are living longer lives, there is a rise in the number of people living with chronic diseases and a rise in the number of persons living with mental health conditions. Despite the important contribution carers make to society, there is limited official recognition of carers in development programmes or in government agendas.

Carers Worldwide is a UK-based NGO established in 2012 to address the challenges facing carers in LMICs.

We currently operate in India, Nepal and Bangladesh, working in partnership with local organisations to transform the lives of over 58,700 carers and family members of those affected by disability and mental illness.

We are the only international NGO working exclusively and strategically with unpaid family carers in LMICs with a strong belief that carers require recognition, inclusion and support in order to improve the quality of their lives and those for whom they care.

OUR APPROACH

The Carers Worldwide model comprises 5 core elements: carers' support groups; health services; advocacy; respite and short breaks; and employment, training and education. Together, these elements holistically promote the wellbeing of carers.

We act as a catalyst to facilitate rapid change in awareness, attitudes and service provision for carers by forming strategic partnerships with local NGOs and other well established organisations who can implement our model.

To increase our impact we work closely with policy makers in government, NGOs and INGOs at local, state and national level to create systemic change in attitudes and support for carers.

OUR WORK IN INDIA

From a pilot project with just 250 carers in 2012, our work has now changed the lives of almost 42,000 carers and family members across 4 states of India. We currently work with 7 NGO partners in Odisha, Karnataka, Andhra Pradesh and Jharkhand. We have also registered Carers Worldwide India, our first independent in-country entity which will allow us to mobilise local resources and expand our work with a range of stakeholders.

Our Strategy is to:

- ensure carer-specific services are developed to lessen the burden of caring and improve the quality of life of carers and those for whom they care
- promote carers' participation in their own development by empowering them to engage with local carers networks and district-level Carers Associations to demand their rights and services from government at local, state and national level



THE WORKSHOP



In September 2019, a state-level workshop was proposed to be held in Karnataka for the South.

The aim of the proposed workshops was to exchange experiences and knowledge, encourage action to be taken that will shape policy, develop existing partnerships and build new, long-term networks with a diverse range of stakeholders who can support the rights of family carers throughout India.

We seek to acknowledge and build upon the understanding that the number of persons requiring care will continue to grow due to demographic changes, and that it is essential to protect and promote the health and wellbeing of carers which will enable them continue to provide high-quality care for those they care for.

WORKSHOP OBJECTIVES

- i. Develop a clear understanding about the role of unpaid caring and the challenges unpaid carers face
- ii. Provide a platform for Carers Worldwide and their Indian-based partners to share insights on their work with carers
- iii. Offer information about existing policies that can be utilized to empower carers

WORKSHOP OUTCOMES

- i. A network of stakeholders who are knowledgeable and interested in the carer's issue
- ii. The creation of a space from which empowered carers can share their experiences
- iii. An increase in the number of carers accessing benefits and resources available through existing policies



INFORMATION FOR WORKSHOP PARTICIPANTS

Attendees included government representatives, academic institutions, relevant NGOs, corporations, funders, supporters and media outlets. During the workshops, participants:

- i. Shared and discussed results from a review of existing legislation and policies which are relevant to carers
- ii. Shared and discussed results from a recent review of our current project taking place in Odisha—which has found that 70% of carers within that project are now accessing government benefits
- iii. Were provided spaces for discussion between representatives of Carers Worldwide and other workshop participants
- iv. Proposed and planned future action that will be taken to ensure carers can obtain and access their rights

KEY MESSAGES FROM WORKSHOP

This section presents the key messages that arose out of the workshop in relation to the three workshop objectives presented above. 5 sessions were held with contributions from expert speakers, partner staff and carers (all of whom are named in Annex 2). A special mention is given to all the moderators and facilitators of the sessions who were: Dr Srikala Bharath, Professor of Psychiatry; Dr. B. Indiradevi Professor of Neuro Surgery, NIMHANS; Dr Thelma Narayan; Mrs Indumathi Rao, CBR Network, Bangalore; Prathima Murthy, Professor and HOD, Department of Psychiatry; Dr L. Suman Professor of Clinical Psychology NIMHANS; Prathima Murthy, Professor and HOD, Department of Psychiatry; Dr L. Suman Professor of Clinical Psychology , NIMHANS; Mrs K. Leelavathi, IAS, Director Department of Empowerment of Differently Abled and Senior Citizens; and Dr N Janardhana, Additional Professor, NIMHANS.



OBJECTIVE 1: Develop a clear understanding about the role of unpaid caring and the challenges unpaid carers face

SESSION 1

The first session opened the workshop and set the scene by referring to carers as torch-bearers. Dr. N Janardhana highlighted the fact that at some point in our lives we will all perform the role of caring, be it for the short-term or the long-term, and that this role will disrupt the schedule of our lives. He then stated that carers do not get the recognition that they deserve, and that stakeholders and NGOs should include a carer's component to their existing work to reduce the burden that carers face.

Shri V.S. Basavaraj Commissioner Persons with Disability Act Government of Karnataka supported the comment by Dr. N Janardhana in regard to existing NGOs needing to shift their focus from the solely on persons with disabilities to including elements that focus on carers. He raised the point that collective work and structural change is required to support carers and that a social model should be point in place.

