

# Global State of Care

In every country around the world, individuals with disabilities, chronic health issues or frailty rely on unpaid care from family and friends. Known as unpaid carers<sup>1</sup>, their role can range from helping with daily activities to more complex medical care. Although there are invaluable emotional benefits to providing care, being an unpaid carer can be time-consuming and take a heavy toll on the carer's health and well-being.

According to the International Alliance of Carer Organizations, unpaid caregiving has become one of the most important social and economic policy issues worldwide.<sup>ii</sup> As the population ages, **unpaid carers will continue to play a critical role** in every society, providing substantial economic value globally.

The International Alliance of Carer Organizations (IACO) is a global entity that provides cohesive direction, facilitates information sharing, and actively advocates for carers around the world. To advance this goal, IACO partnered with Embracing Carers™ in 2017 to fill the need for better support and recognition of unpaid carers. The initiative is focused on improving their health and wellness, while increasing awareness and support for them around the globe. The Embracing Carers™ *Carer Report: Embracing the Critical Role of Carers Around the World*, set the stage by identifying four core aims to provide support for unpaid carers. Among them was the need to activate policy by identifying and advancing legislative action among policy makers, governments and international public health organizations.

The **Global State of Care Report** was developed to facilitate policy discussions around the world by providing a global assessment of unpaid carer needs, sharing of best practices, and identifying the core elements of a global carer action plan.







The report found that unpaid carers are gradually being recognized for the invaluable role they play. Governments and countries of all sizes are starting to take action to support the carer community. And just as importantly, carer organizations around the world are advocating for governmental policy changes that consider unpaid carers' concerns and the challenges they face.

Now is the time to take advantage of the opportunities and create a coordinated global action to address the needs of millions of unpaid carers around the world. The **Global State of Care Report** provides the foundation for the development of a strategy that will improve the quality of life and support the needs of all unpaid carers.

<sup>i</sup> IACO defines an unpaid carer as "an individual, such as a family member, neighbor, friend or other significant individual, who takes on a caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness. The terms caregiver, family caregiver and carer are used interchangeably by IACO members."

<sup>ii</sup> International Alliance of Carer Organizations. (2018). Page 1. <http://www.internationalcarers.org>. [Date Accessed: 16 July 2018]







**Embracing Carers™** global advisors have determined support measures as a blueprint to address the needs of unpaid carers.

-  Legislation
-  Financial support
-  Working arrangements
-  Pension credits
-  Respite care
-  Information and training

## Number of Carers

Official number **2.7 Million<sup>i</sup>**  
 Percentage of population **11%**



Current Practices	Opportunities to Increase Support
 <p>Unpaid carers are formally recognized in Australia.<sup>ii</sup></p>	<p>Increase levels of discussion and bring awareness to the unmet challenges that unpaid carers continue to face.</p>
 <p>The Australian Government provides a Carers Allowance, an income supplement available to people who provide daily care in a private home to a person with disability or a severe medical condition.<sup>iii</sup> A Carer Supplement is an annual payment for recipients of the Carer Allowance for each person being cared for.<sup>iv</sup></p>	<p>Address delays that unpaid carers face when accessing support payments.</p>
 <p>Basic work entitlements are protected by Australia's Fair Work Act (2009). Those who provide unpaid care and are in the workforce are entitled to request flexible working conditions and may be eligible for paid leave, unpaid leave and compassionate leave.<sup>v</sup></p>	<p>Increase access to flexible working conditions.</p>
 <p>Australia does not have a pension credits system, but the government provides a payment called a Carer Payment to unpaid carers who provide full-time care and pass an income test.<sup>vi</sup></p>	<p>Revise Carer Payment eligibility requirements to increase access, especially for unpaid carers of people who have episodic conditions.</p>
 <p>The Department of Social Services funds organizations to help unpaid carers access emergency respite and respite subsidies. Planned respite is available through the Aged Care System.<sup>vii</sup></p>	<p>Increase respite care funding and make respite care services more readily available and easier to access.</p>
 <p>Unpaid carers can access a range of nationally provided digital services including counseling, peer support, coaching and education. Unpaid carers can identify and connect to face-to-face services in their locality through the Government's Carer Gateway website and call center.<sup>vii</sup></p>	<p>Increase awareness of training and services currently available to unpaid carers.</p>
<div style="display: flex; justify-content: space-between;"> <div data-bbox="126 1785 186 1837"> <p>Legislation</p> </div> <div data-bbox="613 1785 673 1837"> <p>Working arrangements</p> </div> <div data-bbox="1096 1785 1153 1837"> <p>Respite care</p> </div> </div> <div style="display: flex; justify-content: space-between; margin-top: 10px;"> <div data-bbox="126 1858 186 1911"> <p>Financial support</p> </div> <div data-bbox="613 1858 673 1911"> <p>Pension credits</p> </div> <div data-bbox="1096 1858 1153 1911"> <p>Information and training</p> </div> </div>	

## Government Recognition

Carer Recognition Act (2010)

Aged Care Act (1997)

National Disability Strategy and Mental Health Strategy

Legislation at a state and territory level

## References

i Australian Government Department of Social Services. (2018). Supporting Carers. Page 1. <https://www.dss.gov.au/disability-and-carers/carers>. [Date Accessed: 16 July 2018]

ii Australian Government Carer Gateway. (2017). Legal Rights for Carers. Page 1. <https://www.carergateway.gov.au/legal-rights-for-carers>. [Date Accessed: 16 July 2018]

iii Australian Government Department of Social Services. (2016). Carer Allowance. Page 1. <https://www.dss.gov.au/disability-and-carers/benefits-payments/carers-allowance>. [Date Accessed: 16 July 2018]

iv Australian Government Department of Social Services. (2016). Carer Supplement. Page 1. <https://www.dss.gov.au/disability-and-carers/benefits-payments/carers-supplement>. [Date Accessed: 16 July 2018]

v Australian Government Fair Work Ombudsman. (2017). Requests for flexible working arrangements and the National Employment Standards Fact Sheet. Page 1. <https://www.fairwork.gov.au/how-we-will-help/templates-and-guides/fact-sheets/minimum-workplace-entitlements/requests-for-flexible-working-arrangements>. [Date Accessed: 16 July 2018]

vi Australian Government Department of Social Services. (2016). Carer Payment. Page 1. <https://www.dss.gov.au/disability-and-carers/benefits-payments/carers-payment>. [Date Accessed: 16 July 2018]







vii Australian Government MyAgedCare. (2017). Respite Care. Page 1. <https://www.myagedcare.gov.au/respice-care>. [Date Accessed: 16 July 2018]







viii Australian Government Department of Social Services. (2018). Supporting Carers. Page 1. <https://www.dss.gov.au/disability-and-carers/carers>. [Date Accessed: 16 July 2018]