Mrs Sulochana Das Commissioner Persons with Disability Act Government of Odisha discussed the fact that carers never have free time and that they need more support from government, society and organisations. During her talk, she declared that the Government is empathetic to the situation

of carers and made a promise to share the issue of carers across other states in Odisha outside of those were projects are currently active.

“I promise to share the issue of carers across other states in Odisha outside of those were projects are currently active.” - Mrs Sulochana Das Commissioner Persons with Disability Act Government of Odisha

Mr Anil Patil, Founder and Executive Director of Carers Worldwide spoke of the importance in recognising the role of carers and the need to acknowledge and advocate for their rights. He also shared his own personal story that was the motivation behind the establishment of Carers Worldwide.

The final key comment from the first session from Dr Gururaju who raised the issue that according to the National Mental Health Survey in India there are 115 million persons in India who require care. He also noted that the number of persons living with chronic diseases will continue to rise in the future and that this is going to increase the demand for carers. Going forward, three actions should be taken to look after the wellbeing of carers and those steps are:

- Knowledge sharing
- Preparing and developing the skills of carers
- Establishing Frameworks at an Official level to support carers

SESSION 4

In session 4, Mr. Alex Rodrigues suggested that the issue of caring is not going to be raised by the state and that Carers Self-Help Groups and Federations need to come into the public domain and create a movement for change. The solution to the problems carers face lies within society.

Dr Rachit Negi discussed the work of the Live Love Laugh Foundation and how they are collaborating with Carers Worldwide to design a model for carers that can be presented to Government with the aim of it being rolled out across the country.



Mr Manoj Chandran spoke about how the Mental Health organisation, White Swan Foundation, has created content specifically for carers. Attention needs to be given on how to educate carers to be good carers but also for them to learn about their own rights and empower themselves.

Dr Rajani P Deputy Director DMHP Karnataka State Health & Family Welfare Services presented the 2017 Mental Health Act and how the health profession and Government could support carers of persons living with Mental Illness.

OBJECTIVE 2: Provide a platform for Carers Worldwide and their Indian-based partners to share insights on their work with carers

SESSION 2

The second session gave an opportunity for the South Indian project partners of Carers and the carers they work with to showcase their successes and achievements to date. EKTA noted that they have covered a total of 634 villages in their district and have worked with 1501 carers who are members of carers groups. WORD shared information about health camps that they have established and alternative care centres. SACRED shared a story about carers engaging in new livelihood opportunities since becoming involved in the Carers Project and watching YouTube videos on how to make food products which they now sell for a profit. SAMUHA presented their plans to increase their advocacy efforts to influence policy change for carers at the Government level and carers shared personal stories about how they used to contemplate suicide but how those feelings and thoughts have subsided since becoming involved with the Carers Project. SPREAD drew attention to the increase in benefits that they have assisted carers and their families in accessing from the Government – a total of 30 million rupees over 2 years across 4 blocks in 1 district.

Several carers shared their inspiring stories:

- Chaitan Naraji, Vice-President of Maa Birakhamba Block-Level Federation, Odisha, who stated that Carers and Persons with Disability issues were not formally recognized but after Carers Groups were formed, they have started to be recognized at the Gram Panchayat and Block Level with PRI, Health, and Education departments paying particular attention. This is very good recognition for the carers.
- Kotramma from Muddaballi village of Koppal Taluk, Karnataka expressed she was not aware of any schemes or programs before joining the carers groups but since joining has learned many things and has built the confidence to make demands for her entitlements from the local Gram Panchayath.
- Somanath Jani from Khajuripud village, Laxmipur Block, Koraput discussed how carers group members are now applying and benefitting from different government entitlements and how there has been an income increase for many carers who have taken up different livelihood activities.

“Carers and Persons with Disability issues were not formally recognized but after Carers Groups were formed, they have started to be recognized.” - Chaitan Naraji, Vice-President of Maa Birakhamba Block-Level Federation

To conclude the second session, Dr. B. Indiradevi stressed that changing the economic situation of carers is beneficial to the lives of carers and their families but that alone is not enough, and stakeholders need to be aware of the mental stress that carers face.

OBJECTIVE 3: Offer information about existing policies that can be utilized to empower carers

SESSION 3

The third session opened with Mr Manoj Chandran discussing the newly-launched Karnataka State-Level Carers Forum. The Forum is a multi-task committee focusing on a range of carers of persons with disability, cancer, old-age etc. The purpose of the forum is to promote recognition, raise voices and promote inclusion of carers, and to develop a state-level strategy framework. The forum held its first meeting this year and there is a call for such forums to be established in other states of India.



Victoria Nicholson introduced a Policy Review which has recently been compiled by staff of Carers Worldwide. The Policy Review can be found in full in Annex 1.

Policy Review

The policy review introduces a selection of existing legislation, policies and schemes in India that could be utilized by carers in order to improve their economic and social wellbeing. Texts which refer specifically to carers have been included in the review; however, such references are scarce. The review also includes legislation, policies and schemes that could be made applicable to carers, even if they do not refer to carers specifically. As well as discussing which existing entitlements and benefits could be accessed by carers, the review makes suggestions on how existing legislation, policies and schemes could be further developed to offer even greater protection for carers.

It is hoped that the review will be used as a starting point to encourage future discussions on policy engagement and advocacy processes that will transform the lives of carers and, in turn, those they care for.

Policies Discussed

The following legislation, policies and schemes are discussed in the review: Mahatma Gandhi National Rural Employment Guarantee (MGNREG) Act 2005; The Maintenance and Welfare of Parents and Senior Citizens Act 2007; National Policy on Senior Citizens 2011; Indira Gandhi Old Age Pension Scheme; Mental Healthcare Act 2017; The Rights of Persons with Disabilities Act 2016; The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act 2017; Income Tax Act, 1961; The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999; Right of Children to Free and Compulsory Education Act 2009; Draft Labour Code on Social Security 2018.

In this session Deepa S who is Head of Diversity & Inclusion at DelleMC, India raised the issue that caring affects the whole of society, including the workplace. Those residing in urban areas, and employees of corporations are also carers so questions need to be asked about what companies can do to create inclusive work environments for those with caring responsibilities.

To conclude this session, the Government Commissioners said that in order to access rights and benefits, carers need to make specific set demands about exactly what they need and put these in writing. There needs to be formal recording of the needs of carers too e.g. doctors specifying what carers needs when they are treating those the carers care for.

FUTURE PLAN

SESSION 5

The workshop concluded with an addition to the key objectives and implemented discussion on future action that should be taken in order to increase recognition of carers and to improve the access carers have to their rights. During this discussion, the Government Commissioners repeated that when carers have **specific plans and demands**, that is when the Government can determine what resources to allocate to carers.

Proposed ideas and calls for further action included:

Action by Government	Professional Bodies
<ul style="list-style-type: none"> - Provide “half-way” homes / centres. E.g. when person has traumatic brain injury they are discharged from hospital and return straight home which places huge burden and pressure on carers - Carers should receive Carer ID cards from the Government that would entitle them to financial benefits / Launch specific ‘schemes for caregivers’ - Compensation should be provided to carers for transport costs of taking their relatives to medical appointments - Can Government conduct surveys to identify carers and then give them provisions accordingly? - Carers of persons with high support needs need to be able to access skills so they can earn an income - Upcoming, and future disability census should include 1 or 2 questions about carers 	<ul style="list-style-type: none"> - How can service providers provide constructive support to caregivers? - Can medical professionals make recommendation on how many hours additional support caregivers should receive from professionals (e.g. alternative care providers) for persons with high support needs? Can recommendations for assistive technologies for care recipients be made too? - A “Caregiver skill-building” programme should be developed (e.g. How to Care) and this programme should be formalized (NIHMANS currently does such work with caregivers but not as formalized programme) - Research should be carried out by professional bodies (e.g. NIHMANS) so it can be published in International Journals

Action by Carers

- Carers should network and raise their needs with the Government Mental Health Body in their State
- Carers should discuss their needs and wants with institutions (for example, NIHMANS) and institutions should use this information to devise new schemes with Government for carers
- Carers should call to be included in various, relevant formal committees?

Action by NGOs

- Establish more Community Day Care Centres
- Ensure carers are receiving all Government benefits and accessing schemes which are currently available
- Discussion about carers is currently only focusing on 4 states in India but this needs to be widened

WORKSHOP SUMMARY

In the Regional Learning Exchange Workshop, it was acknowledged that carers play a vital role within our society and that measures should be in place to educate carers on how to be effective and efficient care providers. It was also realised that the role of caring creates a combination of economic, social and psychological problems for the carers themselves which negatively affects their own quality of life. Going forward, it was agreed that all stakeholders should join together to ensure carers access and utilize existing schemes and benefits that are available to them. Stakeholders should also assist carers with advocating for new, specific demands that they require to improve their wellbeing.



ANNEX 1 | POLICY REVIEW

Carers in India

Policy Review

September 2019



Carers Worldwide Policy Review for Carers in India

Purpose of this Policy Review:

The purpose of this policy review is to provide carers, and organisations who work with carers, a summary of existing legislation, policies and schemes which offer entitlements and benefits that could be accessed by carers. The review also offers numerous suggestions on ways in which existing legislation, policies and schemes could be developed in order to offer further support to carers; ideas of which could be advocated for by carers, carers groups, and organisation working with carers.

Important Notice:

This is not an exhaustive list of policies, provisions or potential areas for advocacy. This is a selection of existing key policies relating to carers and this review is to act as the start of a policy engagement and advocacy process. Comments, suggestions and expressions of interest to be further involved should be sent to anil.patil@carersworldwide.org

Executive Comment

This policy review introduces a selection of existing legislation, policies and schemes in India that could be utilized by carers in order to improve their economic and social wellbeing.

Texts which refer specifically to carers have been included in this review; however, such references are scarce. The review also includes legislation, policies and schemes that could be made applicable to carers, even if they do not refer to carers specifically.