## Number of Carers

Official number **8.1 Million<sup>i</sup>**  
Percentage of population **28%**



Current Practices	Opportunities to Increase Support
 <p>There is no federal legislation formally recognizing unpaid carers. The Manitoba Caregiver Recognition Act sets out principles and actions for government and non-government agencies to support unpaid carers.<sup>ii</sup></p>	<p>Safeguard the health and well-being of unpaid carers by ensuring they are formally recognized and their needs are identified and supported through specific assessment tools.</p>
 <p>Although unpaid carers are not formally recognized, financial supports are available. The Caregiving Recognition Benefit is for those caring for veterans. The Canada Caregiver Credit is a tax credit.<sup>iii</sup> Nova Scotia provides direct allowances.<sup>iv</sup></p>	<p>Minimize excessive financial burden placed on unpaid carers through a range of options that alleviate out-of-pocket expenses and address reduced income due to employment loss.</p>
 <p>Canadian law prohibits discrimination based on a person's family caregiving responsibilities. Federally regulated employees have job protection while they are receiving caregiving benefits and the right to request more flexible work arrangements. The Employment Insurance Act entitles employees to three different income benefits: the Compassionate Care Benefit, the Family Caregiver Benefit for Children and the Family Caregiver Benefit for Adults.<sup>v</sup></p>	<p>Support flexible workplace/educational environments that respect caregiving obligations.</p>
 <p>The Canadian Pension Plan offers protection against periods where individuals may have low or zero earnings for a variety of reasons, including to provide care to a family member.<sup>vi</sup></p>	<p>Increase pension contributions for employees who need to leave the workplace to provide care.</p>
 <p>Respite care is provided through publicly funded home care programs administered by each province and territory. These programs provide in-home respite services. Facility-based respite and adult day programs enable unpaid carers to take extended time away.<sup>vii</sup></p>	<p>Provide adequate support and access to flexible respite.</p>
 <p>Caregiver Readiness is a national informational campaign through the Canadian federal government consisting of user-friendly tip sheets, checklists and a video.</p>	<p>Enable unpaid carers to access user friendly information and education. Fund research and knowledge dissemination as a foundation for evidence-informed decision making.</p>

 Legislation	 Working arrangements	 Respite care
 Financial support	 Pension credits	 Information and training

## Government Recognition

Caregiver Recognition Act (Manitoba, 2011)

Employment Insurance Act (1996)

Canadian Human Rights Act (1985)

---







## References







- i Statistics Canada. (2012). Portrait of Caregivers. Page 4. <https://www150.statcan.gc.ca/n1/pub/89-652-x/89-652-x2013001-eng.htm>. [Date Accessed: 16 July 2018]
- ii The Change Foundation. (2016). Legislation Supporting Family Caregivers in Canadian Jurisdictions and Selected International Jurisdictions. Page 4.
- iii Carers Canada. (2017). Advancing Collective Priorities, A Canadian Carer Strategy. Page 6. [http://www.carerscanada.ca/wp-content/uploads/2018/03/Advancing-Collective-Priorities\\_web3.pdf](http://www.carerscanada.ca/wp-content/uploads/2018/03/Advancing-Collective-Priorities_web3.pdf). [Date Accessed: 16 July 2018]
- iv Carers Canada. (2017). Advancing Collective Priorities, A Canadian Carer Strategy. Page 16. [http://www.carerscanada.ca/wp-content/uploads/2018/03/Advancing-Collective-Priorities\\_web3.pdf](http://www.carerscanada.ca/wp-content/uploads/2018/03/Advancing-Collective-Priorities_web3.pdf). [Date Accessed: 16 July 2018]
- v Carers Canada. (2017). Advancing Collective Priorities, A Canadian Carer Strategy. Page 7. [http://www.carerscanada.ca/wp-content/uploads/2018/03/Advancing-Collective-Priorities\\_web3.pdf](http://www.carerscanada.ca/wp-content/uploads/2018/03/Advancing-Collective-Priorities_web3.pdf). [Date Accessed: 16 July 2018]
- vi Government of Canada. (2017). Canada Pension Plan. Page 1. <https://www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-benefit/eligibility.html>. [Date Accessed: 16 July 2018]
- vii Canadian Home Care Association. (2013). Portraits of Home Care in Canada. Page 20. <http://www.cdnhomecare.ca/content.php?doc=293>. [Date Accessed: 18 July 2018]