As well as discussing which existing entitlements and benefits could be accessed by carers, this review makes suggestions on how existing legislation, policies and schemes could be further developed to offer even greater protection for carers.

It is hoped that this review will be used as a starting point to encourage future discussions on policy engagement and advocacy processes that will transform the lives of carers and, in turn, those they care for.

Policies Discussed

The following legislation, policies and schemes are discussed in this review:

- Mahatma Gandhi National Rural Employment Guarantee (MGNREG) Act 2005
- The Maintenance and Welfare of Parents and Senior Citizens Act 2007
- National Policy on Senior Citizens 2011
- Indira Gandhi Old Age Pension Scheme
- Mental Healthcare Act 2017
- The Rights of Persons with Disabilities Act 2016
- The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act 2017
- Income Tax Act, 1961
- The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999
- Right of Children to Free and Compulsory Education Act 2009
- Draft Labour Code on Social Security 2018

Mahatma Gandhi National Rural Employment Guarantee Act 2005

Key information:

This Act entitles rural households up to 100 days unskilled, manual work per financial year. The scheme is to proactively include SECC (Social Economic Caste Census) vulnerable households. Work shall be provided to applicants within 15 days of a registered demand for work and the work site should preferably be within 5km of the applicant's residence. There is a provision for children under 5 years old who accompany a female worker to be looked after by another person on the work site.

How this Act could be used by carers

- If a female is a carer of a child under 5 years old then the child should be cared for onsite whilst the female works as there is no stipulation in the Act that children with disabilities or illness are not eligible to be looked after. This means female carers of children under 5 years old should be able to access work via this Act without having to be concerned about finding alternative care arrangements.

How this Act could be improved

- Could the Act be extended to include male workers who care for a child under 5 years old, as opposed to just female carers?

- Could the Act be extended to offer onsite care to all care recipients, not just children under 5 years old, which would significantly increase the eligibility of persons to work under the Act?
- Could the onsite care be provided by a carer who could care for their own care recipient, and others at the same time?
- There is provision for people to be employed to provide water to other workers. Could this be a position for a carer so that they do not have to go to work in the field?
- If a carer is unable to leave the house to work because they are caring for a relative with high dependency needs, could their caring duties be classed as eligible work and therefore be remunerated?

The Maintenance and Welfare of Parents and Senior Citizens Act 2007

Key information:

This Act is concerned with the welfare of senior citizens i.e. persons aged 60 and above, and parents i.e. biological, adoptive, step-father/step-mother. If a senior citizen or parent cannot maintain themselves from their own earnings, or from property they own, they can claim financial support against children who are not minors, or if childless, against a relative. Such a claim can be made against relatives residing outside of India. The act also provides that State Governments may establish and maintain old age homes, beginning with at least one in each district, to accommodate a minimum of 150 senior citizens who do not have sufficient means to sustain themselves.

NB: This Act does not apply to the states of Jammu and Kashmir.

How this Act could be used by carers

In households where a senior citizen is being cared for, and they are unable to financially sustain them self, the senior citizen could apply for financial support from other relatives which could help alleviate financial hardship in the household. An example would be:

- *A 60 years old husband with dementia lives with his wife . The husband cannot work, and neither can the wife as she cares for him full-time. The spouses have three adult children who do not reside with them. The husband could claim financial support from his children which would reduce the economic burden on both him and his wife.*

- In instances of financial distress (and when children/other relatives have insufficient income in which to claim against) there is an option for the senior citizen to enter an old age home, (space permitting) which may alleviate family members from the challenges of caring.

How this Act could be improved

- Call for, in addition to old age homes, other alternative caring mechanisms e.g. community caring centres to be established to provide day-time care? This would allow the senior citizen to remain living at home whilst also providing the carer with free time in which they could pursue livelihood opportunities or have respite.

National Policy on Senior Citizens 2011

Key information:

This Policy demands States, within the limits of their economic capacity, to make provisions for public assistance for persons old age i.e. 60 years and above. The Policy believes that the concept of 'ageing at home' should be promoted, with institutional care being a last resort and therefore encourages the development of a formal and informal social support system, so that the capacity of the family to take care of senior citizens is strengthened. In order to strengthen the family system so that it continues to play the role of primary caregiver in old age; by sensitizing younger generations should be sensitized and tax incentives should be offered to those taking care of the older family members.

States are advised to implement 'The Maintenance and Welfare of Parents and Senior Citizens Act 2007' (as discussed on the previous page) and to set up tribunals so that elderly parents unable to maintain themselves are not abandoned and neglected. States should also administer the 'Indira Gandhi Old Age Pension Scheme' (as discussed below).

States should set up assisted-living facilities for abandoned senior citizens. Non-institutional services, such as by voluntary organisations, are to be promoted and supported, in order to strengthen the capacity of senior citizens and their families with dealing with the issue of ageing. Provisions for training geriatric healthcare specialists to provide care to the elderly at affordable prices should also be in place.

The Policy also establishes a National Council for Senior Citizens.

How this Policy could be used by carers

- Tax incentives should be provided to carers caring for elderly family members.
- As the Policy promotes family/informal caring, it is reasonable to demand for provisions to be put in place that makes informal caring practically and financially possible.
- The potential provision of affordable geriatric

care may reduce the burden of caring on family carers.

How this Policy could be improved

- Suggest caregivers are represented on the National Council for Senior Citizens as they were not included in the council composition recommended in the policy (including carers who are of old age themselves).

Indira Gandhi Old Age Pension Scheme

Key information:

This Scheme was introduced under the National Social Assistance Programme (NSAP) which provides social assistance benefits to poor households in India. Under the IGNOAPS scheme, persons 60 years old and above who reside in a household that lives below the poverty line, are entitled to receive a non-contributory pension. Applicants must be destitute and having no regular source of financial support from family members or any other sources. An additional amount of money is available for eligible senior citizens who have concomitant responsibility for grand-children and women.

Documents required to apply for the scheme are: application form; proof of age (the age certificate needs to be obtained from a medical officer and to be attested by a block-level medical officer); income certificate; Below Poverty Line (BPL) card in the name of applicant; bank pass book or post office passbook; and passport size photographs.

How this Scheme could be used by carers

- A person who is eligible for this pension, and who is also a carer of grandchildren or other females, will be able to receive an additional allowance.

How this Scheme could be improved

- Expand the policy so any one in poverty over 60 who cares for anyone, not just grand-children and women e.g. a disabled son, husband etc. should receive additional pension.

Mental Healthcare Act 2017

Key information:

Caregiver is defined in this Act as 'a person who resides with a person with mental illness and is responsible for providing care to that person and includes a relative or any other person who performs this function, either free or with remuneration'. The Act states that the appropriate Government, within its economic capacity, shall provide persons with mental illness treatment in a manner which enables them to continue to live in the community and with their families. The Act calls for mental health services to support the family of a person with mental illness. When budgeting for the provision of mental health services, the government shall ensure adequacy, priority, progress and equity. Equity means in terms of fair allocation of resources taking in to account the health, social and economic burden of mental illness on individuals, their families and care-givers.

The Act establishes a Central Mental Health Authority and State Mental Health Authorities, all of which must include two persons who care for persons with mental illness, or organisations representing carers.

How this Act could be used by carers

- Mental health services are to support family of person with mental illness.
- As the Policy promotes family/informal caring, it is reasonable to demand for provisions to be put in place that makes informal caring practically and financially possible.
- Governments must provide mental health services that take in to consideration the health, social and economic burden of mental illness on families and carers.
- There must be representation by carers, or

organisations working with carers, on the Central and State Mental Health Authorities.

How this Act could be improved

- Call for a research component to be added and have carers involved in any research committees.
- Call for the inclusion of a provision for health assessments for carers to ensure their own health and wellbeing.
- Call for a provision for respite and short breaks for carers to be part of State's mental health treatment planning.

The Rights of Persons with Disabilities Act 2016

Key information:

Caregiver is defined in this Act as 'a person, including parents and other family members, who with or without payment provides care, support or assistance to a person with disability.' Within the limits of its economic capacity, the appropriate Government shall provide a carer's allowance to carers of disabled persons with high support needs. The appropriate Government shall endeavour that persons with disabilities are given access to other community support services, e.g. personal assistance necessary to support living. Government shall also: initiate capacity building programmes, including training in independent living and community relationships for families, members of community and other stakeholders and care providers on caregiving and support.

How this Act could be used by carers

- Caregivers allowance is available for those caring for persons with high support needs.
- There is a provision for persons with disabilities to have access to other support e.g. personal assistance, which could reduce caring demands on families
- The Act states caregiving training should be provided

How this Act could be improved

- There is a Central Advisory Board on Disability, State Advisory Boards on Disability and District-

Level Committees but no inclusion for representation of caregivers.

- Call for a research component to be added and have carers involved in any research committees.
- Call for the inclusion of a provision for health assessments for carers to ensure their own health and wellbeing.
- Call for a provision for respite and short breaks for carers.
- Call for the provision of a transport allowance for carers taking their disabled relatives to medical or therapy appointments/treatment.

The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act 2017

Key information:

The Act states that HIV-related discrimination can occur against those residing with, or who used to reside with, a person living with HIV/AIDs. Protected persons under the Act include those residing with, or who used to reside with, a person living with HIV/AIDs. The Act holds that protected persons are not to be denied/terminated from employment unless an employer can prove the nature and extent of admin/financial hardship from providing reasonable accommodation to enable protected person to be employed.

Central and State Governments shall take measures to facilitate better access to welfare schemes to persons affected (including protected persons) by HIV and shall frame schemes to address needs of all protected persons. Central Government is to provide guidelines for care, support and treatment of children infected by HIV.

If a minor aged 12 to 18 is sufficiently mature, and is managing the affairs of a family affected by HIV/AIDS then they shall be deemed competent to act as a guardian of other siblings below 18 years old (if both parents / legal guardians infected). Parents may appoint an adult relative or friend to act as legal guardian of children upon incapacity (or death).