## Number of Carers

Official number **2.1 Million<sup>i</sup>**  
 Percentage of population **3.3%**



Current Practices	Opportunities to Increase Support
 <p>The Law on the Adaptation of Society to Aging (loi relative à l'adaptation de la société au vieillissement), defines an unpaid carer as someone who regularly assists, on a non-professional basis, to perform some or all the acts of daily living of a frail elderly person.<sup>ii</sup></p>	<p>Increase funding to implement the Law on the Adaptation of Society to Aging in a consistent manner.</p>
 <p>Unpaid carers receive indirect financial support through the personalized independence allowance, intended to partly cover expenses to ensure autonomy of elderly people, and the disability allowance, a personalized allowance for disabled people.<sup>iii</sup></p>	<p>Reduce bureaucratic obstacles, making it easier for unpaid carers to obtain support for their dependent.</p>
 <p>An unpaid carer can request leave without pay to care for a loved one with loss of autonomy or disability for up to three months in a split way or in the form of part-time work.<sup>iv</sup></p>	<p>Current legislation on flexible working arrangements is promising, but the implementation and funding of these new measures at a regional level remains limited.</p>
 <p>Unpaid carers that have stopped working to look after a child or an adult with a disability in the family home can benefit, under certain conditions, from the old-age insurance of a family carer which guarantees continuity in pension rights and can benefit from an extension of the term of the old-age insurance. Unpaid carers may also be able to claim a full pension from age 65 instead of age 67.<sup>v</sup></p>	<p>Revise eligibility requirements allowing unpaid carers to more easily access old-age insurance.</p>
 <p>The Law on the Adaptation of Society to Aging gives unpaid carers the right to take a break in the form of an annual lump sum to finance day care or temporary accommodation.<sup>vi</sup></p>	<p>Provide more funding for professional household services, professional respite and day-and-night-care.</p>
 <p>A government sponsored <a href="#">online</a> platform provides a comprehensive source of information related to unpaid carers in terms of new regulations, laws and support, including economic incentives, training and psychosocial support. The French Association of Carers offers six online <a href="#">training modules</a> for unpaid carers.</p>	<p>Increase awareness of training and services currently available to unpaid carers.</p>

 Legislation	 Working arrangements	 Respite care
 Financial support	 Pension credits	 Information and training

## Government Recognition

Law on the Adaptation of Society to Aging (2015)

French Social and Family Action Code (2015)

\*As an EU Member State, France is impacted by the proposal for a [Directive on the Work-Life Balance for Parents and Carers](#), which covers carers' leave and flexible working arrangements.

---







## References







- i ECPC and EUROCARERS. (2017). White Paper on Cancer Carers. Page 24. <http://www.ecpc.org/WhitePaperOnCancerCarers.pdf>. [Date Accessed: 16 July 2018]
- ii French Government. (2016). The law on the adaptation of society to aging. Page 1. <https://www.pour-les-personnes-agees.gouv.fr/actualites/la-loi-relative-ladaptation-de-la-societe-au-vieillissement>. [Date Accessed: 16 July 2018]
- iii European Commission. France - Long-term care. Page 1. <http://ec.europa.eu/social/main.jsp?catId=1110&langId=en&intPageId=4536>. [Date Accessed: 16 July 2018]
- iv Aidant Attitude. (2017). Caregivers, what rights and tools do you have? Page 1. <https://aidantattitude.fr/2018/01/17/vos-droits-tant-quaidants.php/>. [Date Accessed: 16 July 2018]
- v French Association of Carers. Retirement for Carers. Page 1. <https://www.aidants.fr/fiche-pratique-retraite-pour-aidants>. [Date Accessed: 16 July 2018]
- vi French Government. (2016). The law on the adaptation of society to aging. Page 1. <https://www.pour-les-personnes-agees.gouv.fr/actualites/la-loi-relative-ladaptation-de-la-societe-au-vieillissement>. [Date Accessed: 16 July 2018]

## Number of Carers

Official number **3.2 Million<sup>i</sup>**  
Percentage of population **4%**



Current Practices	Opportunities to Increase Support
 Unpaid carers are legally recognized.	Increase funding to fully implement current policy initiatives.
 The German Government provides either a Care Allowance or home care in-kind to the dependent person, but not the unpaid carer directly. <sup>ii</sup>	Reduce bureaucratic obstacles to make it easier for unpaid carers to obtain support for their dependent.
 The Act to Improve Compatibility between Family, Care and Work gives employees a right to partial leave of absence for up to 24 months if they are looking after a close relative requiring long-term care in the home environment. <sup>iii</sup>	Continue to promote a work-life balance by providing education and driving awareness on employment leave programs available to unpaid carers.
 The German Government provides non-contributory pension credits, accident insurance and unemployment insurance to unpaid carers that qualify. <sup>iv</sup>	Pass legislation to provide a secured pension income directly to unpaid carers.
 The German Government provides subsidies to relieve unpaid carers through respite care and short-term care. <sup>v</sup>	Provide more funding for professional household services, professional respite and day- and night-care.
 Long-term care insurance offers care courses in which unpaid carers can learn practical skills either in groups or individually at home. In addition to this, group training sessions offer the opportunity to exchange experiences with other unpaid carers. <sup>vi</sup>	Increase awareness and education of training and services currently available to unpaid carers.

 Legislation	 Working arrangements	 Respite care
 Financial support	 Pension credits	 Information and training



## Government Recognition

Care Realignment Law (2013)

Family Care Act (2015)

Care Support Acts I, II and III (2015 to 2017)

Home Care Leave Act (2015)

\*As an EU Member State, Germany is impacted by the proposal for a [Directive on the Work-Life Balance for Parents and Carers](#), which covers carers' leave and flexible working arrangements.

## References

- i ECPC and EUROCARERS. (2017). White Paper on Cancer Carers. Page 24. <http://www.ecpc.org/WhitePaperOnCancerCarers.pdf>. [Date Accessed: 16 July 2018]
- ii GBE Kompakt. (2015). Informal caregivers - Germany's largest nursing service. Page 2. [http://www.rki.de/EN/Content/Health\\_Monitoring/Health\\_Reporting/GBEDownloadsK/2015\\_3\\_informal\\_caregivers.pdf?\\_\\_blob=publicationFile](http://www.rki.de/EN/Content/Health_Monitoring/Health_Reporting/GBEDownloadsK/2015_3_informal_caregivers.pdf?__blob=publicationFile). [Date Accessed: 16 July 2018]
- iii Ibid.
- iv European Commission. Germany - Benefits for those in need of care. Page 1. <http://ec.europa.eu/social/main.jsp?langId=en&catId=1111&intPageId=4548&>. [Date Accessed: 16 July 2018]
- v GBE Kompakt. (2015). Informal caregivers - Germany's largest nursing service. Page 2. [http://www.rki.de/EN/Content/Health\\_Monitoring/Health\\_Reporting/GBEDownloadsK/2015\\_3\\_informal\\_caregivers.pdf?\\_\\_blob=publicationFile](http://www.rki.de/EN/Content/Health_Monitoring/Health_Reporting/GBEDownloadsK/2015_3_informal_caregivers.pdf?__blob=publicationFile). [Date Accessed: 16 July 2018]
- vi Ibid.