How this Act could be used by carers

- If a carer residing with a HIV-positive person is in employment, there may be the possibility to request flexible working hours as 'reasonable accommodation' to fit around caring responsibilities (provided that this will not cause too much hardship to employer).
- Demand that Central and State Governments are take action to facilitate better access to welfare schemes to persons affected by HIV, which includes carers who reside with a HIV+ person.

How this Act could be improved

- Call for a provision for carers allowance/

compensation for caring.

- Call for the inclusion of a provision for health assessments for carers to ensure their own health and wellbeing.
- Call for carers to be prioritized in livelihood schemes to increase financial security of the family/for carers to start home-based income generation activities that can co-exist with caring responsibilities.
- Call for a provision for respite and short breaks for carers.
- Call for the provision of a transport allowance for carers taking their disabled relatives to medical or therapy appointments/treatment.

Income Tax Act, 1961

Key information:

Section 80DD gives tax benefits to individuals who support a spouse, child, parent or sibling with special/medical needs. Can claim a fixed deductible amount of Rs. 75,000 if dependent's degree of disability is 40% - 80% or Rs. 125,000 if over 80%. The amount is fixed which means it is independent of the amount spent on the dependent's treatment, provided at least some expense is incurred by the taxpayer for treatment. The taxpayer is not allowed this deduction if the dependent has claimed a deduction under section 80U for himself/herself. The taxpayer must have incurred expenses for medical treatment (including nursing), training or rehabilitation of the dependent, or have deposited in an insurance scheme for maintenance of the dependent.

Documents required to obtain the tax relief include: a copy of a medical certificate, which authenticates the disability of the dependant; Form 10-IA is to be completed if the disabled dependant has autism, cerebral palsy or multiple disabilities; a self-declaration certificate, mentioning the expenses incurred on the medical treatment (including nursing, rehabilitation and training) of the disabled dependant is to be completed by the carer; and if a claim is being made for the payment made towards insurance policies taken out on behalf of the disabled dependant, then the actual receipts of the expenses need to be maintained and submitted.

How this Act could be used by carers

- Providing conditions are met, carers can claim a fixed deductible amount of Rs. 75,000 rupees if the dependent's degree of disability is 40% - 80% or Rs. 125,000 if the disability is over 80%.

How this Act could be improved

- Call for tax deduction to be permitted even in

instances where the dependent claims tax deduction under Section 80U.

- Call for tax deduction to be made available for carers of persons whose disability is below 40%.
- Call for the list of permissible dependents to be widened from spouses, children, parents and siblings, to include friends, aunties, uncles, cousins etc.

The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999

Key information:

This Trust was established with the following relevant objectives:

- to strengthen facilities to provide support to persons with disability to live within their own families
- to promote measures for the care and protection of persons with disability in the event of death of their parents or guardians
- to evolve procedure for the appointment of guardians and trustees for persons with disability requiring such protection (a parent of a person with disability or his relative may make an application to the local level committee for appointment of any person of his choice to act as a guardian of the persons with disability; and every person appointed as a guardian of a person with a disability under this Act shall, wherever required, either have the care of such persons of disability and his property or be responsible for the maintenance of the person with disability.)

The Trust is to focus on:

- programmes which promote independent living in the community for persons with disability by creating a conducive environment in the community; counseling and training of family members of persons with disability; setting up of adult training units, individual and group homes
- any programme which promotes respite care, foster family care or day care service for persons with disability
- setting up of residential hostels and residential homes for persons with disability

The Act created a body/board for the Trust which composes of nine members, three of whom shall be from associations of parents of persons with autism, cerebral palsy, mental retardation and multiple disability and from associations of persons with disability.

NB: This Act does not apply to the states of Jammu and Kashmir.

How this Act could be used by carers

- Carers who are member of parent associations for children with autism, cerebral palsy, mental retardation or multiple disabilities can apply to be elected to the Trust's board.
- Trust is to focus on counselling and training of family members of persons with disability, which will help carers.
- Can demand the Trust to focus on projects which strengthen the protection for those with disabilities in the event of death of their parents/guardians (what will happened to their loved one when they die is a common concern of carers).
- As the Act promotes that disabled persons should live in the community, it is reasonable to

demand for provisions to be put in place that makes informal caring practically and financially possible.

How this Act could be improved

- Could a provision for carers allowance be included within the Act?
- The Act does not provide a definition of carer but defines guardianship. Could the definition of guardianship be expanded to include carers?
- The Act allows parents who are members of parent associations to become members of the board but could this be widened to include any person who identifies as a carer of persons with cerebral palsy, mental retardation or multiple disabilities?

Right of Children to Free and Compulsory Education Act 2009

Key information:

The Act stipulates that every child aged 6 to 14 years old shall have the right to free and compulsory education in a neighborhood school till completion of elementary education. It is the duty of every parent or guardian to admit or cause to be admitted their child. No child shall be liable to pay any kind of fee, charges or expenses which may prevent him or her from pursuing and completing the elementary education. Children suffering from disability shall have right to pursue free and compulsory education in accordance with Persons with Disabilities Act 1996.