## Number of Carers







Official number







**Unknown<sup>i</sup>**

Percentage of population

**Unknown**



Current Practices	Opportunities to Increase Support
 <p>Unpaid carers are not formally recognized in India. The Right to Persons with Disability 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.<sup>ii</sup></p>	<p>Strengthen the collective voice of unpaid carers at the community, regional and national level to legally recognize unpaid carers in policy initiatives.</p>
 <p>India does not provide direct financial support to unpaid carers. The Right to Persons with Disability Act 2016 has a provision for a carer allowance to persons with disabilities with high support needs, but that provision has not yet been implemented.<sup>iii</sup></p>	<p>Provide direct financial support to unpaid carers through private and/or public sectors.</p>
 <p>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.<sup>iv</sup></p>	<p>Bring about systemic change in the India workforce, allowing unpaid carers to care for their family and be a part of the formal workforce.</p>
 <p>India does not have a well-developed social security system and work-related pension is only available to those in the formal sector.<sup>v</sup></p>	<p>Revamp the social security system in India, recognizing the entire workforce and not just the 10% that are in the formal workforce.</p>
 <p>Respite care is short supply, inaccessible or unaffordable.<sup>vi</sup></p>	<p>Increase respite care funding and make respite care services affordable and more readily available.</p>
 <p>Carers Worldwide facilitates employment, training and education opportunities tailored to exist alongside caring responsibilities.</p>	<p>Add funding to support programs and initiatives.</p>

 Legislation	 Working arrangements	 Respite care
 Financial support	 Pension credits	 Information and training

## Government Recognition

Rights of Persons with Disabilities Act (2016)

Mental Healthcare Bill (2016)

---







## References

- 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. Page 10. <https://www.carersworldwide.org/wp-content/uploads/2018/06/Commonwealth-Foundation-Evaluation-Report.pdf>. [Date Accessed: 16 July 2018]
- iii Ibid.
- iv Ageing International. (2016). Care Needs and Caregivers: Associations and Effects of Living Arrangements on Caregiving to Older Adults in India. Page 3. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4877410/>. [Date Accessed: 16 July 2018]
- v Ibid.
- vi The Hindu. (2016). Help for the Caregiver. Page 1. <https://www.thehindu.com/sci-tech/health/help-for-the-caregiver/article5116330.ece>. [Date Accessed: 16 July 2018]

## Number of Carers

Official number **4 Million<sup>i</sup>**  
 Percentage of population **7%**



Current Practices	Opportunities to Increase Support
 <p>Unpaid carers are formally recognized in Italy. In 2017, a fund was established for the financial coverage of legislative measures aimed at recognizing the social and economic value of the unpaid carer.<sup>ii</sup></p>	<p>Expand the definition of unpaid carer, improve full policy implementation of the 2018 Budget Law and decrease regional fragmentation.</p>
 <p>Unpaid carers may receive a Carers Allowance if the person for whom they care fits the definition of "invalid" (i.e. they are unable to accomplish activities of daily living).<sup>iii</sup></p>	<p>Provide financial support to all unpaid carers, not just the unpaid carer of the disabled or ill person.</p>
 <p>Nationally, unpaid carers are entitled up to 3 days' leave per month. This leave is fully paid by the INPS (the national social security agency) or another social security agency. Up to 2 years' unpaid leave can be taken in a staggered manner.<sup>iv</sup></p>	<p>Provide a national employment policy which includes paid and flexible care leave, flexible working conditions, and the promotion of a work-life balance.</p>
 <p>A form of early retirement is allowed for some categories of workers considered to be disadvantaged, including unpaid carers.<sup>v</sup></p>	<p>Allow for early retirement pension credits for unpaid carers.</p>
 <p>There is no national respite care available, but in some regions, measures have been introduced to give the unpaid carer rest periods or breaks (holidays or temporary detachment).<sup>vi</sup></p>	<p>Nationally recognize respite care as a right and provide more funding to implement respite care in all regions.</p>
 <p>A general information service provides information about support services, but it varies per region.<sup>vii</sup></p>	<p>Provide support to regions to increase education and training to unpaid carers.</p>



Legislation



Working arrangements



Respite care



Financial support



Pension credits



Information and training

## Government Recognition

Budget Law (2018)

Regional laws and policies

\*As an EU Member State, Italy is impacted by the proposal for a [Directive on the Work-Life Balance for Parents and Carers](#), which covers carers' leave and flexible working arrangements.







## References







- i ECPC and EUROCARERS. (2017). White Paper on Cancer Carers. Page 24. <http://www.ecpc.org/WhitePaperOnCancerCarers.pdf>. [Date Accessed: 16 July 2018]
- ii EUROCARERS. (2017). A Fund to support the caring role of informal carers has been established by national law. Page 1. <http://eurocarers.org/News-from-Italy-A-Fund-to-support-informal-carers-has-been-established-by-national-law>. [Date Accessed: 16 July 2018]
- iii Alzheimer Europe. (2009). Italy Social Support Systems. Page 1. <https://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/2007-Social-support-systems/Italy>. [Date Accessed: 16 July 2018]
- iv Ibid.
- v Library of Congress. (2017). Italy: Early Retirement Benefits. Page 1. <http://www.loc.gov/law/foreign-news/article/italy-early-retirement-benefits/>. [Date Accessed: 16 July 2018]
- vi Alzheimer Europe. (2009). Italy Social Support Systems. Page 1. <https://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/2007-Social-support-systems/Italy>. [Date Accessed: 16 July 2018]
- vii Ibid.

## Number of Carers

Official number **427,000<sup>i</sup>**  
Percentage of population **0.9%**



Current Practices	Opportunities to Increase Support
 <p>The Law 39/2006 on the Promotion of Personal Autonomy and Care for Dependent People (Dependency Law) defines unpaid carers as people of the family not linked to a professionalized attention service.<sup>ii</sup> It is important to note that certain regions in Spain have a broader definition of an unpaid carer.</p>	Expand the definition of unpaid carer on a national level.
 <p>The Spanish Government provides financial benefits for dependent people if they cannot access social services as a first option. This support will pay for care costs in an accredited center or for care offered by non-professional carers, such as family members.<sup>iii</sup></p>	Reduce the bureaucratic hurdles so unpaid carers can easily receive financial support for care recipients.
 <p>Unpaid carers are entitled to unpaid leave up to two years to take care of a family member for reasons of age, accident, illness or disability.<sup>iv</sup></p>	Provide a national employment policy which includes paid and flexible care leave, flexible working conditions, and the promotion of a work-life balance.
 <p>Only those unpaid carers who actively participated in the workforce can benefit from retirement pension. They have a right to flexible or partial retirement if they meet certain conditions.<sup>v</sup></p>	Improve pension rights and benefits for unpaid carers that had to leave the workforce to provide care.
 <p>There are limited respite care services depending on the region where the unpaid carer lives.</p>	Nationally recognize respite care as a right and provide more funding to implement respite care in all regions.
 <p>Training of unpaid carers at the regional level was regulated by a resolution to the Dependency Law. It requires regions to train and assess the skills of all carers.<sup>vi</sup></p>	Provide support to regions to increase education and training. Implement an integrated approach of community support to unpaid carers so they can access community-based services.

 Legislation	 Working arrangements	 Respite care
 Financial support	 Pension credits	 Information and training

## Government Recognition

Law 39/2006 of Promotion of the Autonomy and Care of People in a Dependent Situation

Regional laws and policies

\*As an EU Member State, Spain is impacted by the proposal for a [Directive on the Work-Life Balance for Parents and Carers](#), which covers carers' leave and flexible working arrangements.

---







## References







- i ECPC and EUROCARERS. (2017). White Paper on Cancer Carers. Page 24. <http://www.ecpc.org/WhitePaperOnCancerCarers.pdf>. [Date Accessed: 16 July 2018]
- ii Spain Ministry of Employment and Social Security. (2009). Agreement on common accreditation criteria for training and information for non-professional carers. Page 1. [http://www.boe.es/diario\\_boe/txt.php?id=BOE-A-2009-18959](http://www.boe.es/diario_boe/txt.php?id=BOE-A-2009-18959). [Date Accessed: 16 July 2018]
- iii European Commission. Spain Care for Dependents. Page 1. <http://ec.europa.eu/social/main.jsp?catId=1129&langId=en&intPageId=4798>. [Date Accessed: 16 July 2018]
- iv Spain Ministry of Employment and Social Security. (2015). Royal Legislative Decree approving the revised text of the Law on the Workers' Statute. Page 1. [http://www.seg-social.es/Internet\\_1/Normativa/index.htm?dDocName=095296&C1=1001&C2=2010&C3=3036&C4=4015](http://www.seg-social.es/Internet_1/Normativa/index.htm?dDocName=095296&C1=1001&C2=2010&C3=3036&C4=4015). [Date Accessed: 16 July 2018]
- v European Commission. Spain - Ordinary, partial and flexible retirement pension. Page 1. <http://ec.europa.eu/social/main.jsp?catId=1129&langId=en&intPageId=4795>. [Date Accessed: 16 July 2018]
- vi Spain Ministry of Employment and Social Security. (2009). Agreement on common accreditation criteria for training and information for non-professional carers. Page 1. [http://www.boe.es/diario\\_boe/txt.php?id=BOE-A-2009-18959](http://www.boe.es/diario_boe/txt.php?id=BOE-A-2009-18959). [Date Accessed: 16 July 2018]

## Number of Carers

Official number **6.5 Million<sup>i</sup>**  
 Percentage of population **10.3%**



Current Practices	Opportunities to Increase Support
 <p>Unpaid carers are legally defined as people who look after family members, friends, or others because of long-term physical or mental ill health or disability, or care needs related to old age.<sup>ii</sup></p>	<p>Increase levels of discussion highlighting the unmet challenges that unpaid carers continue to face in the UK.</p>
 <p>The Carers Allowance is the main benefit for unpaid carers in the UK. The unpaid carer must meet specific criteria to qualify and may not be able to receive another financial benefit in addition to the Carers Allowance.<sup>iii</sup></p>	<p>Provide increased education to unpaid carers on their rights for financial support.</p>
 <p>Unpaid carers can request flexible working hours, time off and leave for care, but paid leave appears to be subject to negotiation between employers and employees, rather than a guaranteed right.<sup>iv</sup></p>	<p>Expand unpaid carers rights for paid leave.</p>
 <p>Unpaid carers who are pension age will receive a State Pension, but they cannot receive the full amount of both the Carer's Allowance and the State Pension at the same time.<sup>v</sup> A system of pension credits to the State Pension can be claimed by unpaid carers of working aged if they fulfill the entitlement criteria.</p>	<p>Increase financial support for unpaid carers so they may receive both a State Pension and a Carer's Allowance.</p>
 <p>Various forms of respite care or breaks may be provided after an assessment of the unpaid carer or the person from whom they care is completed.<sup>vi</sup></p>	<p>Provide more government funding for additional respite care.</p>
 <p>Carers UK provides training and information to unpaid carers throughout the UK. Local councils provide information and may provide training.</p>	<p>Increase awareness of training and services available to unpaid carers. This includes information about caring and condition management. Provide support to organizations that already provide training and information to unpaid carers. Increase identification and support from health bodies and the wider system.</p>

 Legislation	 Working arrangements	 Respite care
 Financial support	 Pension credits	 Information and training



## Government Recognition

Care Act (England, 2014)

Carers Act (Scotland, 2014)

Social Services and Well-being Act (Wales, 2014)

Carers and Direct Payments Act (Northern Ireland, 2002)