There is an obligation on the appropriate Government to ensure compulsory admission, attendance and completion of elementary education by every child aged 6 to 14 years old; and to ensure that weaker sections and disadvantaged groups are not discriminated against in pursuing education. Disadvantaged groups are defined as scheduled castes, scheduled tribes, socially and educationally backward classes or such other groups having disadvantage owing to social, cultural, economical, geographical, linguistic, gender or other such factors specified by the appropriate Government. A child belonging to a weaker section means a child whose parent or guardian has an annual income that is lower than the minimum limit specified by the appropriate Government.

The Act requires surveys to be conducted which monitor all neighbourhoods, identify children requiring education, and set up facilities for providing it. It is the first legislation in the world that puts the responsibility of ensuring enrolment, attendance and completion of education on the Government.

NB: This Act does not apply to the states of Jammu and Kashmir.

How this Act could be used by carers

- In regards to child carers, there is nothing in the Act that stipulates that they are not entitled to free education. This means that the Governments should be demanded to put provisions in place that will enable child carers to attend school. These provision should not be at an expense to the child, or their family, as no expenses that could prevent a child from pursuing education are permitted.
- In regards to adult carers of children with

disabilities, the Act states that such children shall have the right to education so provisions should be put in place that would enable the child to attend school. This would provide respite hours for adult carers during school hours.

How this Act could be improved

- Call for there to be recognition and specific identification of child carers as a disadvantaged group which will ensure they cannot be discriminated against when trying to access education.

Draft Labour Code on Social Security 2018

This is a draft Code that is currently under review and should be monitored to see if it passes. The Code intends to amalgamate, simplify and rationalize all existing Labour Laws relating to Social Security. The Code is expected to apply to both the organized and unorganized sector (93% of workers in India are in the unorganized sector^{xii}).

Conclusion

This policy brief has provided a non-exhaustive list of legislation, policies and schemes in India that could be utilized by carers as a means to improve their economic and social wellbeing.

The policy brief has also provided ideas for advocacy action that could be taken to further strengthen existing legislation, policies and schemes

and as a result offer a greater level of protection to carers. The suggestions made are not static and should be treated as a starting point for future advocacy discussions.

It is recommended that a watchful eye is kept on the progression of the Draft Labour Code on Social Security which could provide additional benefits and entitlements to carers who may be in insecure employment in the unorganized sector.

Carers Practices in India

Number of Carers:

- Official number: Unknownⁱ
- Percentage population: Unknownⁱ

Current Practices	Opportunities to Increase Support
Unpaid carers are not formally recognised in India. The RPWD Act 2016 defines “a carer as any person including parents and other family members who with or without payment provides care, support or assistance to a person with disability” ⁱⁱ	Strengthen the collective voice of unpaid carers at the district, state, regional and national level to recognise unpaid carers in policy initiatives
India does not provide direct financial support to unpaid carers. The RPWD Act 2016 has a provision for carer allowance to PWD’s with high support needs, but that provision has not yet been implemented across the country ⁱⁱⁱ	Provide direct financial support to unpaid carers through private and/or public sectors
A majority of the workforce in India belongs to the informal sector, and therefore does not receive benefits such as paid leave or flexible working arrangements ^{iv}	Bring about systemic change in the India workforce, allowing unpaid carers to care for their family and be part of the formal workforce
India does not have a well-developed social security system and work-related pension is only available to those in the formal sector ^v	Revamp the social security system in India, recognising the entire workforce and not just 10% that are in the formal workforce
Respite care is short supply, inaccessible or unaffordable ^{vi}	Increase respite care funding and make respite care services affordable and more readily available
Carers Worldwide facilitates employment, training and education opportunities tailored to exist alongside caring responsibilities	Add funding to support programmes and initiatives

ⁱ The census does not collect carer related data as the role of the unpaid carer is not formally recognized within Indian society

ⁱⁱ Commonwealth Foundation and Carers Worldwide (2017) ‘Promoting the Recognition and Inclusion of Carers of the Disabled and Mentally ill in India’ <https://www.carersworldwide.org/wp-content/uploads/2018/06/Commonwealth-Foundation-Evaluation-Report.pdf>

ⁱⁱⁱ Ibid.

^{iv} Ageing International (2016) ‘Care Needs and Caregivers:

Associations and Effects of Living Arrangements on Caregiving to Older Adults in India’ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4877410/>

^v International Alliance of Carer Organisation (2018) ‘Global State of Care Report’ <https://internationalcarers.org/wp-content/uploads/2018/11/IACO-EC-GSoC-Report-FINAL-10-20-18-.pdf>

^{vi} The Hindu (2016) ‘Help for the Caregiver’ <https://www.thehindu.com/news/national/karnataka/A-helping-hand-for-caregivers-in-Bidar/article16072918.ece>

ABOUT CARERS WORLDWIDE

Carers Worldwide works through well-established local partner organisations to meet the physical, emotional, economic and social needs of carers in developing countries. 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 carer and the person receiving care. In summary, we are advocating for the following changes: legislation, working arrangements, financial support, respite care, pension credits, information and training.