Employment Rights Act (1996)

Work and Families Act (2006)

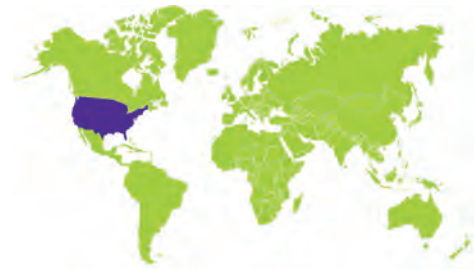
---







## References







- i House of Commons Library. (2017). Carers Briefing Paper. Page 3. <https://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7756>. [Date Accessed: 16 July 2018]
- ii Ibid.
- iii Carers UK. (2018). Carer's Allowance. Page 3. <https://www.carersuk.org/images/Factsheets/Carers-Allowance-2018-19-FINAL.pdf>. [Date Accessed: 16 July 2018]
- iv Carers UK. (2016). Your Rights in Work. Page 2-3. <http://www.carersuk.org/files/helpandadvice/2613/factsheet-uk1031-your-rights-in-work.pdf>. [Date Accessed: 16 July 2018]
- v Carers UK. (2018). Carer's Allowance. Page 10. <https://www.carersuk.org/images/Factsheets/Carers-Allowance-2018-19-FINAL.pdf>. [Date Accessed: 16 July 2018]
- vi National Health Service. (2018). Carers' breaks and respite care. Page 1. <https://www.nhs.uk/conditions/social-care-and-support/breaks-for-carers-respitecare/>. [Date Accessed: 16 July 2018]

## Number of Carers

Official number **43.5 Million<sup>i</sup>**  
 Percentage of population **13%**



Current Practices	Opportunities to Increase Support
 <p>Unpaid carers are formally recognized but are not considered a protected class at the federal level.<sup>ii</sup></p>	<p>Nationally recognize unpaid carers as a federally protected class. Pass federal legislation that gives unpaid carers the right to an assessment of their needs.</p>
 <p>Unpaid carers can receive some financial assistance, income, or tax breaks that can reduce the burden of the cost of caregiving. These options are embedded in various government programs and tax incentives if certain qualifying criteria are met.<sup>iii</sup> Through the Kupuna Caregivers Act, Hawaii provides financial assistance to support employed carers to remain in the workforce.<sup>iv</sup></p>	<p>Create one national initiative that provides financial support to unpaid carers.</p>
 <p>The US lacks a national mandate on comprehensive paid family leave. California, Rhode Island, New York and New Jersey provide some variation of paid family leave.<sup>v</sup></p>	<p>Create a national mandate for paid family leave and financially support employers that promote a work-life balance.</p>
 <p>Unpaid carers can apply for Social Security disability benefits for the care recipient. There are two types of disability benefits; Supplemental Security Income (need based) and Social Security Disability (based on previous employment).<sup>vi</sup></p>	<p>Pass federal legislation that would provide a Social Security pension credit of up to five years of uncompensated care, to unpaid carers for the time they would have earned wages but could not due to their caring responsibilities.</p>
 <p>Respite programs for unpaid carers are provided under the National Family Caregiver Support Program and the Lifespan Respite Care Act of 2006, which was intended to improve the delivery and quality of respite care services available to families across all age and disability groups.<sup>vii</sup> Other federal programs offer limited access to respite services.</p>	<p>Make respite care more readily available and easier to access.</p>
 <p>Unpaid carers have access to training and information through the non-profit organizations Family Caregiver Alliance, AARP, the National Alliance for Caregiving, and the Caregiver Action Network. The VA Caregiver Support Program and the National Family Caregiver Support Program both offer training and educational resources.<sup>viii</sup></p>	<p>Increase awareness of training and services currently available to unpaid carers.</p>

 Legislation	 Working arrangements	 Respite care
 Financial support	 Pension credits	 Information and training

## Government Recognition

Recognize, Assist, Support and Engage (R.A.I.S.E.) Family Caregivers Act

The Lifespan Respite Care Act of 2006

Older Americans Act

Family and Medical Leave Act

Caregivers and Veterans Omnibus Health Services Act

VA Mission Act

## State-specific Legislation:

The Caregiver Advise, Record, Enable (C.A.R.E.) Act

The Kupuna Caregivers Act in Hawaii

Medicaid Consumer-Directed Care Program (also known as Cash and Counseling), available under Home- and Community-Based Services Waiver Program

Paid Family and Medical Leave

Older Americans Act - National Family Caregiver Support Program

State Caregiving Task Force Legislation

## References

- i AARP. (2015). 2015 Report: Caregiving in the U.S. Page 11. <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>. [Date Accessed: 16 July 2018]
- ii Ohio State Bar Association. (2016). Laws Protect Employees Who Serve as Caregivers. Page 1. <https://www.ohiobar.org/ForPublic/Resources/LawYouCanUse/Pages/Laws-Protect-Employees-Who-Serve-as-Caregivers.aspx>. [Date Accessed: 16 July 2018]
- iii Caregiver Homes from Seniorlink. (2017). Financial Support for Caregivers. Page 1. <https://blog.caregiverhomes.com/financial-support-for-caregivers-the-ultimate-guide-to-home-care-costs-financial-aid-and-financial-planning-for-caregivers>. [Date Accessed: 16 July 2018]
- iv Hawaii Aging and Disability Resource Center. (2017). Kupuna Caregivers Program. Page 1. [https://hawaiiadrc.org/Portals/\\_AgencySite/KCG%20Info%20sheet%20071117\\_FINAL.pdf](https://hawaiiadrc.org/Portals/_AgencySite/KCG%20Info%20sheet%20071117_FINAL.pdf). [Date Accessed: 16 July 2018]
- v Caregiver Homes from Seniorlink. (2017). Financial Support for Caregivers. Page 1. <https://blog.caregiverhomes.com/financial-support-for-caregivers-the-ultimate-guide-to-home-care-costs-financial-aid-and-financial-planning-for-caregivers>. [Date Accessed: 16 July 2018]
- vi Disability Benefits Center. (2016). Applying as a Caregiver of an Adult with an Illness. Page 1. <https://www.disabilitybenefitscenter.org/blog/applying-as-caregiver>. [Date Accessed: 16 July 2018]
- vii Administration for Community Living. Lifespan Respite Care Program. Page 1. <https://www.acl.gov/index.php/programs/support-caregivers/lifespan-respite-care-program>. [Date Accessed: 16 July 2018]
- viii US Department of Veteran Affairs. VA Caregiver Support. Page 1. <https://www.caregiver.va.gov/>. [Date Accessed: 16 July 2018]

# Advancing Global Priorities

Unpaid carers face similar financial, emotional and physical strains due to their caring responsibilities. Non-profit organizations, governments, businesses, health and education systems worldwide are recognizing the essential role of unpaid carers and the need to support them.