For more information visit: www.carersworldwide.org

This Policy Review document was made in collaboration with:
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ANNEX 2 | WORKSHOP TIMETABLE

Time	Particulars	Presenter
Session I - Welcome and Setting the Context		
10.00am to 11.00am	Welcome	Dr. Thirumoorthy Psychiatric Social Work, NIMHANS
	Background to the Workshop and its Purpose	Dr. N Janardhana, Additional Professor, NIMHANS
	Introduction to Carers Worldwide	Dr Anil Patil, Founder and Executive Director, Carers Worldwide
	Sharing of carers experiences	Carers from CW partner organization
	Inaugural Address	Mrs Shashikala A Jolle Honorable Minister Women and Child Development ,Empowerment of Differently Abled and Senior Citizens Government of Karnataka
	Presidential Address	Dr SK Chaturvedi, Senior Professor, Department of Psychiatry , NIMHANS
Chief Guest	Shri. V.S.Basavaraj Commissioner Persons with Disability Act Government of Karnataka Mrs. Sulochana Das Commissioner Persons with Disability Act Government of Odisha	
	Vote of Thanks	Dr. N Janardhana

TEA BREAK 11.00 Am to 11.15 AM

Session II – Changing Carers’ Lives		
Facilitators: Dr Srikala Bharath, Professor of Psychiatry and Dr. B. Indiradevi Professor of Neuro Surgery , NIMHANS		
11.15am to 12.15am	Presentation of Project Interventions on the Ground	Carers Support Groups - Ekta
		Health Services - WORD

		Respite and Alternative Care – SACRED
		Employment Training and Education – SACRED
		Carers Federations/Associations - SAMUHA Samarthya
		Accessing Government schemes and Entitlements – SPREAD
	Carers sharing their personal stories	Varsha , Kotramma and Savithri - Samarthya Koppal Mhaboob Bee and Mastan Bee and Thoofan Raju - Sacred Kurnool Chaitanya Naraji and Anitha Majhi - SPREAD Koraput Shaktirekha Boi and Somanatha Jani - WORD Koraput Samari Rana and Danurjaya Khara - EKTA Koraput

Session III - Need for a Twin Track Approach – for Carers and Care Recipients

Moderators: Dr Thelma Narayan and Mrs Indumathi Rao- CBR Network, Bangalore

12.15pm to 1.30pm	Karnataka State Level Carers Forum	Mr. Manoj Chandran, CEO, White Swan Foundation
	Presentation of Government Developmental Policy Review	Ms. Victoria Nicholson, Carers Worldwide
	State Government Initiatives and Programmes for Meeting the Needs of Carers - Carers Networking	Commissioners of Persons with Disabilities Act Two States (Karnataka and Odisha) - Mr. V.S.Basavaraju, Karnataka - Mrs. Sulochana Das, Odisha
	Q & A Session	Dr Thelma Narayan and Mrs Indumati Rao

LUNCH BREAK – 1.30 PM to 2.15 PM

Session IV – Panel Discussion

Moderators: Prathima Murthy , Professor and HOD, Department of Psychiatry, Dr L. Suman Professor of Clinical Psychology NIMHANS

2.15pm to 3.15pm	Need for Advocacy for Family Carers	Mr. Alex Rodrigues, Disability NGO's Alliance (DNA)
	Wellbeing of Family Carers	Mrs. Chandrika from Milana

	Recognition of Carers Needs - Funder Perspective	Dr Rachit Negi, The Live Love Laugh Foundation
	PWMI Carers Perspectives – Mental Health Care Act 2017 Provisions for Carers	Dr. Rajani P Deputy Director DMHP Karnataka State Health & Family Welfare services
	Caregivers perspectives	Mr. Manoj Chandran, CEO, White Swan Foundation

Session V – The Road Ahead

Chair person : Mrs K. Leelavathi, IAS, Director Department of Empowerment of Differently Abled and Senior Citizens

3.15pm to 4.15pm	<p>Small Group Work and Input from Carers Worldwide Representatives to Work on Forward Action Planning:</p> <ul style="list-style-type: none"> - Application of New Legislation – RPD Act, MH Act, Roles of National Resource Institution - Gaps in Research/Knowledge/Funding Action Points – - What are the Specific Schemes and Programs of Support for Carers? - Identify 2 Short-term, and 2 Long-term Goals and Set who is Responsible for Action - Sharing from Groups and Summing up 	<p>Mr. KV Rajanna, Former State Commissioner for Persons with Disabilities Act Government of Karnataka</p> <p>Mrs. Suchita Somashekharaiiah Founder Managing Director Shristi Special Academy Bangalore</p>
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Session VI – Close / Valedictory

Moderator: Dr N Janardhana

4.15 to 4.45pm	Welcome	Dr. N Janardhana
	Summary of Day's Proceedings	Ms. Victoria Nicholson, Carers Worldwide
	Sharing of Experiences	Participants

	Valedictory Address	Mrs. K. Leelavathy IAS , Director Department of Empowerment of Differently Abled and Senior Citizens
	Presidential Address	Dr K Sekar, Registrar, NIMHANS, Bangalore
	Vote of Thanks	Mr. Natesha NK, Carers Worldwide

HIGH TEA AND NETWORKING

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