**Five advocacy priorities** adopted by select national carer organizations shape the framework of universal needs embraced by the International Alliance of Carer Organizations. These global goals serve as a reference for the development of legislation, policy and programs that support unpaid carers around the world.



Safeguard the health and well-being of unpaid carers.



Create flexible workplace and educational environments.



Minimize the financial burden placed on unpaid carers.



Invest in research to support evidence-informed decision making.



Enable access to user friendly information and education.

Together IACO and Embracing Carers™ will work to bring these goals to life and identify innovative practices that are addressing these priorities and making a far-reaching impact on the lives of unpaid carers. These programs serve as best practices that can be replicated and modeled around the world.

Join the movement at  
[www.embracingcarers.com](http://www.embracingcarers.com)



## Global Advocacy Priority



Safeguard the health and well-being of unpaid carers



Include unpaid carers as part of the care team

In Ontario, Canada it is estimated that there are **3.3 million unpaid caregivers**<sup>1</sup> providing care for family members, friends, neighbors or colleagues. These unpaid caregivers share a common frustration – the lack of integration in healthcare systems.

**The Change Foundation**, an independent charitable foundation that focuses on improving the experience of Ontario's unpaid caregivers and health providers, saw a need to address this challenge. Changing CARE, the action phase of the Change Foundation's ***Out of the Shadows and Into the Circle strategic plan***, identified four thematic needs and created select partnerships to develop solutions driving greater unpaid caregiver and healthcare system integration.

## Key Activities Needed to Support Unpaid Caregiver Healthcare System Integration

**Communication**—Better communication and information exchange between unpaid caregivers and health care providers.

**Assessment**—More identification and assessment of unpaid caregivers to determine their needs, abilities, and expectations.

**Recognition**—Formal recognition of the role unpaid caregivers play in the healthcare system by the patient's care teams and by caregivers themselves.

**Education**—More opportunities for unpaid caregiver support and education to develop key care skills, from counselling to medical task training.

## Changing CARE with Innovative Partnerships

Four select partnerships bring focus to different facets of the unpaid caregiver experience from a multitude of perspectives. These community-driven projects are comprised of locally-based organizations, programs and health systems with unpaid caregivers as equal partners. The initiatives identified are developed to address key issues, while building resources and content that can be scaled to the broader community.

### 1 Connecting the Dots... Easier Transitions for Family Caregivers

Addresses the needs of unpaid caregivers through defining and recognizing their role, and co-designing systems of care provisions and communication that meet their needs.

**Partner Organizations:** Huron Perth Healthcare Alliance; One Care Home and Community Support Services; North Perth Family Health Team; STAR Family Health; Southwest Local Health Integration Network

**Promotional materials** encouraging people to self-identify as an unpaid caregiver to their primary care practitioners. They are distributed through primary care practices. Community services are then made available when needed.

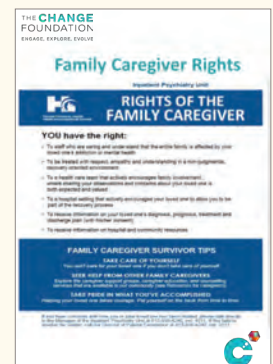


### 2 Embrace Develops practices with unpaid caregivers to better support, recognize, and embrace their vital role in the recovery of their family members with addiction and mental health issues.

**Partner Organizations:** The Cornwall & District Family Support Group; Cornwall Hospital, Community Addiction and Mental Health Services

**Activated unpaid caregiver friendly framework, which includes:**

- 1 | Unpaid caregivers as part of the patient's care team.
- 2 | Local resources and information to help unpaid caregivers navigate the health system for their family member and themselves.
- 3 | A resource hub – a virtual and physician space in the hospital where unpaid caregivers can turn to for reliable information.
- 4 | Showcasing unpaid caregiver and provider stories to promote understanding, learning and communication.
- 5 | Visual identification which unpaid caregivers wear in the hospital to help staff recognize who they are and the role they play.



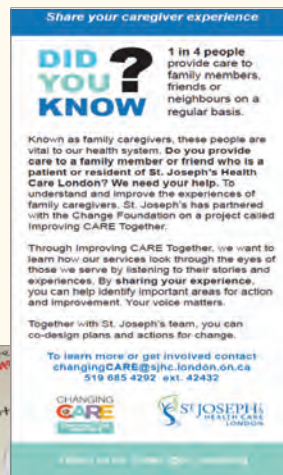
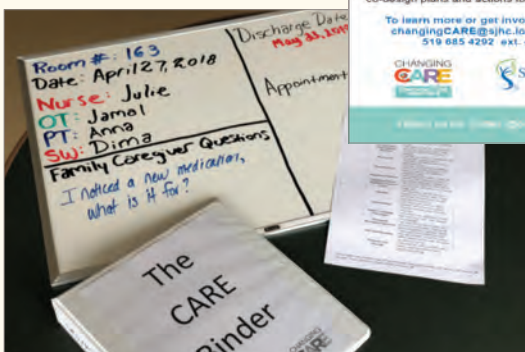
## Changing CARE with Innovative Partnerships continued

### 3 Improving CARE Together

Improve the acknowledgement of and input from unpaid caregivers in programs and organizational planning.

**Partner Organization:** St. Joseph's Health Care London

Care partnership with patients, residents, families and unpaid caregivers **providing promotional materials** aimed at unpaid caregivers posted around the hospital. Includes useful tools for patients and unpaid caregivers including a list for every patient with the names and role of their care team; a discharge binder that people can take home with them with instructions and follow up information.



### 4 Cultivating Change: The Caregiver Friendly Hospital and Community Hub

Redesigns the unpaid caregiver experience using the concept of the caregiver friendly hospital and community hub.

**Partner Organization:** Sinai Health System and WoodGreen Community Services

**Multi-level engagement** to support identification and support of unpaid caregivers.

- ID badge provided to unpaid caregivers to wear when they are in health care facilities.
- Information campaigns encouraging unpaid caregivers to identify themselves as caregivers to their health care teams.
- Caregiver resource center on the main floor of a community hospital, educational workshops and referrals to community supports.



## References

i The Change Foundation. (2016). A Profile of Family Caregivers in Ontario. Page 10. <https://www.changefoundation.ca/profile-of-family-caregivers-ontario/>. {Date Accessed: 16 July 2018}



## Global Advocacy Priority



Create flexible workplace and educational environments that respect caregiving obligations.

In developing countries, unpaid carers are systematically overlooked and irrespective of the vital role they play in the health and wellbeing of the nation, their voices remain unheard within society. Although they are one of the most vulnerable groups due to isolation, social stigma and exclusion, they receive almost no recognition from policy makers, government agencies or service providers. As a result, predicting the population of unpaid carers in these societies remains an impossible task. However, with extreme barriers to employment and gender inequality further exacerbating the problem, the effects of caring on physical, mental health and emotional wellbeing can be devastating.

**Carers Worldwide** is working exclusively and strategically with unpaid carers in India, Nepal and Bangladesh.

## The Carers Worldwide Model

The Carers Worldwide development model holistically tackles poverty, isolation and the physical and mental health issues commonly experienced by unpaid carers in developing countries. Working in partnership with local NGOs, Carers Worldwide builds local capacity and knowledge of carer related issues and solutions, collaborates to create and implement carer specific services and support infrastructure, and forms multi-stakeholder advocacy networks to drive sustainable change.

### The 5 drivers of change:

- Carer support groups:** created to reduce loneliness and isolation through social interaction and emotional support
- Health services:** offering health assessments, information and support and opening pathways to physical and mental health services
- Respite:** developing community based, high quality alternative care options, including community caring centers
- Employment, training and education:** providing direct training and support, and creating access to jobs, training or education that can coexist alongside caring responsibilities
- Advocacy:** strengthening the collective voice of unpaid carers through training that builds their capacity to advocate for changes in policy and practice



## Carers Worldwide

### 1 Empowerment through Employment

In India, **up to 97% of unpaid carers and their families live below the poverty line.**<sup>1</sup> Carers Worldwide helps unpaid carers to establish livelihoods that coexist with their caring responsibilities. They facilitate training to build the capacity of local NGOs and unpaid carers. They offer mentoring for staff facilitators and ensure that unpaid carers have one-on-one support to establish a home-based business such as tailoring, embroidery, and making jewelry or incense sticks. Some unpaid carers have even launched their own small farms or shops. Financial support is made possible with loans through carer groups, which were established as part of the Carers Worldwide program, giving unpaid carers the early support they need to begin their journey to financial sustainability.



#### Roshan

Roshan is 20 years old and cares for her brother at home alongside her mother. She received training in embroidery and tailoring through one of the Carers Worldwide Programs. Roshan set up a small business selling the jewelry and clothing she makes. She receives ongoing emotional support and training through a local carers group. She trains other unpaid carers to become embroiderers and tailors so they can earn a living by working from home.

Carers Worldwide continued

## 2 Pathways to a Brighter Future for Child Carers

Carers Worldwide is striving to make change by identifying child carers and working with them to return to school, build social connections at child carers groups and provide welfare assessments and support.



### Ramanjinamma

Ramanjinamma cares for both of her parents. Her lack of education and socialization means that she will likely enter adulthood without the necessary communication skills or qualifications to attain employment. Carers Worldwide is working with children like Ramanjinamma, to help them to access the assistance they need, including:

- Creating alternative care arrangements and providing a break from caring so that child carers can attend school.
- Providing uniforms, books and equipment to enable child carers to assimilate and catch up on their missed education.
- Training local NGOs and community-based services to offer support.
- Creating friendship groups for child carers for emotional and social support.

## References

i Carers Worldwide. (2018). Impact Report. Page 8. [https://www.carersworldwide.org/wp-content/uploads/2018/05/CW\\_Impact\\_Report\\_2018\\_.pdf](https://www.carersworldwide.org/wp-content/uploads/2018/05/CW_Impact_Report_2018_.pdf). [Date Accessed: 30 July 2018]



# Supporting Carers

The **Global State of Care Report** highlights the growing policy momentum to support unpaid carers. Unpaid carers are increasingly falling under the policy spotlight and garnering the attention of politicians thanks to advocacy efforts in many of these countries. However, much more can be done to support unpaid carers in terms of financial, practical and emotional support. Further efforts are needed to ensure the health and well-being of unpaid carers across the world.

IACO and Embracing Carers™ will continue to provide strong and committed leadership, establish a global understanding, recognition and support for unpaid carers around the world.

For those of us who are, and for those of us who will be unpaid carers in the future, the cost of caring will impact our lives, emotionally, economically, socially and physically.

**As we create a global action plan for carers, we encourage everyone to take action and support unpaid carers in your community:**

- 1 | Identify a carer organization in your country. If one doesn't exist, be a catalyst for starting one. You can find IACO's Carer Toolkit on their website.
- 2 | Find out how you can support carer advocacy efforts in your country.
- 3 | Share information with friends and family. Use #EmbracingCarers and #CareForACarer on social media.

Change can  
only happen  
with the help of  
many voices

Join the movement at  
[www.embracingcarers.com](http://www.embracingcarers.com)